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**“STILL HERE, TRYING TO FIND MY WAY”:
UNDERSTANDING EXPERIENCES OF HIV DISRUPTION AND
REORGANIZATION AMONG OLDER AFRICAN AMERICANS IN DETROIT**

by

ANDREA LYNN NEVEDAL

DISSERTATION

Submitted to the Graduate School

of Wayne State University,

Detroit, Michigan

in partial fulfillment of the requirements

for the degree of

DOCTOR OF PHILOSOPHY

2012

MAJOR: ANTHROPOLOGY

Approved by:

Advisor

Date

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2012

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DEDICATION

To the people who participated in my dissertation research.

In special memory of Melvin, Sheila and Willie
who died after this research was conducted.

ACKNOWLEDGMENTS

I would like to acknowledge my dissertation committee for their ongoing support and guidance throughout graduate school. I am thankful to have worked with a wonderful group of committee members who were genuinely interested and dedicated to their student's success. I would especially like to acknowledge Dr. Andrea Sankar, the chair of my dissertation committee, for hiring me as research assistant for the HAART Project when I started graduate school and for the opportunity to learn more about anthropological methods and research outside of the classroom setting. Thank you for teaching me about research, how to "think" like an anthropologist, and for consistent support, constructive feedback, and guidance throughout my graduate school years. Thank you for making this project possible by allowing me to build my dissertation off of data from the HAART Project. I would also like to acknowledge my other committee members for their ongoing support. First, thank you to Dr. Briller for consistently providing support, advice, and guidance throughout graduate school and for taking the time to share your expertise and to answer my questions. Also, thank you to Dr. Luborsky for inspiring me to apply for the pre-doctoral training program at the Institute of Gerontology, encouraging me to have my own voice, and to think more critically. Finally, I would like to thank Dr. Lichtenberg for allowing me to participate in the excellent training program at the Institute of Gerontology and to learn more about the field of aging from various disciplines.

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SECTION I: BACKGROUND AND SIGNIFICANCE

Section I provides the background and significance for this dissertation research on understanding HIV disruption and reorganization among older HIV positive African Americans in Detroit. Section I is divided into three chapters. Chapter 1 provides a general introduction and discusses literature related to anthropology of aging with a focus on aging among African Americans. Chapter 2 provides a discussion of the history of HIV among older adults and epidemiological information on older African Americans with HIV. Chapter 3 describes how an anthropological approach to the life course is the major theoretical framework used to understand the experiences of aging with HIV.

CHAPTER 1

INTRODUCTION

“I THOUGHT I’D BE LIVING SOMEWHERE WITH A WHITE PICKET FENCE”:

OLDER AFRICAN AMERICANS LIVING WITH HIV IN DETROIT

PROLOGUE

I thought I’d be high end. I went to a university in northern Michigan. I didn’t think I’d have all the children I had. I thought I’d be living somewhere with a white, you know, a white picket fence and all that shit. I just thought I’d have it going on more than I got it going on. You understand. I thought I would be carrying a briefcase because I went to college, right. Then I got pregnant with that big thing you see there (points to a picture of her son). They had an Air Force base up in northern Michigan. I was on the outskirts, right. I got pregnant with him instead of going to class. I took pride in him. It was the first time I went away from home ‘cause I went away to school when I was 17, right. And uh, I thought I would, I thought my life would be totally, totally, totally, so totally different than it is here, not in my wildest dreams. (Laughs) And I just thought my life would be much more so on a silver platter. I knew, you have childish [dreams], but I was not that naïve. I just knew I would be, I thought I was gonna have me the best man and married to the best man in the world and he was gonna take care of me and I was gonna take care of him like the *Leave it to Beaver* family, (laughs), *Ozzy and Harriet*, that type of shit. That’s what I thought my life was going to be like. You go out and get your job, you do everything in order, you go to school and get your education, you get your degrees or whatever degrees you want, or if you want to stop at the BA or stop at the master’s or whatever, I thought I would do that. I thought I would meet a young man, we’d have a house, cars, we’d have some children. I thought that’s how my life would be. But my life did not turn out that way but I deal with my life as it is. (Laughs). But that’s how I thought. (Patrice Dissertation Interview 2009, Age 51, HIV+ 8 years)

Patrice’s life story underscores the primary focus of this dissertation on understanding cultural expectations of the life course and what happens when life course expectations may be disrupted due to life changing events such as an HIV diagnosis. In her story, Patrice talked about the dreams she had when she was

younger and she described what she thought her life would be like as she became older. Her discussion of a hoping to have a house with “white picket fence” and living a life like the *Leave It to Beaver* family provided important insight into some of the cultural ideals and models that shape normative life course expectations. Anticipations and perceptions of the future are often rooted in culturally based life course expectations (e.g., education, house, family, car, marriage, romantic love), about the way life should occur and the various roles (e.g., mother/father, wife/husband) one should occupy throughout life. Patrice also emphasized how she thought her life would be “in order” and how she thought her life would play out in a linear series of events and roles. Her perception of the life course as “orderly” and linear is culturally relevant and will be further discussed in Chapter 3.

As will be discussed throughout this dissertation, life does not always occur as planned, and people experience various disruptions to their dreams and plans for the future. Patrice’s pregnancy shortly after going away to college was one of the various life disruptions she experienced prior to acquiring HIV that ultimately influenced her life turning out “totally” different than she expected. Patrice also illustrates how cultural values and beliefs greatly influence perceptions of the way life should be played out. In addition, she underscored the ways in which people begin to make sense of how their lives contradict or compare with cultural ideals and expectations. Life disruptions can impact life goals and expectations. As a result, people are often forced to create new ways of thinking about the life course. As people try to make sense of the disruptions they experience they often establish new ways to go about living their life.

This dissertation is based on a study of thirteen older African Americans, their life histories, and their long-term experiences of aging with HIV in the city of Detroit (See Appendix A for participant case studies). This dissertation study builds off of a larger parent study called the HAART Project. The HAART Project was a longitudinal study of HIV positive African Americans (aged 18 and older) and their adherence to Highly Acting Anti-Retroviral Therapy (HAART). For the dissertation research, I recruited older adults from the HAART project in order to explore the extent to which people experienced disruptions from aging with HIV and to what extent they reorganized their lives in response to disruptions from HIV.

An anthropological approach to the life course theory and Becker's (1997)¹ framework of life course disruption were used to help make sense of the stories and discussions from this group of older people. The findings from this research provide information on the types of disruptions people experience while living with HIV and the ways they go about making sense or reorganizing life after an HIV diagnosis. This dissertation also provides information on the long-term experience and process of living with HIV. By studying how HIV may disrupt the lives of older African Americans with HIV, the goal was to gain a better understanding of the culturally meaningful categories associated with various phases of the life course.

STUDY AIMS AND SCOPE

Purpose and Research Questions

The purpose of the dissertation research was to understand how the socio-cultural consequences of living and aging with a stigmatizing illness such as HIV influences the

¹ Life course theory and Becker's (1997) framework of life course disruption are discussed in Chapter 3.

life course expectations and experiences of older HIV positive African Americans in Detroit. The main research questions for this dissertation were: (1) To what extent and in what ways can an HIV diagnosis disrupt the normative experiences and expectations for older African Americans living in Detroit, and (2) To what extent and how do people reorganize their lives after experiencing disruptions from HIV? An anthropological approach to the life course was used to explore how cultural constructions of illness impact life events, expectations, and identities of people. The study of the relationship between HIV and aging was used to help extend anthropological theories of the life course and the constructs of life disruption and life reorganization. This research can help improve the health of people in Michigan by providing empirical data about and analysis of the emerging health problem of HIV among older adults and will expand our understanding of the health challenges facing Michigan's older African Americans.

Specific Aims

The specific aims for the dissertation research were to:

- (1) Identify and describe how HIV disrupts and poses challenges to a person's ability to achieve life stage specific goals
- (2) Identify and describe how older adults reorganize life in response to an HIV diagnosis and disruptions from living with HIV
- (3) Understand how timing of HIV diagnosis (e.g. diagnosis cohort², life stage, duration) influences life course events and expectations
- (4) Describe the ethnographic setting of living with HIV among older HIV positive African Americans in Detroit

² People diagnosed prior to 1986, before azidothymidine (AZT) therapy, when HIV was an invariably fatal disease are likely to have had a different experience than those diagnosed in the HAART era (post-1995) when HIV became a chronic illness. The focus on diagnosis cohort will depend on the number of older adults available in each category that participate in the study.

Rationales

Stereotypes about aging have profoundly influenced our understanding of aging with HIV and perceptions of HIV risk among older people. Therefore, this dissertation aimed to provide new insight by understanding the experiences of living with HIV among older African Americans. This anthropological dissertation draws upon other disciplines such as gerontology and epidemiology to provide a more holistic understanding of aging with a stigmatizing illness among a small group of older African Americans in Detroit. There were several different rationales from anthropology, gerontology, and epidemiology for conducting this dissertation research.

The anthropological rationales included (1) to study how HIV can disrupt and influence an individual's ability to fulfill key life course stages (e.g., partnership formation, childbearing, respect for the elderly), (2) to understand the socio-cultural consequences of aging with HIV, a highly stigmatizing illness, (3) to identify how people make sense of and integrate HIV experiences into their normative expectations for aging and to provide insight into both non-normative and normative aging processes, (4) to learn how life course disruption provides insight into cultural responses to change, and (5) to consider the relevance of Becker's (1997) framework of life course disruption for this population.

The gerontological rationales for this dissertation included (1) to recognize how the increase in global population aging influences the need for understanding the lived experiences of older people, (2) to explore how aging and HIV research have been influenced by cultural stereotypes of the asexual older person, (3) to bring attention to the practices, beliefs, and importance of sexuality and intimacy throughout people's

lives, and (4) to identify how an HIV status impacts later life course expectations and intersects with the aging process.

The epidemiological rationales for this research were (1) people aged fifty and older are the fastest growing age group with HIV/AIDS, (2) older people are expected to make up half of all cases of HIV/AIDS by 2015 due to improvements in medications allowing people to live longer and increased testing of older adults, and (3) African Americans are disproportionately affected by HIV/AIDS.

The following chapters (1-3) in Section I of this dissertation describe the background and significance of this dissertation research by discussing and reviewing literature on anthropology of aging, epidemiology of HIV among older adults, and an anthropological approach to the life course.

ANTHROPOLOGY OF AGING AND AGING AMONG AFRICAN AMERICANS

The dearth of work on health issues related to aging in medical anthropology reflects the American stereotypes about aging and the aged as uninteresting and devoid of relevance for critical issues in contemporary life...a focus on health and aging can inform critical medical anthropology (Becker and Kaufman 1995:183)

Despite increases in anthropological attention to health and aging, seventeen years later Becker and Kaufman's point about the shortage of research in aging and medical anthropology in part remains true. Today, there are still key areas of research that remain understudied such as African American aging, African American perceptions of the life course and sexuality in later life. This section will provide a discussion of the history of literature in aging research. It begins with a discussion that focuses on the fact that the attempt to surmise the aging process among humans is not a new phenomenon, and how the general study of aging, known as gerontology, developed out of changing demographic transitions in human populations. This section will also discuss at what point anthropologists began formally studying aging and provide a quick review of key areas and contributions of anthropology of aging research. Lastly, this section will discuss a few key references to the literature on aging among African Americans in sociology and gerontology and then briefly summarize the main areas of research on older African Americans thus far.

ANTHROPOLOGY OF AGING

What is the anthropology of age and aging? Aging is a universal human experience. However, anthropological approaches to aging recognize the role of culture in influencing the aging process and perceptions of life course. In addition, anthropologists recognize how the experience of aging, treatment directed towards

older people, and perceptions of how one “should age” or how a “good old age” is determined can vary greatly across cultures (Keith et al. 1994; Sokolovsky 2009b). Aging experience is contextualized on many different levels. On an individual level, the uniqueness of individual autonomy and life experiences plays a crucial role in the aging experience and how aging is perceived (Fry 2003; Keith et al. 1994). The aging experience also occurs as a collective/social experience because there are culturally defined norms and expectations about aging that play a role in how people perceive aging and what is defined as ‘normal’ experiences of aging (Fry 2003; Keith et al. 1994). Aging also involves both biological, psychological, and physiological changes in development that occur over time, but the way in which the processes of aging are interpreted and experienced are shaped by cultural and social norms and expectations that occur within the confines of cultural, social, historical, political, individual and economic contexts (Fry 2003; Keith et al. 1994).

THE DEVELOPMENT OF THE DISCIPLINE OF AGING AND AGING RESEARCH

Gerontology (1930s)

When did people begin to study the life course, aging, and old age as a formal discipline? Philosophers illustrated some of the earliest documented ideas about human development and aging during the ancient Greek and Roman eras (Holstein and Gubrium 2000; Mannheim 1952; Nisbet 1969). However, the formal study and scientific inquiry of aging that we now refer to in gerontology and anthropology did not occur until the 20th century (Binstock and George 1996). In the 20th century, the average age of people dramatically increased, which brought about a need for understanding aging and

old age (Achenbaum 1996; Binstock and George 1996). Achenbaum's (1996) chapter "Historical Perspectives on Aging" discusses how the emergence of gerontology, the study of aging from the broadest perspective, arose out of changing demographic transitions of human populations and dramatic increases in life expectancy. Approximately two-thirds of the increase in life expectancy as we know today occurred after 1900 (Achenbaum 1996). The increase in life expectancy is a result of improved sanitation and nutrition, increased control over infectious disease, and more advanced medical care (Achenbaum 1996). The change from shorter to longer life expectancies resulted in dramatic increases in populations of older people (Achenbaum 1996). The ability to control infectious diseases played a major role in improving life expectancy. A result of people living longer and into old age was the increase the number of chronic diseases and conditions. The increase in the aging population along with the decline in infectious disease to an increase in chronic disease among human populations during the 20th century created a need for scientists to begin to study aging as a scientific problem. In the United States during the mid-1930s the field of Gerontology developed out of the increased focus on aging research and the demand for professionalization and organization of aging researchers (Wook-Park 2008). In 1939, Cowdry and Allen published a pivotal book named *Problems of Ageing: Biological and Medical Aspects* (Cowdry and Allen 1939; Wook-Park 2008). This book was the first significant compilation of multi-disciplinary research on aging. In 1945, the authors from *Problems of Ageing* established the professional organization named the Gerontological Society of America (Wook-Park 2008). The field of gerontology developed in the era of "Big Science" (Achenbaum 1996). Researchers in gerontology took advantage of the new

scientific opportunities to develop a better understanding of the processes of aging. As the field of gerontology developed, other disciplines such as psychology, sociology, and anthropology also began to apply their frameworks and orientations to contribute to the understanding of age and aging (Wook-Park 2008).

Sociology – Cross-Cultural Aging (1940s)

In 1945, Simmons, a sociologist, was one of the first to formally explore and utilize ethnographic data to understand aging (Simmons 1945). Simmons used the Human Relations Area Files (HRAF), secondary data, to examine the status and treatment of the aged in primitive societies (Clark 1967; Simmons 1945). He used records from 19th century ethnographers, missionaries, and colonists to conduct his analysis (Clark 1967; Simmons 1945). Simmons' work helped to recognize the complexity involved with studying age/aging and cross-cultural variation in aging. Simmons documented various cross-cultural complexities of aging, but was unable to come up with a simplistic theory of aging. While Simmons was the first to analyze ethnographic data and relate it to aging, there were limitations in his research methods. The major limitation of his research involved the use of secondary data sources that were unreliable and inconsistent in their data collection and methods. Simmons had to rely on the interpretations of other people, which made it difficult to know if their data was scientifically sound, reliable or valid. These inconsistencies made it difficult to make scientific and cross-cultural comparisons of aging populations and to develop a universal theory of aging. Simmons work illustrated the need for more rigorous cross-cultural aging research.

Development of a Life Course Perspective (1950s-1960s)

After Simmons' research in the 1940s, the development of the life course perspective was another major breakthrough in aging research. The life course perspective emerged out of the need for understanding human development across life span and the importance of historical, structural and cultural context in shaping human lives (Elder 1994). Prior to the life course perspective, theories of human development were static and linear, and focused on development as it occurred in infancy and early childhood (Clark 1967; Elder 1994). These theories of human development did not consider the impact of history, social structure, or culture on shaping development (Elder 1994). Early perspectives of human development were limited because they could not explain broader questions related to human development that addressed life span continuity and change (Elder 1994).

In the 1960s Elder, a sociologist and psychologist, became a key researcher in the development of the life course perspective (Elder and Johnson 2003). Elder helped transform perspectives of fixed/static theories of socialization and child development to the development of a more dynamic and fluid view of human development (Elder 1974; Elder and Johnson 2003; Elder 1994). Elder's work emphasized the relationship between human agency, history, experiences of work or employment patterns, social support and coping in shaping the lives of people (Elder 1974; Elder and Johnson 2003; Elder 1994). A life course perspective recognized that as individuals aged, their experiences could be understood by understanding the social and historical contexts in which they lived (Elder 1974; Elder and Johnson 2003; Elder 1994). The life course approach emerged as a new area of inquiry in human development because it emphasized the importance of time, human agency, and social experiences (Elder

1974; Elder and Johnson 2003). Life course theory focused on how individual lives were influenced by social interaction and the processes by which they evolved due to changing social, historical and cultural environments (Elder 1974; Elder and Johnson 2003; Elder 1994). The emergence of the life course perspective therefore transformed the previously static and linear notions of aging and human development.

Early Anthropology of Aging (1950s and 1960s)

Anthropologists have historically relied on older informants as purveyors of important cultural information (Clark 1967; Keith 1979). Early Anthropologists also often studied the rites and practices of cultural groups as they occurred throughout the human life cycle (Clark 1967). Anthropologists studied age in relation to how cultural groups functioned or were structured. However, discussions about aging were often rooted in other key areas of interest such as kinship and domestic groups rather than the study of aging itself (Clark 1967). It wasn't until the late 1970s that anthropologists began to formally recognize the need for studying aging and age. In the 1950s and 1960s, a small number of anthropologists were beginning to study the relationship between culture and aging. The Association of Anthropology and Gerontology (AAGE), was formed in 1978 as a result of the growing emphasis of aging studies in anthropology (Sokolovsky 2009a). This group functioned as a means of uniting anthropologists interested in aging issues and to promote further aging research. After the development of the AAGE and up to the present time, there has been an abundant amount of aging research.

During the 1950s-1960s anthropologists began to formulate new perspectives on aging that rejected previously static or fixed notions of human development present in

psychological perspectives. During this time anthropologists also began to focus on collecting their own ethnographic data rather than relying on secondary data. As noted earlier, Simmons' work with the HRAF files provided a starting point to discuss cross-cultural aging. However, anthropologists recognized the need for collecting their own data in order to develop more consistent, comparable and rigorous methods in order to discover cross-cultural patterns and perspectives in aging and the role of culture in influencing the aging experience.

The work of Fortes, Neugarten, Clark and Cowgill provided some of the key ideas in how anthropologists began to think about the role of culture in relation to the meaning of age, aging, and later life experiences (Clark 1967; Cowgill and Holmes 1972; Fortes 1963; Neugarten and Hagestead 1976). Fortes' research on African societies studied how societies use age grades and age sets to organize and regulate how people transition from one life stage to another (Fortes 1963; Fortes and Evans-Pritchard 1963; Goody 1958). Age grades provide different social roles and duties based on culturally defined age groups. Societies can have one age grade or multiple age grades (Fortes 1963; Neugarten and Hagestead 1976). Western societies have multiple age grades or levels of achieving maturity (e.g. driving, voting, drinking, social security). Age sets occur in societies when groups of people move through the life cycle collectively and form tightly bound groups performing specific tasks (Fortes 1963; Neugarten and Hagestead 1976). Age grades and age sets are not necessarily determined by the number of years since birth, but rather are culturally defined. In studies of kinship, anthropologists like Fortes examined how age influenced an individual's rights and duties. The way in which different cultures determine and use

maturational differences tends to vary. The concept of age has many different interpretations and uses in relation to the life course. However, anthropologists recognize that age functions to provide cues and information about the social and cultural expectations, experiences and roles of people (Neugarten and Hagestead 1976; Settersten 2003). Clark and Anderson examined culture and aging among older people in San Francisco, California (Clark and Anderson 1980). Clark, a pioneer in medical anthropology and anthropology of aging, was interested in the question “Why have anthropologists forgotten about the period between marriage and funeral” (Clark 1967:55; Clark and Anderson 1967)? Clark was one of the first to carry out field research emphasizing the concept of culture in gerontology. Clark and Anderson drew from the culture and personality framework to understand mental illness and wellness in late life. They hypothesized that there was a relationship between cultural values and mental health in late life. They looked at how core American values emphasized the importance of independence and individualism yet proved maladaptive in late life (Clark 1967; Clark and Anderson 1967). People who modified their values to correspond with different expectations of old age seemed to experience more successful aging and mental health in later life. Another contribution of Clark’s work was her ability to reflect on U.S. culture and discuss how negative attitudes about aging and old age had an influence on why anthropologists ignored aging as an important discipline and area of inquiry (Clark 1967). They rejected psychological assumptions that personality and development were formed and set in stone in childhood. Instead Clark and Anderson believed that behavior and personality are shaped by culture and are learned continuously throughout the life course. “People must learn to grow old just like one

learns to grow up (Clark 1967:63).” Clark also thought that cultural beliefs about aging and old age impact anthropologist lack of interest in aging and emphasis on earlier phases of life.

Anthropology of Aging (1970s)

In the 1970s, the subfield of anthropology of aging was beginning to develop. More anthropologists were conducting ethnographic investigations that were specifically organized around the concept of aging. During this time, anthropologists were beginning to recognize the impact of the aging population and the need for studying social issues related to aging and older people (Ikels and Beall 2001). Many of the studies during this time focused on how older people maintained ties with their adult children who lived elsewhere, developed social relationships in their aging communities, and participated in meaningful activities in old age (Ikels and Beall 2001).

During the 1970s, there was a major emphasis on the impact of modernization on aging. Modernization theory became a major theory in gerontology and anthropology. Cowgill, a sociologist, and Holmes, an anthropologist, developed one of the most explicit theories on aging and modernization (Cowgill and Holmes 1972). Their theory described the increased marginalization of older people as it related to increased modernization. They believed as modernization increased, the status and treatment of the elderly decreased.

Despite the increased popularity of modernization theory, anthropologists were beginning to critique the cross-cultural application of modernization theory. As anthropologists collected more data in different cultural contexts, they found data that both supported and disproved modernization theory (Ikels and Beall 2001).

Modernization theory was becoming recognized as being too functional, and it did not apply in cross-cultural settings. The status of the elderly did not decline in every context and not all societies elevated the status of the elderly. Another major criticism of modernization theory was that it did not consider inter- or intra-group variation among older people. Cross-cultural research illustrated the various ways elderly people were perceived and affected by modernization and ultimately illustrated the limited application of modernization theory.

Anthropology of Aging (1980s and 1990s)

In the 1980s and 1990s, anthropologists shifted their interest from cross-cultural and overseas research to the research conducted in communities in the United States. The changing political and economic contexts that followed World War II and the Cold War influenced the shifts in anthropological research (Vesperi and Sokolovsky 1995). For example, government officials of former US and European colonies were concerned about foreign researchers conducting studies among their people and how information could be misused to the benefit the United States or Europe. Anthropologists experienced difficulties in gaining permission and access to conduct overseas fieldwork. As a result, anthropologists who were interested in aging began to focus on biomedical and other nontraditional settings within mainstream North American society (Vesperi and Sokolovsky 1995). The shift to studying anthropology in the United States brought about new problems for anthropologists, as they struggled to justify their research methods and objectives in terms that non-anthropological service providers, policymakers, and funders would find acceptable (Vesperi and Sokolovsky 1995). Anthropologists had to tailor their research on aging to the interests of employers and

funding agencies who were concerned about cost effective health care, care-giving, and long-term care. Anthropological research was also used to understand the cultural factors that could affect the receipt or delivery of health care, physical decline and disability among the aging population (Kaufman and Morgan 2005; Sokolovsky 2009b; Vesperi and Sokolovsky 1995). What is known about aging in anthropological research has been limited to the agendas of funding agencies (Kaufman and Morgan 2005; Sokolovsky 2009b; Vesperi and Sokolovsky 1995).

Anthropology of Aging Overview

The interest in anthropology of aging has dramatically increased since the 1980s. The subfield of aging in anthropology has provided important insight and new perspectives on understanding the life course. Some of the major areas that anthropologists have studied in regard to age and aging include (1) cross-cultural aging and biomedicine, (2) cultural life course, (3) illness experience and care-giving in old age, (4) beginnings and ends of life, (5) aging communities, and (6) subjective experience of aging.

Cross Cultural Aging and Biomedicine

Anthropology of aging research has critiqued assumptions of the universality experiences and conditions associated with aging. Through cross-cultural research, anthropologists have learned how culture influences the extent in which age related changes or conditions such as menopause and Alzheimer's are experienced or occur in various societies. Research by Lock (1993) *Encounters with Aging: Mythologies of Menopause in Japan and North America* and Cohen (1998) *No Aging in India: Alzheimer's, the Bad Family, and Other Modern Things* provide examples of cross-

cultural differences and interpretations of aging experiences. Lock (1993) and Cohen (1998) examine multiple meanings associated with the aging body and the importance of cultural context in understanding the aging experience and how older people are treated. They are similar in that they set out to study the extent to which specific diseases/conditions are cross-cultural and discover differences in how the aging body is perceived in other cultures. Lock's (1993) research on menopause in the US and Japan critiqued Western notions of the universality of menopause. Lock (1993) examined how symptoms and experiences of menopause in the US are not necessarily a part of the normal aging experience in Japan (Ikels and Beall 2001:132).

Cohen's (1998) research on Alzheimer's in India and the US was used to critique biomedical reductionism of aging. Cohen (1998) examined how the aging body was treated in two different cultural contexts and when changes in the aging body mattered/became a concern to people. His work challenged popular assumptions of universality of Alzheimer's symptoms and suggested the importance of recognizing how local practices and treatments in response to aging were shaped by culture and political economy. In India, Cohen (1998) learned how the aging body was treated as a family crisis and result of modernity whereas in the United States the aging body was treated as diseased. Anthropological research has helped address important questions such as: To what extent is aging biological and universal? How do different societies deal with different aging phenomena? How does the use of biomedicine to treat age related change vary cross-culturally? Anthropologists have illustrated the importance of understanding the cultural context in order to understand how biological or physiological changes associated with aging are interpreted.

Cultural Life Course

Anthropologists have contributed to new ideas about the life course. Keith et al. (1994) collected data in the 1980s for Project AGE which consisted of a collaborative and comparative approach to understanding how the life course and the processes of aging were conceptualized in seven different cultural contexts. The researchers emphasized the importance of conceptualizing aging from a holistic perspective that incorporated social, cultural and physical elements. In conducting their research, Keith et al. (1994) realized how underlying assumptions about aging influenced their original questions, and as a result, had to modify their research questions to better understand the meaning of aging in various contexts. A major component of their cross-cultural research included the use of the Age Game (Keith et al. 1994). The Age Game was a technique used to examine how different cultures conceptualized phases of the life course along with characteristics associated with the corresponding phases of life. As a result, some aspects or assumptions of the Western life course were non-existent or irrelevant regarding how other cultures perceived the life course (Keith et al. 1994). For example, among non-industrial societies such as the !Kung people of South Africa questions about the importance of age or use of chronological time were culturally irrelevant components of the life course (Keith et al. 1994). The research from Project AGE reported various ways the life course could be conceptualized cross-culturally. Chronocentric-based understandings of the life course should not be assumed among other cultures. As a result of Project AGE, it is important to realize the cultural context of various societies in order to understand how the life course is conceptualized and the impact of culture in shaping the process and experience of aging.

Treatment of the Aged

Anthropological research has provided important insight on understanding how people in other cultures treat the aged and dying. Research in this area also provides insight regarding the special role that cultural values have upon influencing the aging experience and the management of age related changes as they relate to health and functionality. One area of special interest involves how aging is perceived, manifested, interpreted, and managed by others in various cultural contexts in industrial and nonindustrial societies. Glasock's (1983) research focused on culturally defined meanings of "intact" and "decrepit" older people (Glasock 1983a). The characteristics associated with "intact" or "decrepit" depended on the cultural values and contexts of a particular society. Glasock's research explored the treatment of the aged in nonindustrial societies (Glasock 1983a; b). Death hastening is a practice that is used to deal with burdensome older adults that are deemed "decrepit" (Glasock 1983a; b). Death hastening practices towards the "decrepit" take form in various ways such as lack of support from members, isolation from the community, or killing (Glasock 1983a; b). For example, some cultures may emphasize the importance of mobility in order for an older adult to be considered "intact", and mental or cognitive decline may not be a major concern (Glasock 1983a). A highly mobile society where assistive devices such as wheelchairs or canes are unavailable or not conducive to the environment may then perceive immobile older adults as a burden despite being cognitively "intact" (Glasock 1983a). In other contexts, mobility may be less of a concern, but mental or cognitive decline may be seen as a burdensome characteristic of a "decrepit" older adult (Glasock 1983a). The values and characteristics associated with what constitutes an "intact"

older adult versus a “decrepit” or burdensome older adult may vary depending on the cultural values and contexts of the aging environment (Glascock 1983a; b).

Beginnings and Ends of life

More recently, anthropologists have studied how medical technologies influence the beginnings and ends of life, the production of life and death, the unclear boundaries between life and death, and the increased interest in socio-political debates concerning when life begins and ends. This area of study relies on a more flexible notion of the life course. Anthropologists can contribute to understanding the cultural effects of biomedicine, its impact on identity (e.g., bio citizenship), and how biomedicine and technology can alter the beginning/ending of life and/or prolong life (Kaufman 2005). For example, Kaufman’s (2005) research focused on the process of dying in American hospitals. Interviews with the dying, family and friends and health care staff provided insight on the multiple perspectives and various aspects of the processes and practices that occurred when a person was dying in a hospital (Kaufman 2005). Kaufman discussed how the processes and practices associated with dying provided a rich understanding of cultural values and an insight on end of life practices in the United States (Kaufman 2005).

Aging Communities

The study of aging communities is another research area that is of interest to anthropologists. Ethnographies by Becker (1980) *Growing Old in Silence* and Myerhoff (1978) *Number Our Days* provide rich examples of the ways in which aging within a specific community influences the aging experience. Through the use of ethnography, these anthropologists were able to explore how involvement in different communities

affected the aging experience. Their research contributes to anthropological understandings of how belonging to a community of older people may provide cultural resources to improve the aging experience (e.g. Jewish Community Center, Deaf culture). Becker's (1980) book, *Growing Old in Silence*, examined how the crisis of deafness at a young age played a role in the lifelong experiences of deaf elders. The Deaf community focused on the importance of the group not the individual (Becker 1980). Many Deaf people experienced isolation from the hearing community throughout their lives and found more satisfaction in the Deaf community (Becker 1980). The tight-knit Deaf community helped to provide key resources for older Deaf people as they aged. Myerhoff's (1978) book, *Number Our Days*, explored aging among Jewish Elders at the Aliyah Jewish Community Center in Venice Beach, Los Angeles. Myerhoff's research focused on the day-to-day experiences, performances, and rituals of the members of the community center and how their actions helped create a sense of community (Myerhoff 1978). At the same time, Myerhoff's work examined intra-cultural variation by exploring how disputes among community members reflected different perceptions of religious beliefs and practices (Myerhoff 1978). The different activities at the community center played an important role in the seniors' sense of self and the aging experience. Her work illustrated the variation in experiences of old age that included both successes and losses.

The research by Becker and Myerhoff provide insight on the extents to which aging within a specific community may provide elders with more resources and strategies for aging versus those who are not part of an aging community.

Subjective Experience and Meaning of Aging to Older People

To what extent does aging really matter to the aged? Kaufman's (1986) *Ageless Self* focused on a narrative analysis of life history narratives to assess and examine how older people perceived the process of aging and to what extent aging played a role in their sense of self and wellbeing. Kaufman critiqued the quest for understanding the "meaning of old age" and reported that older people might not recognize aging or being older as being an important aspect of their identity (Kaufman 1986).

Now that I have provided a brief overview of selected works in gerontology and anthropology, the following section will focus specifically on aging among older African Americans.

AGING AMONG OLDER AFRICAN AMERICANS – ANTHROPOLOGY

To what extent does ethnicity play a role in the aging experience in the United States? Despite the general increase in aging research in anthropology over the last few decades, very few anthropologists have studied concepts such as aging in African American populations or the meaning of later life and the life course expectations among populations of older African Americans. While searching the published literature during the course of this research, attempts to locate and reference anthropological and ethnographic books written specifically on aging among older African Americans were limited. Since this dissertation research is about older African Americans and their experiences of aging with HIV, I was interested in reviewing the body of literature on African Americans and later life. The following paragraphs provide a brief overview of some of literature written by anthropologists in the area of aging as it pertains to African Americans.

The Cultural Context of Aging: Worldwide Perspectives provides a collection of chapters devoted to anthropological research on aging and includes a few chapters on older African Americans (Sokolovsky 1997; 2009b). The major focus of the chapters on African Americans and aging describe how adversity and inequality (e.g. racism, disability, and poverty) may negatively influence health status and other opportunities in life but do not necessarily correlate with negative life satisfaction for older African Americans. Some of the main topics highlighted in the chapters are Multiple Jeopardy vs. Ethnic Compensation theories of aging, the important role of grandparents in African American social networks, and the use of culturally relevant concepts, such as wisdom and maturity rather than old age.

Section IV³ and Chapters 12⁴ and 20⁵ in *The Cultural Context of Aging: Worldwide Perspectives* describe to what extent ethnicity may make a difference in the experience of aging and critiques the use of various hypotheses to understand minority aging (Sokolovsky 2009c). The Multiple Jeopardy Hypothesis refers to how minority status and old age are assumed to be associated with increased disadvantages and inequalities (Sokolovsky 2009c). Whereas, the Ethnic Compensation perspective suggests that while older minorities may experience more inequality or disadvantages, older minorities have developed mechanisms for resisting adversity (Sokolovsky 2009c). Anthropologists in aging research tend to support the Ethnic Compensation perspective as a means for understanding minority aging. However, Sokolovsky discusses the important policy implications of overly simplistic perspectives to explain experiences of aging among minorities (Sokolovsky 2009c). Policies informed by the

³ Section IV of 1997 and 2009 editions are similar.

⁴ Chapter 12 is from the 1997 edition

⁵ Chapter 20 is from the 2009 edition

Multiple Jeopardy Hypothesis may provide more funding because of the emphasis on the inequalities in aging (Sokolovsky 2009c). Policies informed by the Ethnic Compensation hypothesis, emphasizing only the positive or adaptive strategies of aging minorities, might try to reduce funding or social services (Sokolovsky 2009c). Most literature on ethnicity tends to fall into the two extremes, either negative or positive understandings of aging (Sokolovsky 2009c). Research on aging minorities is in need of additional theoretical frameworks (Sokolovsky 2009c).

Chapter 23, “Aging, Disability, and Ethnicity: An African American Woman's Story”, written by Deppen-Wood et al. (1997) provides an in-depth case study on Ms. Evers, an older African American woman with polio. The authors critiqued the use of the Multiple Jeopardy Hypothesis because it failed to recognize how cultural context, life events, and the individual played a role in how aging was experienced or perceived (Deppen-Wood et al. 1997). The Multiple Jeopardy Hypothesis assumes that minority status and old age correlate with negative life experience (Deppen-Wood et al. 1997). This book chapter, which details the life-long experiences of living with polio, a physical impairment, discussed the ways Ms. Evers' life story challenged the Ethnic Compensation hypothesis (Deppen-Wood et al. 1997). Despite experiencing a lifelong disability and the consequent adversity, Ms. Evers learned how to reorganize her life in response to polio, in order to participate “in meaningful activities” (Deppen-Wood et al. 1997). The authors argue that health or minority status do not determine how life is experienced/perceived, nor does it determine well-being or life satisfaction (Deppen-Wood et al. 1997).

Chapter 19, “Uncle Ed, Super Runner, and the Fry Cook: Old Men on the Street”, written by Sokolovsky and Cohen (1997) was not specifically focused on African American aging but provided a case study of Miles, an older African American man living on the streets of New York, in an area known as The Bowery. The story of Miles, “the fry cook”, provided a life history of how a series of life events related to health problems and job loss influenced his transition to a life on the streets (Sokolovsky and Cohen 1997). Miles’s story provided some of the larger challenges that older men living on the streets may experience. Miles struggled with finding proper housing and chose street living instead of the poor housing conditions of single room occupancy (SRO) homes (Sokolovsky and Cohen 1997). His story also described how older men are often targeted for attacks on the street and the strategies of resilience such as drinking alcohol and networking with older men in order to survive street living (Sokolovsky and Cohen 1997).

Chapter 24, “African Americans Growing Older in Chicago: Living in a Time and Place of Change”, by Iris (2009) discusses how older African Americans are important assets to the community and maintaining social ties. Iris’ (2009) research is a three-year qualitative study of ten older African American men and women living in Evergreen, Chicago. Iris (2009) collected life history narratives in addition to information on social and family networks and health histories in order to learn about health beliefs and aging. The research by Iris highlighted the important role of elder African Americans in providing for their families and larger social networks. Grandparenting was one of the major ways these elders were instrumental in the support of

their families. Iris highlighted how older African Americans had an important role in the providing resources and maintaining social ties to the community.

Chapter 25, "Age of Wisdom: Elderly Black Women in Family and Church", by Peterson (1997) discussed how research on perceptions of aging among older African American women should focus on the meaning of wisdom rather than the meaning of aging or old age. Peterson emphasized that wisdom was a more culturally relevant word for discussing aging among older African American women. Wise women were perceived to be nurturers and disciplinarians. Wise women also helped to maintain strong kinship ties by helping to take care of children. Peterson discussed how maturity is usually associated with overcoming a struggle or becoming a grandparent. It is important to recognize the role of cultural context in understanding maturity. Peterson discussed how perceptions of aging and maturity were greatly influenced by African American cultural heritage and experiences of "slavery and oppression within a dominant white culture" (Peterson 1997). Additional insight was given about how the age of becoming a grandparent was related to the life course of African Americans. Among African Americans, being between the ages of 42 and 57 was perceived as the appropriate time for becoming a grandparent, whereas becoming a grandparent between the ages of 25 and 38 was disruptive to normal life course expectations and responsibilities. Peterson also discussed how older African American women often provided services to their church and in return received material or emotional support and leadership roles. In summary, Peterson's (1997) research on perceptions of aging and the life course among African Americans emphasized how lived experiences,

associated with grandparenthood and overcoming struggles, were related to ideas about wisdom and maturity rather than chronological age.

Outside of the chapters in *The Cultural Context of Aging* by Sokolovsky (1997); (Sokolovsky 2009b) on minority aging, there are a limited number of anthropological research articles on African Americans and later life or aging. Becker and Newsom's (2005) research provides some of the most informative work on aging minorities, chronic illness and the life course. The article, "Identity and Resilience Among Persons with HIV: A Rural African American Experience", by Becker and Newsom (2005) provided an overview and critique of gerontological literature on older African Americans and researched how older African Americans reorganize their lives in response to adversities and illness. The authors pointed out that gerontological literature has provided very little emphasis on understanding how older African Americans experienced living with chronic illness later in life. Their key criticisms of gerontological literature on aging African Americans were (1) the emphasis on pathologies and deficit models of aging, (2) the focus on African Americans as a homogenous population, and (3) the lack of attention to socio-cultural and historical context in shaping the lived experiences of older African Americans (Becker and Newsom 2005). They critiqued the Double Jeopardy Hypothesis⁶ as an inadequate way to understand the experiences of aging among African Americans. As stated by Becker and Newsom, hypotheses on minority aging often focused on the "pathologies and deficits" without recognizing the ways older minorities drew from cultural resources as a mechanism for dealing with inequality and chronic illness (Becker and Newsom 2005:S214). This hypothesis did

⁶ Double Jeopardy is a hypothesis that is similar to the Multiple Jeopardy Hypothesis that was discussed in the previous section

not take into account the cultural contexts and the lived experiences of individuals and how they interpreted their own illness experiences. It also did not consider how resilience or resistance to inequality could positively impact the health of older minorities.

The research by Becker and Newsom (2005) consisted of a longitudinal research project with in-depth interviews of 38 older African Americans. Their objective was to understand the how older African Americans responded to illness in later life and to what extent older minorities drew from cultural resources or strategies in order to deal with illness. Becker and Newsom stated that many African Americans developed strategies to deal with the challenges of racism and other inequalities and described how these strategies may help people adapt to the challenges of living with chronic illness in later life (Becker and Newsom 2005). Data analysis included thematic analysis of philosophy, autonomy, spirituality, resilience, and discrimination to understand illness experience. As a result of their research, they discovered that older African Americans often expressed resilient philosophies to dealing with living with a chronic illness (Becker and Newsom 2005). In order to gain a better understanding of aging among African Americans, future research should explore the cultural resources and strategies of resilience older adults use in different cultural contexts, how strategies of resilience in response to chronic illness will provide new insight in understanding the process of aging, and the importance of contextualizing the experience of racism in order to better understand aging among older minorities (Becker and Newsom 2005).

An article by Perkins-Taylor (2001), "Place Identification and Positive Realities of Aging", described how the life histories of older African Americans were collected to

learn about how place and identity are tied to experiences of aging. Perkins-Taylor (2001) found that despite statistics that illustrate that older African Americans have experienced increased health and economic inequalities along with discrimination, they may not necessarily identify aging as a negative process. One of the main points of Perkins-Taylor's article is that "lived experiences of the elderly play a significant role in their adjustments in dealing with later contingencies" (Perkins-Taylor 2001:8). The collection of life histories provided insight on the series of individual and community life events and challenges that people experienced (e.g. financial hardship, health problems, racism, and war). In addition, the life histories also provided information on the positive and/or negative memories associated with the place of aging and how these memories can influence the identity of older adults. Perkins-Taylor reported that the older African Americans interviewed identified the small Midwestern Town where they were from as a place of "strong community and family ties" (Perkins-Taylor 2001:16). The strong social and community ties proved adaptive in dealing with the challenges that occurred throughout their lives and in the challenges associated with aging. This research further underscored the importance of understanding how aging "in place" or how "a place" could affect the well-being of older African Americans.

Other Perspectives on Aging African Americans

Anthropologists emphasize the importance of understanding how cultural context, individual interpretations, and life histories can impact the experience of aging among African Americans. Anthropologists who study aging have critiqued simplistic frameworks used to explain the experience of minority aging such as the Double or Multiple Jeopardy Hypothesis or the Ethnic Compensation Hypothesis. Despite

critiques, anthropologists have devoted very little attention to researching and developing alternative understandings of one of the largest minority groups of older adults in the United States, African Americans. To date, very few anthropologists have studied the life course and aging experiences of older African Americans. Alternative models drawn from John Henryism and Sojourner Syndrome may provide alternative understanding of African American aging and illness experience in later life. These models look at the relationship between “race, class and gender as interlocking rather than additive” (Dressler et al. 1998; Mullings 2005; Mullings and Wali 2000). The John Henryism Hypothesis refers to folklore about an African American man who worked himself to death (Dressler et al. 1998). John Henryism reflects cultural beliefs, ideas and expectations regarding the importance of work ethic among African American men and how many may overwork themselves in attempts to succeed or overcome adversity at the expense of their health and wellbeing (Dressler et al. 1998).

Sojourner Syndrome is a similar cultural framework for understanding African American women’s experiences of dealing with the stress of managing multiple roles and responsibilities while also dealing with issues of discrimination and inequality and its negative impact on health (Mullings 2005; Mullings and Wali 2000; Upton 2003). Cultural models such as John Henryism or Sojourner Syndrome may provide some insight regarding the understanding of why older African Americans experience increased health problems and their coping strategies for dealing with challenges of inequality and chronic illness (Mullings 2005; Mullings and Wali 2000; Upton 2003). Until more research is conducted using these frameworks, it is unclear to what extent

these models can help refine ideas about the relationship between lived experience, race, inequality, and health.

Why might older African Americans be ignored in anthropology? I speculate that there are a variety of reasons why little attention has been given to aging African Americans. Historically, the field of anthropology has been dominated by white males (Lancaster and Di Leonardo 1997). While the number of black anthropologists has increased since the 1970s and 1980s, black anthropologists make up a small proportion of all anthropologists today (Association of Black Anthropologists 2012). In addition to this, the study of aging and old age is not an area of study that is emphasized by black anthropologists. Perhaps, this is also an issue related to exoticism in anthropology. Anthropologists, regardless of whether they are white or black, may not find the study of older African Americans to be “exotic” enough. When white anthropologists have studied African Americans, they tend to focus on “exotic” African Americans, such as those who are living in poverty, are using drugs, and/or are homeless (Lancaster and Di Leonardo 1997).

Another explanation for avoiding the study of aging African Americans is that anthropologists may be concerned about misrepresenting African Americans (Lancaster and Di Leonardo 1997). The extent to which a person can study a culture that is different from their own is a popular debate in Anthropology. Some anthropologists argue that being a member of the cultural group can also bias a person’s research while others argue that being an outsider can also bias a person’s research. This dissertation brings attention to the need for research on an understudied area in anthropology. Anthropologists can provide important insight by studying minority aging, especially

among older African Americans. It is important to take into account multiple variables in order to gain a better understanding of experiences in later life. Anthropologists can help shift current “tunnel vision” emphasis in literature that describes aging exclusively as a negative or a positive experience. The literature needs more variety in theoretical frameworks of how old age and aging are understood, experienced and perceived among older African Americans.

Therefore, in order to allow for a more holistic understanding of this topic area, which is fundamental to this dissertation, several key works in sociology and gerontology that can help provide some additional insight on aging among African Americans will also be discussed. Literature from sociologists and gerontologists can help provide a broader understanding of aging among African Americans by focusing in on the structural and biological components of aging.

Communities of Care Ball et al. (2005) and *A Different Shade of Gray* (Newman 2003) are two important examples of in-depth research that provides insight on the social and structural concerns related to minority aging. The research is complementary to anthropology because they include in-depth interviews and provide a more ‘ethnographic’ approach to research among older African Americans. Both books rely on national statistics and qualitative/quantitative data for their research analysis. The research is sociological in nature because they emphasize larger structural issues and provide information on policy implications and reforms.

Communities of Care Ball et al. (2005) examined different types of assisted living facilities (ALFs) from a variety of different perspectives in order to learn about the range of experiences at ALFs. The perspectives were obtained from three categories of

individuals including the individuals who ran the facilities, the individuals who lived in the facilities, and the family members of individuals who lived in the facilities. Ball et al. (2005) provide a discussion of how to reform policies to better improve the conditions and options for elderly African Americans. They examined why people go into ALFs and their experience of being there and then provided data on the range of different types of ALFs. The main argument by Ball et al. (2005) was that smaller scale ALFs could be an important and supportive environment for older African Americans who are unable to afford larger scale or more luxurious ALFs. Unfortunately, the smaller scale and independently owned ALFs are usually unable to make large profits like other forms of assisted living. Smaller scale ALFs are often overburdened with excessive paperwork that becomes unmanageable for the owner. As a result, many of the smaller scale ALFs often risk losing out on funding and/or support mechanisms that help them stay in business. This research helps address important questions regarding how race, gender, and culture affect the quality of, access to, and cost of care. These questions have broad implications for the policy, administration, and operation of smaller scale ALFs.

Newman (2003), an anthropologist by training, has since shifted to a more sociological approach and explored in *A Different Shade of Gray* how the experiences of aging among marginalized minorities in the inner city was drastically different from people with higher socioeconomic status and were aging in other places. The life histories of middle aged and older African Americans, Puerto Ricans, and Dominicans in New York City were used to help examine the particular experiences and contexts that shape the social and economic status of older minority adults. Newman's major

argument was that despite the resilient strategies of inner city elderly, many were aging “faster” than other older adults because of the lifelong racism and inequalities in health, economics, and education that shaped their pathways to old age. Newman’s (2003) research aimed to improve and reform policies that many older minorities relied on and provided an insight on developing alternative forms of support for this marginalized group of older people.

In summary, sociological research on older African Americans focuses on larger structural issues and concerns related to policy reform. By understanding how sociologists focus on aging among older African Americans, anthropologists can have a better understanding of the larger social and structural environment in which aging takes place.

The following articles by Taylor et al. (2009) and Jackson and Sellers (2001) provide insight on some of the more contemporary gerontological research on older African Americans. “Organizational Religious Behavior Among Older African Americans” explores gender differences among older African Americans in relation to participation of religious activities (Taylor et al. 2009). The research draws from a subgroup taken from a larger survey administered through a National Survey of American Life. The authors provided a literature review on the relationship between religious involvement and African Americans. Taylor et al. (2009) suggest that while African Americans often report high involvement in religious activities, participation in religious activities tends to increase with older age. Taylor et al. (2009) also note that little is known about how much time older African Americans spend participating in religious activities or what types of religious activities they participate in. Their research

confirmed the high level of religious participation by older African Americans. Men reported spending more time in religious activities than women, and they discovered that men participated in a wider range of church-related activities in comparison to women. Religious activities for men included various leadership roles, business meetings, choir, and Bible study, but also included unstructured non-ministry activity at the church such as maintenance work. Conversely, women mostly participated in more traditional or structured church or congregation activities, such as attending service or Bible study. The increased activity of older African American men illustrated that the church “becomes a venue in which older African American men can retain or achieve important work roles, status, and prestige even if they are currently not employed” (Taylor et al. 2009:454). Taylor et al. (2009:455) note that Black churches have historically provided opportunities for participation in leadership roles and in improving human capital for black men who were unable to participate in leadership roles due to Jim Crow laws and other forms of racism.

Jackson and Sellers (2001) in “Health and The Elderly” emphasized the importance of a life course perspective in understanding how lived experiences, socioeconomic conditions, historical cohorts, and discrimination can impact the long-term and later life health outcomes for older African Americans. The authors discussed how more research on aging among African Americans in gerontology had begun to focus on such things as heterogeneity, vulnerabilities, and the importance of family (Jackson and Sellers 2001). Historically, most literature focused on African Americans as a homogenous population (Jackson and Sellers 2001). Instead, Jackson and Sellers (2001) support the need for research by exploring the heterogeneity of African

Americans, especially older African Americans. By exploring heterogeneity, researchers can learn about the variation in beliefs and values, socioeconomic conditions and lived experiences among older African Americans. Jackson and Sellers (2001) were particularly interested in reforming policies to address how structural barriers and discrimination impact life events, opportunities, and health outcomes for blacks across the life course. Older African Americans are one of the fastest growing groups of older adults (Federal Interagency Forum on Aging Related Statistics 2012). Family life and strong social ties are another main area of research among older African Americans (Stack 1974). Research on African Americans has identified how the strength of the family and kinship ties in with providing resources for people who experience a wide range of inequalities (Stack 1974). Jackson and Sellers (2001) urge researchers to incorporate life course perspectives in their research in order to provide a more contextualized understanding of aging among African Americans and to better inform US policy for aging African Americans.

This dissertation research draws from anthropology, sociology, and gerontology in order to provide a more informed view along with a much better understanding of the experiences of older HIV positive African Americans that were interviewed. At the same time, the comprehensive literature search that was a part of this dissertation will provide a more clear sense of where gaps exist in the literature. This research will also assist in instituting a better understanding of aging among older African Americans and the general aging experience as well as assist in establishing the future direction of further studies of this type. In summary, there are eight major points to consider prior to conducting aging research among older African Americans:

- (1) Current aging hypotheses, such as Double or Multiple Jeopardy and Ethnic Compensation, do not provide enough insight on the experience of aging among older African Americans. Researchers need to work towards developing new frameworks for understanding aging in this population. It is important to note that the types of hypotheses developed have important policy implications and can impact the types of resources and sources of support available to older African Americans.
- (2) Anthropologists recognize the importance of recognizing cultural context, individual autonomy and life events, and how they influence the aging experience for older African Americans.
- (3) Anthropologists have focused on the strategies of resistance or resilience that older African Americans use to deal with chronic illness and adversity. Older African Americans often use these strategies to draw from community resources and to make contributions to maintaining ties to the community.
- (4) The role of being a grandparent is also an important area of study in older African Americans. Research has shown that grandparents are instrumental in providing important resources for their family and in maintaining kinship ties.
- (5) Through the study of aging among African Americans, it is important to ask culturally relevant questions and to use more meaningful terminology such as “wise” or “wisdom” rather than using general terms such as “old age” or “elder”. More research is needed to understand the meaning of aging in this population.
- (6) Structural and social inequalities and policies can impact the aging experience and the access to resources and health outcomes for older African Americans.
- (7) Research has shown that older African Americans are highly religious. However, more ethnographic research is required regarding the ways in which older African Americans participate and engage in spiritual and religious activities.
- (8) Much of the research on older African Americans has focused on making black and white comparisons and in providing homogenous perspectives of older African Americans. It is important to also focus on intra-cultural variation among older African Americans. Gerontology and sociology tend to focus on larger structural implications for aging, while anthropology can provide some of the more in-depth cultural understanding of the aging experience. While the research on older African Americans is limited, the research thus far provides a general platform of ideas and a framework to draw from.

Chapter 1 discussed the literature on aging that included an anthropological approach to aging and a review of the literature on aging among African Americans. The next chapter provides an overview of an epidemiological understanding of HIV among older adults with an emphasis on older African Americans with HIV.

CHAPTER 2

EPIDEMIOLOGY OF HIV/AIDS AMONG OLDER ADULTS AND OLDER AFRICAN AMERICANS

BACKGROUND ON OLDER ADULTS AND HIV/AIDS

This dissertation aims to identify the extent to which HIV/AIDS impacts the life course expectations for older African Americans living with HIV and how these older adults reorganize their lives in response to disruptions from this stigmatizing and chronic disease. The focus of Chapter 2 is an epidemiological understanding of the history of the HIV/AIDS epidemic in relation to older adults, what is known about HIV/AIDS among older adults, and also how the disease impacts older African Americans. Throughout the history of the HIV/AIDS epidemic, research has focused primarily on younger adults. However, researchers are beginning to understand the importance of studying older people (age fifty and older⁷) with HIV/AIDS (Orel et al. 2004). Originally, older adults were thought to make up only a small percentage of HIV/AIDS cases. Throughout the HIV epidemic older adults were often ignored in HIV research and testing due to ageist beliefs that older adults did not participate in HIV risk behaviors (Mack and Ory 2003). Most researchers assumed the exposure of older adults was due to contaminated blood transfusions. According to findings by Mack and Ory (2003) while some older adults were exposed to HIV through contaminated blood transfusions, most older adults

⁷ Age 50 and older has been used in HIV research to represent older adults because HIV progression can speed up the aging process (Rickabaugh et al. 2011). Gerontologists do not consider 50 years of age to be a marker of social and behavioral conditions associated with older age (Sankar et al. 2011). Its use in HIV-related social and behavioral research may limit the validity of the findings in understanding issues associated with aging and HIV (Sankar et al. 2011).

acquired the virus through unprotected sex or injection drug use (IDU). Despite popular perceptions that older adults are not at risk for HIV, older adults have become the fastest growing age group with HIV/AIDS (Sankar et al. 2011). Currently⁸, older adults are make up about approximately 25 percent of the total number of HIV/AIDS cases in the United States and 15 percent of all new cases (CDC 2008a; b; Sankar et al. 2011). Older adults also make up 39 percent of all AIDS cases in the US (CDC 2008a). By the year 2015, the Centers for Disease Control and Prevention (CDC) estimate that older adults will account for approximately half of all HIV/AIDS cases (Effros et al. 2008). Among all older adults, the subgroup of African Americans is disproportionately affected by HIV/AIDS and account for about half of all HIV/AIDS cases (CDC 2007; 2008a; b). In Southeast Michigan, the Department of Community Health reported that the city of Detroit accounted for 52 percent of new cases of HIV and older adults accounted for 16 percent of these new cases of HIV/AIDS (Michigan Department of Community Health 2008).

Why was there an increase in older adults with HIV/AIDS? Two major factors influenced the rise in number of older adults with HIV: (1) new diagnoses of older adults and (2) improvements in highly active antiretroviral therapy (HAART) allowing people with HIV to live longer. Despite rising numbers of older adults with HIV/AIDS, older age groups are often excluded in HIV/AIDS surveillance research because of assumptions that they do not engage in HIV risk behavior (CDC 2008a; b; Mack and Ory 2003). Research by Levy et al. (2007) report that some surveys collecting data on sexual practices and HIV risk have deliberately excluded older adults because of assumptions that they would not be an appropriate source of data. For these reasons, the incidence

⁸ Current estimates from the CDC are based on statistics from 2005 and were last updated in 2008.

and prevalence and the true burden of the disease may not be fully understood among older adults (Brown and Sankar 1998). It is also important to note these biases and how they may impact current and past statistics on HIV/AIDS among older adults.

Research to date suggests that (1) ageism impacts diagnosis, treatment, prevention and perceptions of risk (Wooten-Bielski 1999), (2) processes of aging interact with HIV disease to produce increased co-morbidities and poorer immune reconstitution (Justice et al. 2001), and (3) older chronological age is associated with poorer HIV outcomes (Stoff et al. 2004). Late diagnoses along with aging may be the reason why older adults often progress to AIDS faster than younger adults, have decreased survival, and experience increased co-morbidities (Justice et al. 2001). Lack of HIV awareness among older adults and similarities between symptoms of HIV and aging make it difficult for health care providers and older adults to identify or suspect HIV/AIDS (Siegal et al. 1999; Wooten-Bielski 1999). Research on immune response to antiretroviral therapy among older adults have produced mixed results (AIDS InfoNet 2012). Some research suggests that although older adults may be more adherent to antiretroviral therapy than younger adults, their immune responses are lower. Other research suggests older adults may not respond to HAART therapy as well as younger adults because older adults may have more difficulty taking medications and they may experience increased side effects from complex drug regimens used to treat multiple health conditions (Catz et al. 2001). Overall, research to date suggests that HIV/AIDS speeds up the processes of aging in older adults resulting in increased co-morbidities in comparison to younger adults (Rickabaugh et al. 2011). Ageism has negatively

impacted prevention, detection, treatment, and research on older adults with HIV/AIDS (CDC 2008a; b).

Because of the overall increase in general medical treatments available to improve the health and functioning of the general population of older adults, many adults are healthier and are more sexually active than in previous years and are able to engage in lifelong risk behaviors associated with HIV. Increased rates of divorce and the death or abandonment of a long-term partners in later life has influenced why many older people find themselves looking for new partners and may engage in HIV risk behaviors such as unprotected sex (NIA 2008). Low condom use among older adults is due in part to perceptions that older adults are not at risk for HIV, lack of concern about pregnancy, and age-related physiological changes that make condom use problematic (e.g. erectile dysfunction) (CDC 2008a; b). US cultural beliefs about the reasons to use condoms (e.g., to prevent pregnancy, to project from risky sexual behavior) have negatively impact condom use among older adults. People who initiate the use of condoms are often associated with disease or risky behavior. Therefore, many older men and women may have difficulty initiating the use of condoms in casual or long-term partnerships out of fear of what their sexual partner may think. Older adults are also more likely to seroconvert if exposed to HIV due to changes in skin elasticity and thinning of the skin which causes more friction and tears in the skin allowing the virus to enter the body (NIA 2008). As stated above, there are many reasons why older adults are at increased risk for HIV if exposed or may not take the necessary precautions needed to protect themselves from HIV even if they have the knowledge of how HIV is transmitted and prevented.

As the population ages and people are living longer with HIV, we know very little about the socio-cultural consequences resulting from testing positive for HIV as an older adult, aging with HIV, and the ways people readjust their lives in response to living with HIV over time. Given the changing epidemiological picture of the disease, it is imperative that we initiate the study of the interaction of social and cultural features of aging with HIV. Research on older adults with HIV has not fully explored the variation in older adults' experiences with HIV or the extent to which HIV impacts life course expectations. Most HIV/AIDS related literature treats older adults as a homogenous population, which does not allow researchers to identify potential and significant variations in the experiences and outcomes of older adults with HIV/AIDS (Sankar et al. 2011).

Older African Americans with HIV/AIDS

African Americans represent an important subgroup of HIV/AIDS cases because they are twelve times more likely to be infected with HIV than other ethnic groups (CDC 2007). Although African Americans account for only 13 percent of the U.S. population, they make up approximately 50 percent of all HIV/AIDS cases (CDC 2007). The rates of HIV/AIDS among African Americans in Metro Detroit were higher than the national average and were estimated to be about 69 percent of the total number of all HIV/AIDS (Michigan Department of Community Health 2011a). Between 2004 and 2008 the number of new cases of HIV/AIDS among African American⁹ women has decreased by about 9 percent while overall they accounted for about 73 percent of all HIV/AIDS cases among women in Michigan (Michigan Department of Community Health 2011b). From

⁹ Michigan Department of Community Health reported the highest modes of transmission were 60 percent heterosexual sex and 21 percent were injection drug use (IDU).

2004 to 2008, the number of new cases of HIV/AIDS reported among African American¹⁰ men has increased by about 2 percent while overall they account for about 62 percent of all HIV/AIDS cases among men in Michigan (Michigan Department of Community Health 2011a; b). Social, economic, and political factors interact to create a wide range of inequalities that can influence differences in health outcomes and experiences of living with HIV/AIDS for African Americans in comparison to other ethnic groups. African Americans have higher burdens of disease, morbidity, and mortality rates than other ethnic groups and are often diagnosed and treated later than whites (McGinnis et al. 2003).

In research on African Americans with HIV/AIDS, most researchers have focused on ethnic group comparisons (e.g., blacks and whites) or assumed African Americans are a homogenous population rather than exploring intra-group variation. Brown and Sankar (1998) discuss the importance of understanding intra-group variation among older African Americans with HIV/AIDS. Fourteen years have passed since Brown and Sankar's (1998) article, yet very few research studies on HIV/AIDS have attempted to focus specifically on older African Americans, and little is known about intra-group variation within this subgroup. In addition to health disparities, African Americans may also experience differences in the social consequences of having HIV (Brown and Sankar 1998). For example, African Americans, in comparison to other groups, report higher HIV related stigma. Increased stigma may negatively influence their mental health status, their ability to disclose their status, and their ability to receive proper social support (Rodgers-Farmer 1999). African Americans also report increased

¹⁰ Michigan Department of Community Health reported for men: men who have sex with men (MSM) were 53 percent and IDU were 12 percent.

distrust of health research and increased dissatisfaction of health care providers which can negatively influence health seeking behavior and health outcomes. Older African Americans aging with HIV present a significant public health problem because not only do they account for more than half of older adults with HIV/AIDS in Michigan, but are also more likely to experience unequal access to care and treatment for both their HIV and other age-related health problems (CDC 2008a; b; Michigan Department of Community Health 2008). Health inequalities and a glimpse of the social consequences of living with HIV as described above can play an important role in how HIV influences the lives and illness experiences of African Americans as they age that may differ from other populations. Cultural sensitivity and recognition of how racism is interconnected with socioeconomic and health inequalities are needed in order to understand the socio-cultural consequences of living with HIV among older African Americans.

While research on older adults with HIV has focused on health status and health inequalities, we know little about the socio-cultural consequences of aging with HIV. Understanding the social consequences of living with HIV as an older adult is important in order to develop appropriate needs assessments, resources and treatments required for older adults. One way of looking at ongoing life with HIV is through the use of a life course approach. A life course approach is used in many different disciplines such as anthropology, sociology, history, psychology, gerontology and epidemiology. An anthropological approach to the life course emphasizes the socio-cultural contexts of human development rather than biological and psychological models of development. In addition, research on older adults with HIV has not fully explored the variation in older adults' experiences with HIV or the extent to which HIV disrupts life course expectations

of people as they age. This approach to studying HIV and age hinders our ability to identify potentially significant variations in the experiences and outcomes of older adults with HIV.

Research to date has focused on health, socioeconomic, and clinical challenges, however what is less understood are the socio-cultural aspects of living with HIV. This dissertation research aims to extend current HIV literature to identify and describe the social and cultural challenges of aging with HIV. How might the socio-cultural consequences of living with HIV differ for older adults or as people age with HIV? How might the challenges associated with aging with HIV disrupt the life course expectations and life course trajectories of older African Americans with HIV? As older African Americans experience higher rates of HIV along with higher rates of co-morbidities, how do these health challenges correspond with life course stage expectations and trajectories? How does living with a highly stigmatizing disease defy cultural norms and life course expectations? What are the social consequences of having HIV as an older African American? How do the social and health consequences of living with HIV challenge the life course trajectories of older African Americans with HIV?

Chapter 2 discussed what is known in the epidemiological literature about older adults with HIV and older African Americans with HIV. This chapter also outlined the history of the HIV epidemic in relation to older adults and to what extent research has explored the experiences of older African Americans who are living with HIV. The next chapter describes life course theory, the main theoretical framework of this dissertation.

CHAPTER 3

ANTHROPOLOGY OF THE LIFE COURSE

In all societies, the course of life is structured by expectations about each phase of life, and meaning is assigned to specific life events and the roles that accompany them. When expectations about the course of life are not met, people experience inner chaos and disruption. Such disruptions represent loss of the future. Restoring order to life necessitates reworking understandings of the self and the world, redefining the disruption and life itself. (Becker 1997:4)

INTRODUCTION

This chapter provides background information on the main theoretical framework used for the dissertation research known as life course theory. Life course theory is used as a conceptual guideline for exploring the research question, “How does living with HIV influence life experiences of older African Americans with HIV?” More specifically, the dissertation aims to identify (1) the extent to which HIV causes life disruption, (2) how people go about reorganizing their life in response to disruption and (3) how time and timing may influence the long term experiences of living with HIV. This chapter will provide an overview of life course theory and the major concepts known as life disruption, life reorganization, and time/timing. The primary goal of the dissertation research was to identify and describe to what extent living with HIV influences the life course expectations¹¹ and experiences of disruption among older HIV positive African Americans. The dissertation focused on how an HIV diagnosis could result in sociocultural consequences (e.g. disability, illness, loss of job, stigma) that

¹¹ As described by Fry, life trajectories refer to the series of events that occur in a person’s life and the unfolding of events that occur throughout a person’s lifetime.

affect the day-to-day lives of people and how perceptions of living with HIV could change over time.

The dissertation research draws from anthropological studies of the life course and key concepts known as life course disruption, life reorganization, and time/timing. Since 1950s, anthropologists have refined notions about the social components of human development known as the life course. In anthropology:

The life course is the culturally defined script of normatively expected stages and transitions for the socially defined person.... The life course provides a broad shared timetable for evaluating the “on-time-ness” or the “off-time-ness” of expectable events and social development, from childhood to retirement. (Scheer and Luborsky 1991:1174)

The life course is not a predetermined, static set of stages that an individual goes through. It is not predetermined by biological or psychological cycles or spans of life. The way in which the life course is expressed among individuals or groups depends on the interplay of different factors including culture, individual agency, social structure, history, time, place, setting, political economy, and social interaction. In all cultures, the life course is structured by expectations about each phase of life (Becker 1994). Meaning is assigned to phases of life (e.g., adulthood) and roles associated during these phases of life (e.g., driving, voting) (Becker 1994).

In *The Life Course as Cultural Construct*, Fry describes four key components to understanding an anthropological approach to the life course: (1) Temporal Phenomena, (2) Individual Phenomena, (3) Socio-cultural Phenomena, and (4) Complex Phenomena (Fry 2003). Temporal Phenomena refers to the importance of understanding cultural construction of time in relation to the life course and how aging is

a lifelong process throughout the life course (Fry 2003). Individual Phenomena refers to individual uniqueness and autonomy of life course experiences and the individual's own interpretation of and influence on the life course (Fry 2003:273). Sociocultural Phenomena refers to how individuals experience their life course within a specific sociocultural context and the influence of the sociocultural context on life course expectations (Fry 2003). Lastly, Fry describes the life course as Complex Phenomena because of the multidimensional nature of the construct (e.g. biological and social age, individual autonomy, cultural context). Because the life course framework is complex, it encourages the integration of ideas and methods from many different disciplines and perspectives (Fry 2003). In summary, a life course approach is a set of conceptual and methodological tools for enriching our understanding of the many domains in which human lives unfold. A life course approach is a useful tool for studying HIV and aging because it brings us closer to studying the whole person by focusing on the multidimensional aspects of a person's life and understanding a person's life over a longer period of time.

BECKER'S FRAMEWORK OF LIFE DISRUPTION AND REORGANIZATION

Life disruption and life reorganization are important components of the life course perspective and are two of the primary analytic constructs used to frame the dissertation research. Becker's (1997) discussion in *Disrupted Lives: How people create meaning in a chaotic world* describes concepts of life reorganization and disruption that will be used to evaluate how and to what extent HIV disrupts the lives of older African Americans. A life reorganization perspective identifies how people reorganize their life in response to a disruption (Becker 1997). Life disruption occurs when something such as an event

(e.g. car accident) or illness (e.g. HIV diagnosis) alters the normal expectations for a particular phase of life. Becker's research centers on how people reorganize their lives or learn to create meaning of the life disruptions they experience.

Becker's research on people seeking treatment for infertility found that when expectations about the life course (e.g., expectation to have children) are not met (e.g., difficulty conceiving, infertility), people often experience "inner chaos and disruption" in their lives (Becker 1994). Disruptions create disconnects in the individual's expectations and perceptions of how life is supposed to occur in the future. Becker discusses how in the United States the life course, or how life is supposed to occur, is often thought of as a linear and orderly set of phases and expectations. In the United States, cultural beliefs emphasizing individualism, self-responsibility, and a linear life course influence how people respond to disruption and shape why people often feel the need for creating a sense of continuity after a disruption. Becker refers to continuity as the process of recreating order or reorganizing life after a disruption. By studying the disruptions in a person's life we can look at the conflict between cultural beliefs and ideals of how things should be in comparison to how they actually are. The ways people interpret and make sense of a particular disruption may differ depending on a wide range of factors (e.g. timing, individual life experiences). Becker's approach to understanding the life course includes not only the person's individual life experiences and values but also the cultural ideals of what life should have been like prior to an "event" and the ways in which people respond or reorganize in response to a disruption. By utilizing the disruption and reorganization approach, researchers can identify culturally perceived barriers to what happens when life course expectations are not met.

Becker's approach to the life course focuses primarily on life disruption, reorganization, and continuity.

A life course reorganization approach to understanding HIV experience emphasizes how a stigmatizing and chronic illness such as HIV may disrupt a person's ability to fulfill normative life course expectations. In addition, the ability to fulfill stage specific roles may vary and change over time depending on the timing or life course stage of living with HIV (Becker 1994; Luborsky 1994a; b; c). Drawing from Becker's conceptual framework, this dissertation evaluates how and to what extent HIV disrupts older African Americans lives and the ways they reorganize their life in response to the disruption. The types of disruptions older African Americans with HIV experience may differ from those of other ethnic groups (Deppen et al. 1997). This research hypothesized that there may be different patterns of life reorganization based on the timing of HIV diagnosis. Examples of questions drawing from a life reorganization approach include: (1) How might an HIV diagnosis influence a person's life goals and expectations? (2) In what ways has HIV impacted your life goals and expectations? (3) What was your initial response to being diagnosed with HIV? (4) Have your perceptions of living with HIV changed over time? (5) After learning about your HIV status, what are the ways in which you have or have not reorganized your life?

Other Research on Life Disruption and Reorganization

Since Becker's work on life course disruption and reorganization, other researchers have drawn from Becker's research to examine alternative perspectives on how people make sense of illness experience (e.g., Bletzer (2007); Hinojosa et al. (2008). In "Constructions of Continuity after Stroke", Hinojosa et al. (2008) analyzed the

perceptions of veterans one month after being hospitalized for a stroke. Their research emphasized concepts of constructing continuity because some veterans did not experience change/disruption since onset of stroke and constructing disruption because other veterans experienced change/disruption since onset of stroke. Hinojosa et al. found that while the majority of the veterans interviewed were constructing disruption, the main area of emphasis for their article was on how some of the veterans were constructing continuity. The authors presented the concept of constructing continuity to contrast with Becker's (1997) framework of life disruption. The authors discussed how cultural perceptions of aging as a gradual decline and the use of religion to deal with difficult situations were two important factors to explain why some people constructed continuity after a stroke. Hinojosa et al.'s research discussed how interpretations of stroke may differ and that some people may not view stroke as a disruption. The onset of illness such as a stroke may not result in disruption and some individuals may experience continuity after stroke.

Hinojosa et al.'s research is presented to provide an alternative perspective on Becker's framework that illness results in disruption. After reading the article by (Hinojosa et al. 2008) and comparing it to Becker's (1997) research on life reorganization and continuity, it seemed that Becker did not expect all people who experience illness to experience disruption. Instead, Becker focused on disruption as a rich area of study to understand what happens when life course expectations are not met and how people make sense or reorganize their lives in response to disruption. Hinojosa et al.'s emphasis on response to illness experience as constructing continuity is a slightly different emphasis than Becker's. Hinojosa et al. were interested in why

some people experienced continuity after an illness that is often assumed to be disruptive. Both perspectives provided important insight into understanding what happens after an illness and why some people experienced disruption and why some people experienced continuity. An understanding of the possibility of disruption and/or continuity is essential in understanding what happens after the onset of illness. This discussion of disruption and continuity after the onset of an illness will be further addressed in the findings and discussion of this dissertation.

Bletzer's (2007) research article, "Identity and Resilience Among Persons with HIV: A Rural African American Experience", explores the life histories of two HIV positive African Americans and provides information regarding how people respond to an HIV diagnosis. Bletzer's (2007) article is framed as a counterargument to Becker's framework on life course disruption and reorganization. The life stories of James and Amanda described living with HIV as an interruption rather than a disruption. Bletzer (2007:172) states that "disruption from having HIV is not imbued with disappointment and confusion" as emphasized in Becker's research on disruption resulting from illness. This article is useful in that it provides an alternative perspective that disruption is not necessarily a consequence of an illness (an often assumed disruption). James and Amanda emphasized reorganization and resiliency rather than disruption.

In reviewing Bletzer's (2007) discussion, it is important to note that only two histories out of a sample of 127 participants' life histories were included for discussion in his paper. While Bletzer provides a rationale for the selection of James's and Amanda's stories, Bletzer does not provide an explanation or brief overview of the findings from the other 125 participants. This lack of discussion makes me curious as to why Bletzer

left out these details. If the author had such a large sample to draw from, then why did he only include in the article the stories from only two individuals? Were James and Amanda presented because they were the only two individuals interviewed that contrasted Becker's model? How did the other 125 participants' stories compare to the two stories he discussed in the article?

The approaches of Becker, Hinojosa et al., and Bletzer will be discussed later on in the findings and discussion of this dissertation. Becker's research provided the major theoretical framework for the development and analysis of this research. However, Hinojosa et al. and Bletzer provided additional and alternative insight into how people may interpret and respond to the onset of an illness. These three perspectives will be considered in making sense of the findings from the 13 older African Americans included in this dissertation research.

LIFE COURSE CONSTRUCTS OF TIME AND TIMING

Time and timing were other important constructs of life course theory. This dissertation underscores the importance of understanding the meaning of time and timing to identify and describe how HIV experiences and expectations may change as older African Americans age with HIV. Anthropologists have uncovered the deeply rooted cultural meanings and expectations associated with time. Measures of time are culturally constructed and cross-culturally variable (Trostle 2005). Anthropologists recognize how time is related to social development and to the social organization or structure of a society. In the United States, chronological age is often used as a marker of important socially defined roles and the expectations associated with various phases of life such as youth, adulthood, and old age (e.g. driving, voting, drinking, social

security). Chronological age can be used as a general guideline in the life course in the United States. However, chronological age alone does not necessarily determine or define where a person is situated within in the life course and may not provide the same meaning in different cultural contexts.

As discussed by Settersten (2003) in “Propositions and Controversies in Life-Course Scholarship”, there are various ways of measuring time in the human life course: (1) historical time, (2) lifetime (e.g. the number of years since birth), and (3) social time (e.g. work, voting). Settersten describes how chronological age often functions as a mechanism for plotting social and cultural expectations about experiences, roles and events that should happen throughout a life or lives (Settersten 2003). Chronological age can function as a means for organizing social structures of society along with regulating relationships between members of a society.

Time and Timing in HIV/AIDS Research to Date

The application of time and timing in research to date on aging with HIV/AIDS has focused on relatively specific areas such as duration of HIV/AIDS, prevention/detection/treatment and quantitative and cross-sectional measures of clinical or psychosocial status. The first main area of HIV/AIDS research on time is in the area of the duration of HIV/AIDS. Advancements in antiretroviral therapies (ARTs) have dramatically increased the length of time that individuals are living with HIV/AIDS and are allowing many individuals to live into old age. HIV has changed from a once acute disease to a disease that is more long-term and chronic. HIV/AIDS is presently incurable but is often managed with medications. As a result, HIV/AIDS research has emphasized increasing the duration of living with HIV/AIDS by exploring the complex

interaction between the progression of the virus and the aging body and the efficacy of ART.

The second main area of where time has been a useful area of study in HIV/AIDS research is in the area of prevention and detection and treatment. Cultural beliefs about older adults as being “off time” for engaging in HIV/AIDS risk behavior have negatively impacted prevention, testing and treatment. As a result, older adults have been ignored throughout the HIV/AIDS epidemic and in prevention and detection efforts. However, more recently researchers have discovered how timing has become more important in understanding HIV/AIDS because of the increased number of people being diagnosed with and aging with HIV/AIDS. Despite increases in the total number of older adults living with HIV/AIDS, there is often a delay in the timing of diagnosis and treatment of older adults. As a result of delayed diagnosis and treatment, older adults can experience faster progression of the virus and increased co-morbidity which can negatively impact the long-term prognosis and the overall experience of living with HIV/AIDS.

The third main area in HIV/AIDS research on time is in the use of cross-sectional and quantitative measurement of psychosocial and clinical status. This area of HIV/AIDS research tends to utilize snapshots of HIV/AIDS experience and quantitative measures such as CD4 counts/viral load measures, depression, adherence to HAART, quality of life, stigma, and physical functioning. In summary, HIV/AIDS research has utilized the concepts of time and timing mostly in relation to duration of HIV/AIDS, prevention, detection, and treatment and cross-sectional, quantitative measures of psychosocial status. These measures can provide important information about

experiences of living with HIV/AIDS. However, what is unknown is the extent to which quantitative, cross sectional measures can capture the wide-range and long-term experiences of people who are aging with HIV/AIDS. Despite what has been discussed in research to date in HIV/AIDS, there are still ways in which the study of time can provide additional insight into the experience of aging with HIV/AIDS. The next section of this chapter discusses how this dissertation research provides insight on an under-researched application of time and timing among HIV positive older adults.

Time and Timing: Making Sense of Qualitative and Longitudinal Data

Looking beyond what was discussed in the previous section on how time has been understood in HIV/AIDS research to date, it is important to note that little is known about how the length of time living with HIV and the timing of living with HIV can impact the socio-cultural experiences of people who are aging with HIV/AIDS (Stoff 2004). Therefore, this section of the chapter aims to incorporate the use of time and timing in a different and less understood way by focusing on the sociocultural consequences of living with HIV/AIDS rather than an emphasis on the clinical duration, prevention/detection or cross-sectional psychosocial measurements of aging with HIV/AIDS. As will be discussed in Chapter 6 of the findings, the way the sociocultural consequences of living with HIV/AIDS were explored was through the identification of the presence of HIV disruption and/or reorganization at earlier and later phases of living with HIV/AIDS. In addition, Chapter 6 will provide insight into the ways the sociocultural consequences in the form of life disruption and reorganization may change over time.

The purpose of exploring time in relation to life disruption and reorganization was to learn about the wide range of experiences that people may undergo while aging with

HIV/AIDS. After the initial HIV diagnosis, the interpretation of the illness experience can be shaped by challenges, disruptions, periods of stability, and various other factors that occur throughout life. The challenges and concerns of people living with HIV may differ depending on the timing (e.g., early/initial diagnosis and later phase of living with HIV/AIDS, start/end of ART). As will be discussed in Chapter 6, the focus on timing (e.g. early and later phases of living with HIV/AIDS) and the comparison of points in time was to provide important insight into the experience of life course disruption and reorganization among older African Americans living with HIV/AIDS. This approach was used to help fulfill a need for information on the long-term sociocultural consequences of aging with HIV/AIDS and the extent to which disruptions from living with HIV/AIDS may or may not change as one ages with HIV.

The dissertation also extends a discussion by Merriam et al in “Time and Its Relationship to Development in the Life Course: Some Reflections From a Study of HIV-Positive Adults” about how the use of chronological age does not provide enough insight on the experience of living with HIV (Merriam et al. 2001).¹² This article provided some insight and starting points for thinking about the experience of living with HIV with a life course perspective. Merriam et al. (2001) emphasized how looking beyond chronological age is needed to explore the importance of historical and social timing to help explain the experience of living with HIV. A person’s life history, timing of HIV diagnosis in the life course, and length of time living with HIV can have an effect on life pathways, expectations, quality of life, and illness experiences. Living with HIV as an older adult may bring about unique challenges and experiences that may differ from

¹² Merriam is not an anthropologist. Merriam’s background is Adult Education. However, the article is relevant in addressing the social and biological aspects of age.

living with HIV as a younger person. For example, people diagnosed in their 30s or 40s may worry that HIV would disrupt their ability to have children, whereas people in their 50s may worry that HIV would influence their ability to see their grandchildren grow-up. A life course approach helps identify if there are differences in illness experiences depending on the phase of the life during which an older adult is diagnosed, the historical cohort they are diagnosed with HIV, and/or the duration of living with HIV. As described earlier, an aim of this dissertation research was to describe the importance of time and its role in shaping the experiences of living with HIV at different points throughout the life course. Potentially there could be a range of experiences and concerns about HIV for people aged 50 and older, depending on the timing of their diagnosis and the phases of life in which they live with HIV. Example probes that were asked of interviewees to determine the construction of the life course approach and time included: (1) Tell me the story of your life (2) When were you diagnosed with HIV? (3) Tell about your life since living with HIV, and (4) How has HIV influenced your life over the years?

In summary, an anthropological approach to life course theory underscores the culturally meaningful aspects of aging and provides insight about the culturally shared expectations that individuals have that are associated with various phases of the life course. By recognizing the culturally defined and shared expectations that individuals have about the life course, then we can arrive at a better understanding of the ways in which lives can be disrupted and the strategies people use to reorganize their lives in response to disruptions they experience.

Chapters 1 through 3 in the first section of this dissertation provided an overview of the background and significance on a life course approach to understanding the experiences of older African Americans who are living with HIV. Chapter 1 reviewed the history of anthropology and aging literature with a focus on older African Americans. Chapter 2 provided an overview of understanding the epidemiology of HIV among older adults and older African Americans. Chapter 3 discussed and described an anthropological approach to the life course as the major theoretical framework for this dissertation. In Chapters 4 and 5 in the next section will provide information about the design, methods, sample, and research site for this dissertation research.

SECTION II

PROJECT OVERVIEW

Section II is divided into two chapters. Chapter 4 provides an overview of the design, methods, sample, and analysis for the dissertation research. Chapter 5 provides past and present background information about the city of Detroit, the primary research site for this dissertation research.

CHAPTER 4

DESIGN, METHODS, AND SAMPLE

Chapter 4 is divided into two main parts, Part I and Part II. Part I describes the longitudinal design of this dissertation research along with an overview of the methodology, sample characteristics, research domains and analysis procedures. Part II describes the process of “getting the data” for a longitudinal research project with a focus on the challenges and contexts of recruiting participants and conducting interviews.

CHAPTER 4, PART I: DESIGN, METHODS, SAMPLE, AND ANALYSIS

A longitudinal approach was used to study the nature and the meaning of living with HIV among older HIV positive African Americans. This longitudinal study consisted of secondary data collected from older HIV positive African Americans during the HAART Project (n=43), follow-up dissertation interviews with a smaller subsample of the older adults from the HAART Project (n=13), and interviews with health care professionals (n=3) knowledgeable of HIV and aging.

HAART Project

Part of the data used for this dissertation research stems from a larger study called the HAART Project. The HAART project took place from 2002 to 2008 and was a longitudinal study of adherence to anti-retroviral therapy among HIV positive African Americans in Detroit [NIH #RO1AI049113]. Participants were interviewed up to eight times over a period of five years. Data from the HAART project provided important

background information for developing the research questions specific to HIV and aging and also provided the sample of older adults with HIV/AIDS (Sankar et al. 2002-2006). The HAART project data consisted of both qualitative (e.g. life history narratives, HIV narratives) and quantitative measures (e.g. demographic, psychosocial, clinic data).

HAART Project Sample

The original HAART project sample included 138 HIV positive African Americans from the Detroit area. Participants were divided into two major groups based on length of time on medication, (1) “long-term”¹³ (n=96) and (2) “naïve”¹⁴ (n=42). The participants ranged in age from 23 to 84 years old. Approximately 65 percent of participants were men (n=90), 34 percent were women (n=47), and 1 percent were transgender (n=1). As of 2009, 95 participants were 49 years of age and younger while 43 were age fifty and older. The majority of the participants were diagnosed during the HAART era¹⁵ (n=98) while the other participants were diagnosed during the AZT era (n=37) or diagnosed pre-AZT (n=3). Of the 43 older adults in the sample, 74 percent “aged in”¹⁶ with HIV (n=32) while 26 percent were diagnosed with HIV as an older adult¹⁷ (n=11). The majority of the older adults were diagnosed in the HAART era (n=30) and the remaining people were diagnosed in the AZT era (n=13).

¹³ “Long-term” participants had taken HAART medications for 6 months to 3 years.

¹⁴ “Naïve” participants had taken HAART medications for 3 months or less.

¹⁵ HAART era 1996-present, AZT era is 1987-1995, Pre-AZT is pre-1987

¹⁶ “Aged in” refers to people diagnosed with HIV prior to age 50 but have aged with HIV to age 50 and older.

¹⁷ Diagnosed with HIV at age 50 or older

Dissertation Project

The dissertation research and writing process took place over a period of five years. Proposal and grant writing took place from June 2007 to August 2008. The study was approved by the Human Investigation Committee (HIC) at Wayne State University in September 2008. Participants were recruited and interviewed from December 2008 to September 2009. Interviews were transcribed from January 2009 to January 2010. Analysis and writing took place from January 2009 to 2012.

Dissertation Study Characteristics

The following list provides an overview of the study characteristics for the dissertation research:

- (a) Recruitment. At the conclusion of the HAART Project, all participants were asked for permission to be contacted for future research studies. All forty-three of the older adults agreed and signed a release to be contacted for future research. Contact via telephone was attempted for all of the older adults who consented to follow up research.
- (b) Inclusion. Sero-positive status, age fifty and older as of 2009 (the start of the dissertation study), self-identified as African American, and a participant of the HAART project.
- (c) Exclusion. Cognitively impaired, people dying from another disease, people suffering from an uncontrollable illness, and people who were living in a hospital. The reasons why these factors were part of the exclusion criteria of the project were because of extensive mental, physical and/or cognitive conditions that could interfere with a person's ability to be interviewed. People who did not participate in the HAART project were excluded.
- (d) Screening. Older adults were originally screened for HIV status and ethnicity when they were included into the HAART Project. Screening for the dissertation research focused on consent to participate in a follow-up interview and to confirm their health status (e.g., able to participate in an interview, not hospitalized).

- (e) Attrition. Due to the risks involved in relying on a limited number of potentially hard to reach participants from an already existing sample, alternative strategies were prepared as a backup to the original goals and aims. For example, alternative goals and aims included: (1) revising research questions to address the sample available (e.g., all women sample might have changed the focus to later life course for older women); (2) conducting multiple interviews with a smaller number of participants; (3) recruiting new older adults with HIV outside of the HAART Project; (4) focusing more on health professionals knowledgeable of HIV and aging.

RESEARCH PHASES

The dissertation consisted of two main phases of research to (1) organize and develop background information on HIV and aging and (2) conduct follow-up interviews with older participants from the HAART project.

Phase 1

The goal of Phase 1 was to (1) organize, refine, and analyze an existing data set on older African Americans with HIV (N=43), (2) conduct semi-structured interviews with health care professionals (HCP)¹⁸ knowledgeable of aging and HIV, and (3) utilize the background information on older adults with HIV to develop the questionnaire.

Health Care Professionals

The interviews with the health care professionals were used as a strategy for developing a questionnaire for the older adults with HIV and for establishing rapport with professionals working with older adults with HIV in case there was difficulty in recruiting from the HAART project. One HCP in particular was approved by the HIC to provide updated contact information for potential HAART Project participants. Interviews with the HCP took place at a location of their choice (e.g., office or coffee shop). The

¹⁸ See Appendix C: Interview Questions for Health Professionals

interviews were audio-recorded and lasted approximately 1-2 hours. General note taking during the interviews was used instead of verbatim transcription of the interviews.

Three health care professionals (one man and two women) were recruited and interviewed from Detroit area infectious disease clinics and the department of public health. The professionals were selected because they worked with, treated, or interacted with some of the older adults from the HAART project or were knowledgeable about older adults and HIV. The sample of health care professionals included a nurse practitioner, a research nurse, and a public health administrator. Interviews with the health care professionals were used to collect background information on HIV and aging and to assist in obtaining updated contact information on lost-to-follow-up participants. The data collected from the interviews with the health care professionals was used to help identify topics or questions for the interviews with the older adults with HIV.

Phase 2

The goal of Phase 2 of the dissertation research was to collect new data focused on HIV disruption, life reorganization and aging through one semi-structured, face-to-face interview with each older participant recruited from the HAART project. Interviews with the older adults included follow-up questions from the HAART Project but emphasized learning about the experiences and challenges that occurred as people learned to live and age with HIV¹⁹. A purposive sampling strategy was used to correspond with the design of the research project that was based on (1) a meaning centered approach and (2) a hard-to-reach population (Bernard 2002). Follow-up interviews were attempted with all of the older adults from the HAART Project (N=43).

¹⁹ See Appendix D: Interview Questions for Older Adults

However, only 14²⁰ interviews were conducted because the remaining participants were either lost to follow up (N=17) or deceased (N=13). The participants who were interviewed were given twenty-five dollars as compensation for their time and for participating in the dissertation study. The participants were given the option of an on-campus interview or an in-home interview. The majority of participants (77 percent) chose the in-home interviews for various reasons, such as lack of transportation, convenience, and/or health problems (e.g., disability). The interviews were not conducted all at once but instead were spread out over a period of about nine months to allow for questionnaire refinement, verification that the data collected addressed the specific aims and goals of the study, and for developing ways to probe on key topics in the remaining interviews.

Dissertation Sample of Older Adults

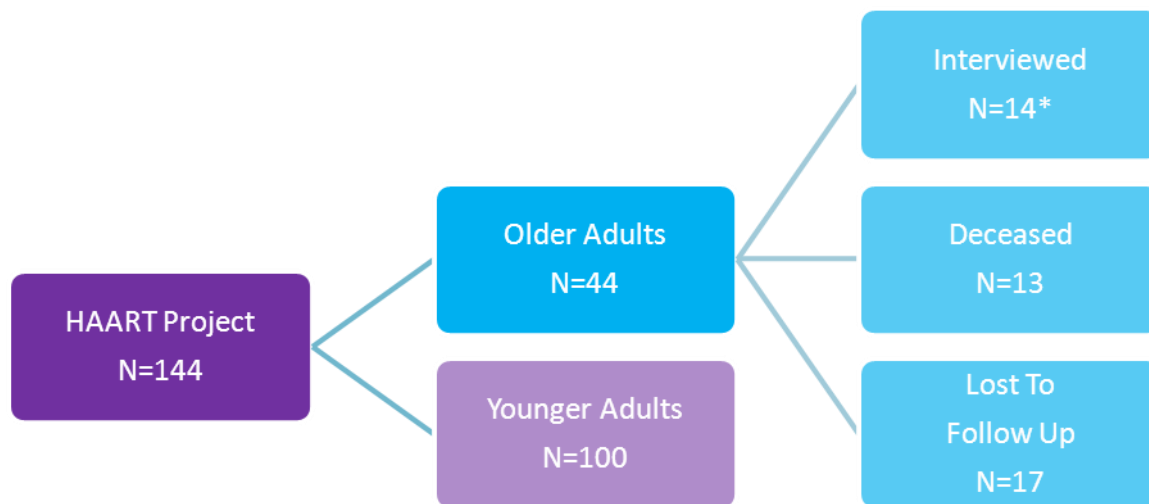
Thirteen²¹ older adults were included in the final sample for the dissertation research. The participants ranged in age from 51 to 78 years of age (mean age=59). There were slightly more men (n=8) than women (n=5). About half of the participants had completed high school or received a GED (n=6). Four participants attended two years of college or trade school and one participant attended graduate school. The education statuses of the remaining two participants were unknown. As of 2009 the participants had been living with HIV from 6 to 24 years (mean=10 years). The majority of the participants “aged in” or were diagnosed with HIV at age 49 or younger (n=10) while three participants were aged 50 and older when they were diagnosed with HIV.

²⁰ I interviewed 14 participants from the HAART project but one woman had an incorrect birth date and was 45 years of age. Thirteen participants were included in the final sample of older adults.

²¹ One additional interview was conducted, but the participant was younger than 50 and removed from the study.

The mode of transmission or HIV risk group was split almost evenly between three groups: (1) heterosexual sex (n=4), (2) injection drug use (IDU) (n=4), and (3) men who have sex with men (MSM) (n=5).

Figure 1. HAART Project and Dissertation Sample



*I interviewed 14 participants from the HAART project but one woman had an incorrect birth date and was 45 years of age. Thirteen participants were included in the final sample of older adults.

Table 1. Dissertation Sample by Gender

Dissertation Sample N=13	Men N=8	Women N=5
Age Range (51-78, Mean 58)		
50-59	6	3
60-69	1	2
70-79	1	0
Marital Status		
Single	3	0
Married/domestic partnership	1	1
Divorced/separated	4	4
Education		
High School	4	3
Two-year College	2	2
Graduate School	1	0
Unknown	1	0
Employment Status		
Employed	1	0
Unemployed	5	5
Retired	2	0
Home		
Rent	6	4
Own	2	1
Own Car		
Yes	4	0
No	4	5
Income Since HIV		
Very Comfortable	2	0
Somewhat comfortable	3	2
Just got by	1	2
Hardly got by	1	1
Unknown	1	0

Table 2. Demographics by Participant

Participant Demographics	Age 2009	Gender	HIV Risk Group	Age at Diagnosis	HIV Duration 2009
Alvin	78	Male	MSM ²²	Older	6
Donald	60	Male	MSM	Older	8
Gerard	56	Male	MSM	Younger	8
James	54	Male	IDU ²³ , Hetero ²⁴	Younger	24
Leonard	56	Male	MSM	Younger	9
Loretta	66	Female	Hetero	Older	8
Marion	62	Female	Hetero	Older	10
Melvin	59	Male	Hetero	Older	6
Mildred	56	Female	Hetero	Younger	7
Patrice	51	Female	Hetero	Younger	8
Sheila	53	Female	IDU, Hetero	Younger	10
Wally	51	Male	Hetero	Younger	12
Willie	53	Male	MSM	Younger	18

²² MSM (men who have sex with men)

²³ IDU (injection drug use)

²⁴ Hetero (unprotected heterosexual sex)

RESEARCH MEASURES AND ANALYSIS

This section describes the research measures and data analysis process for the dissertation research. The interviews with the older adults focused on HIV disruption and life reorganization along with aging with HIV. Semi-structured and in-depth interviews were used to allow individuals to explore the areas of interest and salience to them, and to evaluate the social consequences of the disease on their lives. The dissertation interview questions were based off of the following topic areas: (1) the disruptions that people experience when living with HIV, (2) how people reorganize their lives in response to HIV disruption, and (3) how living with HIV impacts various aspects of a person's life (e.g., health, daily activities, relationships, work). With the permission of the HAART Project principal investigator, portions of the HAART dataset were also used as needed to triangulate findings from the follow-up interviews and/or to provide more in-depth background information for each participant (e.g., life history and HIV narratives). The use of multiple data points helped to provide a more holistic and longitudinal understanding of the experiences aging with HIV among the participants.

Open-ended and semi-structured questions were used to elicit data for the specific aims regarding (1) life reorganization, (2) life disruption, (3) timing/aging with HIV, and (4) ethnographic setting of aging with HIV. The dataset from the HAART project and the new data collected during the dissertation interviews with health care professionals and older adults helped to provide data on the following research domains (see Appendix B for research domains chart):

- (1) Life Reorganization and Life Disruption Domains. These research domains were primarily qualitative and were used to identify: (1) the personal meanings of living with HIV in later life; (2) to what extent people reorganized their life in response to HIV; (3) to what extent does HIV disrupt, challenge, or change the lives of

older adults; and (4) how does HIV influence life course expectations, life events, and social/sexual relationships.

- (2) Timing of HIV Domains. The domains for timing were both qualitative and quantitative and provided data on how different components of timing (e.g., historical cohort, diagnosis, life course stage, duration) might influence the experiences of living with HIV as an older African American.
- (3) Aging with HIV Domains. The domains for aging with HIV were both qualitative and quantitative. The domains provided data on the similarities and differences between aging with HIV narratives, health status and psychosocial measures of older adults with HIV, and important topics and concerns related to aging with HIV that were identified by older adults and health professionals.
- (4) Ethnographic Setting Domains. The domains for the ethnographic setting were both qualitative (e.g., participant discussions about Detroit) and quantitative (e.g., statistics of Detroit) and provided data on how context of living in the city of Detroit (e.g., challenges, strategies, barriers to resources) shaped the experience of living with HIV among older African Americans.

Qualitative Measures and Analysis

Qualitative measures are often used to learn about under researched topics or areas of inquiry (Abel and Sankar 1995). The ethnographic approach of this dissertation research was necessary for understanding how HIV influenced the experiences of older African Americans with HIV. The qualitative data gathered from multiple data points²⁵ were important in obtaining information about the personal and ongoing experiences of living with HIV. The qualitative and open-ended approach to the interviewing process also allowed for input from the participants and emerging topics. A quantitative approach relying on only standardized, closed questions and/or clinical measures would not have provided the type of data sought for this dissertation research. A qualitative methodology was used to draw out information on participant perspectives, experiences, and stories and to allow participants to self-identify

²⁵ A strength of the proposed research is that it utilizes in depth background information from existing interviews but also allows the opportunity to collect new data.

meaningful categories (Abel and Sankar 1995). Qualitative techniques help provide a more in-depth means for identifying, describing, and understanding complex human behavior that occurs in specific contexts. The qualitative techniques used were more conducive for the smaller sample of this dissertation research. The qualitative domains used for the dissertation research were open-ended ethnographic questions, discussions, and narratives. The data for the research domains came from the existing HAART project and the new data collected during the dissertation research.

The design of the dissertation offered an opportunity to systematically explore individual, cultural, and environmental dimensions on the ways older African Americans experienced HIV disruptions and reorganized life in response to disruptions from HIV. Building on specific aims 1-4, the major goals for data analysis procedures focused on the primary study concerns to (1) identify the self-defined categories used to describe how people reorganized life in response to HIV, (2) discover to what extent HIV disrupted life course expectations, (3) determine if timing of diagnosis, duration of living with HIV, and/or year of diagnosis played a role in how people describe their experience and reorganization of life with HIV, and (4) describe the ethnographic setting of living with HIV as an older adult. Interviews were audio-recorded, transcribed verbatim, and formatted as Word documents, and imported into ATLAS.ti, a qualitative software program. The major techniques used for the qualitative data analysis are described below.

- (a) Transcription. The audio files from the thirteen interviews with older participants were transcribed verbatim. Transcribing was a form of data analysis. The process of transcribing the interviews provided an opportunity to reflect on the overall interview, to record key themes and topics discussed by the participant, to identify missing data, and to develop strategies for following up on important topics in the remaining interviews.

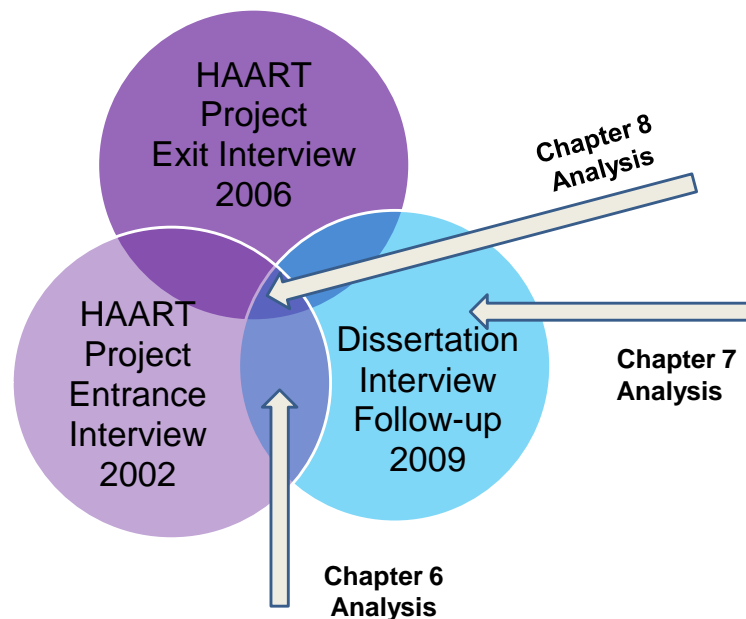
- (b) Coding. ATLAS.ti was used to conduct open and closed coding throughout the transcripts. Closed coding was based on a predetermined set of codes or themes used to sort through the transcripts (Bernard 2002). Examples of the closed coded included HIV disruption and aging. Open coding was a process in which codes were developed based on themes or topics that emerged while reading the transcripts (e.g., importance of sexuality and intimacy, normalcy with HIV) (Bernard 2002). Coding was used for the analysis of the data presented in chapters 6 and 8.
- (c) Pile-sorting. Pile-sorting was a technique used for analyzing small summaries of the data and/or grouping small sections of the data into categories or topics (Bernard 2002). The process of pile-sorting helped to develop additional open codes and identify emerging categories (e.g., themes about intimacy). Pile-sorting was also used to identify the range of participant responses that were associated with a predetermined code or theme. Pile-sorting was also used to check the validity of the codes and to analyze responses to specific questions (e.g. living with HIV). Pile-sorting was used for the analysis of the data presented in Chapter 7.
- (d) Content Analysis. ATLAS.ti was used to conduct a content analysis of specific codes. Content analysis is the process of systematically applying certain codes to specific sections of text (Bernard 2002). The results of the coding from content are then counted and discussed (Bernard 2002). Content analysis was used for the analysis of the data presented in chapters 6 and 8.

Quantitative Measures and Analysis

While the focus of this dissertation was on qualitative measures and analysis, some quantitative measures were also used. Quantitative measures are typically used to provide a means of surveying large populations in order to summarize, assess, and/or generalize information about a particular population or groups of people. Quantitative measures are especially helpful when a population size is too large to conduct in-depth interviews; however, quantitative research domains can also be used to learn about the general characteristics of smaller populations or samples. Some of the quantitative measures that were collected for the HAART Project and the dissertation research were demographic information, psychosocial and standardized assessments, and clinic data. Quantitative and standardized measures were entered

into SPSS, a quantitative software program. The majority of the data for the quantitative domains came from the existing HAART project database. Due to the small sample size of the dissertation research, statistical techniques (e.g. t-tests, chi square) were not appropriate for exploring further relationships between the study variables.

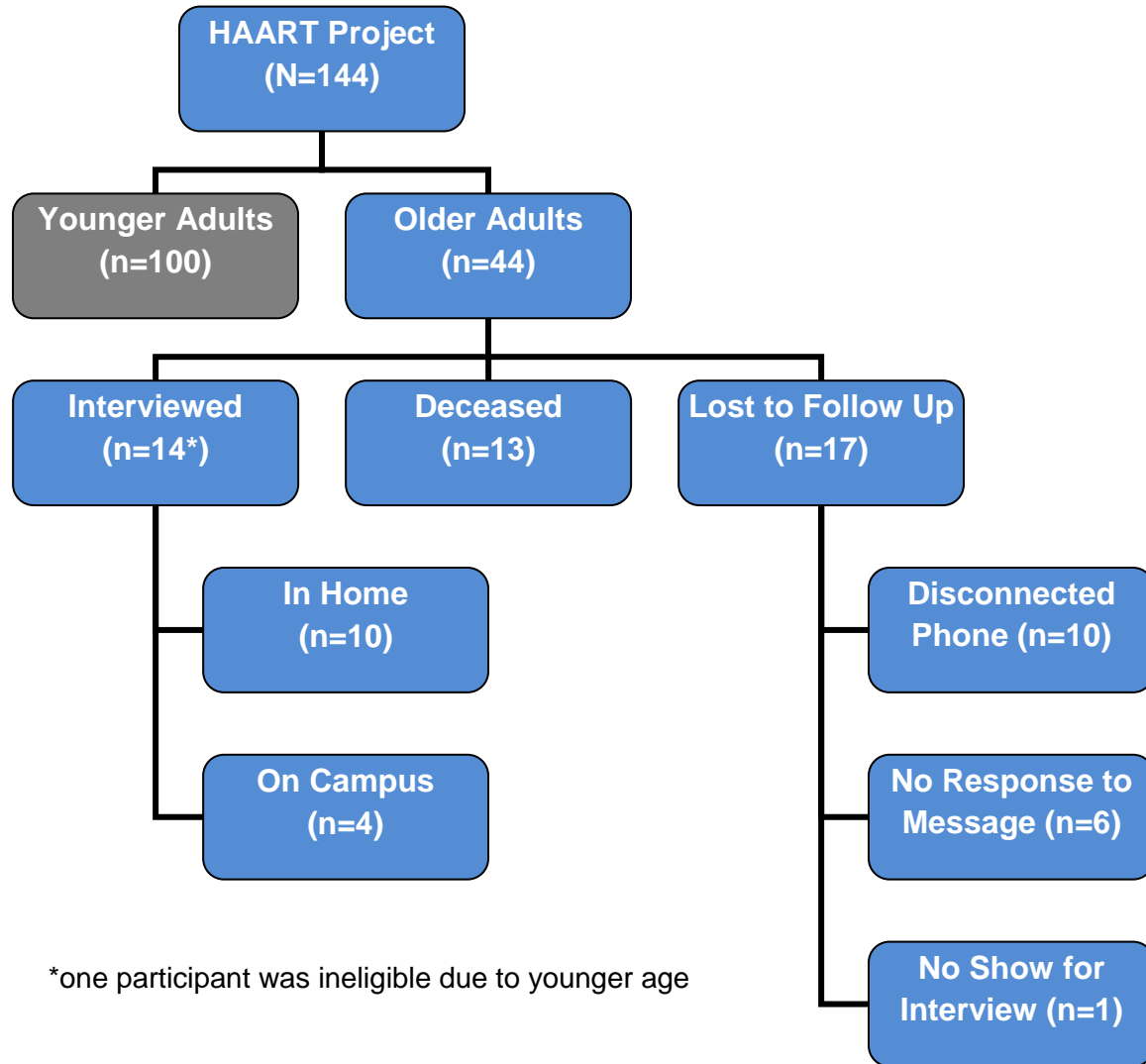
Figure 2. Dissertation Analysis and Data Time Points



Part I of Chapter 4 provided an overview of the design, methods, sample, and analysis for the dissertation research. Part II of Chapter 4 provides additional information about the process of “getting the data”.

CHAPTER 4, PART II: “GETTING THE DATA”

Part II of Chapter 4 discusses the process of “getting the data” and the specific techniques used to (1) recruit for a longitudinal study among a hard to reach population and (2) address challenges that occurred during the interview process. The dissertation research did not have a main field site like traditional ethnographies in anthropological research. Instead the data collection took place at various Detroit area sites such as participants’ homes, a university office space, a coffee shop, a clinic office, and the city health department. Because the project focused on the lived experiences of older adults with HIV, in-depth face-to-face interviews were needed. Participant observation at one particular site was not a viable option to effectively address the aims of the project. Due to the stigmatizing nature of HIV, private individual interviews were necessary to maintain the confidentiality of the participants’ statuses.

Figure 3. Recruitment**RECRUITMENT AND FOLLOW-UP PROCEDURES**

This section discusses the steps and techniques used for recruiting the older participants from the HAART project. In addition, this section also provides data on the remaining participants who were not recruited for this research. While developing the research proposal, several questions and concerns were raised about the feasibility of a longitudinal project and in recruiting participants for follow-up interviews. Prior to

contacting the participants, time was spent addressing and working through solutions to potential problems. Some of the main concerns were (1) how difficult it might be to get in touch with participants, (2) whether or not participants would remember the HAART project, (3) how willing participants would be to participate, (4) the possibility that some participants were no longer alive, and (5) what to do if a participant could not be reached via telephone. Would the original plan of recruiting from the HAART project be sufficient for this dissertation project, or would a new sample need to be recruited? There were several different types of challenges that occurred throughout the recruiting process. To promote recruitment for this study a three-stage process was developed that included (1) creating a preliminary list of phone numbers and phone calls, (2) searching for death certificate for the remaining participants, and (3) searching for updated contact information for the lost-to-follow-up participants.

Step 1: Phone Numbers and Phone Calls

Step 1 was used to develop a preliminary list of all of the potential older adults to recruit and to conduct the first round of phone calls. The recruitment process started with a careful review of the available information on the older participants from the HAART project and locating any missing information from the HAART Project data files. A master spreadsheet of all of the potential older participants, their contact information, and other general information provided a starting point for recruitment and the initial phone calls. During the first round of phone calls, participants were divided into two major groups: (1) male and female, (2) naïve and long-term. Participants were selected from the categories as a means of diversifying the sample; however, after encountering many disconnected numbers, it became apparent that dividing the sample into

categories would not be necessary, because everyone who was willing needed to be interviewed.

At the time of the first round of calls, several years had passed since the participants were interviewed for the HAART project. A general script was used to (1) remind the participants of the HAART project, (2) introduce myself as a former HAART project research assistant, (3) reference their former interviewer, and (4) provide a brief introduction to the dissertation project. Another concern was the decrease in compensation for the dissertation project in comparison to the HAART project. Fortunately, people were understanding and interested in the participating despite offering them only half of the compensation they received previously. A script for voicemail messages and messages for family/friends was also developed. The script for the messages had to provide enough information to trigger their memory about the HAART project while at the same time did not reveal information about HIV/AIDS or any indication of their illness (e.g., "This is Andrea from Wayne State University. I'm following up on a research project that you participated in").

After attempting to call all 43 of the potential participants and finding out that many phone numbers were disconnected, plan B needed to be implemented in order to recruit more people for the study. From the preliminary list and first round of phone calls only a few interviews were scheduled. Of the people who were successfully reached via telephone, all agreed to participate in the project. If updated contact information could be found, then the chances of enrolling participants would increase. Finding up-to-date phone numbers from online databases (e.g., White Pages, Anywho) was problematic because of the use of cell phones instead of landline phones. In

addition, based on previous experiences while working for the HAART project, some participants with financial difficulties had trouble paying phone bills, used prepaid phones that had limited connectivity, and/or relocated and changed their phone number. Since several years had passed since the HAART project, death searches were also conducted.

General Phone Techniques

- (a) If the participant answered, then I introduced myself as a person following up from the HAART project and informed them of my study and asked if they would be interested in participating.
- (b) If the participant did not answer, I left a message stating that I was from Wayne State University and calling about a research project that they previously participated in. Sometimes this message was left with a family member.
- (c) A few times a family member stated the participant was deceased. Condolences were given to the family member and they were thanked for the information. The participant's death status was then confirmed with <http://rootsweb.ancestry.com>.
- (d) If the number was disconnected, then the participant was moved to a separate list to try to locate updated information. A research nurse of an HIV/AIDS clinic suggested using <http://www.anywho.com/online>, an online resource that provided a free site for looking up addresses and phone numbers. This site provided some successful updates in participant information; however, it was often difficult to determine the possible updated information because there were multiples of similar names or abbreviated names. It was difficult to determine if the person listed was the former participant of the HAART project.

Step 2: Death Searches

All participants who were not reached via telephone were moved to the second and third steps of recruitment. The second step of recruitment involved the use of www.rootsweb.ancestry.com, a free online death search database using participant Social Security numbers. If the participant was deceased, a small file with the name and date of death would appear. If the participant was not found in the database, it was

assumed that the participant was still alive. Social Security numbers were extremely important in conducting this longitudinal research because they provided the unique information needed for death search engines. The death search process was repeated three times (e.g. start, middle, finish of data collection) during the dissertation recruitment phase. About 28 percent (n=12) of the older participants from the HAART project had died at some time between the HAART Project and the dissertation research. Two participants who were interviewed for the dissertation research died within a year after our interview raising the total number of deceased older adults to 14. The death searches provided important information on the participants that were lost to follow-up.

Step 3: Clinic Updates

If the participant was not determined to be deceased but was still lost to follow-up, they were added to a list that was given to a Cindy, a research nurse at a Detroit area infectious disease clinic where many of the participants were patients. In the development of the dissertation proposal it was assumed that alternate sources of access to contact information would be needed. Rapport with Cindy was established early on in the development of the dissertation proposal to determine if she would be willing to help provide updated contact information as needed. Cindy was approved by the Wayne State University Human Investigation Committee to provide updated contact information based on hospital medical records. This backup plan with alternative mechanisms for accessing updated contact information was extremely important for this longitudinal research; however, despite attempts to collect updated information, some participants remained lost to follow-up because no new information was available. After

receiving updates from the clinic, Step 1, the process of calling participants, continued in attempt to enroll the remaining participants.

After repeating Steps 1 through 3 several times, 15 participants were reached via telephone. All participants reached via telephone agreed to participate in an interview; however, one participant who agreed to an interview rescheduled his interview but then became lost to follow-up. Another participant was interviewed, but was not included in the final sample because of an error in her date of birth; she was younger than 50. After approximately nine months of recruiting, 3 health professionals were interviewed, 14 HAART Project participants were interviewed, 12 participants were deceased, and 17 participants were lost to follow-up. The Human Investigation Committee approved letters to be sent out to the 17 lost-to-follow-up participants; however, due to time constraints and the length of time spent recruiting participants, data collection was ceased after nine months in order to shift the focus to transcription, analysis, and writing.

Recommendations for Longitudinal Recruitment

The following list provides some recommendations for conducting follow-up interviews for a longitudinal research study. The principal Investigator (PI) of a larger parent study who anticipates that other researchers or students may want to follow-up with their sample should before the completion of the study:

- (1) Receive HIC approval for participant consent to be contacted for future research
- (2) Ask participants for alternate and/or updated contact information to establish an alternate source for receiving up-to-date contact information
- (3) Ask for Social Security numbers if they do not already have them to conduct death searches

- (4) Review the master list of participants to ensure information is accurate and up to date

For researchers who are attempting to recruit a sample from a larger parent study, they should:

- (1) Prepare HIC paperwork so that backup strategies for recruiting participants and accessing up-to-date information on participants are approved.
- (2) Create a master list of participants and identify and locate any missing data. The researcher should think about potential problems or issues with recruitment and develop solutions such as conducting death searches with Social Security numbers, using web-based people searches, and establishing alternate mechanisms for receiving contact information.

After reviewing the recruitment process, the next section provides information about the interview process.

INTERVIEW PROCESSES AND CHALLENGES

This section provides information about the interview process and some of the challenges that occurred throughout the interview process.

Pre-Interview Preparation

After a participant agreed to enroll in the study, they were given a choice of an in-home or on-campus interview. For the in-home interviews, participants were asked to schedule a time that would be private and uninterrupted by other people. The day before the interview, a reminder call was given to the participant to confirm the time, date, and location and/or to offer an opportunity to reschedule, if needed. The friendly reminder call served to establish rapport with participants and gauge the participants' interest in the interview. Prior to the interview, the life history narrative of the participant from the HAART project was reviewed. A life history review provided the opportunity to

learn about the participant and take notes on some of the key points discussed in their life stories²⁶ and to note their previous HAART Project interviewer. Mentioning the previous interviewer during my interaction with the participants was a way to establish rapport²⁷. Participants often asked for an update on their former interviewer²⁸. A few of the participants mentioned how they enjoyed receiving Christmas cards from the HAART Project. After the dissertation interviews were completed, thank-you notes were sent to the participants. Christmas cards were also sent to the participants as a means of maintaining the rapport.

Interview Locations

For the in-home interviews, participants were asked to schedule a time that would be private and uninterrupted by other people. Some of the participants did not have cars, were elderly, ill and/or were unable to make an on-campus interview. Some of the other participants however preferred an on-campus interview because of privacy concerns.

At the beginning of the study there was uncertainty regarding where the interviews should take place because there were a few prior safety issues that occurred after the initial screening during the HAART project²⁹. After a few uncomfortable situations with female interviewers and male participants, the HAART Project changed the interview policy and required all interviews with the opposite gender to be conducted

²⁶ The life history narratives provided much insight on the range of life challenges and situations of growing up that the participants experienced (e.g. marginalized sexuality, sexual abuse, drug abuse, segregation)

²⁷ I remained friends with many of the HAART interviewers and my sister was also an interviewer.

²⁸ Many of the participants became close with their former interviewers because they met up to 7 times.

²⁹ Before inclusion in the HAART Project, the project director completed an in home screening for all participants. The in home screening was conducted in order to verify the safety of the participant's home or neighborhood along with eliminating any potentially dangerous participants. This process helped was established as a safety measure for the interviewers.

on campus (unless it had already been determined that safety was not an issue); however, at the start of the dissertation research, it became apparent that adherence to this policy would result in losing potential participants. The ability to conduct in-home interviews was crucial in promoting the success of the research. Only four out of the fourteen interviews took place on campus. Visiting participants' homes also provided a much richer ethnographic experience and the opportunity to learn about the contexts of daily living that would not have been identified otherwise through on-campus interviews.

The in-home interviews also provided insight on the range of housing and living conditions of the participants. There were a few instances where the neighborhoods were very run down. For example, when interviewing Alvin, he pointed out that he had a broken living room window from a robbery at his house the week before. While he was away in the hospital for prostate surgery his house was broken into. He stated that he kept a gun in the house and had an alarm system to provide a level of protection and safety. He was relieved that the people who committed the robbery did not find his gun. The surrounding neighborhood was declining, and there were houses on the block with boarded-up windows and graffiti. Upon starting an interview with another male participant, Willie, he jokingly asked if I came with a bodyguard. He was surprised that I came to his home alone and later talked about how there were many drug users in his neighborhood. When using the bathroom at Willie's home, I also noticed the plumbing was in disrepair.

Even though some of the neighborhoods that my participants lived in were impoverished or had higher rates of crime, I did not encounter any safety issues while conducting the interviews. Most of my interviews were conducted in the morning and

early afternoon hours in order to avoid being alone at night. My experience of living in the city of Detroit for over seven years provided important insight and familiarity to the dynamics of the city and nearby neighborhoods where the study participants lived. I also felt that if a participant's home location was too dangerous, they would have probably suggested an on-campus interview. The reminder calls prior to interviews and the flexibility in interview locations were important factors for successfully completing the interviews.

Lack of In-home Privacy and Talking About HIV

This section discusses some of the challenges related to the lack of privacy in participants' homes and concerns about talking about HIV/AIDS during these in-home interviews. Participants were asked to pick a day and time that would be private and uninterrupted by others during the interview; however, upon arriving to the interview location, a new set of challenges arose during four out of the six in-home interviews with female participants. The challenge of having other people present in the home during the interviews only occurred with the women. For instance, two of the women were living with other family members and the other two had unanticipated visitors at the time of their in-home interview. Even though the interviews were ideally supposed to be scheduled during a private time, the dynamics of daily life situations arose, and other people were present in the home.

When realizing there were other people present in the home, I was concerned about protecting the privacy of my participants and asked if family members and visitors knew their status. They informed me of who was in the house and who did or did not know their status. The participants were given the option to reschedule the interview,

but they all chose to go through with the interview despite the presence and disruptions from other people. As a result, we developed code words for HIV such as “the stuff” or “it” and whispered or stopped talking if someone entered the room we were interviewing in.

While interviewing Patrice, she told me there were some electrical and water problems in the neighborhood and that her sister and her sister’s boyfriend who lived down the street were staying at her house for the day. She revealed that her sister knew of her HIV status but the boyfriend did not. Patrice’s teenage son was also home during our interview, but she informed me that he knew of her status. We were careful about mentioning HIV/AIDS though so that we did not reveal her status to her sister’s boyfriend. Patrice suggested that we call HIV/AIDS “the stuff” since that was a term that she regularly used.

While interviewing another participant³⁰ in her basement, her eight-year-old daughter would sneak down the stairs to eavesdrop while we were talking. Her daughter did not know about her HIV status or that her mother had any form of an illness. This same participant’s brother came by during our interview and he also did not know her status. During our interview we would listen for people walking down the basement stairs and were careful about mentioning the words HIV and AIDS.

When arriving to interview Mildred at her apartment, she told me she had a guest sleeping in another room who did not know her status. I asked her if we should reschedule the interview, but she did not want to. I suggested that we substitute a word for HIV/AIDS so that we would not accidentally disclose her status to her guest. We also talked quietly to reduce the chances of the guest hearing our conversation.

³⁰ This participant was removed from the study because she was younger than 50

During the interview with Sheila, her husband was home and knew of her status. However, there were a few points where she whispered information to me that her husband was not aware of. For example, her husband did not know the actual date of her HIV diagnosis. She was diagnosed prior to their relationship and did not disclose her status to him until five years into their marriage. When she disclosed she pretended that she had recently found out about her status during a routine check-up with her doctor.

Talking about HIV was not an everyday task for the older African Americans who were interviewed. As described above, very few of the visitors in the participants' homes knew of their status, even immediate family members and children. In addition, even when the participant disclosed their status to other members of their household or visitors, they did not necessarily discuss details of their HIV status with these people on a regular basis, if ever.

Emotional Contexts of Interview

As mentioned in the previous section, talking about HIV was not necessarily an everyday event for the people who were interviewed. The interview process brought up various emotions for participants. The participants were also offered an opportunity to reflect back on their life with HIV and about the information provided during the HAART project that started about seven years prior to my interviews with them. Since the participants were familiar with the HAART project, they were familiar with the interview process and the personal nature of some of the questioning. Some of the participants cried and expressed emotions of sadness, happiness, anger and frustration when talking about their life stories and life experiences. Some of the participants made jokes

or commented about the intensity of the questions. Some of the participants also remarked how some questions caused them to think about disruptive and emotional points of their life. The open-ended questions provided an opportunity for people to share various insights on their experiences and outlook on life that was perhaps not shared with others. For some participants, open ended questions provided a source of frustration if they were unsure of how to answer a particular question.

While the interviewing conducted for this research was not supposed to be a therapy session, my training in anthropology had taught me to try to be an empathic and non-judgmental interviewer and listener. During an interview with Willie, he told me how talking with me was therapeutic and more helpful than his previous experiences with psychiatrists. Other participants mentioned at the end of the interview how they felt comfortable talking with me and were able to share personal information that they had not talked about with other people. Many of the participants hugged me as I left their homes. The intimacy shared during the interviews was anticipated because of my prior understanding of the nature of the HAART project interviews.

Other participants discussed how the interview process forced them to reflect on emotional aspects of their lives that they had not thought about in a long time. During an interview with Wally he commented on how “deep” the questions were. After an interview with Donald, he called to tell me that since our interview he had been thinking about his responses and the questions. He asked for my address because he mentioned that he might want to type up some additional information for me to add to the questions; I never received additional information from him.

Some of the participants were very emotional at certain points in the interview. Leonard reflected back on how he was molested as a child and his thoughts about his sexual identity. He also talked about anger towards his mother for not protecting him. Patrice cried during the interview and said how our interview brought up some hidden emotions that she had not talked about in a long time. There were times when I felt saddened by what my participants were talking about but I tried to remind myself that I needed to keep my emotions under control in order to maintain the focus of the interviews. My previous experiences of reading through the HAART project transcripts helped to prepare me for the deeply emotional conversations that could occur during interviews and the types of traumatic events (e.g., rape, abuse) experienced by some of the participants.

When I began my interviews I did not know what to expect from the participants. I did not know if they would open up to me. My familiarity with the HAART project interviewers, project protocol and interactions with participants during the HAART project was a major factor in establishing rapport with the participants. Most importantly, I wanted to be empathetic to the participants and make them feel comfortable in sharing personal information. At the same time I also was conscious of creating a balance between establishing rapport while also maintaining boundaries in my role as an interviewer. At the end of the interviews I thanked the participants and tried to convey my appreciation for their willingness to open up to me and to share deeply personal information.

Lengthy Interviews and Maintaining Focus

Another challenge that occurred during the interview process was maintaining active listening and attention to the topics for lengthy interviews. Some of the interviews lasted over three hours and were without breaks. Before the interviews started I told the participants that if they were not feeling well or were tired to let me know and we could take a break or stop the interview. When the interviews were especially long I made a point of offering another opportunity to take a break. The lengthy interview process was informative, but it was also tiring and draining at times for both the interviewer and the participant. In some cases, when the interviews were approaching three hours, the strategy was to focus on what was most important and skip over certain sections or questions.

During the interviews some participants would go off track from the topic. Even though the side talk was interesting, it was not necessarily relevant to the research goals. In these cases I would listen to the participant and if they paused I would then try to move on the next question. There was a fine balance between being polite yet assertive enough to keep focused on the research agenda. One particular interview posed more challenges than the others because the participant often sidetracked with discussions about the Bible. During the interview with Melvin he was very interested in having a theological discussion and asking specific biblical questions. In addition, Melvin suffered from memory loss and other side effects from a severe closed head injury. Without trying to offend him, he often had to be redirected to the questions and topics of the interview. There were a few times of feeling caught off guard and feeling

the need to briefly answer his questions to help establish rapport and to keep him engaged in responding to the questions he was asked.

In some other cases when participants were feeling tired from the interview questions they would say they already talked about a particular question. In these instances it was acknowledged that some questions seemed repetitive since sometimes they may have already addressed a topic earlier in the interview. It was explained that they were being asked all the questions in case they wanted to add additional input. Participants were also given the option to not answer certain questions if they did not feel comfortable doing so.

Chapter 4 Summary

Chapter 4 provided an overview of the design, methods, sample and analysis for this dissertation research. In addition, the chapter also discussed and described the process of recruiting and interviewing participants. First and foremost, it was important to anticipate potential problems and concerns and develop multiple plans of action to address the problems that could occur. As a result of the challenges associated with the recruitment and data collection process, a major lesson that was learned was the value added by anthropological research methods that emphasize “being flexible”. “Being flexible” allowed for the development of a variety of different techniques and resolutions needed for conducting this dissertation research. The following chapter provides a brief overview of the city of Detroit, the primary research site of this dissertation.

CHAPTER 5

“DETROIT IS LIKE A DOUBLE-EDGED SWORD”:

UNDERSTANDING THE CONTEXTS OF DETROIT

Detroit is like a double-edged sword. Detroit is like it has a lot of good things in it like Campus Martius and the Hart Plaza and Belle Isle and things like that. But then on the flip side you got like any other urban city. You got to be worried about your gangs. I don't like the fact that when you call 911, the 911 information wants to ask you a million questions while you're having a heart attack. By the time they get to you, you will be dead. You know, the phone in your hand, when they get here you'll have the phone gripped in your hand – dead. And they'll still be asking you questions... You can't believe in none of your city council politicians – you can't believe in nobody. You can't believe in your city council, the mayor, the governor, I mean the list goes on and on. And they fix up parts of Detroit but the parts that they fix up are not the parts that need to be fixed up. It's like neighborhoods like this where there are children - is where they need to come through and clean up and make it decent. It's got so bad in Detroit it's dippin' right on over into the suburbs. They are starting to get a taste of what we're getting here in Detroit. Then they're raggin' on Detroit so bad with the insurance and you know. Like I said it's a double edged sword with Detroit. To where you know if you move too far one way you're gonna get cut. If you move too far the other way you're gonna get cut. So you've got to stay in a narrow space. And that's tight, it's really tight. (Sheila Dissertation Interview 2009, Age 53, HIV+ 10 years)

As discussed by Sheila, the expression “a double-edged sword” can be used to think about the various perspectives and contexts of living in the city of Detroit. The expression can provide important insight when making sense of the history of Detroit and the structural inequality experienced among African Americans living in Detroit. In addition, this expression can also be used when thinking about how Detroit and African Americans in Detroit have been portrayed in statistical reports, discussions about poverty and crime, media, history, and politics. In order to have a better understanding of this dissertation research it is important to have a general overview of the context of

the city of Detroit from various perspectives. Statistical reports on the demographics of Detroit's population along with historical information may provide important insight about the city, yet do not provide information on the personal stories of people who are currently living in the city. The stories and perspectives from participants add meaning and relevance to the statistics and insight on the way of life among some of the people who are living in Detroit. This chapter describes the various ways that "Detroit is like a doubled-edged sword" through the presentation of statistics, history, politics, and the perspectives of the participants who were interviewed for this dissertation research.

THE "MOTOR CITY"

The city of Detroit was founded in 1701 and is known in the Midwest as one of the oldest cities (Farley et al. 2000). Detroit is often referred to as the "Motor City" because of its role in the development of the U.S. automotive industry in the early 1900s. The history of Detroit and the past and present experiences of day-to-day living have been heavily influenced by the ups and downs of the automobile industry. Many people who live in Detroit and in the surrounding suburbs are influenced and affected by the economics and culture of the automobile industry in various ways.

In 2009, when the interviews for the dissertation were collected, the Big Three automakers (Ford, GM, and Chrysler) experienced extreme financial troubles resulting from increased competition from foreign car companies and the rising costs of oil (Maynard 2003). GM and Chrysler filed for bankruptcy and Ford barely made it through the crisis (Okrent 2009). I myself³¹ a Detroiter and many other people in the Metro Detroit area, their families and friends were concerned for the future of the U.S. auto

³¹ My father was a member of the UAW and is a of Ford Motor Company retiree. My parents were very concerned about his retirement benefits and their livelihood. I knew many people who lost jobs and or were negatively impacted by the financial problems of the auto industry.

industry and its negative impact on the livelihood of those who were affected by the crisis. When talking about Detroit, one of the participants, Wally, described his concerns about how the auto industry crisis had impacted his family:

I remember Detroit was thriving then, the automobile. I didn't like the way that went down too. Because my mother worked all her life with General Motors and then for them to just take them peoples' benefits and stuff like that. I never would think that all the money that those people went through, the Big Three except Ford. Ford has been here the longest. I would never, would have ever thought it went down like that. It was a shock to me. I don't like that. (Wally Dissertation Interview 2009, Age 51, HIV+ 12 years)

The ups and downs of the automotive industry have played a major role in shaping Detroit's history, economics and local culture since the early 1900s. When the local automobile industry was thriving, people throughout the Metro Detroit area benefited from the increased economic growth and employment opportunities. However, the overreliance on the auto industry resulted in many people in the Metro Detroit area suffering through the loss of jobs and income when the auto industry experienced financial troubles, slowed production, or a reduced demand for workers To understand the context of Detroit today it is important to review the history of development of the auto industry and the migration of southern African Americans to Detroit.

The Great Migration and the Ups and Downs of the Auto Industry

The migration of African Americans to the city of Detroit was heavily influenced by the development of the auto industry. In the early 1900s and prior to the Great Migration, the population of African Americans in Detroit was only 5,741 (Martin 1992; United States Bureau of the Census 1910). African Americans made up only about one

percent of the total population of Detroit (Martin 1992; United States Bureau of the Census 1910). The development of the auto industry in the early 20th century created a demand for workers in the automotive factories. As a result, whites and African Americans from the south moved to the city of Detroit for work in the auto industry. During the Great Migration that occurred from about 1916 to 1930, approximately one million African Americans from the south ventured to northern cities such as Detroit (Marks 1989). These African Americans migrated from the rural south to the northern city of Detroit for jobs and hoped for a better life than what was available in the south. The total population in Detroit increased rapidly in the early part of the 20th century from about 285,704 in 1900 to about 1,568,662 in 1930 (Shreve et al. 2012). With the rapidly increasing population, there was intense competition for jobs and housing.

Despite being driven by promises of and hopes for jobs and a better life, many African Americans who migrated to Detroit also found they were unable to find jobs and had limited access to proper housing, food, education, and other resources. Despite freedom from slavery and “separate but equal” laws, African Americans found no equal opportunity in jobs, housing, and education. Those who moved to Detroit in search of better opportunities still struggled with inequality and racism in the forms of dangerous working conditions, lower wages, and long working hours. The real estate market and landlords in Detroit also marginalized and excluded African Americans from new housing developments that were being built. Many African Americans were refused loans to purchase homes and were excluded from renting in certain areas (Sugrue 2008; 2011). As a result, many were forced to live in inadequate, crowded, unsanitary, and racially segregated housing with high rental prices (Sugrue 2008; 2011). With the

influx of southern migrants to Detroit, there were increased tensions between African Americans and whites and between northern African Americans and southern African Americans (Martin 1992). Faith-based institutions (e.g., churches) and other organizations (e.g., civil rights organizations) provided assistance to those in need and to resist oppression but were unable to completely resolve the various hardships that were experienced by many African Americans who were living in Detroit (Martin 1992).

The period of the Great Depression marked a time of a decreased demand for automobile production and other types of factory work and resulted in high rates of unemployment. During the Depression era, racial tensions were exacerbated when businesses would often replace white workers who picketed for better working conditions with black “strike breakers” (Sugrue 2008). These practices created tension between blacks and whites in the workplace and negatively influence efforts to unionize.

In the years during and after World War II, another wave of about 60,000 southern African Americans migrated to Detroit in search of better opportunities and employment in the automobile and related industries (Sugrue 2008). The economy during this period rebounded and there was an increased demand for the automobiles and the production of military-related equipment, which thus increased the number of jobs available and the need for workers. The competition for jobs and housing was a major point of tension between African Americans and whites in Detroit. The increase in employment opportunities during World War II also fueled increasing racial tensions between groups because of competition for jobs and inequality in hiring practices. These industries offered jobs with pay higher than other types of jobs available and thus fueled the incentive for many African Americans from the South to move to Detroit.

While these jobs provided an opportunity for increased pay and supposed upward mobility, African Americans were often given jobs with the most menial, dangerous or marginalized working conditions and were often denied promotions despite proper training or skills. Preferential treatment was given to whites in the form of better jobs, promotions, and improved working conditions and better benefits and higher wages.

In the 20th century Detroit's population grew rapidly as the U.S. auto industry developed and its population reached an all-time high of almost two million people in the 1950s (Southeast Michigan Council of Governments 2012). Because of the rapid increase in Detroit's population during this period housing was limited and there was increased demand for new housing that was being built. "The NAACP and the UAW lobbied hard for affordable housing for new migrants but were met with fierce resistance" (Sugrue 2008:66-67). For example, when the Sojourner Truth Housing Project was being built in 1942, it was a major source of tension between African Americans and whites about who would be allowed to live in the new housing. Despite resistance from whites, black activists persisted and protested by picketing and sending numerous letters to housing officials and were eventually granted rights to live in the Sojourner Truth Housing Project (Sugrue 2008:66-67).

Major race riots and increasing suburbanization underscored a history of institutionalized racism (e.g., inequality in housing and jobs) and heightened racial tensions between African Americans and whites in the Metro Detroit area. In 1943, a major race riot of about 100,000 people broke out at and around a large Detroit park named Belle Isle (Sugrue 2005). After reaching a peak in the population in the 1950s, the population of Detroit began to steadily decline. The process of whites moving out

of Detroit to the suburbs was referred to as “white flight” and this process of “suburbanization” radically influenced future population and social dynamics and increased the racial segregation of the Metro Detroit area (Sugrue 2005). Whites moved to the suburbs for increased employment opportunities as automotive factories and related businesses began to expand beyond Detroit and into the suburbs. The suburbs of Detroit also began to offer better housing opportunities and citywide resources for whites. As the suburbs became whiter and richer in resources, the city of “Detroit became blacker³² and poorer” (Sugrue 2005). In 1967 another major race riot occurred after police raided an after-hours drinking establishment. It is important to note that African Americans and whites who supported the Civil Rights Movement living in Detroit did not passively accept the inequality experienced in Detroit’s workplaces, housing, and schools. Picketing and protesting, joining civil rights organizations, unions, and activist groups, and rioting were various ways in which people resisted racism and fought for equality in Detroit (Georgakas and Surkin 1998). Despite efforts of the Civil Rights Movement, African Americans in Detroit were still faced with racism, segregation, inequality, and inadequate resources. The overwhelming inequality experienced by African Americans influenced why many remained in Detroit and were left to experience the continuing negative effects of a dwindling population, a reduction of city resources and a decrease in economic opportunities.

This section on the origins of the “Motor City” described the development of the auto industry in Detroit and its relationship to the migration of African Americans to Detroit. The various economic ups and downs of the auto industry and the racially

³² With the exception of the suburb of Southfield.

segregated neighborhoods that occurred throughout the 20th century have persisted over time and illustrate some of the major ongoing struggles and key characteristics of life as it is experienced in present day Detroit. The changing technologies in the auto industry and the competitive markets that began to take shape mid-century played a major role in the deindustrialization of Detroit. The deindustrialization of Detroit was illustrated by the closure of a number of automotive factories and related businesses and the subsequent decrease in the need for factory workers in Detroit and the suburbs. The discussion of the history of the auto industry in Detroit, the migration of African Americans to Detroit, and institutionalized racism in many facets of life, such as the workplace and housing, help set a framework for understanding the current contexts of life in the city of Detroit.

PRESENT-DAY STATISTICS OF DETROIT

The 2010 U.S. Census reported there were a total of 713,777 people living in Detroit. From 2000 to 2010 the population decreased by 25 percent (United States Bureau of the Census 2010). The total number of people living in the city has dwindled over the years due to people continuing to move from Detroit into the suburbs due in part to decreased economic opportunities in Detroit and upward mobility. The Census also reported that of 269,445 housing properties available, 79,725 were unoccupied (United States Bureau of the Census 2010). As discussed in the previous section regarding “white flight” and the “blackening” of Detroit in the middle to later part of the 20th century, the city of Detroit consists of a predominately African American population. Approximately 83 percent (590,226) of the people living in Detroit in 2010 self-identified

as African American and 11 percent (75,758) self-identified as white (United States Bureau of the Census 2010).

Detroit ranks sixth out of 49 of the poorest of the largest cities in the United States (Metzger and Booza 2002). From 2006 to 2010, 34.5 percent of Detroiters lived below the poverty level compared to 14.8 percent statewide. The percentage of people living in poverty increased 8.4 percent from 2000 to 2010. The per capita income for Detroiters was \$15,062, about 10,000 dollars less per year than the per capita income in the state of Michigan (United States Bureau of the Census 2010). The National Institute for Literacy reported that 47 percent of Detroiters were functionally illiterate, compared to 18 percent of Michiganders (National Institute for Literacy 2011). The rate of people with a high school diploma was just below 70 percent which was also lower than the average statewide percentage of 80% (National Institute for Literacy 2011). In 2009, over one-third of Detroit's population did not have health care coverage (Jankowski 2011). The Wayne State University Center for Urban Studies estimated that in 2009 that 25 percent of Detroiters were unemployed and 40 percent were underemployed³³ (Stokan 2010). These statistics reflect some of the struggles of city of Detroit and the dire economic circumstances of decreased funding for city resources, high unemployment, and marginalized housing. To gain a more holistic understanding of Detroit it is important to include some of the discussions from the participants who were interviewed for this dissertation research.

³³ Underemployed is a term that refers to people who are more qualified for the jobs they are working in or are working less hours than they want (cite)>

PARTICIPANT PERSPECTIVES OF DETROIT

Historical accounts and statistical reports provide some information in understanding the context of Detroit. However, it is important to share the perceptions and opinions of the participants who live in Detroit and were interviewed for this dissertation research. As discussed in the introduction, Sheila described Detroit as a “double-edged sword” because she believed there were challenges and benefits of living in the city of Detroit. Discussions with other participants also underscored Sheila’s perception of Detroit.

Challenges of Living in Detroit

When talking with the participants, many emphasized economic distress, declining neighborhoods, and corrupt politicians as key challenges to living in the city of Detroit.

Economic Distress

The participants described the deleterious impact of economic distress on Detroit. The poor economy both nationally and locally has impacted the daily lives of people living in Detroit. For example, the decline in housing market values has made it difficult to sell homes and relocate. In addition, the lack of job opportunities and high unemployment has influenced high rates of poverty. Donald, a retired psychologist in a higher income bracket than the other participants, had the financial means to move out of the city of Detroit but felt he needed to wait until the housing market improved to sell his house.

I don't like Detroit. So I wanted to move and did some renovations and stuff but that's when the housing market went down so you can't get anything for it right now. So I feel stuck for right now. But yeah, when things get better, I definitely want to leave. (Donald Dissertation Interview 2009, Age 60, HIV+ 8 years)

When talking with Mildred, she talked about actively searching for a job by attending job fairs and going to the library to search online for potential job opportunities, but she was unable to find a job. Mildred stated:

I don't like the economy right now because there's not no jobs here and that's about the hurting part here right now because there's no work. If you don't have the ability or no car or anything of that nature or money of that nature to go searching somewhere in another city for a job you're just lost. You'll just have to be here and deal with it the best you can so that's where I'm at. (Mildred Dissertation Interview 2009, Age 56, HIV+ 7 years).

Mildred's options for obtaining work were limited. Since having HIV, she could no longer work as maintenance person cleaning buildings because the harsh chemicals and exposure to germs could make her sick. She described feeling frustrated by the overall lack of opportunities to improve her economic situation.

In addition to the steep decline in housing market values and lack of jobs, ten out of the thirteen participants were living in poverty. These participants described the difficulties of living off of a low income and disability. Participants reported unemployment and underemployment problems in Detroit, poorer health associated with HIV, and medication side-effects as some of the major factors why they were unable to work and were living in poverty. The experience of poverty and HIV can create an increased sense of marginalization from society. For example, one participant named Willie talked about how living with HIV and living in poverty impacted his feelings of experiencing a decreased sense of connectedness to society. However,

his recent acquisition of used material items, that he could not otherwise afford, has increased his sense of belonging. Willie stated:

I've been able to go to [thrift stores] where people with low incomes can go and get a beautiful big screen television for little or nothing. Things like that have been happening to me. I'm becoming part of society again, I like that. (Willie Dissertation Interview 2009, Age 53, HIV+ 18 years).

The poor economic circumstances such as the declining housing market, lack of jobs, and increased poverty are important challenges to consider when thinking about the context of Detroit and the participants collective experiences of aging with HIV.

Declining Neighborhoods

Despite revitalization efforts of some communities in Detroit such as Woodbridge and Corktown, however the neighborhoods where many of my participants lived had deteriorated over the years. Participants described how their neighborhood and the surrounding neighborhoods were ridden with poverty, drug use, abandoned houses, prostitution, and crime. Participants often made distinctions between themselves and the less desirable behaviors of people in their neighborhood or community. Willie and Gerard both lived in upper flats and their elderly mothers lived below them. They described how their homes have been in their families since the middle of the 20th century and how the neighborhoods have steadily declined over the years. For example, Willie describes the area surrounding his house.

I think it makes it easier to live with HIV because everyone around here is crack heads with HIV. I know all the crack heads in the neighborhoods, all the alcoholics, all the thieves and the rats and the roaches. I made it known – do not fuck with this house...I've been here since 1962 in this house. I know when people are coming or when they leave from the neighborhood. Me being how I am, I get kind of aggressive. I doubly let people know. I call, you know they call reputation, I be hi and bye, so I'm known to be crazy in the neighborhood. There are a lot of people in my neighborhood that don't care that's HIV. They call, well you probably don't

know, they call them crack heads. They smoke the crack rock thing. They smoke marijuana cigarettes but they call them blunts or something like that. And you know. Being in vacant houses and all the junk and prostitution in this area. I don't. I'm not with that. I feel pretty good in my neighborhood. I really do. My door is wide open right now. I dare a crack head to come up here and knock on my door. You would be surprised. I don't live in fear. Just lonely though. Maybe that gives me the courage (Willie Dissertation Interview 2009, Age 53, HIV+ 18 years).

Willie lived in a more rundown area near the Eastside of Detroit and was living in a much lower income bracket than Gerard. When looking around the inside of his home I noticed that his home had major plumbing and structural damage. Willie most likely did not have the financial means to make the types of repairs needed for his home.

In contrast to Willie, Gerard lived in a much more affluent neighborhood on the west-side of Detroit. However, Gerard also talked about how the neighborhoods have declined.

My parents moved to this house when I was three years old. My mother has lived here since 1956. I left for about 20 years and came back just to see, I mean, [to care for my parents]. It's completely different than when I was a child obviously. It was a much nicer area than it is today. (Gerard Dissertation Interview 2009, Age 56, HIV+ 8 years).

Gerard worked full-time as an accountant and was living in a much higher income bracket than Willie. Gerard talked about investing a lot time and money into restoring his historic home. While Gerard's street was very well kept, the surrounding neighborhoods were rundown and depreciating in value.

Corrupt Politicians

In addition to the poor economy and the declining neighborhoods, the topic of corrupt politicians was another major area of emphasis among the participants. During the timeframe of the dissertation research there was an enormous amount of news

coverage of the corruption and downfall of Kwame Kilpatrick, Detroit's mayor, and his associates. As result, many of the participants discussed frustration with the politics and the mayor's misuse of city funds. Wally described how he disliked the politicians in Detroit.

What I don't like about Detroit is the corruption and all the stuff that's going on downtown. It ain't nothing but greed. And they just ran the city to the ground. (Wally Dissertation Interview 2009, Age 51, HIV+ 12 years)

The poor economy, declining neighborhoods and corrupt politicians were some of the major topics discussed when talking about the negative aspects of Detroit.

Benefits of Living in Detroit

Despite the challenges of living in Detroit that were discussed, participants also described how there were also were certain benefits of living in Detroit. Some of the major points discussed as the benefits of living in Detroit included identifying Detroit as place they called home, supportive community networks, and important city resources.

“Detroit is My Home”

When talking about Detroit, many of the participants described a general fondness of living in Detroit and described the city as their home. Patrice described how even though she was originally from Georgia she thought of Detroit as her home.

Detroit is my home. And, uh, it's been my home for years. I have been to a lot of places, right. Another place I wouldn't mind living is Jamaica or Georgia, my background is in Georgia. But Detroit I will truly miss. I love Detroit. Just put that down: I love Detroit. (Patrice Dissertation Interview 2009, Age 51, HIV+ 8 years)

In talking about how Detroit was their home, participants also described the beauty of the city. Wally stated:

What I like about Detroit is...I've been here all my life. It's where I was born. It's really a beautiful city. (Wally Dissertation Interview 2009, Age 51, HIV+ 12 years)

In addition to identifying Detroit as their home, participants also described how strong community networks were an important contributing factor to the benefits of living in Detroit.

Strong Community Networks

Participants talked about living in neighborhoods where the neighbors were very helpful and community-oriented and helped to build strong community networks. While interviewing Alvin, he pointed to the window and said, "Look at my neighbor doing this. He's a champ!" as his neighbor was using a snow blower to remove the snow on his sidewalk. Alvin discussed how the man removing the snow was a new neighbor that he had not known for very long. However, this neighbor unlike the ones he'd known for a long time was helping him out in various ways (e.g., snow removal, taking out his trash). Alvin also mentioned how he noticed how the neighbor did not salt the sidewalk after snow blowing and was concerned that he could not afford to purchase salt. To show his appreciation for the new neighbor's assistance with his yard work, Alvin bought the neighbor a very large bag of salt.

Another participant, Melvin described more generally how he liked his neighbors and the neighborhood he lived in.

The neighbors are absolutely fabulous. I couldn't, myself, if I did have, if I stayed in Detroit, I couldn't ask for a better place to live. I've got a beautiful house, two-car garage. The yard is beautiful. The house is decent. (Melvin Dissertation Interview 2009, Age 59, HIV+ 6 years).

These discussions from the participants illustrate how having good neighbors and being a good neighbor can make a positive impact in the daily lives and community networks of people who are living in Detroit.

City Resources for Low-Income People

Some participants described how, despite living in poverty, the city of Detroit offered important resources for low-income people, such as free entertainment venues and access to specialized HIV care. Willie discussed how he enjoyed going to Hart Plaza, an outdoor location that hosts a variety of free music festivals and other events.

What I like about Detroit is, is that thing they have downtown when they have that free music concert stuff. Oh, I like that because people with low income, don't have no money, can go there with like 20 dollars, get some Hennessey and enjoy life. You know I'm rich. I feel like I'm rich, I feel like I got a hundred dollars walking around listening to music and everything. I'm just by myself with my music on. That is such a beautiful thing. Just like Ford with the baseball. Ooh, it's beautiful, but you gotta be rich. Six dollars for a hotdog and you can't smuggle none in. You have to buy it. And 4.50 for a coke. (Willie Dissertation Interview 2009, Age 53, HIV+ 18 years)

In addition to providing opportunities for people to enjoy low-cost or free leisure activities, the city of Detroit also has a major medical and research hospital that provides health care access to a wide range of people around Metro Detroit, especially uninsured and/or low-income individuals. For example, James described how the Detroit Medical Center and infectious disease clinic provided specialized care for low-income people who are living with HIV.

You know Detroit has...I like that they've got a good center, good health system base for HIV. They've got a good network of things you could do and people who have the knowledge of HIV and can help you with your, you know, help put you on medicine, and they've got a specialty in HIV and you know I like that about it. (James Dissertation Interview 2009, Age 54, HIV+ 24 years)

Budget cuts in Detroit have negatively impacted the types of resources available to lower-income people who are living in Detroit. However, the participants described how the city of Detroit is still able to provide some important systems of support that have improved their quality of life.

Summary of “Detroit Is Like A Double Edged Sword”

This discussion of “Detroit is like a doubled-edged sword” helps to provide a more holistic understanding of the various ways Detroit is portrayed and the various challenges and benefits to living in Detroit. The historical details about the role of Detroit in the development of the auto industry and the migration of African Americans to Detroit along with statistical reports provide important dimensions for making sense of the context of the living situations for people living in the city. However, historical and statistical reports alone are not enough to gain a full understanding of the daily experiences of people who are living in Detroit. The personal perceptions of the city of Detroit that were expressed by participants during the interviews provide an additional layer of information that is helpful in understanding the context of the living situations in Detroit. The personal perceptions of the city of Detroit expressed by participants provide a glimpse of some of the supportive aspects of living in Detroit that may often be overlooked in the plethora of negative reports on Detroit. As stated by Sheila, in order to gain a greater understanding of the context of the city of Detroit it is important to think of a “double-edged sword.” The Chapters 6 through 8 discuss the major findings from this dissertation research.

SECTION III DISSERTATION FINDINGS

The chapters in Section III discuss the analyses and key findings resulting from the dissertation research on understanding the experiences and perceptions of HIV disruption and reorganization among older African Americans living with HIV/AIDS. Chapter 6 focuses on utilizing and refining Becker's life disruption framework in order to understand how older African Americans experience living with HIV in Detroit. Chapter 7 discusses the dialectical relationship between experiences of normalcy and disruption in living with HIV/AIDS. Chapter 8 provides insight into understanding a major type of HIV disruption and the patterns of disruption and reorganization of sexuality and intimacy.

CHAPTER 6

“I NEVER THOUGHT I WOULD WALK DOWN THIS PATH”:

EXPLORING HOW BECKER’S FRAMEWORK OF LIFE DISRUPTION AND REORGANIZATION MAPS ONTO THE PATTERNS OF HIV/AIDS EXPERIENCE AMONG OLDER AFRICAN AMERICANS

INTRODUCTION

I never thought I’d walk down this path that I walked down. But since I walked down this path, I will deal with it each and every day of my life. (Patrice Dissertation Interview 2009, Age 51, HIV+ 8 years)

Patrice highlights one of the various ways participants described how an HIV diagnosis disrupts the normative expectations of the life course. Patrice describes how she deals with HIV “each and every day” to underscore the ongoing nature of the challenges and disruptions resulting from living with HIV. This chapter will provide insight into the meaning of HIV/AIDS disruption and the ways in which people may or may not reorganize their lives in response to the disruptions they experience. This chapter aims to refine and extend Becker’s framework³⁴ on life course disruption and reorganization by applying her framework to understand the ongoing experiences of older African Americans who are living with HIV/AIDS in Detroit. In addition, I was also interested in (1) exploring if Becker’s framework remained stable when utilized in a different population, (2) understanding how a temporal analysis of earlier and later time points might impact the framework, and (3) discussing the meaning of disruptions from HIV and cultural responses to disruption/change. This chapter is divided into several sections to (1) review the core concepts related to the life course and Becker’s

³⁴ Becker’s life course disruption framework was introduced in Chapter 3

framework of life course disruption, (2) discuss how the life course disruption framework was operationalized for the analysis of this dissertation research, (3) present how the findings on the experiences of living with HIV/AIDS help to refine Becker's life disruption framework and the extent that the findings map onto or conflict with Becker's framework, and (4) provide a concluding discussion on Becker's life disruption framework.

SECTION 1: REVISITING THE LIFE COURSE DISRUPTION FRAMEWORK

Key Questions and Concepts

Drawing from Becker's framework of life disruption, the main research questions include: Is HIV interpreted as a life course disruption among older African Americans living with HIV? How does HIV disrupt peoples' lives? How do people reorganize their lives in response to HIV disruptions? Does everyone with HIV experience disruption? The purpose of this chapter was to create a discussion between how Becker's framework of life course disruption may or may not map onto the findings from this dissertation. Before the details of the data analysis and findings are discussed, the key concepts related to the life course and Becker's life disruption framework will be reintroduced³⁵.

As discussed previously, Chapter 3 provided an overview of an Anthropological Approach to the Life Course. Utilizing the life course framework Becker focused on understanding life course disruption and reorganization to research what happens when expectations about the life course are not met due to various life events (e.g., accident) or conditions (e.g., infertility, stroke, chronic illness). Becker emphasizes how after a

³⁵ The life course framework was introduced in Chapter 3.

disruption people reorganize their lives in attempt to create continuity and order in their lives. The life course disruption framework, derived from life course theory is based on the idea that there are culturally defined and shared normative expectations of how a life course should progress (Becker 1997; Fry 2003; Settersten 2003). In understanding the life course, it is important to note that:

Because our conception of the developing person is multidimensional, that conception must include the possibility of both continuity and stability on the one hand and of discontinuity and change on the other. (Settersten 1999:247)

The excerpt above stated by Settersten (1999) in Chapter 6 of *Lives in Time and Place: The Problems and Promises of Developmental Science* highlights the importance of understanding that human lives are made up of periods of continuity/stability and discontinuity/change. Settersten notes that the multi-dimensional nature of human lives that incorporates both change and continuity is a major reason why studying human lives is both complex and methodologically challenging.

The following constructs underscore key aspects of the multidimensional nature of how human lives are understood within the framework of the cultural life course. *Normative* and *normalcy* refer to a state of being or living that corresponds with culturally and individually defined patterns or expectations of the life course (e.g. age norms, on-time events, or roles such as career, marriage, childrearing, education) (Becker 1997). *Life disruption* refers to an abnormal event or experience that deviates from what is culturally or individually expected in the life course (e.g., HIV diagnosis, disability, childlessness, off-time event) (Becker 1997). Becker describes how people who experience disruption often experience feeling different from other members of society and experience a loss of power. *Life disruption* can also be thought of as

change or *discontinuity* because it opposes continuity and refers to instability or irregularities in life course experiences (Settersten 1999). *Life reorganization* refers to the process through which people try to make sense of life, restore order, or to regain stability in life after experiencing disruptions, changes, or deviations from expectations in life (Becker 1997). *Continuity* reflects an “absence of change/discontinuity” (Settersten 1999). As described by Becker, in the U.S., people often feel a strong sense of personal responsibility for reorganizing their lives after experiencing disruption in an attempt to achieve continuity (Becker 1997). Continuity can also be thought of as a temporal concept by exploring how people establish a consistent flow of life pre- and post-disruption (Becker 1997). Continuity can be thought of in relation to life course expectations and also in relation to ordinary daily routines and activities of life. When people experience continuity they regain a sense of power over their lives. Becker argues that continuity is more of an idealized state of being and people may not experience true continuity because of the ongoing disruptions that occur throughout life. As a result, Becker concludes that continuity is an illusion. The application of these concepts to understand the experiences of disruption to HIV/AIDS will be discussed in the following sections.

SECTION 2: OPERATIONALIZING BECKER’S LIFE DISRUPTION FRAMEWORK

Section 2 of the chapter will describe the details of how Becker’s life disruption framework and core concepts were operationalized and utilized for the dissertation in relation to developing questions, coding, and interpreting the experiences of living with HIV/AIDS. This section also discusses the challenges related to using the disruption framework throughout this dissertation research.

Questionnaire Development

Developing a questionnaire based off of the life course framework was one of the challenges that occurred in the earlier phases of the dissertation research. After deciding to apply Becker's disruption framework to understand the experience of living with HIV/AIDS, I wondered how I might ask questions about disruption and reorganization. Because to date little is known about socio-cultural consequences of aging among African Americans with HIV/AIDS, this dissertation was exploratory and was not modeled after previous studies and did rely on an already developed questionnaire. The major questions related to operationalizing the life disruption framework in this research study were (1) how to take a theoretical framework and develop questions that are meaningful and make sense to participants, and (2) how to develop questions from a theoretical framework that does not have already established scale.

This research did not utilize an already established or validated scale such that is often used in psychology or other disciplines. During the earlier phases of the dissertation I spent time brainstorming on the types of questions to ask participants to elicit information about life disruption, reorganization and aging among older African Americans living with HIV/AIDS. During this period, I talked with my dissertation committee members and colleagues, reviewed literature for sample questions on disruption and reorganization, reviewed previous questions from the HAART project, and conducted interviews with health care professionals in order to develop the preliminary questionnaire. As part of the literature review, I was interested in finding other studies on the life course and life disruption to find examples of interview

questions. In my attempt to find example questions, I contacted (Merriam et al. 2001), the authors of a qualitative article on the life course and people living with HIV. However, the authors were unable to share additional information or the specific questions used for their research. The questions for this dissertation research were based primarily off of the main ideas and concepts from Becker³⁶ (1997), Scheer and Luborsky (1991)³⁷, and Settersten and Mayer (1997)³⁸ and Luborsky (2009); Sankar (2009). While these authors did not conduct research on HIV disruption, their research provided important resources for framing the theoretical ideas on the life course and in thinking about how to go about asking questions that would provide insight on the life course disruption. The questions used for this dissertation research were similar and different from the research of Becker (e.g., stroke, infertility) and Luborsky (e.g., Polio) in that the disruptions from HIV were not necessarily due to the loss of bodily functions or bodily expectations. Instead, the focus of this research was on how receiving an HIV diagnosis can also result in social and life course disruptions that can impact normative expectations. The disruptions people experience may not necessarily be related to loss of bodily functions. For example, HIV may not necessarily impact the physical ability to engage in sexually intimate relationships. However, the stigma associated with HIV can negatively impact desire and ability to engage in normative sexual and/or intimate relationships.

The preliminary draft of questions were reviewed by my dissertation committee, submitted to the Human Investigation Committee for approval, and piloted with the first

³⁶ Becker provides example questions on p. 208-209 (bodily functions and bodily expectations).

³⁷ Luborsky explored life reorganization among polio survivors by using life histories and illness narratives.

³⁸ For examples of life course questions and measurements see p. 242-252.

few participants (See Appendixes C and D). The main research questions were: (1) Do people experience life disruptions resulting from an HIV/AIDS diagnosis? (2) What do people identify as major disruptions from living with HIV/AIDS? (3) To what extent do people reorganize their lives in response to life disruptions? (4) Does disruption and reorganization occur at the initial diagnosis or as part of an ongoing process of living with HIV? Per the advice of my committee chairperson I tested the questionnaire out on two participants and then reviewed and transcribed the interviews. The iterative interview process was then used throughout the data collection process and the questions were slightly revised as needed for the remaining interviews.

In developing the interview question guide I began to problematize the ways anthropologists and other qualitative researchers ask research questions. For example, I recognized how the ways one goes about asking about the life course expectations and disruptions are not clearly established or defined in the existing literature. A result of the dissertation research was to develop my own preliminary toolkit for asking about the life course and disruption (See Appendix D). The questions were tested in the interviews with participants and will be used as a reference or starting point for future research in the life course disruption. A later goal of this research was also to begin to think about how to create a network with other researchers who study life course disruption and life course expectations to create a forum for sharing ideas for questions related to the field of life course studies. Theoretical terminology and definitions of the life course do not always translate easily into culturally relevant questions. Anthropologists need to create a dialogue with other researchers as an opportunity to discuss, share and critique questions as they are used in research. A forum on life

course research would provide an opportunity to share information and describe the questions that were effective or were not effective. While standardizing questions may not be appropriate for anthropologists, a more open dialogue about the types of questions to use as anthropologists study life course disruption would help further the field and refine this theoretical framework. Perhaps anthropologists could learn from other disciplines such as psychology and gerontology by publishing more on the types of questions used in research and sharing these resources with other researchers. By creating a forum for talking about the application of life course theory in research, anthropologists could provide insight for other researchers who want to use the life course framework and to refine how the framework has been used to date in research. In order to refine notions of the life course it is important to create conversations about how the life course is talked about in interviews. These discussions could assist anthropologists and other researchers who plan to use life course theory to develop questions and collect data. If anthropologists opened the discussion on the types of challenges experienced in conducting contemporary life course research, we could create a “checks and balances” method of ensuring that this type of research is culturally relevant and valid.

Dataset

Since discussing the process and challenges of developing questions for this dissertation research, the next section will discuss the process of exploring and analyzing the data for HIV disruption and reorganization. This section will address how the interview transcripts were defined, coded, analyzed and interpreted to gain insight into HIV disruption and reorganization. In addition this section will also discuss and

describe the extent to which Becker's framework of life disruption was applicable to the data.

The dataset and analysis of this chapter focus primarily on the data collected at two time points³⁹ : (1) T1 (first interview from the HAART Project) and (2) T2 (dissertation interview). These two time points were used as a means to explore HIV disruption and reorganization and also how duration or a temporal perspective might influence the experience of life disruption and reorganization⁴⁰. The first time point was based on the first interview from the HAART Project and provides data on an earlier phase of living with HIV/AIDS. The HAART Project inclusion criteria for initial entry into the project were based on the initiation of ART therapy: naïve (0-30 days on therapy⁴¹) and long-term (12-30 months on therapy⁴²). At the time of the T1, the participants were at various phases of living with HIV: naïve or long-term to HIV medications; 1 month to 19 years of living with HIV; and were either diagnosed prior to age fifty or at age fifty and older. The data collected during the HAART Project was focused mostly on medication adherence, but also included data on life history and general HIV experiences.

In the later phase, the last point of data collection, the data was collected in 2009 during the dissertation interviews. The dissertation interviews took place approximately five to seven years later depending on when the initial HAART Project interview took place. At the time of the dissertation interviews all participants were aged 50 years and

³⁹ The HAART Project collected up to five years of data on each participant. However, for this chapter I focused on the T1, the first point of data collection for the HAART project. The other interviews from the HAART project were reviewed for an in depth understanding of the participants but not the specific focus of this analysis for this chapter.

⁴⁰ Settersten notes that analyzing two time points is deceptively complicated (Settersten 2003)

⁴¹ The length of time living with HIV among the naïves ranged from 1 month -19 years

⁴² The length of time living with HIV among long-terms ranged from 2-12 years

older, were long-term survivors (e.g. living with HIV for 6-24 years), and had been taking medications for at least five years. During the dissertation interviews, participants were asked questions about HIV disruption, aging with HIV, and general updates about their life and reflections on their earlier and later experiences of living with HIV (See Appendix D).

To help keep the dissertation research manageable, the T1 and T2 were the primary data points for the analysis of this dissertation. However, other time points from the HAART project were also utilized as needed⁴³ to further explore the data based on specific word searches and to clarify experiences of participants if data was missing or limited.

Coding and Analysis

The coding categories were based off of the key concepts of the life course disruption framework that were introduced previously in this chapter. Coding for disruption was based on talk about physical, social and emotional effects resulting from living with the condition HIV/AIDS. Disruption included talk about deviations from life course expectations or discussions about feeling different or marginalized from others. The focus for this analysis was on understanding the various disruptions resulting from HIV rather than general life disruptions (e.g. death in family). Participants' discussions of HIV disruption included the following: emotional distress from diagnosis or while living with HIV/AIDS, symptoms of illness, side-effects from medications, fear of death, stigma, actual or anticipated fear of rejection, negative perceptions of HIV/AIDS, loss of sexuality/intimacy, isolation, and various social losses (e.g. going out, friendships).

⁴³ The HAART Project collected up to eight interviews for each participant.

Coding for reorganization was based on participants who described experiencing some type of disruption resulting from HIV, but who also discussed making adjustments to life, social activities, or daily routines since receiving an HIV/AIDS diagnosis (e.g. establishing a routine to make medications easier to take, ability to make changes in life in order to continue desired behaviors, finding new purpose in life since HIV disruption such as religious involvement, altering sexual and intimate activity). Reorganization also included revised philosophies about how to persevere with HIV/AIDS (e.g., fighting it, not giving up, not as bad as I thought). Reorganization may or may not include normalcy or continuity in life (e.g., learned to engage in normative relations with others despite HIV status vs. reorganized life to avoid intimate and sexual relationships).

Coding for normalcy was based on talk about the absence of HIV disruption. Participants described how HIV was not disruptive to normative life course expectations, life goals, or phases of life. Evidence for normalcy was based on participant discussions about how HIV is not a burden and how they often “forget” they have HIV. Participants also provided evidence of normalcy when talking about how life did not impact life course expectations, goals or stages of life (e.g., “I achieved everything I wanted in life”).

Coding for continuity included categories of normalcy and/or reorganization. Continuity is considered more of an etic⁴⁴ concept because, as described by Becker, continuity is interpreted by the researcher as an illusion or idealized state of being. Normalcy can be perceived as a form of continuity because participants perceive they were able to achieve life course goals, expectations, and phases of life pre- and post-HIV. People who emphasize normalcy in their discussions provide evidence for lack of

⁴⁴ Etic is based on the researcher's perspective or interpretation. Emic is the participant's perspective.

disruption and instead illustrate continuity or a consistent flow of life pre- and post-HIV. Reorganization can also be thought of as a form of continuity because people illustrate how they are able to reestablish certain aspects of their lives that were formerly disrupted and thus create continuity in life. Even though life was disrupted from HIV, participants with reorganization develop techniques or philosophies for creating a sense of continuity in life despite disruptions experienced (e.g. continue to seek intimacy despite HIV disruptions). Coding for continuity was also based on evidence of how people described feeling a personal responsibility for creating order out of disruption (e.g., I did this to myself, I must deal with it). Normalcy and continuity are often defined in the literature as representing an absence of disruption or change. However, Nisbet generalizes how in the U.S. culture people tend to deny change (Nisbet 1969). Therefore normalcy and continuity may not necessarily imply absence of disruption or change and may serve as a as a cultural script for dealing with disruption or trauma.

Coding started off as a two-part process. First, disruption and reorganization were coded by using responses to the questions “Tell me about living with HIV” and “How has HIV influenced your life?” as they occurred in the T1 and T2 interviews, respectively. Second, the entire interview transcript was reviewed in order to code for disruption or reorganization of HIV/AIDS as it may have occurred in other areas of the transcripts. The second round of coding helped to provide more saturation with regard to the data: (1) for participants who did not have the HIV narrative questions due to missing data, (2) for participants with short responses, and (3) to provide more coverage in how life disruption or reorganization might be talked about. The two-step

approach helped to provide a more comprehensive understanding of life disruption and reorganization.

After completing the coding, a general summary on the presence or absence of life disruption and/or reorganization for the T1 and T2 for each participant was created. At this point, I realized there was a great deal of talk about normalcy and continuity during the dissertation interviews. As a result the interviews were reviewed and coded for normalcy and continuity. For the T1 (earlier phase of living with HIV) the participant discussions provided evidence for three major patterns of HIV experience: (1) disruption, (2) disruption and reorganization, and (3) continuity. For the later phase of living with HIV, the participants were again sorted into three main patterns based on evidence of: (1) disruption, (2) disruption and reorganization and (3) continuity. The categories of HIV experience were similar at the earlier and later phases except for a slight change in emphasis for pattern 2. At the T1 participants emphasized disruption but also provided evidence of reorganization, whereas during the T2, the later phase, the participants emphasized reorganization, but also provided evidence of disruption. Pattern (2) was similar at both time points because it included both disruption and reorganization, but with a slight change in emphasis on disruption at the T1 and reorganization at the T2.

Spreadsheets were used (See Table 3) to record and visually display: (1) the summarized experience of HIV for each person; (2) the evidence for the three main types HIV experience at the T1 and T2 (See Figure 3); and (3) if the categories were consistent or changing over time (See Figure 4). The spreadsheets allowed me to explore the extent to which the evidence for the patterns at the two time points were

consistent or changing. A result of this multilevel approach to data analyses was to gain insight into the general experience of living with HIV and how perceptions of HIV and/or disruptions compared at different time points.

The following section, Section 3 of this chapter, discusses the various ways that the data on HIV disruption and reorganization were interpreted and the ways in which the data corresponded with Becker's framework of life disruption. The findings presented in Section 3 are divided into three main parts. Part 1 identifies and describes evidence from the T1 and T2 interviews that support Becker's life disruption framework. Part 2 provides evidence from the T1 and T2 interviews that conflict with Becker's framework. Part 3 presents the findings from the temporal analysis of the patterns from the T1 and T2 interviews to illustrate how some patterns of HIV/AIDS experience support or conflict with Becker's "chaos to order" framework.

SECTION 3: FINDINGS ON HIV DISRUPTION

This section discusses the main findings from this dissertation research on HIV disruption among older African Americans who are living with HIV. This section is divided into several parts (1) to discuss how discussions with participants experiences of living with HIV/AIDS provided evidence for Becker's framework of disruption and reorganization, (2) to describe how some participants provided evidence for different patterns of HIV experience the conflict with Becker's framework, and (3) to refine Becker's framework by using a temporal perspective to understand the experiences of living with HIV/AIDS.

FINDINGS: INTERPRETING HIV EXPERIENCES

When a person is initially diagnosed with HIV, they may suffer from the immediate disruption and also fear of death. Becker states:

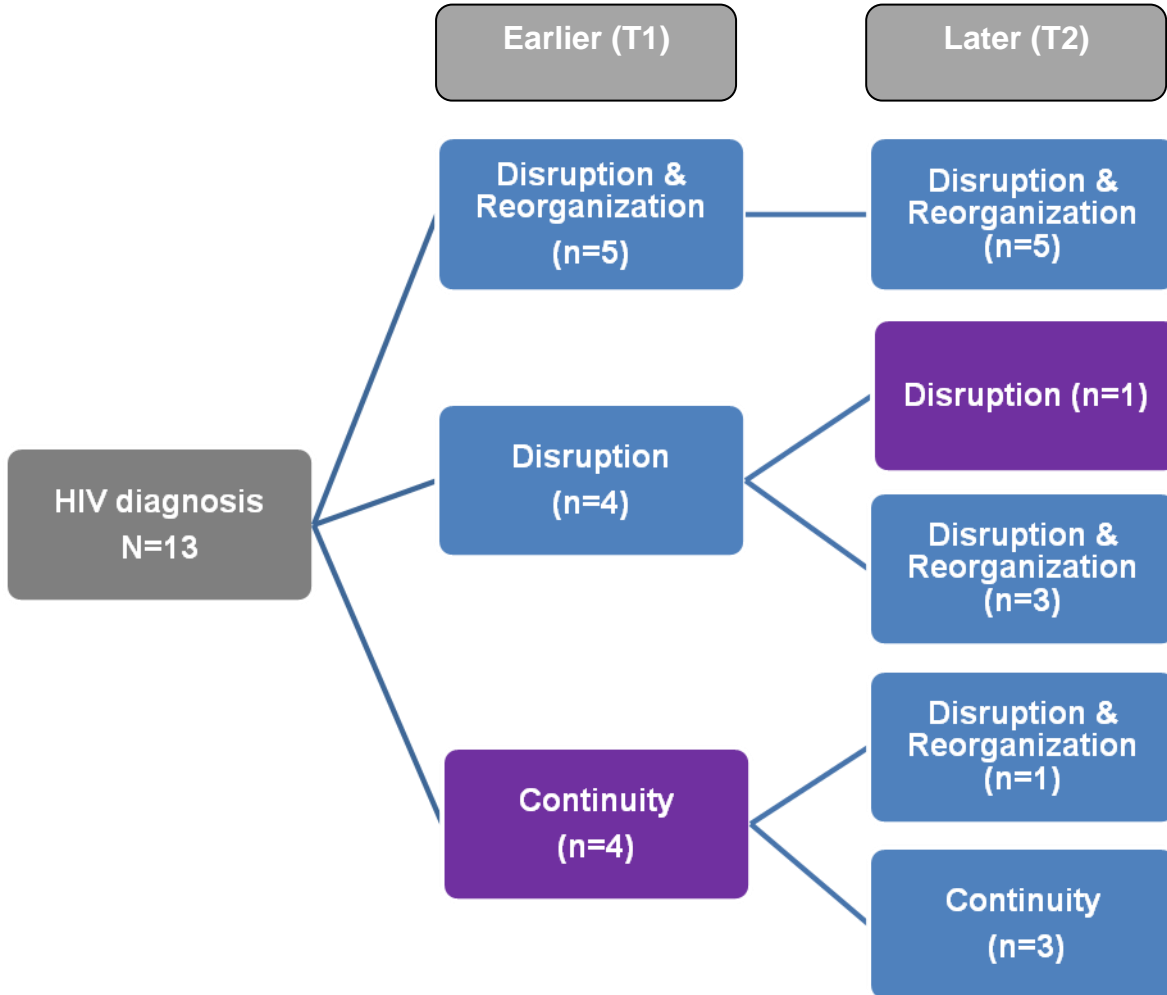
The threat of death temporarily and sometimes permanently, destroys people's sense of order. People who experience the sudden onset of chronic illness face the destruction of life itself, the destruction of the habituated, embodied self as well as the uncertainty about whether they have time left to create themselves a new. (Becker 1997:46)

Becker's discussion of disruption from chronic illness fostered my interest in learning about the various disruptions resulting from HIV and the ways people may or may not reorganize their lives throughout the experience of living with HIV/AIDS. In Becker's book *Disrupted Lives* she underscores how people tend to present their stories in a linear fashion transitioning from experiences of "chaos to order" (Becker 1997:6). Following the analysis of the individual's interpretation of the initial HIV diagnosis, I was interested in understanding how people interpret living with HIV/AIDS many years after the diagnosis. Do people living with HIV/AIDS present similar patterns of experience as suggested by Becker (e.g., "chaos to order)? Do people living with HIV/AIDS experience ongoing or changing disruptions, challenges, periods of stability, reorganization, normalcy, continuity?

As will be discussed throughout this chapter, the analysis reveals how participants' data conveyed three different patterns of interpreting HIV/AIDS. After coding for disruption, reorganization, normalcy, and continuity participants were sorted into three major patterns of HIV experience based on the overarching themes of their stories. The three major patterns were (1) disruption, (2) disruption and reorganization, and (3) continuity. The first part of the findings section for this chapter is based on the analysis of interviews in relation to people who provided evidence in support of Becker's

framework (e.g., disruption and reorganization at the T1 and T2). The second part of the findings for this chapter focuses on how some participants provided evidence for patterns that did not match up with Becker's framework of life disruption (e.g., continuity at T1 and T2, disruption at T2). The third part of the findings for this chapter explores how the patterns of HIV/AIDS experience were explored temporally and the extents to which participants' experiences changed over time.

Figure 4. Interpreting HIV Experiences at Earlier and Later Interviews



Blue = Supports Becker's Framework
 Purple = Conflicts with Becker's Framework

Table 3. Results of Coding By Participant

Participant	HIV Diagnosis	T1 Medication Duration (HIV Duration)	T2 HIV Duration	Early (T1)	Later (T2)
Alvin ¹	2003	Naïve (<1yr HIV)	6yrs	<u>Disruption & Reorganization</u> ²	<u>Disruption & Reorganization</u>
Donald ¹	2001	Long-Term (2 yrs. HIV)	8yrs	Continuity ²	Continuity
Gerard	2001	Long-Term (2 yrs. HIV)	8yrs	Continuity ²	Continuity
James	1985	Naïve (19yrs HIV)	24yrs	Continuity ²	<u>Disruption & Reorganization</u>
Leonard	2000	Long-Term (3 yrs. HIV)	9yrs	Disruption ⁴	Disruption
Loretta ¹	2001	Long-Term (2 yrs. HIV)	8yrs	Disruption ⁴	<u>Disruption & Reorganization</u>
Marion ¹	1999	Long-Term (3 yrs. HIV)	10yrs	Disruption ³	<u>Disruption & Reorganization</u>
Melvin ¹	2003	Naïve (<1yr HIV)	6yrs	<u>Disruption & Reorganization</u> ²	<u>Disruption & Reorganization</u>
Mildred	2002	Naïve (<1yr HIV)	7yrs	<u>Disruption & Reorganization</u> ²	<u>Disruption & Reorganization</u>
Patrice	2001	Long-Term (2 yrs. HIV)	8yrs	Disruption ³	<u>Disruption & Reorganization</u>
Sheila	1999	Naïve (4 yrs. HIV)	10yrs	Continuity ²	Continuity
Wally	1997	Long-Term (6 yrs. HIV)	12yrs	<u>Disruption & Reorganization</u> ³	<u>Disruption & Reorganization</u>
Willie	1991	Long-Term (12 yrs. HIV)	18yrs	<u>Disruption & Reorganization</u> ³	<u>Disruption & Reorganization</u>

¹Diagnosed with HIV/AIDS at age 50 and older.

²T1 Beck's Depression Classification – Low Depression

³T1 Beck's Depression Classification – Moderate Depression

⁴T1 Beck's Depression Classification – Severe Depression

PART 1. FINDING PATTERNS THAT SUPPORT BECKER'S LIFE DISRUPTION AND REORGANIZATION FRAMEWORK

Part 1a. T1 Patterns of Living with HIV/AIDS Supporting Becker's Framework

T1 HIV Disruption

Approximately one-third (n=4, 31%) of the participants provided evidence for experiencing major HIV disruption at the T1, the earliest time point (See Figure 3 and Table 3). This pattern was characterized based on the experience of major HIV disruption without evidence of reorganization or continuity. The discussions from these participants emphasized chaos, difficulty in dealing with HIV, and/or emotional distress. At this earlier phase, three out of five (60%) of the women experienced major HIV disruption in comparison to one out of eight of the men representing major disruption at T1. More women in the major disruption pattern at the T1 might be explained in part due to lower reported SES as described in Table 1. Otherwise it was unclear why more women provided evidence for the disruption category at the T1. The examples from Leonard and Marion are used to help illustrate this pattern of HIV disruption that occurred at the T1. These examples are used to present evidence of the ways HIV can be highly disruptive for people during the early phases of living with HIV.

Leonard

Only one out of eight men (13%) described their experience of living with HIV at the T1 as highly disrupted. In his discussion of disruption Leonard did not discuss life reorganization during the earlier phase after receiving an HIV diagnosis. During the first

interview at the HAART Project in 2003, Leonard, age 50 and HIV positive for 3 years, described living with HIV as:

L⁴⁵: Roller coaster. Nutshell.

I⁴⁶: That's it?

L: That's it.

Leonard's quote illustrates how metaphor is used to identify disruption from living with HIV. However, understanding how HIV disrupts his life was unclear from this quote. As a result, I needed to explore other aspects of his transcript to gain more information on his experience of disruption. He elaborated on his experience of disruption in the following passage from his transcript:

I: Okay. Now if I were to write your life since having HIV as a book, and divide up into a chapter for each part of your life with HIV, what would you want me to make the first chapter and the title?

L: Mm. Oh man. First chapter since finding out. Uh, Internal Hurricane. I went crazy.

I: Is that the title? Internal Hurricane?

L: Mm, because that's what happened to me, you know, and I'm still [laughs].

I: So what would go in that chapter?

L: Disaster, one right after another. Disaster, that would go in there.

I: So, um, then what would the next chapter be?

L: Mm, Survival.

I: What would go in that chapter?

L: Disaster.

I: Disaster again?

L: How many more chapters?

I: It has as many chapters as you would like it to have.

L: Mm. Last chapter Down the Hill. [laughs] The Ride is Over.

I: And what would go in that chapter?

L: Hm, the way to death. Since I have nothing else to look forward to.

(Leonard HAART T1 2003, Age 50, Long-term to HIV meds, HIV+ 3 years)

Leonard's discussion of living with HIV/AIDS was based on experiencing major disruptions and he focused on using words like "roller-coaster", "hurricane", "disaster",

⁴⁵ L = Leonard (pseudonym)

⁴⁶ I = Interviewer from the HAART Project

and “death”. However, it was still unclear about the types of disruptions Leonard was experiencing. After reading through Leonard’s transcript I discovered that the disruptions he experienced from HIV included fear of death, emotional distress and anger, illness and disability resulting from HIV/AIDS, medication side effects, loss of the ability to work and provide for himself, social isolation, loss of intimacy and sexuality, and frustration with the lack of social services provided to him. His story provided insight into understanding the intense suffering occurring during the earlier phases of living with HIV and how some people might not be able to reorganize their lives during the early phases of living with HIV/AIDS.

In contrast with the men of the sample, over half (60%) of the women described their experience of living with HIV at the T1 as characterized by major disruption. During her first interview at the HAART Project, Marion provided a discussion of the disruption she experienced in her story of living with HIV.

M: Um...since I been diagnosed, let me think. [pause] My life is...it's a little empty right now. I'm...I could be a lot happier than what I am. I...don't go out and party like I u-, used to do. I'm more of a homebody. And since I been diagnosed what it really...I know my body's not the same, because...I stay tired a lot and my legs bother me, they swell up. And it-, I really feel em-, I mean...I know being with a man is because I-, me in the shape I am, but I would like to have someone in my life, and right now I don't have anyone because...I guess I'm afraid of being rejected, you know, if you let somebody know well...they might not be that understanding. Being rejected is the biggest thing in my life and talking about it to another man, you know, letting him know.

I: Was there any points along the way between your diagnosis and now that you want to talk about?

M: No, not really. Because like I said right now it's still hard for me to deal with me having it, you know understanding why did this happen? You know, to me, you know. And like I said maybe if I started going to some HIV programs and, and get-, you know, talk to people that's have had it longer than I have, and...maybe talk to someone to show me how to deal

with it, you know be more open with a man, you know, or anyone else. Because sometime, like when I hear it on TV I kind of click it off because I don't want to hear about it, you know I-, by me having it, which I know is stupid. But um...yeah so sometimes I don't even deal with it. I don't even like to think about it. (Marion HAART T1 2002, Age 55, Long-term to HIV meds, HIV+ 3 years)

Marion's story provided additional discussion on disruption and provides examples of the different disruptions she experiences. Some of the disruptions she experienced were emotional distress (e.g. isolation, emptiness, loneliness, fear of rejection from intimate partner, loss of intimacy), physical changes in her body (e.g. fatigue, swelling), and loss of expected social interactions and activities (e.g. going out, partying, dating, companionship). She was also unable to participate in the activities that she did prior to HIV such as going out and dating, not due to physical limitations but because of fear of being rejected by a man and having to disclose her status. Her narrative emphasized disruption without reorganization. She did, however, allude to how becoming involved in HIV programs in the future might be a way to deal with the disruptions she was experiencing.

The stories from Leonard and Marion provided two examples of the intense disruption and suffering people might experience after an HIV/AIDS diagnosis and during the earlier phases of living with HIV/AIDS. The stories from Leonard and Marion will be continued in the section that focuses on later experiences of living with HIV. As suggested in Becker's framework, people often experience disruption from the onset of an illness. Leonard and Marion provided evidence for Becker's framework by highlighting the highly disruptive nature of chronic illness. It is important to note that within the disruption category all of the participants had been long-term on medications

and living with HIV for at least two years. This category illustrates that a highly disruptive experience of living with HIV can occur after living with HIV for several years.

T1 Disruption and Reorganization

In contrast from the participants who emphasized major disruption, this next category consists of participants who described both disruption and reorganization in their experience of living with HIV at the T1. Five out of thirteen participants (38 percent: 50 percent of the men and 20 percent of the women) provided evidence for disruption and reorganization in telling their stories of living with HIV at the T1. Participants within this pattern described a variety of reasons how HIV disrupted their daily lives. These reasons included (1) fear of death, (2) shock of initial diagnosis, (3) loss of intimacy/sexuality, and (4) difficulty adjusting to medications. The fear of death after an HIV diagnosis was common for the participants who were interviewed, but not necessarily the only type of disruption during the earlier phase of living with HIV/AIDS. In response to the diagnosis of HIV/AIDS, participants also discussed difficulties with adjusting to medication regimens, opportunistic infections, and negative mental health statuses. The participants described a variety of different emotions experienced resulting from an HIV/AIDS diagnosis ranging from being scared, angry, sad, and shocked.

While these participants experienced disruption, they also demonstrated evidence for reorganization of living with HIV at the T1. Reorganization was determined based on discussion about making adjustments to their daily life with HIV/AIDS, devising strategies of survival, or developing a resilient philosophy in how to deal with the negative impacts of living with HIV. These participants illustrated how even at

earlier phases of dealing with HIV disruptions they were actively reorganizing their lives and working towards creating a sense of normalcy and continuity. This pattern of disruption and reorganization supports Becker's framework that suggests people who experience disruption make efforts to reorganize and restore their lives to establish a sense of normalcy and continuity. The examples from Alvin and Mildred are used to provide additional insight into understanding the pattern of disruption and reorganization at the T1.

Alvin

Alvin, in a fairly typical response for this group, described disruptions in the form of emotional distress he experienced after learning about his unsuspected HIV/AIDS status. However, Alvin also illustrated reorganization as described in his discussion about 'fighting' HIV/AIDS just like he previously fought and survived cancer. As discussed in his first interview from the HAART Project in 2003, shortly after he was diagnosed, Alvin responded to the HIV narrative question by saying:

He said have you ever...took a, a...HIV test? I said no. Said well have you ever thought about taking one? Said not really, I said I know they're out there and all, but I said I never thought I-, thought about I said because I don't think I have it. He said well, I would like for you to take one. (frustrating) why? He said well, there is some times when...when you have HIV that you have some skin eruption or rashes or what have you. And said...I just want to rule it out. He said would you consent to taking one? Said sure. (tell you what), if you think it's necessary, sure, no problem. So did. And /it came back positive. Said what?

So...I after I went home and sitting down thinking, where do I go from here, what have you. I uh...I let myself have one little cry. Shed some tears one time⁴⁷. Then I had to tell myself, You ain't going to get where you want to get by crying about it, you're going to get where you want to get by fighting it. Then I went back to this cancer thing, when you had cancer, (You thought you was going to die) you didn't die. This ain't going to kill you either, not if you fight it. That's where I am right now. My doctor

⁴⁷ Discussion of disruption – emotional distress from diagnosis

tells me that he will not let me die of AIDS. Hey, I got to believe him. And I got to fight⁴⁸. This is why I'm taking this medicine right now that is laying me low. Until I can get back to him and talk to him about it. To see if there's something else that I can take, that I can go on and get back in the gym and get stronger and everything, the whole works⁴⁹. Um...I, as I said I don't give up easy. And it catch me, this thing catch me, going to catch me running, I ain't going to sit down and do nothing, not, I got to move on. I don't want to think about dying, you know, from it⁵⁰. (Alvin HAART T1 2003, Age 72, Naive to HIV meds, HIV+ a few months)

Despite the emotional distress resulting from his diagnosis, Alvin took on a resilient approach to thinking about living with HIV/AIDS. He survived cancer and would use his survival skills in his approach to dealing with HIV/AIDS⁵¹.

Mildred

During her first HAART Project interview in 2002, Mildred described her life since being HIV positive as focusing on the daily routine of taking medicines, childcare responsibilities and housekeeping.

I: Now earlier you told me a story, you know, the history of your life basically. Now we want to focus in on your life since you found out your diagnosis. Um, could you give me a summary of what it's been like since then?

M: Well, I...[it starts] my day about five o'clock in the morning. Taking pills. And then one in the day, I...take about let's see...take about ten pills a day right now. And it starts at five in the morning, and it...again I take them again around nine-thirty, and then I take them around one o'clock, and then I go back to nine-thirty for last one...seven, quarter to eight in the morning, I put my nephew on the bus that I baby-sit, so I put him on a bus and I get him off the bus at three-thirty, four o'clock. And in between that time...clean-up my apartment, cook my dinner and whatnot. Cook my lunch, and have it all [preserved] and by the time he get home all my stuff is done⁵². (Mildred HAART T1 2002, Age 49, Naive to HIV meds, HIV+ a few months)

⁴⁸ Discussion of reorganization – fighting HIV like he fought cancer

⁴⁹ Discussion of disruption- medicine making me sick

⁵⁰ Discussion of reorganization- not going to give up

⁵¹ Alvin's life history narrative also included talk about survival and learning how to live off the land in the rural south

⁵² Emphasis on routine is discussion of reorganization

At a later point during Mildred's interview she went on to discuss how she also experienced emotional distress from living with HIV (e.g. sadness, loneliness), but had devised strategies to deal with the distress she experienced.

I: Is there anything else you would want to add about your life in general, since you found out?

M: [I get kind of lonely] up in here. (Laughs). I gets out and go walk sometime. And sometime I just get upset, and just sit in here and cry for a while and then read a book. Listen to some music. And just continue on⁵³. (Mildred HAART T1 2002, Age 49, Naive to HIV meds, HIV+ a few months)

Despite experiencing disruptions resulting from living with HIV/AIDS, Mildred also provided evidence of reorganization based on her discussion of establishing a routine for taking medications and strategies for dealing with negative emotions (e.g., reading book, listening to music, taking a walk). Her story emphasized that she was able to "continue on" and survive despite experiencing negative effects from living with HIV/AIDS.

The disruption and reorganization pattern at the T1 (n=5) consisted of four men and one woman, and more were naïve (n=3) than long-term (n=2). This category highlights that even at the earliest phases of living with HIV (less than 30 months for the long-terms and less than 2 months on medications for the naïves) people begin to reorganize in their early experiences disruptions from HIV/AIDS. Alvin and Mildred provided two examples of how, despite describing disruption from living with HIV/AIDS at the T1, these participants also emphasized ways they could reorganize their lives in order to create a sense of normalcy and continuity.

⁵³ Disruption – loneliness but then discussion of reorganization listening to music, etc

The analysis of the T1 interviews provided evidence for two major patterns in support of Becker's framework: (1) disruption and (2) disruption and reorganization. It is important to note that, based on the findings from this sample; I was surprised that the category of disruption at the T1 consisted of all long-term participants. Based on Becker's framework, I would have hypothesized that the pattern characterized by major disruption without reorganization would be comprised of naïve participants who are most new to the experience of living with HIV/AIDS. In addition, I was also surprised by the distribution of the participants in the disruption and reorganization pattern because of the higher number of naïves rather than long-terms within this pattern. Based on Becker's framework I would have suspected the opposite, that more naïve participants would have experienced major disruption without reorganization and more long-terms would have experienced disruption and reorganization.

The next section of findings in support of Becker's framework focuses on the analysis of the T2 interviews (interviews conducted at the time of the dissertation).

Part 1b. T2 Patterns of Living with HIV/AIDS Supporting Becker's Framework

The analysis of the T2 interviews revealed two patterns in support of Becker's framework. These patterns were (1) disruption and reorganization, and (2) continuity.

T2 – Disruption and Reorganization

As one would expect from Becker's framework, the majority (69%) of the participants who were interviewed at the later phase of living with HIV provided evidence for the pattern of disruption and reorganization (n=9). At this later point in time, the participants who emphasized reorganization could be interpreted as corresponding with Becker's research on the how people feel the need to create order

and establish continuity after life disruption. The participants with this pattern were distributed almost evenly between the men/women, naïve/long-term, younger/older diagnosis, and duration categories (2-9 years, 10+ years). At the T2 the disruption and reorganization pattern changed in emphasis in comparison with the T1. At the T2 the participants emphasized reorganization but also experienced disruptions. In referring to living with HIV/AIDS at the later point in time, these participants described how they learned how to adjust to living with their illness and sometimes they even “forget about it”, thus creating a sense of continuity in their lives despite having a sero-positive status⁵⁴.

For these participants, the fear of death subsided as they received reassurance from their doctors about living with HIV and learned how to re-evaluate their understanding of living with HIV and focused on “trying to survive”. This section describes how even though people experienced disruptions from HIV/AIDS they have also developed ways to integrate HIV into their daily lives thus creating a new sense of continuity. The once life threatening disruption resulting from their diagnosis has become reorganized into a normative component of these people’s lives. During the dissertation interviews these older adults described the way HIV impacted their daily lives as “just being there” or “forget that I have it”.⁵⁵ Except for taking the medications, some participants said they rarely thought about HIV on a daily basis.

At the time of the dissertation interview, Alvin focused on how he is dealing much better with living with HIV/AIDS. He takes personal responsibility for his HIV status and

⁵⁴ I will examine this more critically in section 2 on change over time

⁵⁵ It is also important to note that one of the older adults interviewed described HIV as impacting every component of his life. His experiences may be somewhat different than the other participants. He is experiencing some negative side effects from HIV and the medications.

has been able to reorganize his life and perform his normative daily activities such as church involvement. Alvin states:

Dealing with life. Very well. I have changed somewhat. I've learned more and accept more about God than I did at that particular point when this thing first happened... I go to church. I go to choir rehearsal, I sing in the choir. I'm not gonna lie. I learned to live with it and be happy. So I do very well. I'm not going around with my head down or anything of that nature. I continue to live and livin' a better life I think. That's the only way I know how to explain it to you. What I'm trying to say. No I'm not walking around [letting it worry] me, I did it. Nobody made me do it. I didn't know I was doing it but I did it. (Laughs). So I live with it. (Alvin Dissertation Interview 2009, Age 78, HIV+ 6 years)

Even though Alvin's emphasis is on reorganization and is able to establish continuity in some areas of his life while living with HIV/AIDS he also experiences disruption to his sex life. Since his diagnosis he is no longer sexually active.

My ship stopped in the water when I found out about it. It's still in the water where it stopped at. And like I said before I could pursue it but then that means that I got to tell about me and uh, uh, I ain't going that way and I'm not going that way. I don't know of anybody that can make me go that way. (Alvin Dissertation Interview 2009, Age 78, HIV+ 6 years)

Alvin's focus on normative activities and a positive outlook on life illustrated reorganization and continuity. However, despite emphasizing reorganization, Alvin also experienced disruptions to his sex life.

The next example is from Marion who provided additional insight into how people might emphasize reorganization but also experience disruption at a later phase of living with HIV/AIDS. At the time of the dissertation interview Marion provided evidence of reorganization based on how she was better at dealing with HIV, healthy, and was spreading the word about HIV to others. Her health had been great, her viral load was

undetectable, and the medications had become less burdensome for her. Marion stated:

Getting out more you know. I'm communicating with people more about my sickness and trying to let the young people know this is real you know and even with my grandkids - use some kind of protection because this is real. At my age I never know one could have told me I was infected with HIV and 59 years old. I was in my 50s when I found out. I'm dealing with it and I've accepted I take my medicine. When first started out I was taking six pills at 6 in the morning, six at noon, and another six at 6 in the evening. And now I'm down to four pills. I take them in the morning and that's it. (Marion Dissertation Interview 2009, Age 62, HIV+ 10 years)

Despite an emphasis on reorganization and her efforts to restore continuity, Marion also experienced disruptions from HIV. Even though she had made adjustments to living with HIV, Marion struggled with lack of appetite:

My health has been great. It's really been good, I haven't been sick I haven't been back in the hospital. It's just my eating. I don't eat well, I was supposed to have been before I got my teeth pulled too but I chickened out on that. They had a program for HIV but I'm gonna have to call the girl because I had an appointment for the 24th of last month. I think it expires in March of 2009 so but uh, I just don't have an appetite. I don't have an appetite. I'm part of a healthful program they give us Ensure milk for when we losing weight and stuff and they give a 40-dollar money order to go to the grocery store to get some extra food. Like I said I'm doing just great. (Marion Dissertation Interview 2009, Age 62, HIV+ 10 years)

Marion provided evidence of reorganization and was working towards continuity through a positive attitude about her HIV status and in her efforts to communicate with others about HIV. However, she also provided evidence of disruption in her discussions about dealing with dental problems and loss of appetite.

Continuity at T2

The other pattern supporting Becker's framework at a later phase of living with HIV/AIDS was continuity. The continuity (n=3) pattern, was reflective of people who

emphasized continuity and described no major disruptions resulting from living with HIV/AIDS at the later phase. Twenty-five percent of the men and thirteen percent of the women were in the continuity category at the T2. In relation to duration with HIV/AIDS, the continuity pattern consisted of about one-quarter of the naïve and long-terms. There were slightly more people who were diagnosed as older adult (30%) than as younger adults (17%) in this pattern. The stories from Sheila and Gerard will be discussed to illustrate evidence of the continuity pattern at the T2.

During the dissertation interview in 2009, Sheila described how HIV was not perceived as a disruption compared to her other illnesses.

I have considered the other things (clears throat) like the arthritis to be more of a disruption to my life than HIV. The HIV is not really a problem because all it is is HIV. It's not like I have no huge, radical, unknown, invasive something that's going on with me and it's nothing that can be done about it. I mean it's just HIV. I mean, a person that has leukemia they, they immune system is just as bad as a person with HIV but there's nothing that can be did about it. I will not let that be a problem. You, there's nothing you can do about it, so you turn it over and don't worry about it. You deal with the things that you can. And that's what I did. (Sheila Dissertation Interview 2009, Age 53, HIV+ 10 years)

Sheila did not perceive HIV to be a major disruption at this later phase in her life; however, she described how other health problems were more disruptive to her life. For example, she was blind due to a self-inflicted gunshot wound from suicide attempt prior to her HIV/AIDS diagnosis and had many health problems, some resulting from former drug use. She had severe arthritis and mentioned how she could no longer perform basic tasks, such as braiding her hair. When I interviewed her for the dissertation research, she told me how a few months prior she fell down the stairs and broke her arms, which complicated her daily functioning. She was married and her husband

provided much assistance and care-giving on a daily basis. Sheila did not consider HIV to be a disruption to her life, perhaps due in part to how other her ailments and health problems were more disruptive.

During the dissertation interview Gerard did not describe experiencing disruptions from living with HIV. He often referred to his life being the same as it was pre-HIV except for having doctor's appointments and taking medications. However, he didn't think of those as being major disruptions. When asked about what had been going on in his life, he emphasized how his life was the same.

Still in a rocky relationship, still, my mother that has Alzheimer's and lives downstairs she's 88 she's been suffering with it for 7 or 8 years which is very stressful and I've got the added stress of everyone else in this economy and my job security. Aside from that everything is basically that same. My health status, knock on wood, is the same. (Gerard Dissertation Interview 2009, Age 56, HIV+ 8 years)

In the following quote he described how although he had been living with HIV for many years, he had forgotten what life was like pre-HIV.

After this many years it's like I forgot what it was like before I had it. Thank God I haven't had any health issues related to it. (Gerard Dissertation Interview 2009, Age 56, HIV+ 8 years)

HIV/AIDS had not impacted his ability to perform his daily responsibilities and duties as a caregiver for his mother and full-time work as an accountant. Gerard's narratives placed very little emphasis on disruptions from HIV probably because of the overwhelming responsibilities in his life as a caregiver for his mother who lives below him. Much of Gerard's life had been consumed with care-giving for his elderly parents. When he was first interviewed at the HAART project he was care-giving for his father and his mother's health was declining. By exploring the other discussions from Gerard's interviews, we learned how HIV did not take first precedence in his life. He

had little time to focus on his own health and desires because of the burden of care-giving for his mother. Much of the stress in his life was due to having to think of his mother's safety and health twenty-four hours a day.

Continuity at the T2 was slightly higher among men than women and among those with an older versus younger diagnosis. Duration and medication cohorts made up about one-quarter of the people with the continuity category. Both Sheila and Gerard focused on continuity at the later phase of living with HIV. Sheila described how she did not experience major disruption from HIV, but instead she normalized HIV by stating how HIV wasn't a big deal compared to other types of illness. Gerard described himself as not experiencing major disruptions to HIV and described how much his life was the same as it was prior to HIV. It is important to note that while Sheila and Gerard emphasized continuity/no disruption with HIV, they experienced other non-HIV disruptions and burdens, such as other health problems and care-giving responsibilities.

In summary, most of the participants interviewed described disruption and reorganization at the later phase of living with HIV/AIDS. However, it is important to note how the three participants provided evidence for the continuity pattern which provides insight on another approach to interpreting HIV experience but also supports Becker's framework.

The first part of the findings from this chapter is organized based on the patterns of HIV experience that provide evidence for Becker's life disruption and reorganization framework for the T1 and T2 time points. The second part of the findings for this chapter will discuss the patterns of HIV experience that do not support Becker's framework.

PART 2: FINDING PATTERNS THAT CONFLICT WITH BECKER'S FRAMEWORK

The patterns that were discussed in the previous part of this chapter provided evidence for Becker's framework of life course disruption. The following findings are presented to illustrate patterns of HIV/AIDS experience that did not map onto the framework of life disruption and reorganization that was emphasized by Becker. The findings for this section are organized based on the T1 and T2 time points.

Part 2a. T1 Patterns of Living with HIV/AIDS Conflicting with Becker's Framework

T1-Continuity

Drawing from Becker's framework one would expect that participants experienced disruption during the early phases of living with HIV/AIDS. The majority of the participants supported the life disruption framework and provided evidence of experiencing disruption during at the T1 after receiving an HIV/AIDS diagnosis (n=9). However, I discovered that about one-third of the participants (n=4) seemed to conflict with Becker's framework because they described experiencing continuity⁵⁶ since living with HIV/AIDS. Despite of their receiving an HIV diagnosis, what I learned is that some people may not experience or discuss disruptions as described in the majority of the sample. The pattern of continuity included 37 percent of the men and 20 percent of the women. Forty percent of the naïves described their experience as continuity in comparison to 25 percent of the long-terms. The distribution of almost half of the naïves experiencing continuity is surprising because one would think that naïves would be more likely to experience major disruption. What I learned from these findings is that the experience of continuity is not necessarily to be expected of people who are in the

⁵⁶ In conducting the analysis I did notice that these 4 participants had been living with HIV for a minimum of 2 years which may provide some insight into why they do not report disruptions from an HIV diagnosis.

later phases of living with HIV. At the earliest phases of living with HIV/AIDS there are various ways one may interpret the diagnosis. While the pattern of continuity at the T1 contrasts with the disruption framework it does support the U.S. cultural emphasis on the need to create continuity (Nisbet 1969). The emphasis on normalcy can be thought of as an important cultural response to dealing with supposed disruption such as HIV/AIDS.

To help explain the experience of continuity at the T1, the stories of James and Gerard will be provided as examples of this pattern. In James's first interview from the HAART project, he did not describe disruption from living with HIV/AIDS. He believed the diagnosis did not "phase" him because he was heavily using drugs.

I: Earlier you told me a short history of your life. Now, I want to focus on the time since you've been HIV positive. Can you please tell me in a nutshell version your life since having HIV?

J: I never really paid no attention to it. Only when I got sick or something. But I didn't have-, since they told I had HIV I haven't done one thing to stop HIV. Or to help myself with HIV. Until I finally got clean, this last year. Almost a year. Well eight months. And that's the first thing I positively done about my HIV. Because I never went to the doctor about nothing unless I-, it was about some pills or something. I never-, I truly didn't pay it no attention until the last four five years I started being sick, sicker and sicker. I never, I [didn't pay it no attention]. I mean it never stopped me from using drugs [unless I got] pneumonia or asthma, something. [Endocarditis] from shooting drugs. So, it wasn't that only time I thought about it was when I went to the hospital. I was sick. And the doctor would talk to me about it, a contagious disease. (James HAART T1 2004, Age 49, Naive to HIV meds, HIV+ 19 years)

James's early phase of living with HIV was characterized by using drugs rather than dealing with HIV. James described how, despite living with HIV for over eighteen years, he was using heroin during that time and did not think about HIV on a regular basis or experience disruptions due to HIV/AIDS. He described how he continued to participate

in his normal activity of using drugs throughout the earlier phase of living with HIV. James used heroin for over thirty years and didn't stop using drugs until around the time his first interview for the HAART Project. He described how it wasn't until he became sober that he started to think about the impact of HIV on his life. James's story provided an alternative insight into the experiences of living with HIV and how drug addiction may influence why some people may not necessarily think about HIV or identify disruptions from living with HIV.

In Gerard's first interview at the HAART Project in 2003, he discussed how HIV had not really caused a major disruption to his life.

I mean my life hasn't changed except for seeing a doctor on a regular basis and taking the medications. I have had no illness as I am aware, related to the HIV status. Just creates a fear that I may become ill, you know, anytime. Something in my mind that doesn't directly affect my life. That's about all I can say on that.

(Gerard HAART T1 2003, Age 50, Long-term to HIV meds, HIV+ 2 years)

Gerard characterized his life as not experiencing change or major disruption since being HIV positive. He described his experience as not being sick and not having a direct impact on his daily life. He had been able to perform his normal daily activities, working full-time as an accountant and as the primary caregiver for his elderly mother who lived in the flat below him. Outside of work, Gerard spent most of his time caring for his mother who was living with advanced dementia.

The stories of James and Gerard illustrated continuity despite living with HIV/AIDS provided a different perspective of living with HIV/AIDS compared to those people who experienced disruption and made efforts to reorganize their lives in response to disruption. A theme in the discussions with James and with Gerard was their continuing on with their normative activities (e.g. drug use, career, care-giving

roles) and not experiencing expected disruptions from HIV (e.g. illness, taking medications). The next pattern that conflicted with Becker's framework included major disruption at T2.

Part 2b. T2 Patterns of Living with HIV/AIDS Conflicting with Becker's Framework

T2 Disruption

Drawing from Becker's framework one would expect that people in the later phases of living with HIV would have reached some sense of reorganization in their narratives. However, as described by Leonard he was never able to reach some sense of reorganization. This pattern of disruption at the T2 was reflective of only one participant who perceived the experience of living with HIV/AIDS as a major disruption at the later phase of living with HIV without a discussion of normalcy or reorganization. Leonard was a long-term man who was diagnosed with HIV as an older adult. At this later phase of living with HIV, he is what one would consider an outlier in comparison to the other participants who were able to reorganize their lives in response to HIV/AIDS disruptions. Leonard's stories at the T2 did not provide evidence of reorganization or normalcy at this later phase of living with HIV/AIDS and described experiencing severe disruption to his daily living due to HIV/AIDS.

In 2009, during the dissertation interview, Leonard (age 56 and HIV+ 9 years) stated how HIV influenced every aspect of his life:

AN⁵⁷: Would you consider HIV a disruption to your life?

L: Oh, God, yes! Yeah. I mean in every area. In every aspect. Every level it enters into one way or another. You know. So yeah.

AN: Can you give me an example?

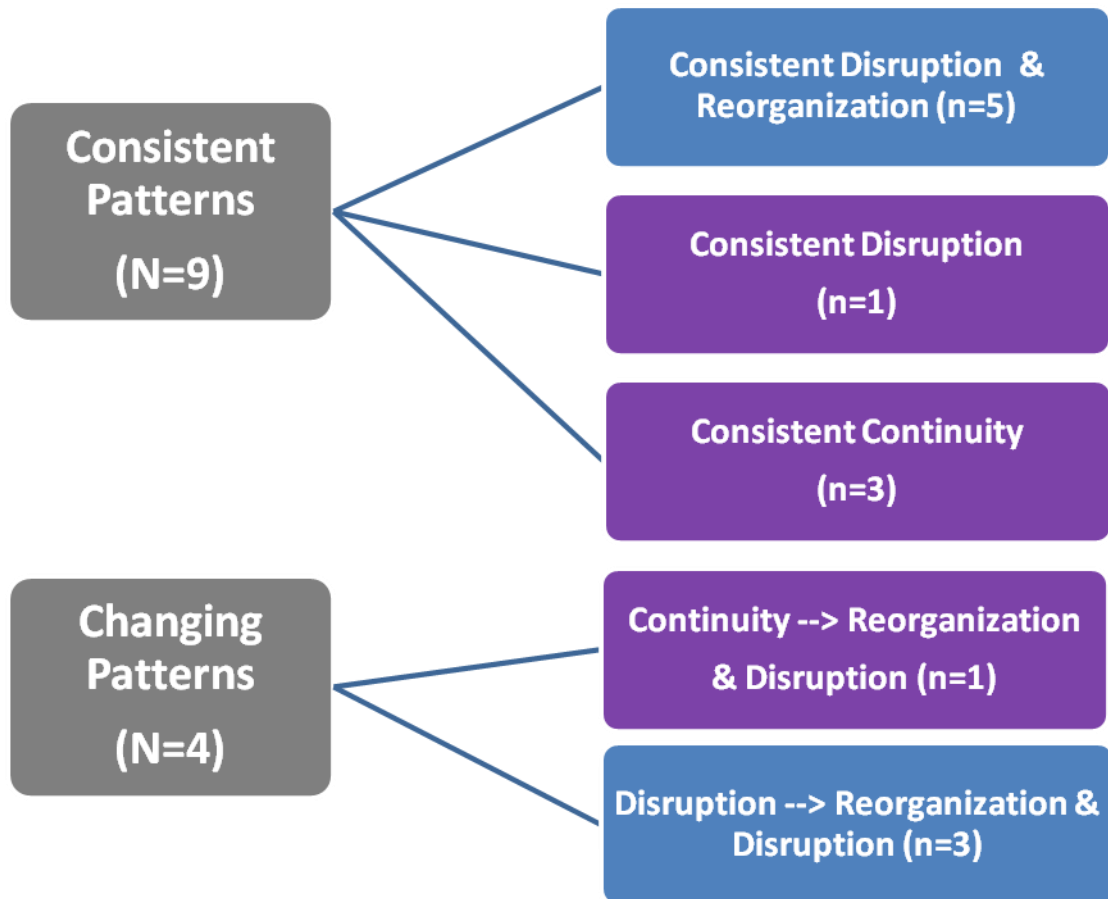
L: Sleeping, eating, thinking, sitting, laying, walking. Uh, breathing, uh..From head to toe it has an effect. (Leonard Dissertation Interview 2009, Age 56, HIV+ 9 years)

⁵⁷ AN refers to Andrea Nevedal as the interviewer

Leonard's quote describes how some people experience severe disruptions at later phases of living with HIV/AIDS. Later phases of living with HIV do not necessarily correlate with reorganization or continuity as was discussed earlier in this chapter.

Part 1 of the findings discussed evidence for Becker's framework of life course disruption. Part 2 of the findings provided insight in the ways that some participants' interpretations of living with HIV did not map onto Becker's framework. The next part, Part 3, provides another way of exploring and refining Becker's framework based on using a temporal perspective to make sense of the coding for disruption, reorganization, and continuity at the T1 and T2.

**Figure 5. Temporal Dimensions to Understanding
Becker's Life Disruption and Reorganization Framework**



Blue = Supports Becker's Framework

Purple = Conflicts with Becker's Framework

PART 3: TEMPORALITY AND THE LIFE DISRUPTION FRAMEWORK

In *Disrupted Lives* Becker notes how after the onset of a disruption people reorganize their lives in an attempt to create normalcy and continuity. To understand the process of reorganization and how people make sense of illness Becker also states:

There is a temporal dimension to illness that affects people's responses to their bodily changes. Both past experiences – including illness, life transitions and other major events and expectations for the future inform current experiences of health and illness. (Becker 1997:39)

In response to Becker's emphasis on temporality, I was interested in exploring how temporal dimensions might give insight into the experiences and socio-cultural consequences of living with HIV/AIDS. By focusing on temporality, I was interested in how people described and made sense of their experiences at different points in time in order to learn about and to think about how living with HIV/AIDS as an ongoing process.

In *Disrupted Lives*, Becker describes how some of her research was longitudinal (e.g., infertility study) and she was interested in looking at change over time as one of her original interests and goals for her book (Becker 1997:207). However, due to limited space and resources for *Disrupted Lives*, Becker notes that she was unable to properly address and explore how a temporal approach would provide additional insight into her framework of life disruption and reorganization (Becker 1997:211). Part 3 of the findings are presented as an attempt to extend what we know about Becker's research on life course disruption and reorganization by addressing how the concepts hold up when using a temporal framework to explore the data and the extent that the patterns may change over time. The initial research question proposed was: After a diagnosis of HIV, do people perceive HIV to be a major life course disruption and to what extent do they go about reorganizing their life in response to disruption? However, secondary

areas of exploration that I was interested in were what happens when the constructs of life disruption and reorganization are analyzed with a temporal perspective, whether the patterns of experiences of HIV disruption and reorganization remain the same or change over time, and whether HIV/AIDS remains a disruption throughout the process of living with HIV/AIDS or dissipates as people become accustomed to living with the illness. The way I went about trying to understand the process of living with HIV/AIDS was by comparing the patterns of HIV/AIDS experience at the T1 and T2. I was curious to find out whether the patterns of living with HIV/AIDS would follow the “chaos to order” trajectory as suggested by Becker.

3a. Consistent and Changing Patterns Of Living with HIV/AIDS

For Part 1 of the findings for this chapter, I identified and described the presence of disruption and reorganization at earlier (T1) and later phases (T2) of living with HIV/AIDS. A result of the analysis of how people talked about their experiences of living with HIV was the identification of three major patterns of experience that were based on evidence of (1) disruption, (2) disruption and reorganization, and (3) continuity. The process of living with HIV/AIDS was not the same for all of the participants. Four out of the thirteen participants (31 percent) provided evidence for major HIV disruption without reorganization at the earlier phase (T1), and one out of thirteen participants provided evidence for major HIV disruption at the later phase (T2). Five out of the thirteen participants (38 percent) provided evidence for disruption and reorganization at the earlier phase (T1) while nine out of the thirteen (69 percent) provided evidence at the later phase (T2). Four of the participants (31 percent) provided evidence for continuity at the earlier phase (T1) while three (23 percent) provided evidence for continuity at the

later phase (T2). These findings indicated the variation in the interpretations of earlier and later phases of living with HIV. Nine (69 percent) participants from the total sample experienced some form of disruption at the earlier phase which increased to ten participants (77 percent) at the later phase. While the majority of participants experienced disruption from HIV, four participants at the earlier phase did provide evidence for HIV disruption to their lives and three at the later phase. Part 1 introduced the patterns of HIV experience that were supportive of Becker's life disruption and reorganization framework. Part 2 introduced the patterns of HIV experience that conflicted with Becker's life disruption framework. The following the next section, discusses the extent to which the patterns of HIV experience remain consistent or changed when the two time points were compared using a temporal perspective.

The comparison of the T1 and T2 time points provided evidence for consistent and changing patterns of HIV/AIDS experience. Within the consistent pattern there was: (1) consistent disruption (n=1), (2) consistent disruption and reorganization (n=5), and (3) consistent continuity (n=3). The consistent pattern was highlighted by the same pattern of HIV experience occurring at the T1 and T2. Nine (69 percent) out of thirteen participants showed a consistent pattern of HIV experience when the T1 and T2 interviews were compared. Seven (88 percent) of the men and two (40 percent) of the women were in the consistent pattern. Five (80 percent) of the naïves were in the consistent pattern but only four (63 percent) of the long-terms were in the consistent pattern. Within the consistent pattern there were three participants diagnosed as an older adult and six diagnosed at a younger age.

The changing pattern consisted of different patterns of HIV experience at the T1 and T2. There were two sub-categories within this changing pattern: (1) disruption at T1 changing to disruption and reorganization at T2 (n=3) and (2) continuity at T1 changing to disruption and reorganization at T2 (n=1). Four (31 percent) out of the thirteen participants provided evidence for a changing pattern of HIV experience when the T1 and T2 interviews were compared. The overall trend among the changing pattern was a transition to a later pattern of disruption and reorganization. The changing pattern consisted of two people diagnosed as a younger adult and two people diagnosed as an older adult. One out of the five naïves was included in changing pattern and three out of the eight long-terms were characterized by this pattern. Within women, three out of five provided evidence for the changing pattern, while only one out of the eight men illustrated this pattern.

Part 3a provided an overview of participant characteristics within the consistent and changing patterns of HIV/AIDS experience. Part 3b will discuss how the findings from the temporal analysis support or conflict with Becker's life disruption framework (see Figure 4).

3b: Temporal Findings That Support Becker's Framework

When analyzing the consistent and changing patterns, I was interested in identifying which patterns supported Becker's life disruption framework (e.g., Chaos to Order). I found that (1) the consistent disruption and reorganization and (2) disruption changing to disruption and reorganization would be most supportive of Becker's framework.

Consistent Disruption and Reorganization (n=5)

Five out of the nine (56 percent) participants who had a consistent pattern described reorganization and disruption at both the T1 and T2. Fifty percent of the men and 20 percent of the women and 60 percent of the naïves and 25 percent of the long-terms were in the consistent reorganization and disruption category. There was a slight change in emphasis from the earlier to later phase of living with HIV for this category. During the earlier phase, participants placed more emphasis on disruption but provided discussions of reorganization. However, during the later phase participants placed more emphasis on reorganization, but also provided discussions of disruption.

Alvin's early and later experiences of living with HIV/AIDS provide an example of how some people may experience consistent reorganization and disruption. Alvin, first interviewed in 2003, provided evidence of HIV disruption and reorganization through his discussion of the side-effects from medications and a resilient philosophy of fighting HIV.

My doctor tells me that he will not let me die of AIDS. Hey, I got to believe him. And I got to fight. This is why I'm taking this medicine right now that is laying me low. Until I can get back to him and talk to him about it. To see if there's something else that I can take, that I can go on and get back in the gym and get stronger and everything, the whole works. Um...I, as I said I don't give up easy. And it catch me, this thing catch me, going to catch me running, I ain't going to sit down and do nothing, not, I got to move on. I

don't want to think about dying, you know, from it. (Alvin HAART T1 2003, Age 72, Naive to HIV meds, HIV+ a few months)

At another point in the interview Alvin used a metaphor of a “sex factory” to describe the importance of his sexuality to his identity and how HIV has disrupted this aspect of this life.

I'm not the same person I used to be. I'll never be again the person I used to be. Because I'm determined that I won't pass this thing on to nobody. Um...I'm scared, I, I've shut down my sex factory. (Alvin HAART T1 2003, Age 72, Naive to HIV meds, HIV+ a few months)

At this earlier point Alvin focused on disruptions from taking medications and having to abruptly stop his sexual activity. Alvin talks about how he's “not the same person” since being HIV and having to quit sexual activity. At the early phase of living with HIV, Alvin experienced a major loss and disruption to his self-identity. Despite the disruptions he experienced, he also provided evidence of life reorganization by developing ways to deal with the physical aspects of HIV. For example, he decided to take medications even if he experienced side-effects and chose to have a resilient and “fighting” mentality in dealing with HIV rather than giving up.

Six years later when Alvin was interviewed for the dissertation research, the later phase, he tended to underscore how he had reorganized various aspects of his life and adapted to living with HIV. Alvin talked about accepting HIV along with his increased involvement with the church which illustrated a pattern of reorganization.

I have changed somewhat. I've learned more and accept more about God than I did at that particular point with this thing first happened. Sort of like growing closer. I go to church. I go to choir rehearsal, I sing in the choir. I'm not gonna lie I learned to live with it and be happy. So I do very well. I'm not going around with my head down or anything of that nature. I continue to live and livin' a better life I think. That's the only way I know how to explain it to you. What I'm trying to say. No I'm not walking

around (letting it worry) me, I did it. Nobody made me do it. I didn't know I was doing it but I did it. (Laughs) So I live with it. (Alvin Dissertation Interview 2009, Age 78, HIV+ 6 years)

Despite the reorganization that Alvin described at this later phase of living with HIV, he continued to experience disruptions to his sexual identity and activity⁵⁸. At this later point in time he used another metaphor to describe his sexuality. The metaphor of a “ship stopped in the water” is his way of explaining how his sex life abruptly stopped since receiving an HIV diagnosis.

Things I used to do that I don't do no more. Instead of trying keep doing them and yet take precautions and maybe not take enough precautions. I just don't do them anymore. I just stopped my ship out in the waters. (Alvin Dissertation Interview 2009, Age 78, HIV+ 6 years)

At both points in time Alvin discussed reorganization and disruption of HIV and provided an example of the consistent pattern of reorganization and disruption while living with HIV. While both of his interviews included talk about disruption and reorganization, in the first interview he focused more on disruption and in the last interview he focused more on reorganization and efforts to restore continuity. Alvin's story of both disruption and reorganization presented a fairly typical type of response to HIV among the people who were interviewed. Adjustments to medications and becoming more accepting of HIV were key aspects of the evidence of life reorganization. Disruption to sexuality was a major and consistent disruption for the majority of the participants.

Disruption at T1 changing to Disruption and Reorganization at T2

Three out of four (75 percent) participants with a changing pattern transitioned from disruption to disruption and reorganization. This group was made up of 100 percent women (60 percent of all the women in the total sample). All of these women

⁵⁸ The discussion of disruptions to sexuality are further discussed in chapters 7 and 8

were on medications long-term and two out of three were diagnosed as an older adult. These participants described their experience as disruption at the T1, but then later at the T2 described their experience of living with HIV as disruption and reorganization. These participants illustrated examples of how some people may not provide evidence of reorganization at early phases of living with HIV but may do so at a later phase.

When Patrice was first interviewed for the HAART Project she described how living with HIV was a major disruption and she feared for her life.

Oh boy. Um...stressful. Um...[I think] about um...it's not a day that I, uh, don't go back that I don't think about...um, my fam-, leaving here. Death.

The ups and downs of having HIV. It ain't no up. (Laughs) There ain't no up with having this stuff. (Patrice HAART T1 2003, Age 45, Long-term to HIV meds, HIV+ 2 years)

Six years later when Patrice was interviewed her discussion conveyed a different perspective than when she was first interviewed at the HAART Project. In 2009, she talked about how living with HIV had become more normalized for her and more of a routine.

I get out and I go to the jazz concerts and some stuff like that. But other than that I live a normal life just like everybody else...My health is uh, my immune is very good, I think the last count was 13, I stay, I've been undetected for so long where it's always under 50, undetected. So I am, will thing about my uh, I think I said years ago my life force, that's when I asked Derrick back then, that's my life force, I know I have to take my pills. Since they downsized them so much it's not a headache anymore. (Patrice Dissertation Interview 2009, Age 51, HIV+ 8 years)

Patrice talked about HIV becoming routine and that she didn't see HIV as being a major disruption in her life, only sometimes.

Well a long time ago yes, not anymore. It's not a disruption in my life. My daily living is the same; I've been living with it so long, hell. This is a routine. So no, it's not a 'ruption, only sometime that, I mean I'm so used

to it now. It's not a 'ruption anymore; no I wouldn't say it was. (Patrice Dissertation Interview 2009, Age 51, HIV+ 8 years)

However, at the same time, she sometimes experienced disruptions such as side effects from her medications in the form of severe headaches.

I have no other associated illnesses with it, like some people have diabetes with it. Some people have cancer with it; some people have different ailments with it, not me. I just got this here. This is enough for me because it has me feeling so many different ways with those pills you take they give you some time you have extreme headache, you understand what I'm saying, where you have to close your eyes, it's the pills does different things to you. (Patrice Dissertation Interview 2009, Age 51, HIV+ 8 years)

Marion's first interview at the HAART Project focused on disruptions from HIV without reorganization. She described how her life since being HIV positive had been "empty". She was unhappy and had become a homebody.

My life is...it's a little empty right now. I'm...I could be a lot happier than what I am. I...don't go out and party like I u-, used to do. I'm more of a homebody. And since I been diagnosed what it really...I know my body's not the same, because...I stay tired a lot and my legs bother me, they swell up. And it-, I really feel em-, I mean...I know being with a man is because I-, me in the shape I am, but I would like to have someone in my life, and right now I don't have anyone because...I guess I'm afraid of being rejected, you know, if you let somebody know well...they might not be that understanding. Being rejected is the biggest thing in my life and talking about it to another man, you know, letting him know. (Marion HAART T1 2002, Age 55, Long-term to HIV meds, HIV+ 3 years)

However, when discussing her experience with HIV seven years later, Marion described both reorganization and disruptions. When asked how things were going, she stated:

My health has been great. It's really been good, I haven't been sick I haven't been back in the hospital. It's just my eating. I don't eat well, I was supposed to have been before I got my teeth pulled too but I chickened out on that. They had a program for HIV but I'm gonna have to call the girl because I had an appointment for the 24th of last month. I think it expires in March of 2009 so but uh, I just don't have an appetite. I don't have an appetite. I'm part of a healthful program they give us Ensure milk for when we losing weight and stuff and they give a 40 dollar money

order to go to the grocery store to get some extra food. Like I said I'm doing just great. (Marion Dissertation Interview 2009, Age 62, HIV+ 10 years)

The major change in Marion is that since the T1 she has reorganized her perspective on HIV. When talking about dealing with the struggles of living with HIV she also includes talk about reorganization such as having a "fighting" attitude towards HIV.

Like I said some days I will lay in the bed feeling sorry for myself. And I'll say no, no. This is not gonna work just because you got HIV you know. I think I'd tell anybody I think I'd rather have HIV than have cancer. So I just get up and do something. Even I don't do anything I'll go and walk to the corner or something like that. But that's my biggest challenge. I'm fighting it. It's not fighting me. Ha Ha. That's about it. (Marion Dissertation Interview 2009, Age 62, HIV+ 10 years)

At the initial HAART interview Marion discussed worrying about rejection from men since being HIV positive. Seven years later she remained afraid of rejection and had difficulty trusting men.

Well, it has impacted my life as far as trust with men. I'll speak and talk and hold a conversation but as far as sex goes even with a condom I don't really want to be bothered. (Marion Dissertation Interview 2009, Age 62, HIV+ 10 years)

Marion focused on fighting HIV and the normalcy that she has created in her life, and she talked about how she tries to deal with disruptions. However, the fear of rejection and difficulty in sexual relations continued to be a major theme in her life. The discussion of disruptions to sexuality will be discussed in Chapter 8. It is important to note that at this later point in her life Marion described how she was doing well overall with HIV but also experiencing disruptions as a result of HIV and outside of her HIV status. Some of the disruptions she experienced resulting from HIV/AIDS included a

lack of appetite and disruptions to her intimate/sex life. She also experienced life disruptions such as the death of close family members that was difficult for her to deal with.

3C: TEMPORAL FINDINGS THAT CONFLICT WITH BECKER'S FRAMEWORK

The following findings provide evidence for three patterns that conflict with Becker's chaos-to-order framework. The first pattern conflicting with Becker's framework included consistent disruption (n=1) while living with HIV/AIDS. The second pattern was based on participants who provided evidence for consistent continuity (n=3) despite receiving an HIV/AIDS diagnosis. The third pattern consisted of participants who provided evidence for of change from continuity to disruption and reorganization (n=1).

Consistent Disruption (n=1)

One out of the nine participants with a consistent pattern described disruption without evidence of reorganization at both the T1 and T2. This participant continued to experience severe disruptions to daily living and did not provide evidence of reorganization or normalcy at the earlier (T1) or later phases (T2) of living with HIV. This pattern conflicted with Becker's theory that suggests how after experiencing disruption people reorganize their lives. The stories from Leonard present how some people do not reorganize after experiencing HIV disruptions.

During his first interview during the HAART Project, Leonard described a variety of different disruptions he experienced from living with HIV. He experienced extreme social isolation, anger and sickness. Leonard stated:

I don't interact hardly at all now with people. Uh, I'm not friendly. I'm angry most of the time. There, so life's the pits. I'm sick, the drugs make me sick, uh, people and places that are supposed to help, don't. Being punished twice is the way that I feel, not only because I am HIV positive, but because of the type of assistance that the system has set up for me, very inadequate. (Leonard HAART T1 2003, Age 50, Long-term to HIV meds, HIV+ 3 years)

It also seems as though his identity as a social person had been disrupted since being HIV positive when he stated that he no longer interacts with people.

During the dissertation interview in 2009 (six years after the first interview), Leonard continued to experience major disruptions from living with HIV. At this later point he focused on how the disruptions he experienced were related to being sick and not being able to take care of himself. As a result these disruptions he had lost his independence and pride. Leonard stated:

I don't have very much stamina so I don't do a lot. I don't go out a lot. I'm at home most of the time. I don't feel like I can even protect myself. You know which keeps me in a lot too because not that something is going to happen to me but I feel so weak that if someone wanted something that I had I'd have to give it to them. You know so that that pride. You know it's a lot of things. Those are the most important things to me. Not being able to be, just take care of myself, you know. And make decisions for myself when I want to make them. And not have to feel like um, [like] I'm being patronized. (Leonard Dissertation Interview 2009, Age 56, HIV+ 9 years)

Leonard struggled with a wide range of challenges from living with poor body image from body wasting, medication side effects, inability to perform daily tasks, and mistreatment from social works and health professionals. He talked about his ongoing struggle with trying to receive proper disability⁵⁹ benefits and dealing with the "system" of doctors and social workers. He was very vocal about his struggle to receive proper resources and disability assistance and the mistreatment he had experienced along the way. The data presented on Leonard emphasizes his consistent negative experiences of living with HIV. His story provides insight into the consistent and intense suffering that can occur throughout the process of living with HIV.

⁵⁹ At one point in the interview he states that he is too sick to work but too healthy to receive proper disability assistance

Leonard was an outlier compared to the other twelve people who were interviewed because the majority of the people interviewed were able to create some sense of reorganization and normalcy at the later phase of living with HIV. Even though his perspective was different than the majority of the participants that were interviewed, his discussions and perspectives should not be ignored. Leonard's perspective provides an alternative understanding of the long-term experience of disruption from living with HIV. Despite living with HIV for almost a decade, he did not provide evidence of reorganization or normalcy as many of the other participants illustrated in the following subcategories.

Consistent Continuity (n=3)

The consistently disruptive experience is a pattern that may occur for some people throughout their experience of living with HIV/AIDS. Three (33 percent) out of the nine participants who illustrated the pattern of consistent continuity at both the T1 and T2. About one quarter of the men and women from the sample were labeled as the consistent normalcy category. These participants emphasized how despite being HIV positive they described their lives as normal and did not experience major disruptions or changes resulting from their diagnosis. This pattern also conflicted with Becker's framework that suggests people will transition from disruption to reorganization. In contrast with Becker's framework, the participants who showed evidence of consistent continuity do not express disruption from living with HIV/AIDS at either of the time points.

Sheila

During the first interview at the HAART Project Sheila described her experiences of living with HIV as not including major disruptions. Her experience of living with HIV was described as positive.

My life since I've been HIV positive, it's been pretty positive. I've been healthy. I've been lucky. And from what the doctor tells me, there's some people, very rare, there's only a few of us, that has HIV and they don't pass it. I don't know what it is, I guess it's something in our system. But the rare few that he was talking about, he let me know that I fit right into that category. (Sheila HAART T1 2003, Age 47, Naive to HIV meds, HIV+ 4 years)

Six years later, during the dissertation interview, Sheila continued with the theme of continuity by focusing on her low viral load levels and reduction in the number of pills she had to take.

Everything has been going pretty good. My HIV is fine. I've gone down to one medication and that's Kaletra. And my viral load is non-detectable...And uh, only to be on one medication is good. Yeah. But I have a lot of other problems. (Sheila Dissertation Interview 2009, Age 53, HIV+ 10 years)

Sheila's experiences of living with HIV had been positive. While she didn't necessarily experience HIV disruption, she did experience disruptions and problems in other areas of her life that seemed to be a major burden in her life.

Like from falling down the steps in there and I broke both wrists. Dealing with chronic pancreatitis and arthritis you know setting up from the bumps and bruises I had. From the drug use and the stuff I did to my body, I'm paying for it now. (Sheila Dissertation Interview 2009, Age 53, HIV+ 10 years)

Sheila's experience of normalcy/no disruption might have been in part due to the various non-HIV related disruptions and ailments going on in her life.

Donald

Donald provides another example of a participant who described continuity at both points in time. During the first interview from the HAART Project Donald stated how, despite the initial shock of the diagnosis, he had experienced no major disruptions or changes since being HIV positive. Donald stated:

First the, uh, shock. Didn't expect it. Then...acceptance. Said, well, okay, you have to do what you have to do and...go into the infectious disease clinic and keeping those appointments and taking the medication. Other than that, my life really hasn't changed. It really has not impacted that much. Of course...you know, you have to be careful about sex, but um...[it's been] very little change. (Donald HAART T1 2003, Age 54, Long-term to HIV meds, HIV+ 2 years)

At the time of the dissertation interview, Donald continued with the continuity discussion of his experience:

It hasn't affected, um, anything I've wanted to do. So, no. Um, and I haven't had any symptoms. I think diabetes is more of a disruption than HIV. (Donald Dissertation Interview 2009, Age 60, HIV+ 8 years)

Similar to Sheila, Donald stated how diabetes (another health problem) was more disruptive than HIV. When asked to clarify why HIV did not disrupt his life, Donald explained to me that he retired a few years after being diagnosed. While he was still working, the medications managed his HIV so that he could work until he retired at age fifty-five. He also discussed how at the point that he was diagnosed with HIV he was already "where I want to be". He accomplished his main life goal of becoming a psychologist. Donald has been enjoying retirement and so far his HIV status had not seemed to disrupt his life goals or daily activities.

Sheila and Donald did not describe experiencing major disruptions resulting from HIV/AIDS, but both participants described how other health problems were more disruptive than HIV. Sheila's explanation for how HIV was not a disruption may have been in part because of the other types of more disruptive health problems and disabilities she was dealing with in her life (e.g. arthritis, pancreatitis, blindness). Donald describes how the timing of his diagnosis, after achieving his life goals, has been a major factor in why HIV has not become a major disruption to his life.

Continuity Changed to Reorganization and Disruption (n=1)

Of the four people who experienced a changing pattern, one participant experienced continuity at the T1, but then later described disruption and reorganization at the T2. This pattern also conflicted with Becker's framework that would suggest that people with HIV would first experience disruption then work towards reorganization. However, in one case, James expressed continuity with HIV/AIDS for many years and did not experience disruption and reorganization until the T2. When James was enrolled at the HAART project he was naïve to medications but had been diagnosed 24 years prior. While this pattern of HIV experience is an outlier among all of the older adults who were interviewed, it illustrates how the experience of disruption may not necessarily have to occur as an earlier experience of living with HIV. For some people, disruption may not occur until a later phase of living with HIV.

When James was first interviewed at the HAART Project he stated how he did not experience disruption resulting from his HIV/AIDS diagnosis. Despite being HIV positive for over 24 years, James did not experience disruption from HIV until after he quit using drugs, about six years before the dissertation interview. James described

how when he was first diagnosed HIV did not disrupt his life because he was too involved in a drug lifestyle to pay attention to his HIV status. Now that James was clean, he was “trying to find his way”. James was more aware of his health and how his HIV status could impact others and was in the process of reorganizing despite disruptions from HIV. For example, he had decided to be more responsible about his HIV status while at the same time he continued with normative/expected behaviors such as dating. As a result, he decided to only date women with HIV. James transitioned from early experiences of no disruption to later experiences of reorganization but also experienced disruptions from HIV/AIDS.

At the time of the T1 HAART Project interview, James’s pattern of living with HIV provided evidence for the continuity pattern because he did not really think about his status or experience disruptions from HIV until he quit using drugs. James was newly sober and just beginning to deal with HIV when he was first interviewed for the HAART project.

It didn't bother me. I mean I done nothing to, you know, make it right. Nothing to-, I kept on living, kept on using. It didn't depress me. I didn't...I blocked it out. Through the drug use. And just kept on doing what I was doing. I didn't miss a beat. (James HAART T1 2004, Age 49, Naive to HIV meds, HIV+ 19 years)

Despite being HIV positive, James described how he was not thinking about HIV when he was using drugs. At the earlier phases of living with HIV, James described how HIV did not prevent him from engaging in the activities or roles that he wanted to engage in. He had been HIV positive for about eighteen years before he became drug free and started taking medications.

Five years after the initial HAART interview, James was interviewed for the dissertation research. At the time of the dissertation interview he had spent almost six years being sober and, from his perspective, had had more time to think about the impact of HIV on his life. His discussion at this later point showed a transition from continuity to a discussion about reorganization and disruption.

Just trying to find my way. Trying to stay focused and uh, uh, trying to stay [clean]. You know I had a drug history. That's how I caught this virus, from intravenous drugs use. So you know I'm coming up on six years. So, you know, you know, when you catch the virus, it's a life changing thing. So, you know, it's a struggle, man, sometimes. So I'm just hanging in there, you know.

Really it doesn't stop me from doing anything; you can do anything, you with the virus. So really hasn't affected me too much in any other area but the romantic area. That's all. ... I try to really only date women that have HIV. (James Dissertation Interview 2009, Age 54, HIV+ 24 years)

James described how living with HIV is a "struggle". Even though he experienced disruptions from HIV, mainly in the area of dating, he reorganized his dating habits by only dating women with HIV.

James's situation is somewhat unique because he did not begin to acknowledge his HIV status or deal with HIV disruptions until later on. James's story is one that transitioned from continuity to disruption and reorganization. His story emphasized that the experience of disruption resulting from HIV/AIDS may not occur until later for some people. Perhaps his transition from drug addiction to sobriety was a turning point in the experience of living with HIV and provided insight into why he did not experience disruptions at first but when sober began to experience disruptions.

The findings presented in 3b and 3c provide insight into patterns of living with HIV/AIDS that support and conflict with Becker's framework of life disruption. The

majority of the findings provide evidence to support Becker's framework when analyzing data from a temporal perspective. However, the use of the temporal framework for comparing the two points in time, spanning five to seven years, revealed three patterns that conflicted with Becker's framework which suggests that Becker's framework needs to be refined. The following discussion in Part 4 of this chapter will provide a discussion and conclusion from the findings discussed in this chapter.

Part 4: DISCUSSION APPLYING BECKER'S FRAMEWORK TO UNDERSTAND EXPERIENCES OF LIVING WITH HIV

This chapter discusses how Becker's theoretical framework of life disruption and reorganization was applied to help understand the experiences of older African Americans who are living with HIV. Part 1 of this chapter reviewed some of the core concepts of the life course and Becker's life disruption and reorganization framework. Part 2 of this chapter discussed how Becker's framework was operationalized throughout the data collection and analysis process. Part 3 of this chapter provided three sections of findings on (1) patterns of living with HIV supporting Becker's framework, (2) patterns of living with HIV conflicting with Becker's framework, and (3) the results of the temporal analysis and comparison of the patterns of living with HIV at the T1 and T2 time points.

Previous research conducted by Becker explored the disruptive nature of chronic illness. Becker also described how U.S. cultural values place an emphasis on continuity, therefore influencing why people feel the need to reorganize their lives in response to the disruptions they experience. The majority of the participants that were interviewed provided support for the disruption and reorganization framework.

However, Becker's framework did not fully explain all of the patterns found in this research. Some individuals did not reorganize after experiencing HIV disruption and some did not describe experiencing the expected HIV disruption but instead emphasized continuity.

Continuity Despite HIV

Despite assumptions that HIV would disrupt peoples' lives, the data revealed additional ways of interpreting HIV. Some of the participants did not experience the "supposed" disruption expected after one receives an HIV diagnosis. Instead some people emphasized continuity (e.g., no change, no disruption). In reviewing related literature on how people respond to change, illness and disability, I identified possible explanations for why some people did not perceive HIV as a disruption.

The first explanation draws from ideas of Deppen-Wood et al. (1997), Hinojosa et al. (2008), and Bletzer (2007), suggesting that interpretations of illness and disability do not necessarily result in negative wellbeing or disruptions. Deppen-Wood et al. (1997) present an in-depth case study of an older African American woman with polio to give insight into how disability does not necessarily become a central part of a person's life or predict negative wellbeing (Deppen-Wood et al. 1997:450). They described how cultural contexts, life events, and the individual are important in understanding how disability and illness are interpreted. From my own research the cases of James (history of drug use) and Sheila (multiple health problems) might have influenced why HIV was not a central part of their life experiences or why they did not perceive HIV to be a major disruption in their lives.

Other authors supporting these ideas were Hinojosa et al. (2008) who explored how veterans responded to stroke and found that stroke did not disrupt their sense of self. Instead these authors suggest that in the wake of a stroke veterans drew from beliefs about normal processes of aging and religion to construct continuity and reinforced their sense of self. Bletzer's (2007) presentation of two case studies from a study of HIV positive African Americans living in the rural south suggests that HIV was perceived as an interruption rather than a disruption. The interruption from HIV fostered the adoption of positive changes in the participants' lives rather than disruption. Their research provides insight into why some of the participants from this dissertation research did not emphasize disruptions from living with HIV. Some people may be able to create meaning and continuity despite experiencing adversity, disability or illness.

A second explanation for why people did not experience the expected disruption from HIV can be understood by understanding values of continuity and order in the U.S culture and American traditions (Nisbet 1969). Nisbet (1969) describes how continuity rather than change is a major theme in American cultural history. People who emphasize continuity (e.g., "no change") after experiencing an expected disruption such as an HIV diagnosis may be in fact reflecting a larger cultural pattern or particular response to change that focuses on continuity. Becker also describes how continuity and order are important U.S. cultural values and components of how the life course is perceived. However, Becker argues that people would first experience disruption from an HIV diagnosis then reorganize to create continuity. Becker's research does not provide evidence for this pattern of why some people do not describe disruption (Becker 1997).

Resiliency among African Americans can provide a third explanation of why some people might emphasize continuity early on in their experiences of living with HIV or emphasize consistent continuity despite living with HIV. Research by Becker and Newsom (2005) suggest that cultural values of independence and continuity influence resilient responses to a history of racism and may influence why African Americans exhibit resilient philosophies in response to chronic illness. However, Becker's research in *Disrupted Lives* (1997) describes a linear process that people would first experience disruption then reorganize their lives in attempt to create continuity. However, I argue that understanding the resilient philosophies behind African Americans' responses to racism and chronic illness might help explain why some of the participants did not experience disruption from living with HIV.

While one might expect people to experience disruption after receiving an HIV diagnosis, I found that some people emphasized continuity instead. The emphasis on continuity seems to conflict with Becker's assumption that people would experience disruption. Are U.S. cultural values of continuity so entrenched in our ideologies that some people never fully experience expected disruptions? Or is that people who emphasize continuity do not centralize the expected disruptions in their life stories because they draw from other important resources such as resiliency and individual life experiences to create continuity?

Consistent Disruption From HIV

How do we make sense of Leonard's story, the participant who experienced consistent disruption? The consistent disruption pattern might indicate how some individuals may not incorporate core cultural values of continuity in their interpretation of

living with HIV. While emphasis on cultural value of continuity seems to be a trend in among the group of older African Americans who were interviewed, as mentioned earlier, life events and individual autonomy are still important in understanding how illness is interpreted and experienced. Research by Sankar et al. (N.d.) on the narratives of HIV positive African Americans reported that a small percentage of people did not draw on cultural scripts to make sense of their HIV experience. A small percent of the sample (10 percent) used individual personal theme scripts to make sense of their HIV experience. People with a personal theme script may perceive their experiences as inconsistent with social norms and therefore may be at risk for social and/or psychological dysfunction (Deppen-Wood et al. 1997; Luborsky 1990; 1993a; Luborsky and Riley 1997). Leonard, the participant who experienced consistent disruption, was categorized as having a personal theme script in previous research by (Sankar et al. N.d.). He also reported severe depression during the HAART Project, which is an example of how personal theme scripts (e.g., consistent disruption) can be related to psychological distress. Leonard's story provided insight into how some people might not fit within the culturally expected norms, suggesting that people will reorganize after experiencing life disruption.

It is also important to note that at the T1 (first HAART Project interview and earlier phase of living with HIV), 31 percent of the participants emphasized major disruption without reorganization which perhaps indicates the highly disruptive nature of the earlier phases of living with HIV. At the T1, people who experience disruptions may not be able to draw on larger cultural scripts of continuity to make sense of their experiences. Sixty percent of the women were in the disruption-only category at the T1

compared to 13 percent of the men. There might be different patterns of living with HIV between men and women during the early phases that could be explored in future research, or, as noted earlier, the lower reported SES among the women of this sample might influence the increased experience of HIV disruption.

Temporal Perspective

What can we learn by exploring life disruption and reorganization from a temporal perspective? A temporal analysis of HIV experiences underscores Settersten's (1999) point that human lives are made up of periods of stability/continuity and instability/change. When comparing the earlier and later point in time, the majority of the participants provided evidence for disruption and reorganization. In addition, there were two changing patterns of HIV experience that also support Settersten's (1999) argument for the multidimensional nature of human lives.

However, the results from this data also identified two consistent patterns of HIV experience among the older HIV positive African Americans that conflict with Settersten's (1999) multidimensional view of human lives and Becker's (1997) disruption to reorganization framework. The participants who described consistent disruption or consistent continuity throughout their experiences of living with HIV provide evidence for alternative ways of interpreting experience. Or perhaps human lives are multidimensional and data from the participants reflect a much longer period of stability (continuity) or instability (disruption) than what one might expect.

This research also indicated that the large majority of people experienced both disruption and reorganization at the same point in time rather than as a linear transition from disruption to reorganization. Reorganization should not necessarily be perceived

as the endpoint. Instead one should think about disruption, life reorganization, and continuity as part of an ongoing process in dealing with HIV, and these do not have to be mutually exclusive categories. As evidenced by the results from this data, one may experience disruption, reorganization, and continuity at any moment in time while living with HIV. People may experience disruptions to certain aspects of their lives and continuity in other aspects.

Future directions for this chapter's research might be to include more than two time points and/or to explore the patterns of consistency and change in disruption and reorganization in other chronic illnesses. Another direction would be to include a larger sample of older African Americans with HIV to explore to what extent demographics or other quantifiable aspects of HIV experience (medication cohort, duration) might statistically relate to the categories and patterns of disruption and reorganization. A larger sample of participants with the disruption-only category might provide additional insight into this particular pattern of HIV experience. The final sample of thirteen participants who were interviewed was too small to run appropriate statistical tests.

The following chapters will discuss additional findings on the experiences of living with HIV/AIDS. Chapter 7 discusses the dialectical relationship between normalcy and disruption. Chapter 8 reports on the findings on disruptions to sexuality and intimacy.

CHAPTER 7

“IN A WAY, YES; IN A WAY, NO”:

CONTRASTING EXPERIENCES OF HIV NORMALCY AND DISRUPTION

AN: Would you consider HIV a disruption to your life?

M: Hm, interesting. (long silence). In a way, yes; in a way, no. Then that's me. Because, uh, there are certain things I'll do, certain I won't do. There are certain lines I'll cross, and certain I won't cross. (Melvin Dissertation Interview 2009, Age 59, HIV+ 6 years)

Melvin provided an example of how he experienced disruptions to his life in some ways, but in other ways he did not experience disruptions. The purpose of this chapter is to understand the experiences of living with HIV/AIDS by making sense of contrasting discussions on normalcy and disruption. This chapter describes (1) an archaeological approach to understanding the inconsistency of talk about HIV/AIDS experience, (2) the dialectical relationship between disruption and normalcy, and (3) the major themes resulting from the analysis of normalcy and disruption. At the start of interviewing the older adults who were living with HIV, the primary focus was on understanding the disruptions that people experienced. But after conducting several interviews, the realization was made that some people expressed having a sense of normalcy when living with HIV/AIDS and that a disruption-only approach would not appropriately capture people's experiences of living with HIV/AIDS. In fact, many of the participants discussed normalcy, but they also described experiencing disruptions from living with HIV. The focus of this chapter is to take a closer look how people often use opposing or inconsistent patterns (e.g. normalcy and disruption) to explain their experience of living with HIV/AIDS.

In encountering participants who described normalcy and disruption, it became apparent that the assumptions regarding how people interpret the experience of living with HIV/AIDS needed to be re-evaluated. The assumption of normalcy and disruption as mutually exclusive categories also needed to be reconsidered. What do we mean by disruption? What do we mean by normalcy? In preparing to write about the HIV/AIDS experience of the older African Americans that were interviewed, there was concern regarding how the contradictions in talk about normalcy and disruption could be properly conveyed. Can people experience normalcy and disruption at the same time, or can people experience normalcy without experiencing any form of disruption or disruptions without normalcy? In choosing to focus on the normative aspects of living with HIV/AIDS, would this diminish the disruptive aspects of a person's life? Also, would focusing on the disruptive aspects of living with HIV diminish the normative aspects of their lives? Therefore, in an effort to correctly report about the experience of normalcy and disruption while living with HIV/AIDS, it is important to take an archeological approach in disentangling the inconsistencies in the participants' discussions.

The Archaeology of Knowledge of HIV/AIDS Experience

This section will describe how an archeological approach was used to make sense of the conflicting discussions about the HIV/AIDS experience. After looking more closely at the interview data collected from the dissertation and HAART Project, it became clear that studying and reporting the experiences of individuals living with HIV was much more complicated than anticipated. Initially, it was felt that people would focus on disruption from living with HIV/AIDS. However, after reading through the transcripts, I noticed that the majority of the participants emphasized a generalized

feeling of normalcy (e.g. “I forget that I have it”, “nothing changed”, “I’m used to it now”) when talking about living with HIV/AIDS. Despite describing normalcy, participants also revealed disruptions (e.g. disruption to sexuality) from living with HIV/AIDS. It became a struggle to determine a way in which to adequately convey and make sense of these contradictory discussions that included normalcy and disruption.

In the process of making sense of the complex and contrasting discussions about living with HIV/AIDS, previous readings from Foucault on deconstructing knowledge in *The Archaeology of Knowledge* and *The Birth of the Clinic* (Foucault 1982; Horrocks and Jevtic 1997) came to mind. Foucault explores epistemology (“How do we know what we know?”) and utilizes an archaeological approach to deconstructing powerful systems of knowledge, such as economics and biomedicine. Foucault’s approach in *The Archaeology of Knowledge* was a good model to follow as a way of deconstructing the complex discussions about the experiences of living with HIV/AIDS. Foucault’s *Archaeology* approach emphasizes multiple layers and understandings and helps to frame how people think about the experience of living with HIV/AIDS. It was necessary to disentangle how the participants conveyed their experience of living with HIV/AIDS and my own interpretations of the data.

By thinking of HIV/AIDS experiences as a layered archeological site, as one begins to unearth each layer, one may begin to discover various understandings or perceptions that stem from the same phenomenon. With this in mind, an archaeological framework was utilized as a technique for data analysis. A variety of different tools such as note-taking, coding, pile-sorting, and thematic analysis were used to help unravel the discussions of normalcy and disruption. In addition, various interviews, the HAART

Project interviews and the dissertation interviews, were also used to explore the various layers of experience and occurrences of normalcy and disruption. This multilevel approach to analyzing the data helped reveal new layers of information, or artifacts, as a means for gaining a richer understanding of the experiences of living with HIV/AIDS.

Drawing from *The Archeology of Knowledge* model, this dissertation examined the multiple layers associated with HIV experience and the various ways normalcy and disruption were experienced throughout the process of living with HIV. At the surface during the dissertation interviews, the majority of the older adults normalized their experience of living with HIV/AIDS by stating how HIV was no longer a “big deal” in their daily lives⁶⁰. Yet, after analyzing, or “digging through”, the surface (the beginning of the interview) and the other layers (e.g., later sections of the interview, interviews at different points in time), I learned that the majority of older adults did in fact experience some level of disruption from living with HIV/AIDS. The type and intensity of the disruptions experienced by the participants sometimes varied over time (e.g., fear of death) and sometimes remained the same (e.g., loss of sexuality). After uncovering the various layers it was possible to see that people could experience both normalcy and disruption in their experience of living with HIV/AIDS. Separately, the various layers provided unique perspectives and together they provided insight into a larger picture of HIV/AIDS experience. The presence of both normalcy and disruption in the participant discussions made understanding the experience of living with HIV/AIDS complex. This

⁶⁰ It is important to note that perhaps participants started out their discussions about normalcy to provide a generalized or global summary of their experience of living with HIV/AIDS. Or perhaps in the introduction of the interview participants felt the need to ‘save face’ or provide a socially acceptable response to describing their experience. But then as we established more rapport or felt more comfortable in talking with me they began to reveal information on the disruptions they were experiencing. This provides a methodological question or challenge.

complexity confirmed the need for various sources of data and approaches to analysis. The following section provides information on how I came to understand the dialectical and interconnected relationship between the life course concepts of normalcy and disruption.

Dialectical Relationship of Normalcy and Disruption

The previous section discussed an archeological approach to thinking about HIV experiences. This section provides insight into the presence of contradictions in how people talk about HIV by drawing from the philosophical tradition of dialectics and Ewing's (1990) model of multiple selves. By encountering inconsistencies in how HIV was discussed, the assumptions made regarding the life course concepts of disruption and normalcy as opposing, mutually exclusive categories of life course experience needed to be reconsidered. At the start of this research, it was assumed that disruption and normalcy were all encompassing and not necessarily experienced together, or that a person might mostly experience disruption and not necessarily normalcy, and vice versa. However, the data collected illustrated that some people may experience a middle range of the spectrum (e.g., not completely disrupted or normalized), or that people may experience disruptions in some ways and normalcy in other ways.

To further the understanding of normalcy and disruption, the philosophical tradition of the dialectical method was referred to. Philosophers have often used the study of dialectics or a dialectical method to understand opposing points of view (e.g. Hegel's Master-Slave Dialectic). Thinking of normalcy and disruption as a dialectical relationship helped to refine the understanding of each concept and how they were and

were not related to each other. Normalcy and disruption typically refer to the different ends of the spectrum of the cultural life course and are essential elements of the life course construct. To understand the life course one must recognize there are both normative and disruptive aspects to the understanding human lives. In order to understand normalcy, one must also understand disruption, and, conversely, in order to understand disruption, one must also understand normalcy. Drawing from these ideas I began to recognize my assumptions about the experience of living HIV/AIDS and realized I needed to disentangle the conflicting ideas presented by my participants. Normalcy in the life course can be described as the culturally defined ideals and expectations of the way life should be. Yet at the same time we know that human lives are complex and multidimensional and do not always play out in a normative and orderly fashion. People often experience disruptions to normalcy (e.g., chronic illness, deaths, hardships, etc.). Disruptions are also culturally defined and represent those chaotic moments or periods of time that separate people from their normative ideals and expectations of how they think their lives should play out. The life course concept is based on notions of normalcy and disruption. In order to understand the interviews of people living with HIV/AIDS it was necessary to explore the range of experiences and the ways experiences might include both normalcy and disruption. Normalcy and disruption, while often described as representing different spectrums of the life course, are in fact very closely related and interconnected. Prior to this research, I thought of normalcy and disruption as separate states of being. However, this research has demonstrated that normalcy and disruption may not be completely isolated from each other. People may experience one or the other or both depending on the particular

contexts of their lives. While on the surface it may seem easier to understand the concepts as in opposition to each other, they may form a symbiotic type of relationship.

Ewing's "The Illusion of Wholeness: Culture, Self, and the Experience of Inconsistency" (1990) provides a model for understanding why there are contradictions in how people talk and can be applied to how people described their HIV experience. Ewing presents examples from dialogue from a study participant named Shamim to explore how "multiple self-representations are organized, contextualized, and negotiated in dialogue" (Ewing 1990:274). Shamim provided examples of various images of herself and some contradictions in self-representation (e.g. good wife, clever politician). Ewing uses examples of various "shifting self-representations" to critique the notion of one single and cohesive self. Ewing states that "a single model of self or person is not adequate for describing how selves are experienced or represented in any culture (Ewing 1990:257)." Instead, Ewing argues that there are multiple and shifting selves instead of one cohesive self, which is why it may seem that people contradict themselves.

Selves are highly context-dependent and mutually inconsistent. There is no overarching, cohesive self that is identifiable to an outside observer...Self-representation and self-experience is constantly changing and people may be unaware of the contradictions that they present. In all cultures people can be observed to project multiple, inconsistent self-representations that are context-dependent and may shift rapidly. (Ewing 1990:251, 259)

Ewing's discussion helps to explain why the people who were interviewed described their experience of living with HIV as normative and disruptive at the same time. In some contexts, living with HIV might not be that disruptive and people may be able to live a normal life. However, in certain contexts, living with HIV might be disruptive for

people. An initial goal was to identify a cohesive pattern to explain people's experience living with HIV. However, there may be more than one "cohesive" pattern of experience. In fact, there are inconsistencies and contradictions in the way people described and represented themselves. Ewing would argue that the emphasis on a cohesive self is an illusion or that the cohesive self includes contradictions and inconsistencies. Ewing's perspective suggests that there is no need to focus on representing one perspective of HIV experience, but that it is important to present multiple perspectives and inconsistencies to shed light on the overall HIV experience. The following section provides a description of the analysis and themes corresponding with talk of normalcy and disruption.

ANALYSIS FOR NORMALCY AND DISRUPTION

The analysis for this chapter was based on coding in ATLAS.ti for normalcy and disruption throughout the dissertation interviews. Even though normalcy and disruption were originally coded as separate categories, as discussed throughout this chapter, it was later determined that there were some areas of overlap in the discussions of these two categories. After coding, all of the quotes for normalcy and disruption were pulled to make a general list of topics and themes resulting from the coded chunks of text. After reading through the quotes on normalcy, two major strategies people used to establish a sense of normalcy while living with HIV were identified: (1) taking HIV medications helps to control physiological aspects of disease and (2) avoiding disclosure of HIV status helps to control social aspects of the disease.

In reading through the coded text based on disruption from the dissertation interviews, intimacy and sexuality emerged as the major ways HIV/AIDS disrupted the

participants' lives. While participants experienced other disruptions, such as medication side effects, the disruption to sexuality and intimacy appeared to be an overarching area of concern and emphasis for the participants. As a result, the T1⁶¹, Texit⁶², and T2⁶³ were coded for any discussion regarding intimacy/sexuality (e.g. relationships with others, sexuality, sexual behaviors, dating, love, marriage). After coding for sexuality and intimacy, chunks of coded text were read and used to generate a list of themes. Five major themes related to disruption to intimacy and sexuality were identified: intimacy, trust, identity, rejection, and sexuality. The following sections provide a more in-depth discussion of the themes emerging from the coding from normalcy and disruption.

Normalcy

I live my life according to my blindness. My HIV is like a second seat to that. Because it don't bother me. It just really don't. I'd forget if it wasn't for the fact that I had to take four pills, and that's two in the morning and two at night. I would completely forget. Sometimes I do forget about my HIV. (Sheila Dissertation Interview 2009, Age 53, HIV+ 10 years)

What does normalcy mean to people who are HIV positive and how do people with HIV create a sense of normalcy after an HIV diagnosis? On the surface, similar to Sheila's statement above, many of the older adults discussed how HIV no longer seemed to affect their daily lives. Participants described feeling as if they "didn't even have it" or that "HIV took a second seat" to their other health problems. Patrice described how, after living with HIV for a long period of time, her perceptions of HIV had changed and she no longer thought of HIV as a disruption.

⁶¹ T1 refers to the first interview from the HAART Project

⁶² Texit refers to the final interview from the HAART Project.

⁶³ T2 refers to the dissertation interview

AN: Would you consider HIV a disruption to your life?

P: Well a long time ago, yes. Not anymore. It's not a disruption in my life. My daily living is the same; I've been living with it so long. Hell, this is a routine. So, no, it's not a 'ruption. Only sometime that, I mean I'm so used to it now. It's not a 'ruption anymore. (Patrice Dissertation Interview 2009, Age 51, HIV+ 8 years)

Patrice's statement corresponds with Becker's description of how people may use references to routines and daily living to indicate that a sense of normalcy has been established. Despite Sheila's and Patrice's comments about normalcy, it wasn't certain how these discussions about their experiences of living with HIV should be reported or interpreted. If a person discusses normalcy do they no longer experience disruption? Besides the daily task of taking HIV medications, many of the participants revealed that they tried not to think about HIV in their daily lives. In understanding the responses of the participants, it is important to note that at the time of the dissertation interviews the participants had been living with HIV for many years, ranging from 6 to 24 years. Many of the participants had learned strategies of living with HIV, so the disruptions to daily living had become less severe and living with HIV had become more routine.

When people discussed experiences of normalcy, they often used phrases like: "It's like I don't have it", "I don't think about it anymore", "I don't feel different", "I don't feel like I'm sick", "It doesn't affect me", and "I forget that I have it." These statements reveal some of the ways people express normalcy despite living with HIV. However, it is important to establish how and when people come to the point of experiencing normalcy. What are the strategies that people used to achieve a sense of normalcy? What was learned from coding for statements of normalcy and thematic analysis was that "feeling normal" was context-dependent and connected to having an underlying

sense of control. Having a sense of control was identified as a major theme because it was the overarching strategy that people used to establish normalcy.

Themes of Normalcy

To feel a sense of normalcy, the participants needed to demonstrate that they had control over their HIV status in two major ways, over the disease itself and over how others perceived them. Control over their HIV status often took place in the form of taking medications to manage their disease and in careful management of who they revealed their status to. Since HIV is presently incurable, the participants underscored the importance of taking medications in order to live and to manage the physical manifestations of their disease. Participants often talked about the role of taking medications in order to survive. Despite struggles with the side effects and establishing a routine of taking medications, participants recognized the importance of medications in ensuring their ongoing and long term survival with HIV/AIDS. Taking medications is a strategy people used to control their HIV and to establish normalcy. For example, as Alvin stated:

You must take that medication. If you don't take that medication, then you are letting yourself in to exit. And I ain't ready to exit yet. Even though I love my Lord I'm not ready to visit him. I don't want to leave here yet. (Alvin Dissertation Interview 2009, Age 78, HIV+ 6 years)

Alvin's quote emphasized the need for taking medications in order to live.

Participants also talked about importance having an undetectable viral load status in order to feel normal. For example, Melvin stated:

I don't feel no different. I don't. I'm not sick or anything like that. Uh, every time that they, like every time they check it - it's way under their radar screen. So it doesn't affect me at all. (Melvin Dissertation Interview 2009, Age 59, HIV+ 6 years)

By taking medications, the participants hoped to live with HIV and to reduce their viral load to an undetectable status which was as close to a normal state as possible while living with HIV (e.g. “like I don’t even have it” or “way under the radar”).

The participants also referred to experiencing a sense of normalcy by controlling the social consequences of living with HIV. The social consequences of HIV were controlled by carefully managing who they revealed their status to. Since the participants knew that people with HIV/AIDS were often stigmatized, they did whatever they could to avoid having others judge them, reject them, or perceive them as abnormal. They told very few people about their status. Medical professionals, immediate family members, a spouse or a friend were the few people who might be aware of their status. Yet, some participants emphasized the importance of avoiding telling people altogether. Alvin had only shared his status with health professionals and one close friend. He stated that he had not shared his status with his family in order to maintain a sense of normalcy.

I have relationship with my family I just don’t talk about that. I don’t talk about that to them. It hasn’t influenced it one way or another in that way. I don’t talk about that. I don’t want to see no disdain in their eyes. I’m supposed to be a leader in that. I messed up. I know I messed up. I ain’t going out there and professing to them that I messed up. I just ain’t gonna talk about it. (Alvin Dissertation Interview 2009, Age 78, HIV+ 6 years)

Since Alvin does not reveal his sero-positive status, he is able to maintain a normative status, fulfill his role as a leader, and maintain his relationship with his family. If the participants avoided or limited the number of people who they revealed their status to, then they could appear and/or feel normal. If they revealed their status, then they would give up a sense of control and have to deal with the potential negative consequences of how people might judge or react to them. By not sharing their status, they are able to

protect their identity as normal and present themselves as normal to others. In summary, normalcy is context-dependent for some people. Controlling the physical and social aspects of HIV was crucial to the participants' experiences of normalcy in living with HIV. Feeling a sense of normalcy might be dependent on various factors of living (e.g. length of time living with HIV, viral suppression, physical symptoms) and may change over time. These findings of normalcy in the way HIV is experienced among older adults underscores Becker's discussion of how people create a sense of continuity and a revised sense of normalcy after a life disruption.

Disruption

Despite describing a sense of normalcy while living with HIV, the majority of the participants also discussed experiencing various types of disruptions. The disruptions people experienced were implicit and explicit and were mostly context dependent around intimate and sexual relationships. The in-depth analysis revealed disruptions may occur in certain contexts of living with HIV. In addition, the type of disruption may also vary throughout the process of living with HIV.

Talk about disruption and normalcy were also not necessarily separate. In fact the discussions of normalcy were also often intertwined with discussions of disruption. This interconnectedness further supports the discussion by Ewing on multiple selves and shifting self-representations. Self-representations may "shift rapidly" depending on the contexts. For example, Mildred described how she lived like a normal person but no longer communicated with people anymore:

AN: To what extent has HIV changed the way you live your life?

M: Only in communicating. I used to communicate with people and what-not. Just as far as being intimate or close to someone that's the only problem. Other than that I live like a normal person. (Mildred Dissertation Interview 2009, Age 56, HIV+ 7 years)

Mildred has created a new state of normal even though she experiences disruptions in her ability to communicate and to establish intimate relationships with other people. HIV may, in fact, have a profound impact on people's lives, but these older adults were resilient in their ability to move past their initial HIV diagnosis and HIV disruptions in order to create a new sense of order and continuity. At the same time what do people give up in order to establish normalcy? Mildred had experienced disruptions to communication and intimacy in order to maintain a sense of normalcy.

The contradictions in how people discussed both normalcy and disruption while living with HIV underscored the complexity in understanding the experience of living with HIV among long-term survivors. The study of intimacy and sexuality was not an original aim of this research. However, intimacy and sexuality became a major focus of data analysis and discussion because of its importance to the older adults interviewed. When asked to talk about their life with HIV, participants often described how their life seemed normal except for their sex life, dating, and communicating with others. Each of the participants described how their intimate and sex lives were disrupted to some extent or abruptly stopped due to their HIV status.

At the start of this research, it was not realized how important intimacy and sexuality would be to this group of older adults. While transcribing the interviews and note-taking, this similar pattern of life disruption from living with HIV was noticed and

began to repeat itself among the older African Americans. To explore disruption more closely, the T1 exit and dissertation interviews were reviewed in order to code for both obvious and subtle discussions about intimacy and sexuality. The various ways intimacy and sexuality were discussed, disrupted, and experienced were revealed from in-depth analysis of the interviews and became a major finding and area of inquiry of this dissertation research. How does living with HIV disrupt intimate relationships? What does it mean when older adults deny themselves an intimate relationship? How do people go about reorganizing their lives in response to disruptions to intimacy? From analysis of the interviews it was noted that talk about 'sex life' would refer to various forms of disruption to intimacy and sexuality such as dating, communication, companionship, loneliness, sex practices, transmission, and love. The damage caused by disruptions and losses of intimacy and sexuality may be more considerable for some than others but nonetheless are important aspects of normal life course expectations. The participants experienced disruptions to physical aspects of sex in addition to a whole range of intimate, social, and emotional interactions that are often strongly associated with wellbeing.

Themes of Disruption

A result of the analysis of disruption to intimacy and sexuality was the identification of five major themes: intimacy, trust, identity, rejection, and sexuality. These five themes are not mutually exclusive, but they help illustrate some of the overarching experiences and contexts of disruptions to intimacy and sexuality due to an HIV diagnosis.

Intimacy refers to a larger umbrella category relating to relationships with others. Disruptions to intimacy often revolved around avoiding relationships with others, difficulty of opening up to others, sharing one's true self, overall lack of close relationships, and/or the desire to establishing intimate relations with others. Intimacy may or may not include a sexual component because it depends on the type of relationship (e.g. dating relationship versus family relationship).

I don't be too intimate with nobody. I've always been that way...On top of that I don't let too many people know anything about me. (Melvin Dissertation Interview 2009, Age 59, HIV+ 6 years)

Participants revealed that intimacy had to do with not being able to open yourself up to other people on a variety of different levels. Talk about intimacy was referred to in statements about "having degrees of relationships", "not being an open person", "having associates not friendships." Intimacy could refer to sexual and nonsexual relationships. Many of the participants avoided intimate relationships on various levels and did not feel comfortable revealing their status to others. Since becoming HIV positive, participants were concerned about their privacy and appearing normal to others. As a result, they often avoided intimate relationships so that they did not have to disclose information about their status, or sometimes participants maintained intimate relationships without disclosing their status.

Trust highlights an important component of understanding relationships with others and is perhaps a subtheme to intimacy. Participants discussed a variety of different ways that disruptions to trust occurred since being HIV positive. Talk about trust was illustrated in statements such as "didn't think we needed to use condom",

“family members opened my mail”, “gossip at support groups,” and “anger for trusting previous partners.”

Identity has to do how people talk about their sense of self and/or would characterize or describe themselves. In some cases, participants revealed how their identity had completely changed while others did not feel very different despite experiencing disruption (e.g. “I’m the same – I’m just not sexually active”). Talk about disruptions to identity included statements such as “I’m not the person I was”, “Thought I was a leper”, “Not human anymore”, and “I don’t have as many women as I used to have.” Talk about identity also included how people wanted to present themselves to others and the situations in which others may have misjudged their identity (e.g. “I was not a crack whore”, “I’m not gay”, “and I’m not a lesbian”).

Rejection refers to a real or anticipated experience when someone does not or might not accept a person. Some participants were afraid of rejection so they avoided relationships completely, while others were more careful or selective. Talk about rejection, a form of disruption, was discussed in statements such as “I’m not sure how to share information and deal with the possible rejection”, “I don’t want to see the disdain in someone’s eyes”, and “My aunt won’t kiss me.”

Sexuality refers to talk about a sexual relationship or aspects of sexuality identity. Sexuality may or may not include talk of intimacy. Talk about disruptions to sexuality included a range of physical, emotional, intimate and identity discussions. Some examples of disruptions to sexuality included “I’m no longer sexual”, “My ship just

stalled in the water”, “I miss the skin-to-skin feeling”, “I don’t want to be bothered”, “We use condos”, and “Changed the way we do things.”

The five themes discussed above describe some of the overarching ways the participants experienced disruptions to intimacy and sexuality. The extent to which the themes occur in each person’s life differs and the level of disruption also differs. These themes bring insight into the range of ways disruption is experienced or understood. Disruption to intimacy and sexuality were a major finding of this dissertation research. This chapter briefly introduces themes of disruption to set the stage for a larger discussion on life reorganization in response to disruption to intimacy and sexuality that will take place in the next chapter.

DISCUSSION OF NORMALCY AND DISRUPTION

This chapter provided information on the analytical journey of making sense of inconsistent talk in how people described the experience of living with HIV/AIDS. The major inconsistency involved how people described normalcy while simultaneously experiencing disruptions resulting from living with HIV. The first section of this chapter focused on Foucault’s (1982) *The Archaeology of Knowledge* approach to help deconstruct the complexities of trying to make sense of the experience of living with HIV/AIDS. Second, a discussion of dialectics and Ewing’s (1990) model of multiple selves was used to understand why people described inconsistencies in the experiences of living with HIV/AIDS. Ewing’s model of multiple and inconsistent selves helped to explain why the participants described both normalcy and disruption when living with HIV. The experience of normalcy and disruption is context dependent. In

certain contexts individuals may experience normalcy, yet in other contexts individuals may experience disruptions.

Third, a discussion of the major themes relating to normalcy and disruption were discussed. For ease and simplicity, the themes of normalcy and disruption were presented as separate sections of this chapter. However, it was recognized that normalcy and disruption are sometimes interconnected and/or are not necessarily mutually exclusive for those who are living and aging with HIV. The goal of this chapter was to try to understand how people interpret their experience of living with HIV and how to convey the normative and disruptive aspects of living with HIV/AIDS. The experience of normalcy and disruption are often context dependent and not necessarily mutually exclusive categories of experience. If a person experiences normalcy it does not guarantee that they do not experience disruption and vice versa. These findings from this chapter underscore the complexity and multidimensional nature of understanding the nature of HIV experience.

After discussing normalcy and disruption in relation to inconsistencies of talk about living with HIV, the next chapter will focus on specifically on how people reorganize their lives in response to a major type of disruption experienced by the participants that were interviewed. This next chapter discusses the area of disruption and reorganization of intimacy and sexuality among older African Americans with HIV/AIDS.

CHAPTER 8

“MY SHIP JUST STALLED IN THE WATER”:

DISRUPTION AND CONTINUITY OF INTIMACY AND SEXUALITY POST-HIV

Things I used to do I don't do them no more. My ship just stalled in the water and I stopped it right there. (Alvin Dissertation Interview 2009, Age 78, HIV+ 6 years)

The original focus of the dissertation was to learn about general disruption from living with HIV rather than to specifically study the sexuality and intimacy patterns of older African Americans who were living with HIV/AIDS. However, the topic of disruption to sexuality and intimacy emerged as a central finding from the interviews with the participants. Alvin's quote about a “ship stalled in the water” illustrated one of the many examples of how the participants described disruptions to sexual and intimate relationships since living with HIV. Chapter 8 focuses on understanding the meaning of a particular type of disruption, to sexuality and intimacy, from living with HIV. An anthropological understanding of the beliefs, values, and life course expectations associated with sexuality and intimacy can provide important insight into the lived experiences and concerns of older adults who are dealing with disruptions resulting from their HIV diagnosis. The way HIV disrupted sexuality and intimacy and how people reorganized their lives differed among the participants. Nonetheless, this chapter underscores how sexuality and intimacy were discussed as a major area of HIV disruption and life course concern for older people living with HIV. The purpose of this chapter is to (1) review literature on sexuality and intimacy to help understand the experiences of the participants, (2) understand the nature of disruption and the meaning of sexuality and intimacy for older people living with HIV/AIDS, and (3) discover how

people reorganized their lives in response to HIV disruptions to sexuality and intimacy.

SECTION 1: LITERATURE ON SEXUALITY AND INTIMACY

What do older adults mean when they say their sex life has changed or been disrupted since being diagnosed with HIV? How are sexuality and intimacy negotiated in the context of living with HIV? How do people with a stigmatizing and infectious disease reorganize or make sense of their lives in response to disruptions to sexuality and intimacy? Section 1 provides a brief overview of some of the ways different disciplines think about sexuality and intimacy. The purpose of reviewing some key literature on sexuality and intimacy is to better understand the disruption that is experienced by older African Americans who are living with HIV. First, some of the ways in which anthropologists study sexuality and intimacy will be discussed. Second, a review of what is known about sexuality in later life from literature in gerontology will be discussed. Third, some of the ways in which sexual and intimate relationships are connected to physiological, developmental, and psychological functioning and wellbeing will be described.

Anthropology of Sexuality and Intimacy

This section discusses some of the ways anthropological perspectives can be used to help understand the experiences of disruption and the meaning of sexuality and intimacy to older African Americans who are living with HIV. The goal of this review is not to provide a comprehensive review of all the literature on anthropology of sexuality. Instead this discussion will provide a selected overview some of the ways

anthropologists may study sexuality as a means of thinking about the larger social world and the experiences of older people living with HIV.

How do cultural beliefs and values influence how we think about the sexuality of older adults? Anthropologists have generally studied the role of sexuality in relationship to cultural practices, beliefs, and values since the 18th century Age of Enlightenment (Lyons and Lyons 2006). However, the anthropological study of the sexuality of older people is limited in part because of U.S. cultural beliefs emphasizing ageist views of older adults' sexualities. The emphasis on older adults as "asexual" has impacted the research interests of anthropologists and shaped why sexuality and intimacy studies tend to focus on "younger" phases of life (e.g., reproduction, sexual maturity, marriage/partnerships) rather than later life, old age, and aging, with a few exceptions (e.g., regulation of sexual practices of older adults with dementia) (Kaufman and Morgan 2005). Popular culture and media often illustrate disapproval of the sexually active older adult and underscore "asexual" assumptions (Blaikie 1999; Morgan and Kunkel 2007; Shweder 1998). Ageism is also evident in the history of how HIV risk has been understood among older adults and in anthropological avoidance in researching the sexuality of aging people (Sankar et al. 2011). There is a disconnect between larger assumptions that older adults are or should be "asexual", and the reality that older adults are in fact often sexually active and that sexuality and intimacy are part of lifelong life course expectations (Barfield 2001; Morgan and Kunkel 2007; Shweder 1998; Tessler Lindau et al. 2007).

What do older adults mean when they say their sex life is disrupted? The loss of physical sex and emotional intimacy was a major disruption among the older people

who were interviewed. An anthropological approach can be used to explore the various cultural beliefs, values and practices in order to understand what is meant when people say the word “sex”. As will be discussed later in this chapter, talk about sex is not strictly limited to sexual behaviors (e.g., intercourse and arousal). Sex may also include a wide range of other behaviors, relationships, beliefs, and perceptions that may or may not include intimacy (e.g., romantic love, companionship, trust). Anthropologists think about sexuality in relation to beliefs about appropriate sexual behaviors and practices, how meaningful sexual relationships are defined or determined, and how sexuality, intimacy and love are expressed or defined cross-culturally (Hirsch et al. 2009).

Hirsch et al. (2009) in *The Secret: Love, Marriage and HIV* provide insight into understanding how beliefs and values about love, intimacy, and marriage may not necessarily protect against HIV risk or deter extramarital affairs. Hirsch et al. explore the intersection of gender, inequality, and beliefs about love to understand the practice of extramarital affairs and the production of HIV risk in five different cultural settings. By studying the intimate relationships and sexual practices of couples in Mexico, Nigeria, Uganda, Vietnam, and Papua New Guinea, Hirsch et al. (2009) gain insight into the complexity of HIV risk and prevention in an area that people often assume is protected from HIV risk. Their cross-cultural ethnographic research “investigates how men’s and women’s ideas about love – and efforts to express love – shape extramarital sex and HIV risk” (Hirsch et al. 2009:9). Their research provides new insight into the meaning of marriage in various cultures and the role of understanding how intimate relationships are negotiated and defined.

While this research is not focused specifically on marriage or infidelity, Hirsch et al.'s (2009) interest in understanding intimate relationships and beliefs about love are relevant for understanding research participants' discussions. This research extends the work of Hirsch et al. by focusing on how sexual and intimate relationships are negotiated when living with HIV and recognizing the various components of what people might refer to when they say "sex" (e.g., physical, emotional, intimate relations).

A Life Course Approach to Understanding Sexuality

A life course framework represents another approach to thinking about sexuality. A life course approach recognizes that sexuality cannot be reduced to just biological (e.g., anatomy, sexual functioning), psychological (e.g., sexual desire, emotions), social (e.g., intimate relationships, immediate social context), or cultural (e.g., sexual scripts, religious and moral beliefs) forces (Carpenter and DeLamater 2012:4). The anthropological framework of the life course⁶⁴ is used to explore the life course expectations and roles associated with sexuality. There are culturally defined norms and expectations about sexuality, sexual behavior and relationships. The anthropological life course framework is utilized as a way of understanding how people living with HIV may experience disruptions in their expectations for sexual and intimate relationships. Disruptions to normative expectations may result in feeling sexually undesirable and involuntary celibacy. To understand sexuality within the life course framework it is important to study the relationship between perceptions/expectations for sexuality and how people respond to disruptions (e.g., HIV diagnosis) to normative expectations for sexuality. An area of inquiry may include disconnects between desire for sexual and intimate relationships and the reality of living with a stigmatizing illness

⁶⁴ Life course is defined in Chapter 3

such as HIV. As will be discussed later, a result of the findings of this research was to uncover some important details on life course expectations and how intimate and sexual relations are negotiated/determined and disrupted among small population of older African Americans who are HIV positive. The findings give insight into the meaning of sexuality and intimacy in later life and how a stigmatizing chronic illness can disrupt core beliefs, values and expectations.

Power and the Politics of Sexuality

What can we learn from understanding how sexual and intimate relationships are negotiated among older HIV positive African Americans? Anthropologists have studied sexuality as a means of thinking about power relations and politics. Sexuality and sexual practices are a mechanism for learning about the rules and regulations of cultural groups and societal organization (Lyons and Lyons 2006). The study of sexuality and sexual practices of different cultures provides insight into relationships between members of a cultural group, power relations within and outside of cultural groups, and how societies are organized and regulated (Hirsch et al. 2009; Lyons and Lyons 2006). The types of sexual practices that are defined as “normal” and “abnormal” can also provide insight into how a culture is organized and can reveal important details about the dominant power relationships in a society.

Gayle Rubin’s (1992) influential article “Thinking Sex: Notes for a Radical Theory of the Politics of Sexuality” discusses how the study of sexuality can be deployed as a tool for gaining understanding of the larger power dynamics and politics of a society. Rubin (1992) outlines how sexuality and sexual deviants have been regulated and policed throughout history in the United States and other societies. The groups of

people and practices determined to be sexually deviant have changed over time and throughout history. Societies highly regulate and police groups of people (e.g., homosexuals) and/or certain sexual practices that are determined to be sexually deviant, while practices and groups of people identified as sexually “normal” are rewarded in society (e.g., legal marriage, tax breaks, insurance benefits). Social anxieties and social stresses are often reflected in the cultural politics of sexuality (e.g., the interconnectedness between political agendas and specific cultural values to regulate sexuality).

Rubin (1992) explains how in the 1980s social anxieties and fears about AIDS influenced negative perceptions of homosexuals and influenced the production of anti-gay politics and policing. “The history of panic that has accompanied new epidemics, and the casualties incurred by their scapegoats, should make everyone pause and consider with extreme skepticism any attempts to justify anti-gay policy initiatives on the basis of AIDS (Rubin 1992:165).” Rubin’s emphasis on understanding the political nature of sexuality provides insight into some of the reasons why HIV is highly disruptive to the sexuality of older African Americans and how fears associated with HIV may influence people to avoid intimacy and sexuality after an HIV diagnosis.

In anthropology, sexuality is a mechanism for studying cultural beliefs, value systems, and life course expectations and practices in addition to exploring the power dynamics and politics of a culture or society. Sexuality can be a tool for trying to understand and think about a larger social world. The various ways anthropologists might think about sexuality and intimacy can be used to think about the experiences and disruptions of sexuality and intimacy among the participants of this research. The next

section on gerontological literature will provide information on what is known about sexuality and intimacy in aging and older adults.

Gerontological Approaches to Understanding Sexuality and Intimacy

Ageism and cultural beliefs that older adults are asexual have limited what is known about the sexuality of older adults and aging populations (Scherrer 2009). However, it is important to understand what is known about sexuality and intimacy among older adults. Scherrer's (2009) article "Images of Sexuality and Aging in Gerontological Literature", provides a comprehensive review of how sexuality has been discussed in 21 gerontological journals from 1988 to 2007. Scherrer identified 88 articles published over a period of 20 years on aging and sexuality in various gerontological journals. Of the literature written on sexuality and aging, there were three main areas of emphasis: (1) confirming sexuality of older adults, (2) diversity in sexual identities and (3) regulation of sexuality. The first area of emphasis is a reaction to popular cultural beliefs emphasizing the asexuality of older adults. This literature is aimed at confirming, recognizing, and defending sexuality as a legitimate area of study among older people. The second main area of emphasis in gerontological literature includes the sexual identities and aging experiences of gay and lesbian older adults. The third area of emphasis describes societal and structural regulation of older adults' sexualities; particularly those aging adults who are living in institutional settings (e.g., assisted living facilities, nursing homes). Adults who are aging in institutions, especially those with dementia, may find their sexuality and intimate relationships are highly regulated and monitored by institutional policies, their families, or staff members. The

policies and regulations imposed by institutions, families, and staff may hinder the sexual expression and wellbeing of these older adults.

Scherrer's (1992) article also discusses key implications for future aging and sexuality research. Due to limited research on the role of sexuality in later life, current policies and regulations may be misinformed and unaware of the needs and concerns regarding sexual expression of older adults. Research is needed to illustrate the continuum and range of sexual desires and practices of older adults. Current literature tends to provide conflicting perspectives of older adults' sexualities as either asexual or sexual. Scherrer's review calls for research on understanding the wide range of sexual desires and practices and needs of older populations. Of the literature on older adults and sexuality, much of the focus is on gay and lesbian older adults who derive their identity from their sexual orientation and hence are the objects of scholarship on sexuality and aging. Research needs to broaden the understanding of sexual identities in later life and explore the identities of those who are heterosexual, transgender, and bisexual. Lastly, due to the monitoring and regulating of the sexual lives of older adults living in institutions, freedom of sexual expression may be limited to heterosexual behaviors, if they are allowed any sexual expression at all. Same-sex relations may often be frowned upon or prohibited in institutional environments. Research is needed on how facilities and institutions regulate the sexualities of older adults and how appropriate sexual behavior is determined.

The discussion of what the participants meant when they say "sex" and the ways they reorganized in response to disruptions to sexuality and intimacy will help address Scherrer's (1992) suggestion for understanding the wide range of desires and practices

of older adults. The multifaceted approach to understanding the sexuality of older people with HIV supports Scherrer's (1992) emphasis on the need for understanding how sexualities of older adults are represented in other literature outside of gerontology and the various ways sexualities are portrayed and regulated in media, literature, research, institutions, and policies. The first two sections focused on anthropological and gerontological approaches to understanding sexuality. The last section of the literature review will focus on psychological and physical understanding of sexuality.

Physiological, Psychological, and Developmental Dimensions of Sexuality

By studying the physiological, psychological, and developmental dimensions of the importance of sexuality and intimacy we can gain insight into other ways of understanding the disruptions experienced by the older African Americans in this study. This section will briefly review how intimate and sexual relationships and tactile touch impact the physiological, psychological, and developmental wellbeing and functioning of people. If older adults living with HIV experience disruptions to their intimate and sexual relations, then they may also experience disruptions to their overall wellbeing and daily functioning.

An article by Khaleque (2004), "Intimate Adult Relationships, Quality of Life and Psychological Adjustment", describes the importance of intimate relationships in relation to psychological functioning and wellbeing. Khaleque (2004) states,

Because intimate relationships satisfy certain psychological needs, individuals who avoid such relationships are likely to feel lonely, anxious, or depressed Disrupted intimate adult relationships tend to make individuals susceptible to many psychological problems including stress, anxiety, substance abuse, suicide, and other forms of psychopathology.

Empirical evidence from previous research has underscored the role of intimate relationships in impacting psychological wellbeing. Avoidance of intimate relationships can negatively impact wellbeing and functioning. The discussion from Khaleque can be used to think about how the psychological aspects of what happens when older adults who are living with HIV experience disruptions to intimate relationships and/or avoid these types of relationships altogether due to HIV stigma.

The article “The Skin, Touch, and Human Development” by anthropologist Montagu (1984) discusses the importance of tactile communication in influencing human development, communicating with others, and expressing various levels of love and intimacy with children, lovers, and family. Montague states the importance of “what we do or not do by way of adequately stimulating the skin of the growing individual may make a considerable difference to the growth and development as a human being” (Montagu 1984:25). Throughout the life course, tactile touch is important because it sends important signals to our brain and nervous system that are crucial for human development. Tactile communication is important for all phases of life and development. When people do not experience tactile stimulation and touch they can experience negative impacts on their development. Tactile touch provides an important dimension to understanding sexuality, human experience, intimacy and wellbeing. Montagu’s (1984) article on the importance of tactile stimulation and touch can provide insight into the potential losses of people who avoid or fear physical intimacy due to HIV/AIDS and how they may be missing out in important components of life course development.

Field's (2010) article "Touch for socio-emotional and physical well-being: a review" builds on the instrumental work of Montagu (1984) and reviews literature on how biomedical testing (e.g., MRI, EKG) provides empirical evidence for the importance of touch for the health and well-being of people. Field's review also discusses the ways touch can provide important cues for communicating intimacy and love. A discussion is provided on "romantic touch" (e.g., caressing, kissing, cuddling) is used to establish positive intimate relationships and improve partner satisfaction (Field 2010:271). Field (2010:373) also describes the various health benefits of touch (e.g., lowering blood pressure, heart rate, and cortisol and increasing oxytocin). Touch is an important dimension of intimate, romantic social relationships and plays an important role in life course development, psychosocial wellbeing, health status, and life course expectations.

While this dissertation research does not focus specifically on touch, this research recognizes the benefits that touch may provide those participants who are engaging in sexual and intimate relationships and the losses experienced by those who avoid those types of relationships. Understanding the importance of touch may provide additional insight into disruptions to sexuality and intimacy among older HIV positive African Americans. Recognizing the physiological, developmental, and psychological dimensions of touch associated with intimate and sexual relationships are important to understanding the various ways people may experience disruption when living with HIV. This literature review on sexuality and intimacy highlights some of the various ways different disciplines may approach understanding sexuality and intimacy. Understanding and integrating the various approaches and perspectives on sexuality

and intimacy are needed to provide a more thoughtful discussion of the socio-cultural consequences of HIV disruption.

METHODOLOGY AND ANALYSIS OF DISRUPTION TO SEXUALITY AND INTIMACY

The findings from this chapter emphasize understanding the meaning of sexuality and intimacy among this group of older African Americans in order to provide insight on: (1) how sexuality and intimacy are important and ongoing life course expectations and (2) how people go about making sense of the disruptions to sexuality and intimacy post-HIV diagnosis. The data utilized for the analysis for this chapter includes interviews from the dissertation research and entrance and exit interviews from the HAART project⁶⁵. Intimacy and sexuality were the two major codes used for the data analysis for this chapter. Transcripts were coded in ATLAS.ti for intimacy and sexuality with special attention to the living with HIV narratives⁶⁶.

The meaning of “sex” to the older adults interviewed included more than the physical dimensions of a sexual encounter. Discussions about sex for the older adults included a wide range of physical, emotional, social, and intimate characteristics. Some of the major topics related to sexuality and intimacy included: disclosure, avoidance, emotions, intimacy, companionship, distrust, love, marriage, masturbation, and intercourse. The participants described the circumstances around disclosure in past and/or current intimate relationships as a means for describing how HIV had impacted their sex or dating lives. I chose to define “intimacy” as referring to any talk about close relationships with others. Intimacy did not necessarily have to include sexual or

⁶⁵ This dissertation research builds on the The HAART Project, the parent study on the longitudinal study of adherence among HIV positive African Americans in Detroit.

⁶⁶ The HIV narratives were based off the question “Tell me your story of living with HIV”

romantic relationships (e.g., friendships, confiding in partner, love, companionship, disclosure). "Sexuality" was defined as talk about a wide range of attitudes, beliefs and practices related to sexual identity and sexual or romantic types of relationships (e.g., intercourse, sexual identity, condoms, touching, kissing, and HIV transmission). Sexuality might or might not include intimacy. Text searches for "sex" and other keywords (e.g., close, love, boyfriend, wife, partner, touch) were also conducted to thoroughly explore the data.

An iterative process was used to read through the coded text for each participant in order to generate additional information about the two coding categories and to confirm the appropriateness of the two coding categories. A brief summary was written for each participant about the intimate and sexual discussions that were present in their transcripts. These summaries provide a small snapshot of life experiences and discussions related to intimacy and sexuality. The summaries for each participant were then pile-sorted into categories based on disruption or continuity of intimacy and sexuality post-HIV diagnosis. There were two major patterns that emerged: (1) participants who experienced major disruption to sexuality and intimacy post-HIV diagnosis and (2) participants who primarily experienced continuity of sexuality and intimacy post-HIV diagnosis. The next section provides the summaries for each participant and is followed by the results of the pile-sorting.

CHAPTER 8 FINDINGS, PART 1: CASE STUDIES OF SEXUALITY AND INTIMACY

The previous sections reviewed literature on various ways of understanding sexuality and intimacy. This section provides a brief case study for each participant to

provide a brief but detailed overview of the way the topic of sexuality and intimacy was discussed during the interviews and to highlight the various ways people experienced disruption or continuity.

Case Studies of Disruption to Sexuality and Intimacy

Leonard

Leonard had terse responses to the HIV narrative question (e.g., “rollercoaster” or “in turmoil”). To learn more about his experiences of living with HIV, his interview was reviewed to explore the extent to which he experienced disruption to intimacy/sexuality. Leonard emphasized how every aspect of his life was severely disrupted by HIV. Leonard is an outlier in comparison to the other participants because he stated how much his life was disrupted by HIV and said he experienced consistent disruption throughout all of his interviews. He stated being HIV+ is “like not being human anymore”. He had not told anyone except his immediate family about his HIV status. Leonard talked about how his body has changed and he no longer feels comfortable exposing his arms and legs to others. During our interview he pointed out the muscle wasting and abnormalities of his body since being HIV positive. He has lost confidence and does not feel comfortable with intimate relationships. Leonard said he has lived his life “on the down-low” and is not an open person. He prefers men but also has had relations with women. He experienced a major life disruption as a young child when he was violated by a family member who sexually molested and raped him. He has anger towards his mother because she never confronted the family member who molested him but instead she was extremely protective and overbearing. He referred to his experience of being molested as a violation of his sexuality and questioned how his first sexual experience being molested by a man has influenced his sexual preferences for men. In his life history narrative he talked a lot about his highly active sex life throughout his teen and adult years where he “conquered” many gay and straight men in the neighborhood. He talked about how he could be in a relationship or even procreate but doesn’t want to bring anyone into the HIV lifestyle. Because of the disabling effects he has experienced from HIV he feels he cannot offer much in a relationship if he were to procreate. He stated that he is not sexually or romantically intimate with others at this point in his life because of the negative experiences of being HIV positive. (Leonard Dissertation Interview 2009, Age 56, HIV+ 9 years)

Alvin

Alvin is a retired auto worker who described himself as having changed recently because he had learned to accept HIV more and is happier now. He is active in his church choir and religious. He found out he was HIV positive after going to the doctor for skin problems. Alvin described how after he learned he was HIV positive he “let himself have one little cry but then decided he was gonna fight it just like he did with cancer”. Alvin takes medications so he will survive even if they make him feel sick. HIV

completely stopped his sex life, or as he said, his “ship in the water” or “sex factory”. He is divorced and has children from his previous marriage. Alvin is also on the “down-low” and does not openly identify as being gay. He is no longer sexually active because he doesn’t want to disclose his status to anyone. He is extremely secretive about his HIV and has only told one person, a good friend who lives out of state, and his doctors. He stated he is quite healthy and his day to day life is pretty normal despite not being sexually active. The loss of sexuality and intimacy is a major disruption to his life but he has learned to live with it. He discussed how he does not want to transmit HIV to anyone and prides himself in being considerate of other people (Alvin Dissertation Interview 2009, Age 78, HIV+ 6 years).

Loretta

When Loretta was first diagnosed she felt like HIV made her life a mess and she was shocked that she had it. Loretta described to me how after learning she was HIV positive she realized that you don’t have to fit the HIV “stereotypes” (e.g., promiscuous, a white gay man or drug user) to become infected. She was suicidal after her diagnosis, but her family helped her realize that “life is worth living.” Since her diagnosis she has been celibate. She wishes she’d had safe sex when she was in a monogamous relationship. Now she doesn’t trust men and doesn’t want to be bothered with the headache of sexual relationships. She studies the Bible and says she is now celibate for religious purposes. She is very close to her family but only a few people in her family know her status. She talks to her grandkids and other family members about HIV but they do not know she has HIV. She discussed how her family is reluctant to listen to her talk about HIV because they don’t think they will get it and say they don’t know anyone who has HIV. (Loretta Dissertation Interview 2009, Age 66, HIV+ 8 years)

Marion

After learning of her HIV status, her life was very empty because she became a homebody and didn’t go out and party like she used to. Her body hasn’t been the same since HIV and now she’s tired a lot. She feels really embarrassed about the thought of having to disclose her status if she is sexually intimate with a man. Being rejected is the “biggest thing”, the biggest fear in her life, and having to let a man know her status would be very difficult for her. At the exit interview she felt like life wasn’t going anywhere, “at a standstill”. She doesn’t like going to bars anymore and is not looking for a man. Her family keeps her happy and looks forward to the time she spends with her dad. Some days she doesn’t feel like doing anything and is depressed. Her siblings are deceased and she is disappointed because they were supposed to grow old together and travel. At the T2, she described how living with HIV is better now but dealing with the loss of her father and other close family members. She talks to others a little more about HIV now but does not necessarily reveal her status unless they are strangers. Her health is good and she isn’t sick from HIV but has other health problems (e.g., weight loss). She takes fewer pills. HIV influenced her trust with men though. She will talk to men but not have sexual relationships with them. She gets angry about not having sexual relationships and misses the intimacy and companionship from

dating. She's learned to deal with it the best she can and tries not to think about HIV on a daily basis. Her former partner had HIV and didn't tell her. He didn't take meds so he died. She wishes she would have used protection in her relationship. (Marion Dissertation Interview 2009, Age 62, HIV+ 10 years)

Willie

Willie was a former medical assistant who always hoped to become a nurse. He loved helping the older people who needed his care. When Willie first found out about his HIV status he thought he was going to die and went through a lot of ups and downs. He was really hard on himself and didn't want to be with anyone and didn't trust anyone. After he entered the AIDS Partnership of Michigan, he learned that HIV wasn't as horrible as he thought and received needed support and benefits. He talked about how he was always an "undercover" homosexual and didn't understand why he had to be different. He said he's "touched in the head", referring his struggles with mental illness. He said that when you don't trust people you just exist. At the time of the dissertation interview he had just started using a computer to socialize anonymously online and said it's better because he didn't feel as ashamed or alone. He said his health was fantastic (e.g., roller skates in neighborhood) but he got tired easily because he was older. He took pain pills for arthritis. He didn't drink or do drugs but enjoyed listening to music for an escape; music was his "weed". Willie described how finding out about his HIV status was traumatic. After finding out his status, he came home and realized he was also abandoned by his partner who he suspects infected him with HIV and he had since had a difficult time opening up to people. No one knew his status. He had to hide his pills from young nieces and nephews who snooped through his drawers. He was not sexually active but did talk about how masturbation and fantasy helped him deal with the loss of sexuality and intimacy. He fantasized about what it would be like to be in love and to have intimacy. He said fantasy was what helped him get through life because he knew he would never have an intimate relationship like most people did. He didn't want to give HIV to anyone and didn't feel comfortable disclosing his status to others. HIV prevented him from being a "real human person". He was celibate and said that would never change. He didn't like support groups because "it's a whorish thing and you don't get education of how to disclose and deal with the rejection". He tried going to a psychiatrist but that wasn't helpful. He said that talking to me was better than any therapy session he ever had. Willie died one year after our interview. (Willie Dissertation Interview 2009, Age 53, HIV+ 18 years)

Mildred

Her first HIV narrative was terse and she mostly talked about her daily routine of taking medications, cleaning house, and babysitting. She mentioned that she gets lonely, upset, and cries but then tries to go for a walk, read, or listen to music and continue on with life. At the T2 she felt like she was changing and feeling stronger about herself. She still feels bad about herself sometimes but realizes there isn't anything she can do about the HIV, and her faith helps her get through each day. She makes sure to take meds but is also getting tired of taking pills. At the dissertation interview she discussed being diagnosed with diabetes, trying to find work but not having any luck, and trying to just deal with life. During the interview we had to whisper

and call HIV 'it' because of someone sleeping in another room who didn't know her status. She had told her neighbor and sister, but the rest of her family didn't know her status. HIV has disrupted her life as far as getting close with people and sexual relationships. She has not been sexually intimate since her diagnosis. She doesn't want to be bothered even though she would want someone to love her and would like the attention. She is afraid that if she told a man that he would reject her and that he wouldn't be open-minded. Ever since her diagnosis, she doesn't let people get close to her. She has never gone to support groups because she thinks there will be too many different attitudes and it will give her a "down-stroke feeling". Her girlfriends ask about her sex life but she keeps quiet. She still goes out to clubs and cabarets sometimes but she doesn't get intimate with men. She tries not to worry about sexual relationships and avoids relationships because she doesn't want to get close to others. Her ex-husband possibly had HIV but she doesn't know for sure. She never told him her status since they weren't together anymore when she found out. She suspects her ex-husband passed away from HIV. (Mildred Dissertation Interview 2009, Age 56, HIV+ 7 years)

Case Studies of Continuity of Sexuality and Intimacy

The following case studies are based on participants who are categorized as continuity of sexuality and intimacy because they were engaging in intimate and sexual relations with others.

James

James discussed how HIV has really only impacted him since he became clean. When he was using drugs he didn't think about taking medications or disclosing his status to others or using protection. He was a long-term heroin user and described himself a guy who idolized living on the streets. He pimped women and was a dirty guy and a crook. James says God helped him find Narcotics Anonymous (NA) and he has been clean for about six years. He now wants to be a family guy and a respectable guy. He has a wife who is in prison who is also HIV positive but they are no longer together. His sister opened his mail and found out he was HIV positive, which he was not happy about. HIV doesn't seem to impact his life too much because he has other health problem from his drug use (e.g., COPD, Hepatitis C). However, he mostly experiences disruptions when it comes to his "sex life" and dating women. He doesn't feel comfortable telling others that he has HIV and only dates women who have HIV. It was unclear if he dates women with HIV so that he doesn't have to disclose the fact that he has HIV or so that he doesn't have to deal with the rejection. He states how he will play games with women who are not HIV positive to avoid being intimate and as a result thinks these women will think he is gay. James avoids being intimate with women who are not HIV positive because he doesn't feel comfortable disclosing his status. Being HIV positive limits his ability to date women and he described how he has not been having much luck finding love with the HIV positive women he's met so far. James describes how finding love and getting married again is important to him because he is

lonely and old now. He is actively looking for a girlfriend at NA meetings and online HIV dating sites. (James Dissertation Interview 2009, Age 54, HIV+ 24 years)

Melvin

Melvin did not have HIV narratives to analyze, so other sections of his interviews were needed to learn how his life may have been disrupted by HIV. He had a closed head injury from being hit by a car while walking home from work and remembers very little about his life prior to the accident. He found out about his HIV status after he came out of a medically induced coma following his accident. He was in the military and was a master mechanic but doesn't know much about the "type" of person he was. He comes from a very religious family but wasn't very religious until after his accident. He studied and taught the Bible, and his spirituality had become an important part of his recovery and identity since his accident. He didn't know how he got HIV and still struggled with learning about what kind of person he was. He had had a long-term intimate relationship with a woman whom he calls his wife. It was unclear to me to what extent they were sexual. He talked about the importance of love and how even though his girlfriend was like a wife there were things she didn't even know about him (e.g., alluding to that he might not have told her about his HIV status). He stated that there were some things that you don't even tell people you are close to and there are different degrees of relationships. He described himself as not being very open with others and how he always kept a wall up when around others. He tried to help others in his religious role as a minister but did not reveal his HIV status. Melvin died about two years after our interview (Melvin Dissertation Interview 2009, Age 59, HIV+ 6 years)

Wally

Wally prides himself on how he used to be with a lot of women (e.g., "that was his thing"). HIV has changed him. Since becoming HIV positive he doesn't have as many girlfriends as he used to have and he doesn't feel comfortable revealing his status. Some women he has told, while others he hasn't told. He is focusing on trying to be honest with women from this point forward. He is currently in a relationship with a woman whom he did not tell his status at first but she found out from other people. She has accepted him. He used to go to therapy sessions but felt like it was mostly gay men who were there so he stopped going. He didn't get HIV from gay sex and emphasizes that he is not gay. He says that he is more wise and cautious now that he has HIV and doesn't live the carefree life he used to live. He's a better father and more compassionate about others. He still struggles with alcohol abuse and has sought treatment in the past. He wants to get married again. He misses the "skin to skin" feeling of having sex without a condom but realizes that he must always use condoms now. (Wally Dissertation Interview 2009, Age 51, HIV+ 12 years)

Gerard

Gerard works full time as an accountant and is heavily burdened with caring for his elderly mother who lives below him. His father is deceased and he is not close with his siblings. He lives with his long-term partner who is also HIV positive. His life hasn't

changed much since being HIV positive except for being more concerned about his health and having more doctor appointments and having to take medications. He talks about how he would have difficulty if he had to go back on the dating market since being HIV positive and older since the gay culture is very youth-oriented. He believes he probably stays in his current relationship out of convenience even though it is not ideal or fulfilling. (Gerard Dissertation Interview 2009, Age 56, HIV+ 8 years)

Patrice

HIV has resulted in health problems and the inability to work, so her doctor put her on disability. She works side jobs, sometimes cooking for older people and caring for her grandchildren. Patrice emphasizes how she is a “moral” person. She says she wasn’t a “whorish” person and didn’t sleep around. She did have unprotected sex, but it was with the same person (her common law husband of 15 years). She didn’t think she would have to use a condom with your husband. She was very angry with him for putting her body and health in jeopardy. He died in 2007. She is a former crack user but specifically stated how she never had sex for drugs. She emphasized that she had a “high character” even when she was using drugs. She currently has a boyfriend who is not HIV positive. It was very difficult for her to tell him but he accepted her. Prior to this relationship she used to feel like a leper because she was lonely and thought she would always be alone because of her HIV status. She stated that God has found her a companion and she is feeling better now about living with HIV. Her children and siblings know of her HIV status. She had a negative experience with an aunt who was afraid to kiss her because of her HIV status. This experience had been very upsetting. She shares her testimony at church but doesn’t talk about HIV and doesn’t want to be an HIV spokesperson. She used to go to support groups but doesn’t go anymore because there was too much drama, jealousy and gossip. (Patrice Dissertation Interview 2009, Age 51, HIV+ 8 years)

Donald

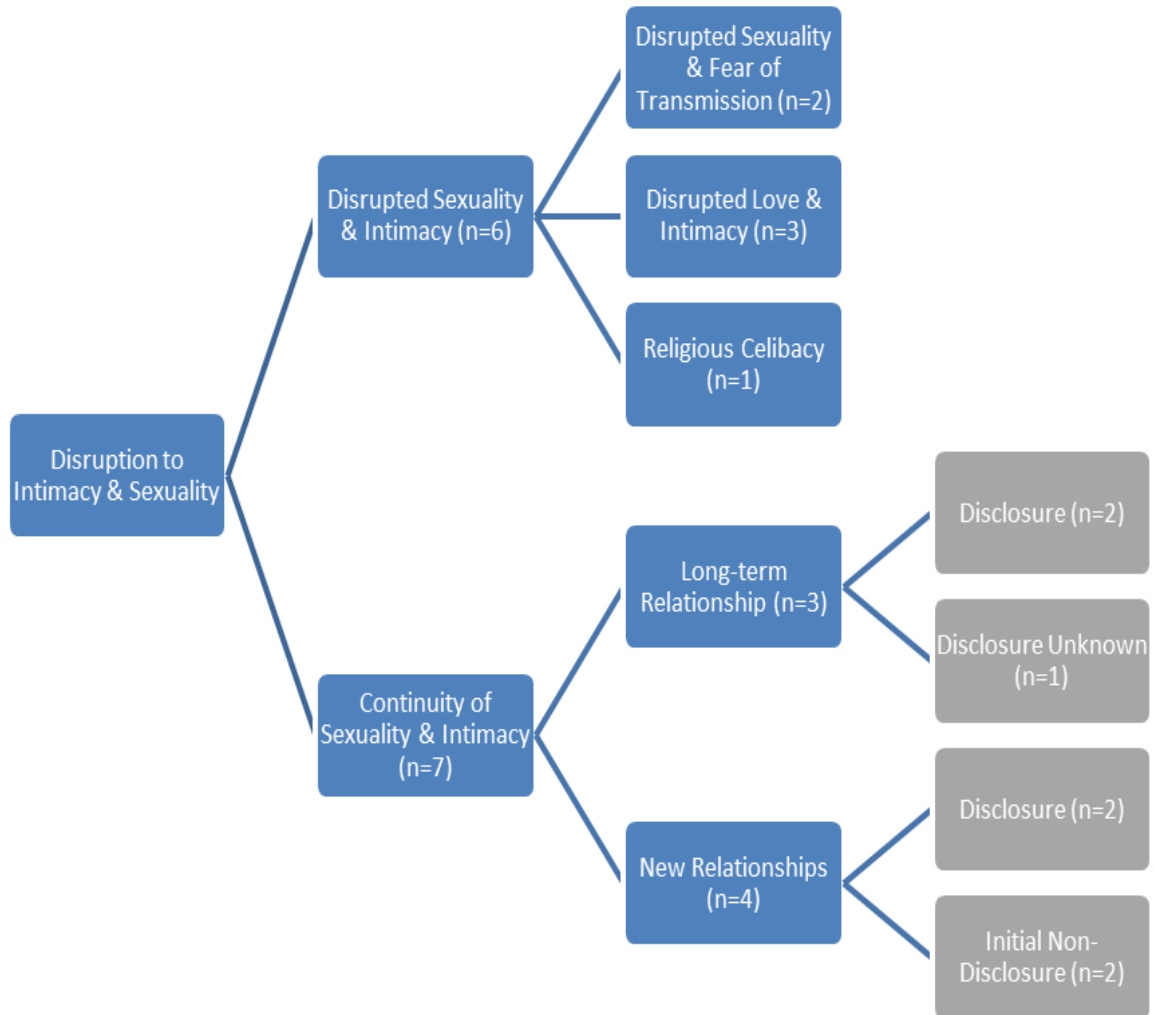
Donald was shocked and depressed when he first found out he was HIV positive but then learned that people could live a long life with HIV. His diabetes is more of a disruption than HIV. HIV hasn’t impacted his life too much but he is more careful about sex now and is more selective. He is a retired psychologist and is now in the “winding down” phase of his life since he’s already accomplished the main goals of his life (e.g., college, becoming a psychologist). During our interview, Donald was quiet and somewhat guarded. He called me after our interview because he was thinking a lot about what we talked about. He said he was going to write me a letter with more information but never did. Donald also discussed how HIV did not really impact his life because he’s already accomplished his life goals. He has only told his sister and his best friend, who is also his partner and who is not HIV positive. Other than that, he doesn’t do much socializing. He and his partner have changed their sexual habits and their sex life isn’t as “wild” as it was pre-HIV. (Donald Dissertation Interview 2009, Age 60, HIV+ 8 years)

Sheila

Sheila survived a gunshot wound to her head after trying to commit suicide prior to her HIV diagnosis. Her blindness is the result of her suicide attempt. HIV takes a second seat to her blindness and other health problems that resulted from her previous drug use. She is on disability and receives Meals On Wheels. Her husband didn't know she was HIV positive when they first started dating. (She whispered that to me during our interview and asked me to pretend that she was more recently diagnosed). She told him after they were together for about five years that she was diagnosed while they were married. She has asked the Lord for forgiveness. They'd had unprotected sex but he hadn't gotten HIV. She said she tried to use condoms but "sometimes you can't tell a man what to do". She believed she was one of the few people who could not transmit HIV since her husband hadn't become infected with the virus. She didn't start medications until later when her Viral Load and CD4 counts were "jumping" around. She had learned to accept and adapt to living with HIV. She used to be scared and hide her HIV but going to the doctor and seeing other people with HIV helped her deal with it better. She realized that there wasn't anything she could do to change HIV, so she "put it in the hands of the Lord". Her HIV was under control and she was down to one medication. She had other health problems, such as severe arthritis (e.g., can no longer braid her hair) and chronic pancreatitis, and relied on her husband for help with activities of daily living (ADLs). Her husband was her only confidant. She described herself as a homebody and didn't get close to others or have friendships "because it's dangerous". She had "associates but no friendships". She wasn't close with her family and discussed how she could love them from afar. She tried to go to support groups, but didn't feel like they were confidential and thought they were going to be gossip groups. She said that she was not sad or depressed and that she was happy. Sheila died about two months after our interview. (Sheila Dissertation Interview 2009, Age 53, HIV+ 10 years)

The case studies discussed above provide a brief synopsis of the participants and highlight some of the major ways HIV has disrupted their sexuality and intimacy with others and the ways some participants have established continuity of their sexual and intimate lives. The next section will focus on how people reorganized their lives in response to disruptions to intimacy and sexuality.

Figure 6. Disruption and Reorganization of Intimacy and Sexuality



CHAPTER 8 FINDINGS, PART 2: DISRUPTION AND REORGANIZATION OF INTIMACY AND SEXUALITY

There were two major patterns that emerged from the data based on disruptions to sexuality and intimacy: (1) disrupted sexuality and intimacy and (2) continuity of sexuality and intimacy. In the first pattern, participants stopped sexual relationships and avoided intimacy with others since being diagnosed with HIV. These participants described fear of rejection, transmission, and betrayal by former partners as some of the ways HIV had disrupted their sexuality and intimacy. In the second pattern, participants were engaging in sexual and intimate relationships post-HIV diagnosis. However, it is important to note that participants in pattern two may also have experienced some disruptions to sexuality and intimacy (e.g., modification of sexual behaviors or limited partner choices) but overall were continuing to engage in intimate and sexual relationships.

PATTERN ONE: DISRUPTED SEXUALITY AND INTIMACY (N=6)

Almost half (46 percent) of the participants who were interviewed were categorized as experiencing major disruptions to sexuality and intimacy. This pattern was characterized by the avoidance of sexual and intimate relationships with others. Within this pattern there were three additional ways of understanding the experience of disruption: (1) sexual activity and fear of transmission, (2) romantic love and intimacy, and (3) religious celibacy. Participants described the various disruptions and losses they experienced since diagnosis. Some participants underscored the disruptions experienced by reflecting on sexual and intimate aspects of their life or identity pre-HIV while describing a change in identity or behavior post-HIV (e.g., “not the same person I

used to be”). Some participants who experienced major disruptions to sexuality and intimacy also described wanting a companion or love, but did not feel capable of an intimate relationship since receiving an HIV diagnosis (e.g., rejection, betrayal, fear of transmission).

Disruption to sexual activity and fear of transmission (n=2)

The narratives of Alvin and Leonard emphasized disruption to sexual activity and intimacy and fear of transmission. At the time of the dissertation interview, Alvin, a 78-year-old male who has been living with HIV for six years, discussed the how his sex life had stopped like a “ship in the water”. In both the T1 and TD interviews, he described how he did not feel like the same person he used to be because he was no longer sexually active. Alvin had experienced an abrupt disruption to his sexuality and intimate relationships with others. He is extremely reluctant to disclose his HIV status and states that only his doctors and one friend know of his status.

I'm not the same person I used to be. I'll never be again the person I used to be. Because I'm determined that I won't pass this thing on to nobody. Um...I'm scared, I, I've shut down my sex factory. Of course, I don't know enough about this thing as to how to handle it. Um...what I have been counseled in...is you got to use condoms. But...you know, they use a condom...there's just about got to be some kind of foreplay. And how far do you go with foreplay. These things I'm not, I'm not comfortable with the foreplay. Um...I don't want nobody to [catch] nothing from me. I don't go around telling nobody that I got HIV. But I, I'm making damn sure that I don't pass it. Don't pass it on to nobody. So that's something that I'm proud of. It's something that I neglected to do, and that was to (laughs) cover all bases. And um...I can't go back and change it now. But I got, but I-, it's, it behooves me to not to pass it on to somebody else. I could...get out there and pass it on, but I wouldn't feel good about myself. So as I said that part of my life has been shut down. And I don't know how to handle it. Not yet. (Alvin HAART T1 2003, Age 72, Naive to HIV meds, HIV+ a few months)

Well, a great deal because. Things I used to do I don't do them no more. My ship just stalled in the water and I stopped it right there. It don't go no

farther than me. That's the way I look at it. I'm not gonna run out there and give it to somebody. I wouldn't wish it on my worst enemy. Because it's something that there is no cure out there for as of yet. But uh just some of the things I used to do as far as being sexually active I'm not anymore. I got memories. I can go back to my memories. (Laughs). Nah, I just stopped being sexually active. I know that there are ways to be, but uh it's a stigma, and um I just don't want to see no disdain in nobody's eyes. Tell them that I have it. I don't. I don't talk about it. I don't go out there telling people about that. My little secret. If I have to with doctors and what have you when they ask about I write it down. But I don't go out there and tell my friends and my neighbors and all that kind of stuff. Only one of my friends knows that. One. Just one. My family don't know. My secret. (Alvin Dissertation Interview 2009, Age 78, HIV+ 6 years)

Despite experiencing severe disruption to his sex life, Alvin talks about how he feels like he is doing the right thing because he has not transmitted the virus to anyone else. By avoiding having to tell others about his HIV status, Alvin can protect his identity and avoid being stigmatized.

Leonard

In 2009, Leonard discussed how he had lost confidence in himself and wouldn't want anyone to go through what he was going through. He experienced negative side effects such as HIV wasting syndrome that has influenced his self-esteem.

Uh, I have uh, I've lost, since I don't look the way I used to look. I've lost a lot of confidence in myself. I still get flirted with, I still get chased, wink wink. Uh, I still have people tell me I'm this and I'm that, but I'm thinking, What are you looking at? You know. Or like, Really? Or, You just being nice or you know so. I think of myself less than I really am. If I wanted to be in a relationship, I could be in one so easily. Um, it's by choice. I won't bring anybody in to this. No. (Leonard Dissertation Interview 2009, Age 56, HIV+ 9 years)

Leonard emphasized how, since experiencing many negative effects of living with HIV, he does not feel that he can offer much in a relationship and would not want someone else to go through a similar experience.

Both Alvin and Leonard emphasized not wanting to give the virus to another person because they do not want to risk causing someone else hardship. Alvin is extremely secretive about his HIV and avoids telling others. Leonard described how he could be sexually active but no longer felt confident because he could not offer anything in a relationship, had poor body image and was living off of disability. Alvin described himself as “being little” but strong because he goes to the gym regularly. Alvin did not emphasize low self-esteem in the way that Leonard did. The difference between Alvin and Leonard in regard to self-esteem might be due to life course phases. Alvin is much older than Leonard and is quite resilient and physically strong at age 78 and life course phase. While Leonard is in his fifties, he might be feeling more “off time” because of the body wasting that he experiences. Overall, both participants’ focused on disruption to sexual behavior and fear of transmission and did not focus as much on the intimate aspects of sexual relationships that are emphasized by the next group of participants.

Disruption to love and intimacy (n=3)

The following participants were no longer sexually active like Alvin and Leonard. However, Willie, Mildred, and Marion focused on the disruptions to and desire for affection, love, and companionship. These participants also emphasized that they were avoiding intimate and sexual relationships because of previous betrayals or potential stigma and rejection upon people learning of their HIV status.

Willie

In the dissertation interview in 2009 with Willie, he said that he felt conflicted between wanting love and affection but avoided intimate and sexual relationships.

Willie felt devastated, betrayed and abandoned shortly after he learned that his partner infected him.

How I contracted [HIV]. It was horrible because the person I got it from. I knew something was funny because when I came home everything was gone out of the house and I didn't even know what was going on and they knew. So I was devastated about that and been like that ever since. That's why I don't trust nobody. (Willie Dissertation Interview 2009, Age 53, HIV+ 18 years)

Willie focused on how he was missing out on the important life course expectations of intimacy, love and affection.

I've always been ashamed of who I really am and how I feel because I felt as though that's the wrong thing and I've been told all my life I'm going to hell and all these negative things. But I know deep down inside I know how I am as a person. I need, you know, affection and love like everyone else. (Willie Dissertation Interview 2009, Age 53, HIV+ 18 years)

At a later point in the interview, Willie emphasized love and affection rather than sex. He also discussed how he could fulfill some of his sexual desires through masturbation.

You're not as bad as I thought [HIV], but it can be, but you don't get as close to people, you don't, they say it's okay to have sex as long as you have cover-up sex. That's for those who like sex, the word "sex". Sex is okay, but I think intimacy and love is more because you carry that with you all the time. My opinion: To each his own. But I'm afraid to get close like that anymore. I'd just rather not. I'd just rather be just friends. If I want to get that type of sex thing ... double-A batteries. Okay. Can't deal with D batteries...Because of the HIV, you cannot have sex when you have HIV. I mean you can have protected sex, but sex ain't nothing to me. It's about, if someone love you and care about you and make you feel good, that to me is love. I can have sex by myself. I can have sex by myself. It ain't about that. (Willie Dissertation Interview 2009, Age 53, HIV+ 18 years)

Willie's avoidance of intimate relationships is in part due to lifelong rejection and isolation he experienced because of being gay and the devastation and betrayal he experienced from his ex-partner.

Mildred

Mildred talked about how overall she is learning to live with HIV, but that her intimate relationships are affected by HIV. She fears that she will be rejected if she discloses her status to a man and at the same time described how she misses being in an intimate relationship.

Ah, no more than being close to someone. I have not since then, for the past years, I have not (had a relationship), I just feel like I don't want to be bothered. I mean I want someone to love me but I mean still you can tell, once you tell it's gonna make them just go away from you, they're not open minded. So I don't, I don't let no one get that close. (Mildred Dissertation Interview 2009, Age 56, HIV+ 7 years)

Marion

Marion talked about how she avoids sexual relationships with men because of trust issues.

It has impacted my life as far as trust with men. I'll speak and talk and hold a conversation, but as far as sex goes, even with a condom, I don't really want to be bothered. (Marion Dissertation Interview 2009, Age 62, HIV+ 10 years)

Later in the interview she discussed feeling conflicted between avoiding relationships but also wanting intimacy and companionship:

I don't be bothered with it. Are you talking about me? I get angry about it a lot because I'm not having sexual relationships. I had a couple of guys who were talking to me but I let them know right then and there. Like I would tell them you don't have to pretend like you like me because you know I have HIV. If you stop calling me fine if you call me fine. I don't want nobody feeling sorry for me, because I don't feel sorry for me. What's gonna happen is gonna happen. If you like me you like me for myself, not for sex, you know. I miss the companionship, like going out with a man, like eating or something like that, but I learned to deal with it, you know. So, damned if I do, damned if I don't. I really don't care. (Marion Dissertation Interview 2009, Age 62, HIV+ 10 years)

Marion's avoidance of relationships ties in with the stress of having to tell someone and having to deal with potential rejection. Despite her decision to avoid relationships, she also described how she was missing out on intimacy and companionship.

Willie, Mildred and Marion highlighted the additional dimensions of how sexuality and intimacy are disrupted for people who are HIV positive. Their narratives focused less on physical acts of sex and more on the intimate aspects of sexual relationships, such as affection, love, and companionship that they've missed since being diagnosed with HIV.

Religious celibacy (n=1)

Loretta

Lastly, Loretta discussed how she avoids relationships with men and focuses on studying the Bible.

No, no. I don't deal with that now. That's too much of a headache. You have to be arguing with a man. I can't be arguing. They say, "Where you going?" That's not your business. I'm grown. So you stay in your house and I'll stay in mine and the rest will be all right. Mm-hm ... I basically study my Bible, and that keeps me kind of level-headed. I don't have to be bothered like that. I just don't want to be involved. Because mine is for religious purposes. (Loretta Dissertation Interview 2009, Age 66, HIV+ 8 years)

Loretta experienced disruption to sexuality and intimacy but focused on a new purpose of religious celibacy since receiving an HIV diagnosis. While she emphasized the religious aspects of her celibacy, she also alluded to the stress that might be involved with having a relationship with a man (e.g., "too much of a headache").

All of the participants from pattern one "disruption to sexuality and intimacy" had become celibate since being diagnosed with HIV. While the participants described reasons for avoiding relationships (e.g., fear of transmission, betrayal of former partner,

religious purposes), I wonder to what extent these participants felt their celibacy was involuntarily due to the stigma associated with revealing their HIV status.

PATTERN 2: CONTINUITY OF SEXUALITY AND INTIMACY (N=7)

Continuity of sexuality and intimacy was the second major pattern in how people described their response to an HIV diagnosis. The participants (N=7) within this pattern were engaging in intimate and sexual relationships with others since being diagnosed with HIV. Among the participants who were engaging in relationships some remained in the same relationships and others were in new relationships since receiving an HIV diagnosis. It is important to note that while this pattern is characterized by continuity, the participants may also experience some types of disruptions (e.g., modification of sexual practices, fewer partners to choose from, and difficulty disclosing status).

Continuity of Long-term Relationships (n=3)

Donald, Gerard, and Melvin were three out of the seven participants within the continuity pattern who remained in a relationship with a long-term partner that they had at the time of their HIV diagnosis. Among this group there were two disclosure patterns: disclosure to partner and disclosure unknown.

Disclosure to Partner (n=2)

Donald and Gerard disclosed their status to their partners. Donald seems to be content in his relationship and HIV has not been a major disruption to his sexuality or intimacy. However, he did mention that since his HIV diagnosis he has modified his practices with his non HIV positive partner.

Well there's only one person, but um, yes, it's changed the way we do some things, but it hasn't been a major obstacle. But before being diagnosed, maybe we were a little (laughs) wilder. (Laughs) But we did.

But now it changes it a little bit, but uh.. It's kind of insignificant. (Donald Dissertation Interview 2009, Age 60, HIV+ 8 years)

Gerard experienced continuity of sexuality and intimacy because he remained in a long-term relationship with his partner who is also HIV positive. However, Gerard also explained how HIV would negatively impact his life if he had to re-enter the dating scene. He also insinuated how he is perhaps settling by staying in this unhappy and less than ideal relationship.

I think about if, you know, if the relationship were to end, if I had to re-enter the dating scene, how that would be a real burden. Aside from my age I've got this health thing that limits the number of people that would find me as someone that they would want to date...Because you'd have to discuss it with strangers, that would be very uncomfortable for me to meet someone and start dating and then have to sit down and reveal your health statistics.

I think that's one reason why I stick in it because it's not ideal. Even just like, just my age limits, I'm sure you're familiar with your studies how we're in a very youth-oriented culture...if I weren't in a relationship, sure. But it's like uh both of us are positive, so. And to my knowledge it's a monogamous relationship, so. (Gerard Dissertation Interview 2009, Age 56, HIV+ 8 years)

Disclosure Unknown (n=1)

Melvin had been in a relationship with the same woman for about twenty years. He referred to her as "the closest thing to ... a wife". They both had children from previous relationships. Even though Melvin was in an intimate relationship, it was unclear if his "wife" knew of his HIV status and to what extent they were sexually active.

There are certain things I won't even tell her. Cause she's the closest thing to me. Close, almost a wife...You don't put your loved one in that kind of position. If you have any care about that, even to the stage of you would know what they would say, would you take that chance? I wouldn't. That's the reason why. You just stop altogether. Or you use protection. The only way that you can, that if you care to be comfortable with your own personal self - you just stop. At least that's the way I take care of mine. At least was how I take care of it. So I'd have peace of mind.

You're put in a whole bunch of situations that it comes to just that. That I have to say sorry Denise not this time. (Melvin Dissertation Interview 2009, Age 59, HIV+ 6 years)

Melvin's "wife" accompanied him to his interview, but she was unaware of what the interview was about. Melvin described himself as not being intimate with people in general as a survival tactic. Even though he was in a close relationship with a woman, there were some things that she didn't know about him.

The narratives of Donald, Gerard and Melvin provide insight into how some people with HIV experience continuity of long-term relationships. Donald and Gerard disclosed their status to their partners, but it was unclear if Melvin disclosed his status to his partner.

Continuity and New Relationships (N=4)

At the time of their dissertation interviews, four out of the seven participants in the continuity group described being in new relationships since receiving an HIV diagnosis. Despite experiencing continuity, these participants also experienced some disruptions since finding out their HIV status. Among this group of participants some people chose to inform their partner about their HIV status while others chose to avoid or delay disclosing their status to their partner.

Disclosure to Partner (n=2)

Patrice said that she does not want to transmit the virus to anyone and is careful about using condoms with her current boyfriend (e.g., even referencing to using two condoms). Patrice was angry when she found out that her former common law husband had infected her. She emphasized that she would not want to do that to

someone else. She described how she was afraid to tell her boyfriend at first, but later she disclosed her status to him and he accepted her.

I'm not a "germer". You know what I'm saying. I don't want to give it to no one. Because no one deserves this. So I'm extra careful...So when I do, I do have a male friend. I know you're gonna get down to that. (Laughs). I know, I know that's gonna be in the interview because y'all do get personal in the interview. Like I said the one did pass that I had for 15 years. Now I have someone else. But as far as he's really..We use condoms and try to be extra [careful], like I said he knows, he accepted, but it was hard to tell him that I was not, you know, I didn't want to. I thought I was gonna live life by myself, but God seemed fit to send me a companion. Which I wouldn't be lonely in the world, because I was concerned about being lonely in the world. Right? Cause the other one had, we had, we had it and I had it so we could deal with it better then that way. But when you have one that don't have it and one that do have it. And it was hard to even tell him about. To start up a relationship where he's not HIV+ and I am. Well that's some real, that's the real dinger dating. Then he wants to be you know sexually active and it was the hardest thing. He thought I was all, he thought I didn't like him. He thought he was a turn off but I was scared to tell him and I didn't want to tell him. I could have laid down and had sex with him but I didn't do that. (Patrice Dissertation Interview 2009, Age 51, HIV+ 8 years)

Even though Patrice is in a relationship, she discussed how difficult it was to disclose her status in order to be in a sexually intimate relationship.

James discussed his experience seeking HIV positive women to date since becoming drug-free. Prior to being drug-free, James did not worry about disclosing his status to women or using protection. James prefers to date women with HIV because he does not feel comfortable disclosing his status to non-HIV positive women.

You know when I meet women who don't know I have the virus, right, and so really if I tried to go in there, like, have sex with them without telling them, then I feel bad, you know. So that's why I try to date women who have the virus. 'Cause I can talk to them about it. 'Cause really I'm not a bad-looking guy. I can, I get women sometimes that don't have the virus. But I shy. They might think I'm gay or something, but I play past the sex thing because I don't want to have to tell them, you know. Even though I can put on a condom, right, but you're still supposed to tell them, right. (James Dissertation Interview 2009, Age 54, HIV+ 24 years)

Even though James experienced continuity by dating and engaging in sexual relationships with women who were HIV positive, he also experienced disruptions because only dating women with HIV limited his options. He described how he recently met a woman online whom he connected with, but when he met her in person she wasn't attractive.

The ones I've met that have HIV, most of them, I don't want them. A friend that's cool to talk to. So my friends say, "Oh, you're trying, your standards are too high." But I just want someone nice to look at for a change...I met me some real scruffies, I don't mean to talk about them, but they just wasn't for me. And it's depressing. (Laughs) I had this lady come all the way from Minnesota. I talked to her online then I started talking to her on the phone. She sent me a picture. In the picture she didn't look that bad, you know. So kept talking to her. Then she drove here from there. Oh, talk about depressing. That was one depressing day. 'Cause my hopes was up so high. And then when she got here I said, "Oh, bummer," you know. (James Dissertation Interview 2009, Age 54, HIV+ 24 years)

James has addressed some of the disruptions to sexuality and intimacy by focusing on dating women with HIV. However, he has been struggling with finding a suitable partner that is HIV positive. After living most of his life on the streets and using heroin, James was now drug-free and interested in finding a partner because, as he says, he is "old and lonely".

Patrice and James provide examples of people who have pursued dating despite being HIV positive. Both talk about the difficulties in having to disclose their HIV status to partners. Patrice is dating someone who is not HIV positive, but James specifically chooses to date women with HIV to help avoid the stigma of having to disclose his status.

Initial Non-Disclosure to Partner (n=2)

Sheila and Wally were in relationships at the time of the dissertation interviews. Both described how they did not disclose their status to their partners until after they were already intimate with them. Sheila discussed how her husband did not know that she was HIV positive when they first met. She told him about her HIV status after they had been together for about five years. Her husband thought that she tested positive after they had already been together.

This is the part I talked to Rico [the former interviewer] that my husband don't know about. Okay, it was like in '87 or '88. I went into the hospital because I had endocarditis and they did some tests and that's when I found out I was HIV [positive]. I got with my husband in '95 but didn't tell him at that time. He found out in 2001 or 2000 something like that. I shouldn't have done it. I've asked for forgiveness for it. The Lord has forgiven me because he don't have anything. (Sheila Dissertation Interview 2009, Age 53, HIV+ 10 years)

Wally described how his girlfriend found out about his HIV status from someone else. After she confronted him about the rumor, he revealed his status to her and she accepted him. He emphasized that he practices safe sex in his relationship.

W: Just watching my [behavior], you know when I engage in sex. But I got me a steady partner now and she knows. Mm-hm. She know. We always practice safe sex.

AN: How was that when you told her?

W: Oh, yeah. She's okay with it. She okay. Yeah. Matter of fact, she had helped me a lot, you know. Yeah, she did help me because she had found out from somebody else. I didn't tell her personally. Um, when she had found out she said, "Wally, you know, you can just tell me. You know, I... I'll be just right there." I fell for her right there. You know, I didn't have no problem. It's been good ever since. And she don't see me no different. You know some people still got the stigma. You know. But you know I don't even pay them type of people no attention. (Wally Dissertation Interview 2009, Age 51, HIV+ 12 years)

The narratives from Sheila and Wally illustrate the importance of engaging in intimate and sexual relationships as an important life course expectation. However, their narratives also illustrate that some people may engage in sexual and intimate relationships and postpone or avoid disclosing their status with new partners.

In summary, there were two major patterns of dealing with sexuality and intimacy after an HIV diagnosis: (1) disrupted sexuality and intimacy and (2) continuity of sexuality and intimacy. A broader discussion of these findings will be described in the next section.

DISCUSSION: MAKING SENSE OF DISRUPTIONS AND CONTINUITY OF SEXUALITY AND INTIMACY WHILE LIVING WITH HIV

This chapter explores the nature of sexuality and intimacy as a major topic and area of concern throughout the interviews with the research participants. The literature review provided in this chapter underscores (1) the ways different disciplines approach understanding sexuality and intimacy and (2) the importance of intimacy and sexuality to life course expectations, human development, and psychosocial wellbeing. The literature review was used to provide a framework for making sense of the findings from the interviews that describe how people reorganize their lives in response to HIV disruptions to sexuality and intimacy. Exploring disruption and continuity of older adults' sexuality and intimacy provides important insight into understanding the experiences of those who are aging with HIV, as well as the general importance of intimacy and sexuality to older adults.

The case studies of each participant provided a brief overview of the various and more personal ways that intimacy and sexuality were important dimensions to an individual's life story. The identification of disruption and continuity patterns of sexuality

and intimacy provided insight into the variation in experiences of living with HIV. The participants reorganized their lives in response to an HIV diagnosis in two major patterns: (1) major disruption of sexuality and intimacy and (2) continuity of sexuality and intimacy. It is important to note while the categories emphasize opposite ends of the spectrum, they are not necessarily mutually exclusive of each other.

The Celibacy Dilemma

Six out of thirteen participants provided evidence for the pattern experiencing major disruption to intimate and sexual relationships after receiving an HIV diagnosis. Experiences of disruption were characterized by the avoidance of sexual and intimate relationships and silence about HIV. These participants experienced the dilemma between becoming celibate to avoid HIV stigma and also experiencing desires for sexual and intimate relationships as an important aspect of their life course expectations. The types of disruptions and losses the participants experienced included physical (e.g., sexual activity), emotional (e.g., anger, trust, love) and social (e.g., companionship, dating) dimensions. Despite what is known about the importance of sexuality and intimacy in the life course, how do we make sense of why about half of the participants avoided sexual and intimate relationships?

The stigma from HIV is highly disruptive to sexuality and intimacy and has a profound impact on the lives of older people who are living with HIV. Perhaps the participants who avoided relationships after an HIV diagnosis opted for celibacy as an attempt to resist the politics and stigma of living with HIV and maintain a sense of power. By becoming celibate, participants could work towards creating a sense of continuity of their identity (e.g., appear as “normal” to others by avoiding disclosure and

relationships with other people). People who experienced disruption to sexuality and intimacy emphasized the importance of not sharing their status with others (e.g., “my little secret”). By not engaging in sexually intimate relationships, these participants were able to resist having to deal with some of the stigma associated with HIV. People who avoid relationships with others are not necessarily avoiding because they no longer desire sexual and intimate relationships but rather to protect their status and sense of self.

One way of thinking about disruptions to sexuality and intimacy is to explore the relationship between power, politics, resistance and the practice of celibacy post-HIV diagnosis. To what extent is post-HIV celibacy an active choice or a consequence of HIV stigma? How does celibacy reveal information about the power dynamics and politics of HIV? While this group of participants experienced disruption to sexuality and intimacy, one may argue that they may have continuity in some ways. By not having sexual or intimate relations with others they remain in power because they control how others perceive them and present themselves as not having HIV to others. A possible motivation for avoiding intimate and sexual relations is to resist HIV stigma and to establish continuity in light of having HIV. Becker (1997:17) in *Disrupted Lives* describes how resistance and politics are often illustrated in the narratives people share. Becker notes that people show “resistance to the status quo by emphasizing statements such as this is who I am or I am not (Becker 1997:17).” How people respond to disruptions to sexuality and intimacy might reflect forms of resistance. People who become celibate after an HIV diagnosis might be using celibacy as a way of resisting HIV stigma imposed by others.

Celibacy and silence about HIV may also be perceived as a way of masking the disruptions people experience or creating an illusion of continuity to others and themselves. Celibacy for these participants may be a form of regaining a sense of power after an HIV diagnosis. By avoiding sexual and intimate relationships, these participants were also able to avoid having to disclose their status to others and resolve the potential problem of having to deal with the possible stigma or rejection that others impose on them.

Another way of thinking about the participants who avoid intimacy and sexual relationships after an HIV diagnosis is to think about involuntary celibacy. Involuntary celibacy may be a consequence of the politics and fears associated with HIV. Participants described feeling fearful of transmitting the virus to others, powerless when they were infected by a former partner, and/or were concerned about how others would respond to them if they disclosed their status.

Are Disruptions to Sexuality and Intimacy Part of the Normal Aging Process?

Are disruptions to sexuality and intimacy part of the challenges and rites of passage of growing older? Cultural beliefs about the asexuality of older adults might lead us to believe that disruptions and losses to sexuality and intimacy are part of a normal process of aging. I argue instead that “normal” aging does not necessarily coincide with disruptions and losses to sexuality/intimacy and that the experience of disruptions to sexuality and intimacy while living with HIV/AIDS presents a profound loss and type of disruption. Loss of sexual functioning and fewer choices for available partners might be expected as people age. The disruptions caused by HIV are not necessarily related to loss of sexual functioning or part of the normal aging process.

The celibate participants experienced profound disruption to sexuality and intimacy. It is important to note that these participants did not discuss how becoming celibate was part of a natural process of winding down with age or part of the normative process of aging. The absence of talk about celibacy as a normative part of the aging process further highlights the extreme loss and disruption experienced by these participants and the importance of sexuality and intimacy throughout the life course. These findings on the importance of intimacy and sexuality in later life with HIV are confirmed by other research stating that desires for intimacy and sexuality do not necessarily decline with age (Morgan and Kunkel 2007). Another important point to note is that people may have relationships that are celibate but intimate; however the participants often avoided intimacy as well. The avoidance of intimate and sexual relationships due to fear of rejection or stigma from HIV might have negative physiological, psychological and developmental consequences for people living with HIV.

Illusion of Continuity

Seven out of thirteen participants provided evidence for continuity by engaging in sexual and intimate relations with others. In analyzing for engagement in sexual and intimate relationships, some of the participants were in long-term partnerships and others were in new partnerships since being diagnosed with HIV. These participants were engaging in sexually intimate relationships, but the ways in which the relationships were negotiated or managed differed (e.g., long-term partners, new partners, disclosure, non-disclosure). Are these participants illustrating resistance to the stigma and politics of HIV by engaging in relationships, or were intimate and sexual

relationships such a high priority for these participants that they were willing to reveal their HIV status?

In Becker's framework of life disruption she concludes that "continuity is an illusion because life is made up of various disruptions" (Becker 1997:190-191). Despite the presence of continuity of sexual and intimate relationships, these participants also experienced some forms of disruption (e.g., delayed disclosure, modification of behaviors, fewer partners, locked in unhappy relationships, missing out in skin/touch feelings). For these individuals, an HIV positive status had negatively influenced their sexual and intimate relationships in various ways. This was apparent from statements made by some of the individuals interviewed regarding the difficulty of disclosing (e.g., fear of rejection, delaying, avoiding), while others remained in less-than-ideal, long-term partnerships to avoid having to enter the dating scene.

The disclosure patterns of people who are living with HIV have important public health implications. As noted in the findings, 54 percent of the participants were engaging in sexually intimate relationships or partnerships. Two out of the seven participants who were engaging in relationships delayed disclosure until the relationship was already established (e.g., married for five years). For one participant, it was unclear if whether or not he disclosed his status to his "wife". Another participant was currently dating women with HIV but revealed he engaged in sexual activity in the past without disclosing his HIV positive status. Over half of the participants who were engaging in relationships had delayed disclosure or avoided disclosure with partners. These findings have implications beyond the individual wellbeing of the participants and provide insight into challenges to secondary transmission prevention in this population.

The desire for sexual and intimate relationships is an important life course expectation, but the diagnosis of HIV may make it extremely difficult for people to reveal their status when engaging in relationships. These participants may also be experiencing the dilemma of engaging in intimate and sexual relationships but have difficulty disclosing their HIV status to their partners.

To understand the experience of intimacy and sexuality among older African Americans who are aging with HIV, one must recognize the pros and cons of avoiding and engaging. Do participants who avoid relationships maintain a sense of power by not having to reveal their status to others or are they succumbing to the political and stigmatizing nature of living with HIV? Do participants who engage in relationships become vulnerable to rejection, stigma, and loss of power, or are they illustrating resistance to the power and politics of HIV stigma? Are disruption and continuity illusory of each other? Did the first group experience disruption to intimacy and sexuality but experience continuity by appearing as not having HIV through celibacy and silence? What can be surmised from the second group of participants who experienced general continuity of intimacy and sexuality while also experiencing disruptions through difficulty disclosing and choice of potential partners? Both situations bring about unique challenges. The experiences of disruption and continuity of sexuality and intimacy underscore a dialectical relationship as was discussed in the previous chapter on normalcy and disruption. Even though there were two different patterns of responses to sexuality and intimacy after an HIV diagnosis both patterns underscored the overall importance of intimacy and sexuality as important life course expectation for people who

are living with HIV. The remaining chapter from this dissertation will provide a discussion.

SECTION IV

DISCUSSION

This dissertation consisted of four major sections. Section I provided a discussion of the background and significance related to aging with HIV. Section II described the design, methods, and research site utilized for this dissertation research. Section III explained the analysis and major findings resulting from the dissertation research. Section IV, Chapter 9 will provide a concluding discussion for this dissertation on a life course approach to understanding the experiences of living with HIV among older African Americans in Detroit. Chapter 9 is divided into five major parts: 1) Overview, 2) African American HIV Narrative, 3) Implications and Recommendations, 4) Limitations, and 5) Future Directions.

CHAPTER 9

DISCUSSION

LIVING WITH HIV IS LIKE:

“READING A BOOK, YOU TURN A PAGE AND YOU ARE INTO A NEW CHAPTER”

During our interview Alvin told me that living with HIV is like “reading a book, you turn a page and you are into a new chapter.” The new chapter of a book symbolized a new chapter in his life and underscored the individual process of figuring out how to live a life with HIV. For Alvin, the new chapter in life was based on creating a sense of normalcy by keeping his HIV status a secret from others and by avoiding situations, such as sexual and intimate relations with others, where he would have to reveal his status. This dissertation research embarked on journey to explore and understand the long-term experiences of thirteen older African Americans and their perceptions of aging with HIV in Detroit. The main goal was to identify to what extent HIV impacted their life course expectations and the ways in which they reorganized their lives in response to the disruptions they experienced. The first specific aim was to identify and describe how older adults reorganized their lives in response to an HIV diagnosis. This aim was addressed throughout all three of the findings chapters 6-8. The second aim was to identify and describe how HIV disrupted and posed challenges to a person’s ability to achieve life stage specific goals. This aim was addressed in chapter 8 on disruptions to sexuality. The third aim was to understand how the timing of an HIV diagnosis (e.g. diagnosis cohort, life stage, and duration) might influence life course events and expectations. This aim was addressed in Chapters 6 and 8. The fourth aim was to

describe the ethnographic setting of living with HIV among older HIV-positive African Americans in Detroit. This aim was addressed primarily in chapters 4-5. The purpose of this chapter is to provide a discussion of some of the major dimensions of this dissertation research and help address some of the major questions posed by others during the dissertation defense.

Temporal Dimensions and Cohort Factors to Understanding HIV Experience

As discussed throughout the dissertation, a goal of this research was to try to understand the process of living with HIV by exploring how the various timing of living with HIV might influence experience or interpretation of living with HIV. When I first planned this dissertation research I anticipated that different temporal dimensions and cohort factors might also influence the experiences of living with HIV. The temporal dimensions included for example duration of living with HIV or taking HIV medications and the analysis of earlier and later points of living with HIV. The cohort factors that I considered included HIV diagnosis cohort, HIV medication cohort, and life course stage at diagnosis. I was interested in exploring how these temporal dimensions and cohort factors might help contextualize the experiences of living with HIV. Contrary to what I expected, I did not identify that the temporal dimensions or cohort factors were a significant factor in influencing experience of HIV disruption or reorganization (See table 3). People who were newly diagnosed, naïve to medications, or diagnosed during an earlier era of HIV medications (e.g., AZT) did not necessarily experience more disruptions than those who had been living with HIV or taking medications for a longer period of time, or diagnosed during the HAART era. I also did not find differences among life stage at diagnosis (older or younger adult) in how HIV experience was

interpreted. In the case of this dissertation research temporal dimensions and cohort factors seemed counterintuitive to what one might expect. Perhaps these findings were due to a sampling problem of not having a large enough people to adequately represent each group of cohorts or temporal dimensions. Or perhaps that cohort factors and temporal dimensions provide contextual details of a person's experience of living with HIV but do not predict how a person will interpret or experience living with HIV.

Applying Becker's Framework to Understand HIV Experience

As a result of the analysis of HIV narratives from the HAART project entrance interviews and the dissertation interviews there were different patterns of how people interpreted their HIV diagnosis and the extent to which they experienced disruptions over time while living with HIV. The analysis of both earlier and later time points revealed how the majority of people provided evidence for Becker's framework by transitioning into the ability to reorganize life after disruptions from HIV. One example includes how some people described experiencing major disruption at the T1 but later provided evidence for reorganization at the T2 despite experiencing ongoing disruptions. A second example includes how some people described experiencing consistent disruptions from living with HIV but also provided evidence for consistent and ongoing reorganization as well. These patterns that support Becker's framework underscore the idea that people often draw from core cultural values of continuity and order in how they respond to change and life disruption such as HIV.

The analysis of the data also revealed how some participants emphasized patterns that did not support Becker's framework of life disruption, including (1) consistent continuity, (2) consistent disruption, and (3) early continuity changing to

disruption and reorganization. By analyzing and comparing the baseline interviews and the dissertation interviews, I was able to take a look at the temporal dimensions of how people make sense of and process their experiences at different points in time. The analysis provided information on additional responses to change and disruption than what was provided in Becker's life disruption framework. Some people did not experience major disruptions as one might expect after receiving an HIV diagnosis. In the case of James, he did not experience disruption until much later in his experience of living with HIV. Lastly, in the case of Leonard he described his entire and ongoing experience of living with HIV as a major disruption. These patterns that conflicted with Becker's framework provide information on human variation and the individual variation in how some people may interpret their experience of living with and the ways they go about responding to HIV. Another implication of these findings highlights the importance of thinking about the experience of living with HIV as a fluid process and perhaps less predictable or linear as one might assume based on by Becker's (1997) model of life disruption.

Rethinking Public Health Notions of Fixing People

In my attempt to understand if people experienced various disruptions from living with HIV at different points in time, I began to think about public health aspirations to "fix" people after receiving a diagnosis of HIV/AIDS. What happens when the major focus is on the biomedical model of "fixing" the physical aspects of disease? Does the focus on "fixing" or "correcting" a health problem minimize or fail to acknowledge the ongoing socio-cultural consequences that people might also experience? The focus on "fixing" a health condition also implies that people will return to a pre-disease state

which is not possible due to the assault on the self that disease entails (Sankar 2012). I argue that attention must also be paid to the socio-cultural dimensions related to the experience of living with HIV. In the case of the older adults living with HIV, management of HIV disease was in many cases under control (e.g., undetectable status), but the socio-cultural consequences of living with HIV, such as disruptions to intimacy and sexuality, identified by informants as key challenges to living with HIV, were not part of routine HIV care. A fixation on “fixing” physical aspects of a disease or condition is only one aspect of the illness experience and may not correlate with how a person is affected by a particular condition.

We must also think of people’s experiences of living with HIV as a fluid process and perhaps less predictable than we might expect due to the uncertainties and multidimensional nature of human lives that can present new challenges. What I learned from the stories of the older adults was that living with HIV often included an ongoing process of disruption and reorganization. We must recognize that even if a person goes through a period of stability they may at any point be presented with disruptions and challenges to living with HIV that could be physical, psychological or social. This perspective highlights the need for understanding and monitoring various factors that can impact how a person experiences living with HIV. Thinking of HIV as an ongoing process can allow us to consider refining the type of care and the types of resources available to people who are living with the disease and to understand the various types of challenges and disruptions that people experience in addition to the ways they may reorganize their lives.

Illusion of Continuity

As discussed in chapter 7, the majority of the participants emphasized normalcy when initially discussing their experiences of living with HIV. However, a thorough analysis of the data identified the complexity and the need for a multilevel understanding of the experiences of living with HIV. For example, during the dissertation interviews participants often described how living with HIV “was no longer a big deal” or that except for taking medications they would “forget” that they had HIV. Yet, the iterative process of reviewing the interviews underscored how, despite an emphasis on normalcy, they often experienced some level of disruption from living with HIV. As a first overall glimpse of the interviews, I might have thought that living with HIV was completely normative and non-disruptive. But in reviewing the transcripts more carefully, I realized how most of the participants described how living with HIV consisted of both normalcy and disruption. Because of the complexity in understanding HIV experience, a rigorous and iterative process of analysis is needed: otherwise, nuances of experience may be overlooked or experience of living with HIV may be oversimplified.

The work of Becker (1997) and Ewing (1990) was utilized to help make sense of the presence of both normalcy and disruption in the participant discussions of living with HIV. As noted in Becker’s (1997) concluding thoughts about her research on life disruption and reorganization, she emphasized that “continuity was an illusion” because people experience various disruptions throughout their lifetime. In addition, Ewing’s (1990) research emphasized how discrepancies in the way people talk are indicative of how identity consists of “multiple selves” rather than one “whole self”. I do not believe one perspective better explains the experiences of living with HIV. However, both

Becker's "illusion of continuity" and Ewing's "illusion of wholeness" can be used as tools to think about the discrepancies of how HIV experience was discussed among the participants. By drawing from the perspectives of Becker and Ewing, I realize how the experience of living with HIV is an ongoing and multidimensional process. To think of living with HIV as strictly disruption or strictly continuity/normalcy would limit our ability to understand the long-term and unpredictable process of living with HIV.

HIV Disruption, Adult Development and Life Course Expectations

After trying to determine whether or not people experienced disruptions after receiving an HIV diagnosis, I was interested in exploring the nature of the disruptions. As part of understanding the nature of HIV disruption I was interested in understanding how HIV influenced adult development and the life course expectations of people. Some people described how an HIV diagnosis was a disgrace and was devastating; but, why or in what ways did people experience disruption? There were numerous ways that HIV disrupted the lives of people (e.g., fear of death, incurable disease, medication side-effects, illness, shock, and stigma). However, when talking with the participants the major complaint or disruption from living with HIV had to do with intimate and sexual relationships with others. HIV disruption can be seen as a disruption to adult development because of the way people had to alter or disengage in intimate and sexual relationships.

To further explore the nature of HIV disruption I was interested in understanding to extent to which the participants have the same life course expectations. While there are culturally normative expectations that influence what people might expect their life to be like, how an individual interprets HIV disruptions and experiences disruptions to adult

development are interconnected with individual life experiences and life course expectations. It is important to note that some of the participants ascribed to “the American Dream” when they talked about what they thought their life would be like compared to the life they ended up living (e.g., Patrice did not think she would be poor or have HIV) or achieved (e.g., Donald accomplished everything he wanted and HIV did not alter his life course expectations). However, the life course expectations and perceptions of the future were not the same for everyone. For example Sheila and James did not describe having the American Dream or having the expectations of living into older adulthood because they were caught up in a drug lifestyle. While there are cultural ideas of what life is supposed to be like, the extent to which people incorporate these norms into their own expectations may differ. It is important to understand individual life stories to better understand the extent to which individual expectations map onto cultural norms and ideals.

HIV Disruption or Normative Life Disruption?

The focus of this dissertation was on HIV disruption, however one might contemplate how talk about general life course disruptions (e.g., not getting the white picket fence) were part of a normative aspect of aging, a developmental process, or due to the disruptions from living with HIV. To some extent, understanding that life course expectations or the American Dream may be disrupted are parts of a developmental process as people come to terms with the fact that all their dreams may not come true. At the same time people might present their life course expectations or image of a possible future as a way of heightening the drama or impact of their HIV experience.

A question to consider is to what extent are the disruptions that people experience just part of a normal process of aging or due to HIV? It is expected that all people will experience disruptions throughout life and to experience disruption is a normative aspect of adult development. However, the types of disruptions experienced by people who are living with HIV, a stigmatizing and incurable condition, such as disruption and loss of sexuality and intimacy are non-normative types of disruptions to life. In my exploration of how HIV disrupted people's lives I found that the majority of people were upset by the disruptions to and the loss of intimacy and sexuality since receiving an HIV diagnosis.

As discussed throughout Chapter 8, this dissertation research identified how sexuality and intimacy were identified by participants as a major type of disruption experienced from living with HIV. In general many of the older adults interviewed did not necessarily view HIV as a major disruption to their day to day life. However, when asked how HIV impacted their life, many participants discussed that HIV changed their sex life. HIV played a major role in people's ability to engage in intimate and sexual relationships with others. The interviews refuted popular beliefs that older adults are asexual and tend to disengage in sexual relations or desires as they age. In fact, many of the older adults discussed the importance of sexual activity, companionship, intimacy, love, and closeness throughout various parts of their interviews and described intimacy as an important part of their life despite living with HIV. Participants who were engaging in sexually intimate relationships also described various ways HIV disrupted their relationships. Even those participants who reorganized their lives and chose not to engage in sexual or intimate relationships since becoming HIV positive discussed the

importance of intimacy and sexuality. These participants also described how avoidance of intimacy and sexuality resulted in their missing out on important life course experiences and expectations.

While the findings from Chapter 8 highlight the importance of sexuality and intimacy to older African Americans who were living with HIV, they also can give insight into expectations about the general aging population. An HIV status did not change the human desire for intimacy and/or sexual relations with others. However, an HIV status influenced the extent people were willing to disclose their status in order to engage in sexual and intimate relationships. In fact, in some cases, participants were willing to engage in sexual relations with others but an HIV status affected their ability to properly inform partners because of anticipated rejection or stigma. By recognizing the importance of intimacy and sexuality and the challenges associated with disclosure researchers can begin to think about how to provide important resources for older African Americans who are aging with HIV. The implications and recommendations for the importance of sexuality and intimacy will be discussed in a later part of this chapter.

Reorganization and Reintegration

As discussed in the findings from this dissertation, the majority of participants described reorganizing their life after experiencing disruptions from living with HIV. Does life reorganization equal life reintegration? In what ways did people have integration? What ways does life reorganization not equal integration? For some people life reorganization did not necessarily equal life reintegration. For other people life reorganization included life reintegration. Some people avoided certain behaviors and

hid their status from others to protect their identity in order to reintegrate into certain aspects of social life (e.g., family, church).

Do socially normative mechanisms for reintegration into life after experiencing disruption work for people living with HIV? Becker discussed how people with strokes received rehabilitation and people with infertility could potentially adopt children to help correct the disruption, but the socially normative processes for reintegration do not address all aspects of an individual's life. For people living with HIV, taking HAART medications might be considered a socially normative adaptation to alleviating the symptoms of HIV and prolonging life. However, managing HIV with medications does not address the social stigma and socio-cultural consequences of living with HIV.

What are the degrees of reintegration into life after disruption? Research by Sankar et al. (N.d.) and Swora (2004) found that a form of reintegration into full adult personhood can be understood from the perspective of moral personhood. Moral personhood can be established by "involvement in HIV outreach or service organizations and through a stated (re)commitment to moral behavior or to a higher authority (e.g., god, family, community) beyond the individual" (Sankar et al. N.d.). Reintegration into social life is very complex. For some people reintegration after experiencing disruptions and stigma from HIV were focused establishing "moral personhood" by "being a good person" despite being tarnished by an HIV status.

Some aspects of people's lives were reintegrated while other aspects were never fully reintegrated (e.g., intimacy). Understanding reintegration into life after disruption is much more nuanced than what was presented in Becker's framework (e.g., partial integration). How did people achieve culturally meaningful reintegration into life and

normalcy? Continuity was based on people being able to do what they wanted to do or what they felt was important. Evolving and redefining what was important in life or finding new meaningful activities to reintegrate into social life and ways to deal with loss of meaningful activities. While participants often discussed how keeping their status a secret from other people was a way to reintegrate, few participants were able to openly share their status with others in an effort to fully reintegrate. Reintegration works in some ways but in other ways it fails. Reorganization of life after HIV does not necessarily equate with complete reintegration into social life.

HIV Compared to Other Conditions

How does HIV compare with other chronic conditions such as Type 2 diabetes? To what extent were the experiences of the older adults specific to HIV or part of the normal expectation for living with chronic illness in general? The experiences of the older people living with HIV were some ways similar to other chronic illness, such as having to deal with ongoing, long-term management of a condition with medications, medical appointments, routine blood work, and potential risks of negative side-effects and threat of death if the viral load is not reduced. However, unlike Type 2 diabetes, HIV cannot be cured with modification of lifestyle factors and is highly stigmatizing. In addition, people who were living with HIV experienced major disruption to intimacy and sexuality. At the same time, participants who described living with both HIV and diabetes described how the daily management of HIV was easier than that of diabetes. In fact, participants described how diabetes (e.g., restricting diet and blood sugar monitoring) was more of a disruption in terms of daily health management than HIV (e.g., besides taking pills and routine blood work people would “forget” about HIV).

While living with HIV includes part of the expectations for living with a chronic illness there are certain socio-cultural consequences (e.g., disruption to sexuality/intimacy) that are unique to the experience of living with HIV.

Life Course Perspective

What is the value added of a life course perspective to understand the experience of living with HIV? A life course perspective adds to our understanding of living with HIV by providing insight into the whole life. A life course perspective also adds to understanding living with HIV by recognizing how the interplay of various factors such as the individual's life story, historical cohort, cultural values, and physiological aspects of disease may impact the illness experience. A life course perspective focuses on contextualizing the entire illness experience rather than focusing on one aspect of HIV. By understanding the life stories of people I was able to gain insight into a person's life course expectations, how they described what life was like pre- and post-HIV, and to contextualize the disruptions of living with HIV and the ways people reorganized their lives in response to HIV.

Discussing Sexuality and Intimacy

After presenting my dissertation research I was asked a variety of different questions about reflecting on my experience of the process of conducting interviews and trying to elicit information on culturally taboo topics of sexuality and HIV. How did people respond to my questions about sexuality? How did my role as a thirty-something, white researcher impact the discussions with older, African Americans who were living with HIV? Are there cultural taboos about older people talking with a younger person about sexuality? What kind of follow-up questions did I ask? Were there certain topics

that were missed? Or certain questions that I should have asked that I did not ask? To what extent did I think the discussion of sexuality provided me with insight into the experience of stigma?

My ability to evoke talk about sexuality and other taboo topics was contingent upon a variety of different factors but primarily on the fact that the participants were part of the former HAART project and they were already familiar with discussing personal and taboo topics. In addition, I was a research assistant on that project so I was familiar with the participants and their former interviewers which played a role in establishing rapport. Another factor to consider was that because these older adults were highly secretive and isolated about talking about HIV in many ways I was seen as a “safe” person to talk to (e.g., confidential, non-judgmental, vested interest in protecting the anonymity of the person). Also perhaps since being a younger white person, participants might have also thought I was a “safe” person to talk to because I was not perceived to be a member of their community. Three years had passed since the last HAART Project interview, and my interview provided an opportunity to discuss taboo topics that the participants would not normally discuss with others. The majority of the participants described how even if someone knew of their HIV status they did not talk about HIV with them on a regular basis.

It is also important to note that while I had a few specific questions about sexuality and intimacy that a lot of the conversation about sexuality and intimacy came up when I asked how HIV disruption. The emphasis on sexuality and intimacy emerged as a central focus because it was highlighted by the participants in their discussions about living with HIV. Some people were more open and comfortable to talking about

sexuality and intimacy (e.g., Patrice and Willie) while others discussed experiencing disruption but did not give specific details about their behavior (e.g., Alvin and Melvin). I tried to probe but at the same time I also realized that some people have different styles of talking and that some people are more comfortable talking about themselves while other people are more terse or guarded. Both types of people can provide important and different ways of understanding disruption to sexuality and intimacy. People who are more open can provide more detailed understanding of the nature of disruption to sexuality and intimacy. At the same time people who mention disruption but do not talk about the details can also highlight the significance of the disruption itself and insight into HIV stigma.

What is the role of sexuality and intimacy in older age? As anthropologists point out in their work on the developmental cycle of domestic groups (e.g., (Goody 1958) and (Vatuk 1992)), the meaning of sexuality changes with adult development (Luborsky 2012; Sankar 2012). In older age, sexuality can signify belonging to the family and society. What does it mean to individuals if they believe they cannot participate sexually in society? I can speculate based on my discussions with the older adults that not being able to engage in sexual and intimate relationships was a disruption and not a normative expectation for aging. Participants did not state that stopping sexual activity and intimate relationships was part of “growing old”. Even though participants revised their life course expectations after receiving an HIV diagnosis, the disruption to sexuality and intimacy alters a person’s ability to participate in culturally normative expectations. Luborsky’s (1994a) article “The Cultural Adversity of Physical Disability: Erosion of Full Adult Personhood” identifies a dilemma of how adaptive devices can improve functional

status among polio survivors yet at the same time the use of these devices erodes perceptions of people as full adult persons. Luborsky's work provides insight into how culture shapes experiences of disability and participation in society as a full adult person or erodes the full adult person status. Luborsky's (1994a) work made me think about how an HIV diagnosis can alter personhood. People living with HIV may experience erosion of full adult personhood on different levels. People may avoid intimate and sexual relationships to avoid public erosion of full adult personhood in order to fulfill culturally normative expectations for adulthood such as being a respected elder or leader. At the same time, when people avoid participating in normative expectations such as intimate and sexual relationships they may also experience the erosion of full adult personhood on a more personal/individualized level.

African American Narrative and HIV Reorganization

As discussed throughout this dissertation the majority of the older African Americans emphasized continuity and reorganization after receiving an HIV diagnosis. Did these people have the certain life skills to help them deal with HIV disruption? Did dealing with previous adversity help some people minimize the HIV disruption they experienced? The emphasis on normalcy and reorganization can be interpreted as in line with other research on U.S. cultural values of personal responsibility in addition to literature on resiliency in among African American responses to adversity. Becker's research underscores how the important value of personal responsibility in the U.S. affects why many people feel the need to create a sense of continuity after experiencing life disruption. In addition, an emphasis on normalcy and reorganization as described by the older adults with HIV could also be understood as a form of resiliency that has

also been discussed in previous research on African Americans with chronic illness (Becker and Newsom 2005; Deppen-Wood et al. 1997).

Did dealing with previous adversity or other health problems help some people deal the HIV disruption? In some cases previous adversity and illness seemed to help people deal with the disruptions from living with HIV. For example, Alvin described how he fought to overcome cancer and would use the same strategy to fight HIV. Sheila also discussed having other more severe health problems to deal with in comparison to HIV. Living with HIV did not alter daily activities and living as much as her blindness and arthritis.

However, experiences of having to deal with adversity, trauma or illness did not predict that a person would better be able to deal with disruptions from living with HIV. In the case of Leonard, the lifelong impact of childhood sexual abuse did not make him more equipped to deal with the disruptions from living with HIV.

The majority of the participants of this research study experienced some form of a serious life disruption, adversity, or traumatic event prior to receiving an HIV diagnosis such as poverty, unemployment, racism/inequality, sexual abuse, illness, injury, and/or addiction. Is the emphasis on normalcy and reorganization a response to dealing with HIV and other life disruptions a unique feature of African American resiliency or part of core cultural U.S. values of personal responsibility? To make sense of the narratives of the older African Americans who were living with HIV/AIDS, it is important to understand the presence of both resiliency (e.g., “going to fight HIV”) and personal responsibility (e.g., “did this to myself and must accept it”).

How might themes of normalcy, resiliency, and personal responsibility be incorporated into strategies for dealing HIV or alter health outcomes and health seeking behavior? How does an emphasis on normalcy, resiliency, and personal responsibility in the narratives of older African Americans with HIV relate to the discussion in Chapter 1 on African American models of health, such as John Henryism and Sojourner Syndrome? These African American models of health are based on the idea that a strong work ethic and having to overcome experiences of racism can negatively impact the health statuses of African Americans (e.g., overworking to the point of damaging one's health).

When older African Americans emphasize normalcy and resiliency despite experiences of disruption, do they miss out in valuable resources needed for alleviating disruptions and adversities that are experienced? Does an emphasis on normalcy or resiliency result in better scores on standardized psychosocial measures or do scores identify a false sense of well-being and/or overlook the disruptions that are experienced? A major challenge from this dissertation research was in trying to make sense of and understand the experiences of living with HIV, especially when people often described how their lives were fine despite living with HIV but then later revealed certain disruptions. When the participants chose to tell their story of living with HIV as a story of continuity, normalcy, and reorganization, did these people mask suffering or experiences of disruption? The in-depth interviewing process revealed that people were experiencing disruption despite reorganization. A concern that I have is whether older African Americans also emphasize continuity with health care providers or, if continuity and resiliency are a core part of African American narratives, are older African

Americans missing out in receiving adequate support or missing out in supportive services and resources that might be able to address some of the disruptions that they are experiencing? For example, though not discussed in the findings from this dissertation, many of the older adults said that they did not want to go to HIV support groups because of concerns that other people may gossip about them or reveal their status to other community members. Maintaining continuity, appearing to not have HIV, was highly important among participants.

IMPLICATIONS AND RECOMMENDATIONS

The implications and recommendations for this dissertation research are discussed below.

Long-term Nature of HIV Experience

- (1) HIV has become more chronic and long-term and people are likely to experience various types of disruptions throughout their experience of living with HIV. The type of disruption and the extent of HIV disruptions can also change over time (e.g., loss of partner, resistance to medications, illness). Due to the fluidity and changing nature of HIV experience it is important that health professionals provide ongoing evaluation and assessments for older African Americans who are aging with HIV.

Emphasis on Normalcy

- (1) Making sense of an individual's experience of living with HIV was complex. While the participants often emphasized normalcy and reorganization they also often experienced disruptions from living with HIV. However, the emphasis on normalcy might provide a false sense of wellbeing to health professionals. It is important to identify and provide resources for the types of disruptions that people experience. Various types of evaluations, discussions, and assessments are needed to determine if older African Americans living with HIV are experiencing disruptions.

- (2) Individual counseling with older adults about disruptions from HIV are needed. While not emphasized specifically in this dissertation, participants described disliking support groups because of concerns about other members of the group gossiping about their status to others in the community or not identifying with members of the group (e.g., drug users, gay). Online support groups might provide a source of support for these older adults while also protecting their confidentiality.

Disruptions to Sexuality and Intimacy

- (1) Health care professionals need to routinely discuss sexuality and intimacy among all older African Americans with HIV (not just people who professionals suspect are engaging in risk behavior).
- (2) Sources of information (e.g., pamphlets, videos) discussing disruptions to sexuality and intimacy and difficulties with disclosure are needed and need to be geared towards older adults.
- (3) Because of the major disruptions experienced, all older adults who are diagnosed with HIV should receive ongoing assessments and screening related to intimacy and sexuality. Evaluations should assess disruption and depression along with unsafe sexual practices.
- (4) Public health messages and other mechanisms are needed for addressing the secondary prevention issue related to older adults who engaging in sexual relations but delay or avoid informing their partners of their status.
- (5) Receiving a diagnosis of HIV disrupts sexuality and intimacy. It is important to address this disruption and provide counseling and other resources for more comfortable ways of being intimate and exploring sexuality while living with HIV. The use of sex therapy by older people who are living with HIV is needed. Suggestions for HIV dating sites might provide a safer, more comfortable environment for certain people who are concerned about stigma and rejection because of their HIV status.
- (6) For people who are celibate and avoid sexual and intimate relationships after receiving an HIV diagnosis, it is important to assess for depression and other indicators of well-being. In addition, massage or touch therapy might be a source of therapeutic intervention for adults who avoid intimate relations with others. Discussions about other forms of exploring sexuality and intimacy for people who are celibate or avoidant are needed (e.g., fantasy, masturbation).

- (7) Assess and provide resources to people who are engaging in relationships but are also experiencing disruptions (e.g., unhappy long-term partnerships, fewer partners to choose from, difficulty disclosing, and dealing with rejection).

LIMITATIONS

Despite the overall successes of this dissertation research project, there were also several limitations to this research. The following list provides some of the major limitations.

- (1) The sample of older adults who were interviewed for the dissertation was smaller than anticipated. I originally hoped to have a larger sample but due to the large number of deceased and lost-to-follow-up participants, my ability to recruit a larger sample was limited. I realize that my data may be limited because it was based on people who were willing and able to participate in the study.
- (2) The longitudinal dataset was a major asset to this dissertation research. However, I experienced limitations in my ability to utilize all of the data and data points as I wanted to. While I spent time trying to thoroughly analyzing the data, there were points where I had to set limits on the amount of data to include for the analysis in order to make the data more manageable for a dissertation chapter and research project.
- (3) Another limitation to the research was some missing data. I should have reviewed the demographic information more carefully before interviewing participants to make sure that everything was up to date and to fill in the missing data. I also should have spent more time thinking about what standardized measures or updated demographic information that should have been collected during the dissertation interviews (e.g., changes in their socio-economic status or living situations)

FUTURE DIRECTIONS

There are various ways that this dissertation could be pursued or continued in the future. The following list provides some examples of the future directions for this dissertation research.

- (1) Replicate this dissertation research with a larger sample of older African Americans with HIV or with a sample of older whites with HIV to see how the findings compare.
- (2) Review the data and apply the findings to additional time points to further explore how the findings hold up with the analysis of additional data points.
- (3) Follow up with the older adults from this dissertation research to try to continue the exploration of their experiences of living with HIV.
- (4) Develop interventions, assessments and screening measures for identifying disruptions from living with HIV for HIV positive older African Americans. Develop ways of providing resources and sources of support for older African Americans who are experiencing disruptions from living with HIV.

FINAL THOUGHTS

Life Beyond HIV Reorganization

What happens after people reorganize their lives in response to HIV? What does the rest of their lives look like? Some people might argue that even after people reorganize their lives in response to HIV – they may still have to deal with other challenges of in their lives such as poverty and racism. Once the participants reorganized after living with HIV, were their experiences of living in Detroit the same? Some might argue that the disruptions that these older African Americans experienced

were the result of political and socioeconomic circumstances or factors such as dealing with racism, poverty, inequality.

I found there were in many ways variations in the experiences of being an African American living with HIV in Detroit. Some people experienced poverty and marginalization even when they reorganized their lives in response to the disruptions from living with HIV (e.g. Mildred lived off food stamps and could not find a job), while other participants, like Gerard, did not have to deal with poverty and marginalization to the same extent (e.g., accountant living in a renovated historic home). The benefits of higher socioeconomic status seemed to stabilize people in their life outside of living with HIV. However, I argue that there are multiple lenses, stances and ways of understanding the experiences of people. What I learned from my dissertation research was that the process of living with HIV was not the same for everyone. I also learned that despite differences in economic situations, education, age, gender, marital status, or choosing to tell a story of continuity, reorganization, or disruption that receiving an HIV diagnosis often resulted in a profound disruption and in many cases a major loss of intimacy and sexuality.

APPENDIX A: PARTICIPANT CASE STUDIES

Alvin

At the time of the dissertation interview Alvin was age 78 and had been living with HIV for six years. I interviewed Alvin at his home and we sat next to each other on the couch as we talked about his experiences of living with HIV. He was pretty pleasant to talk to. However, he was also a bit guarded and was annoyed a few times when my questions were repetitive. He asked if I was paying attention to him or listening to him. I tried to let him know that I was listening but that sometimes the questions were repetitive.

On the day of our interview there was a major snowstorm, so I offered to take off my shoes upon entering his living room. He apologized for the place being dusty but it was actually very neat and orderly. He brought a rug to put under my feet so the dirty slush from my winter boots would not stain the carpet or leave a wet spot. Alvin had a quiet, clean and orderly home with minimal décor. From what I can remember he had black furniture, gold blinds and a mirror in the living room. Alvin lived in a more rundown neighborhood on the Westside of Detroit. The house next to him was abandoned and boarded up and the house next to that was spray painted with graffiti that said “fuck”. He had a large wood board blocking the window of his front room because his home was broken into a few days before our meeting. His home was broken into while he was in the hospital for prostate surgery. He told me that the robbers broke through his front living room window and another window in the back of his house. They stole some money but not that much because his alarm system most likely scared them away. He mentioned that he was concerned that his pistol was stolen but it was not. He told me about his relationship with his neighbors. Since he was recovering from his surgery he had to rest and was unable to shovel his snow or take the garbage out. He talked about how his neighbors who he has known for many years have not helped him or checked on him. However, a newer neighbor who he did not really know was helping him by snow-blowing his sidewalk and taking out his trash. He seemed very thankful and bought the neighbor a fifty-dollar bag of salt because he thought the neighbor did not have the money to buy it. He noticed that when the neighbor was down removing the snow he never salted the sidewalk, so that’s why he bought him the salt.

Alvin described himself as having a small stature but was a fighter and was much stronger than he appeared. He worked out at the gym regularly and described himself as quite healthy despite having HIV and prostate cancer. He said he was probably healthier than me. He talked about changing doctors because his doctor did not help him when he needed him to. He said one can be a good doctor but if doctors were not there for him when he needed them, then how good of a doctor were they?

Alvin was the oldest of the participants and was also diagnosed with HIV at an older age. Alvin was a retired auto worker and was an active member and advocate of the United Automobile Workers of America Union. He owned his home and a car and described himself as quite comfortable financially and was leaving for a cruise in a few weeks. On the day of our interview, the city of Detroit turned off the water in his neighborhood because they were doing repairs to the water line. He offered me tea but then realized the water department shut off the water for the day so he couldn't make tea. Alvin grew up in the South but moved to the Detroit area for work in the auto industry.

At the time of the dissertation interview Alvin talked about reintegrating into life again since having HIV and he was an active member in his church choir. Spirituality was very important to him. He survived cancer and was quite healthy despite having HIV. He recently had a scare that he had cancer again but surprisingly the MRI results were clear. He talked about how the doctor was very surprised. He felt this was a message from God and that he was meant to still be here. He considered himself to be a family leader and role model for others to turn to for advice or being someone who his family could count on. He came from a family of 12 or 14 children. He was the last survivor of his brothers and sisters and got a little bit choked up when he talked about them. Now he helps out his sister-in-law who goes to him for guidance and help. He did not mention having children or grandchildren or if he was straight or gay, even though I knew that he was previously married and had children. From the HAART Project interviews I learned that he was on the "down low" and was not open about his sexual orientation. He talked about how he used to party and was very sexually active in the past but that he does not do that anymore ("shut down his sex factory", "ship stalled in the water"). Only one person knows he has HIV and this person lives in another state. He is very secretive about his status. He went to an HIV support group a few times but said the group was too depressing, so he no longer goes and doesn't need the support.

After I turned off my tape recorder he talked for quite awhile about his relationship to the neighbors and other things. As I was leaving he received another note on his door that the water would be shut down the next day from 9 a.m. to 5 p.m. He did not seem too bothered by it. As I was trying to drive away from his home, my car got stuck in the snow. He could not help me because of his surgery. He watched me from the front door. I borrowed a shovel and spent about 45 minutes shoveling my car out of the snow and ice. He tried to give me advice about how to get my car out of the snow. Finally I was able to leave and I returned his shovel. I joked that if I couldn't get my car out I might have to stay there longer.

Donald

At the time of the dissertation interview Donald was age 60 and had been living with HIV for eight years. Donald had a very light complexion and most likely would pass as white to people who did not know him. He was balding and combed his hair over to the side. He was quite tall and thin. He was a retired clinical psychologist. I interviewed Donald in his home. He was very polite. He was quiet, soft spoken, and seemed to be more cautious and calculated in his responses to the questions. Because of his background in psychology, he was perhaps more used to asking questions and trying to elicit information from others. We sat at the small round table in his recently remodeled kitchen that had been recently updated with all stainless steel appliances. He remodeled his home in hopes to move out of Detroit and into the suburbs, but with the poor housing market values he was going to have to wait a while to sell his home. He said he was an occasional smoker and was recently diagnosed with diabetes and considered diabetes to be more of a disruption than his HIV. He said he had a sweet tooth and also said he could go many hours without eating. His HIV did not seem to affect his health status. He told both his sister and best friend and they accepted his HIV status. Since the HAART project, no major life events happened except for the death of his parents.

Donald had a long-term partner. He believed that he achieved everything that he wanted to prior to receiving his HIV diagnosis (college, becoming a psychologist, retiring). HIV did not disrupt his life goals or expectations. He did mention that maybe since living with HIV he became more selective sexually and wasn't as "wild" with his partner. The only other area in his life where Donald mentioned HIV disruption was that he had wanted to travel to Europe to visit friends but there were travel restrictions for people who were HIV positive. Donald seemed to be enjoying his retirement and daily routine.

Several days after our interview, Donald called me to tell me he began to think more about his responses to the questions and that he wanted to elaborate more. He mentioned sending me a letter or emailing me his thoughts, but I did not hear from him again.

Gerard

I interviewed Gerard in his home. Gerard was 56 and had been living with HIV for 8 years. He lived in a flat above his mother in a very nice neighborhood on the Westside of Detroit. He lived in a completely renovated and immaculate historical home. Gerard was quite a busy man. He worked full time as an accountant and spent his remaining free time caring for his elderly mother who had Alzheimer's. He was concerned about

losing his job because of the economy and was worried that he might be replaced by a younger, cheaper employee. He talked about caring for his mother took up most of his daily life and any extra time he had and made it difficult to live a “normal” life or pursue leisure activities such as traveling, working out, going to concerts, or gardening. In order for him to do leisure activities he would have to pay a caregiver to watch his mother which was very expensive because his mother required around-the-clock care. Caring for his mother was frustrating because sometimes she was very lucid and other days she did not know who he was. He wanted to keep her at home as long as possible but realized that he might have to move her to a nursing home eventually. He worries about retiring because of the economy and because his family tends to live in their hundreds (his mother may live for many years requiring his care). He thinks he might not be able to retire until he is in his seventies. He worries that he doesn't have anyone to care for him in the future if needed. He described himself as an anxious person and worries about his mental health status in the future. Seeing his mother age seemed to make him more aware about his own mortality.

After meeting with Gerard I was concerned that his strong work ethic and care-giving responsibilities might negatively impact his health eventually. He talked about not having support from his partner or siblings. He and his long-term partner lived together and his partner was also HIV positive. I think a lot of the disruptions from HIV that affected other participants did not seem to affect him because he was in a relationship and busy with other responsibilities. Although he did discuss how his relationship was not happy or ideal, he stayed in the relationship perhaps out of convenience so he didn't have to enter the “youth-oriented gay” dating scene. He talked about the support of his gay community of friends. They seemed to provide a major source of social support to him.

Only about five people know his status. His family knows he is gay but not that he has HIV. Other than going to the doctor and settling for an unhappy relationship, Gerard said that HIV did not seem to disrupt his life. His care-giving responsibilities to his mother were a major life course disruption and prevented him from doing many activities and taking the time to focus on his own health. He said he was lucky that his health has been good (e.g., undetectable viral load). He talked about how he needed to get his prostate checked soon because prostate problems ran in his family.

James

James met me on campus office for our interview. At the time of our interview he was 54 and had been living with HIV for 24 years. He had a very long history of using heroin but had been sober more recently. He was tall and had a big smile. He was casually but neatly dressed, wearing baggy jeans, a T-shirt, and sneakers. He took the bus to meet me his interview. He looked much younger than he was, and his long history of drug use and living on the streets did not seem to age his physical appearance. His history of drug use resulted in a wide range of health problems including COPD and hepatitis, as well as HIV. He described how for the first time in his life he was trying to

live like a “normal” and “good” person. He spent most of his life using drugs and living on the streets and “pimping” women that he did not participate in normative expectations, such as working and providing for himself or his family. His ex-wife was in prison and was also HIV positive.

James did not think about HIV until he became sober. While he was using drugs he did not take medications and was not concerned about his health status except for going to the hospital if was very sick. HIV did not disrupt his life until later on when he became sober. Now that he is sober he said that HIV disrupted his dating life. He focused on staying sober by attending NA meetings. His goals were dating HIV positive women to find a partner so he could get married again and getting a job (perhaps in retail) so he could get a two bedroom apartment so his youngest daughter could move in with him. He said that he was old and lonely and wanted to get married to start a new “clean” life with someone. He said that he suffers from having low confidence and low self-esteem.

Leonard

Leonard met me on campus for our interview. At the time of the interview he was 56 years old and had been living with HIV for nine years. He said HIV disrupted every aspect of his life. He described himself as a hermit and it was not by choice. He struggles with many serious side effects and received very little support and acknowledgement from the medical community or social workers. He suffered from muscle wasting and abnormal fat distribution that had lowered his self-esteem. He told me he was meant to be a muscular man like the other men in his family but that HIV has changed his appearance, making him frail. He has not worn short sleeves or shorts out in public in over seven years because of his negative body image and the way HIV has changed his body. He is concerned about being “guinea pig” and getting sick from others. He described himself as being a very verbal person and wanted to get his story out and to let his voice be heard about the problems with the “system”. He hopes that some of the things he talked about would one day make a difference.

He is too sick to work, but “the system” says he’s too healthy to get support. He suffers from diarrhea and other bowel problems from medication side effects. He has tried to work in the past but sometimes would be too sick to go to work. He said that his illness is unpredictable and that he would get fired from a job because he would have to call in when he had bowel problems. HIV disrupts his ability to work, body image, and his self-esteem. HIV is the controller and he is the controlee. He also said he was a fighter and would fight HIV even though he felt like it controlled him. He would have liked to have kids but would have been unable to provide for them. He has no interest in going to

support groups and does not like how they are run. He does have girlfriends who help him and provide support to him.

During the T1 interview when he shared his life story he talked about being molested as a child and wondered how that influenced his sexual orientation and identity. He was upset with his mother for not investigating and confronting the family member who abused him. Instead she sheltered him from the abusive family member and others. He feels that if he was not molested that maybe he would not be gay. He talked about how he was highly sexual before HIV. He often pursued straight men and also hooked up with women. He talked about having a very promiscuous childhood, hooking up all the men and boys from neighborhood and church.

Loretta

Loretta was 66 and had been living with HIV for 8 years when she was interviewed for the dissertation research. She was a small framed woman and her hair was wrapped in a scarf. She lived in a new senior housing complex that was close to a major hospital in Detroit. The complex that she lived in was gated and had guests sign in upon entering the building. She said the parking lot gate closed at night to keep the building safer. She did not have a car but there was a shuttle at her apartment complex that could take her to doctor appointments. She was very nice. She lived in a very tidy one bedroom apartment that was decorated with pictures of her grandkids and great-grandkids. Loretta talked about the importance of family, plans for future family reunions, and about new babies being born in her family. Loretta also talked about her love for playing video games to keep her mind sharp and also enjoyed spending time with family and going to church on Saturday.

She was reluctant to take an HIV test because she was not promiscuous but eventually agreed after being encouraged by her family. She found out that she was HIV positive. Her diagnosis made her rethink about who could acquire the virus. She was shocked by her diagnosis and later found out that her husband also had HIV. She chose religious celibacy and talked about how relationships are too much of a headache. She has had some recent heart problems and also suffers from heartburn. She changed her diet and tries to eat healthier and avoid fried foods.

Loretta mentioned something about talking quietly because the neighbors might be able to overhear us. Only a few people know her status. She tries to talk to her grandkids about HIV but they were not concerned because they said they did not know anyone with it. They don't know she has it, so she thinks that's interesting. She said the virus was undetectable in her and she is down to only one pill. The pills are a daily reminder of her HIV status, but she mostly tries to forget about it. She used to work with the

“mentally challenged” and gave people medications. Her job was too tiring and she chooses not to work anymore. I tried to follow up on her life with probes but she did not like to elaborate too much about her life. She was a very religious/spiritual person. She stopped going to church because of the politics but has since reintegrated and is going again.

Marion

I interviewed Marion in her apartment. At the time we met she was 62 and had been living with HIV for 10 years. She was very friendly and warm. She was tall and thin and made references to being underweight and struggling with eating. She gave me a hug when we met and when I left. She lived in an older apartment complex near a major hospital in Detroit. The apartment complex was a short walk to the clinic and was located near bus stops, so she had access to public transportation if needed. She talked about taking the bus to the mall with a friend for something fun to do. Her apartment was decorated with a small Christmas tree and pictures of her family. Her apartment was very tidy. We sat on the couch next to each other. She was very easy to talk to and told me that I was very easy to talk to and that I made her feel comfortable. She said she has been dealing with a lot of deaths in her family (including her young niece and her father) and having to deal with losing people who she was very close with. She is finally looking forward to focusing on herself. She talked about how caring for family members took a toll on her health. She found an apartment for her brother in the same building so she could try to keep him off drugs and off the streets. She showed me a hospice book that was very helpful to her. She told her family about her HIV status and they are accepting and supportive but they never ask her about it. She said her father left when she was eight years old and her mother was not very affectionate or loving. She was very close with her grandmother.

She feels she is healthy overall (undetected since 2005) except for difficulty keeping weight on, but she is concerned about getting sick from other people’s germs. HIV hasn’t negatively impacted her health except for feeling fatigued. Even though she is tired a lot, she said if she had the money she would make sure to go to the casino more often. She talked about how HIV disrupted her ability to trust men. She gets upset about the disruptions to her sex life and ability to have a companion. She would like a companion to spend time with and someone who she could go to HIV support groups with. Sometimes she gets upset about having HIV and will just stay in bed. But she also said that she is fighting HIV and that she’d rather have HIV than cancer. Having HIV has not really impacted her life goals though. She used to work in a nursing home but said that she doesn’t work anymore because she is lazy. She tries to help other

people in her building who have health problems by doing their laundry and other housekeeping.

She told me a story about a young man who hit on her when she was looking good. She told him that “sometimes what looks good isn’t good for you.” When he told her he didn’t understand, she told him that she had HIV. I thought that was very interesting and that she was so open and willing to help others.

Melvin

Melvin and I met on campus and his “wife” came with him but waited outside of our interview. Melvin was 59 years old and had been living with HIV for six years. The interview with Melvin was the longest interview of the group and was the most challenging because Melvin often wanted to discuss the Bible and have biblical discussions about the origins of religion. I often found myself trying to figure out how to reorient the conversation to the dissertation topics while Melvin was trying to create a preacher-student relationship. He was very clean cut and wore his Sunday best (slacks, a dress shirt and dress shoes, cologne). He was short and had more of a stocky build. Melvin was a former auto mechanic, but much of his identity remained unknown (the memory of who he was and the kind of life he lived was lost) since being hit by a car while walking home from work one day. Melvin spent several years in the hospital in a medically induced coma and had multiple broken and shattered bones. When he woke up he was told that he was HIV positive. He received a closed head injury and still struggled with knowing who he was and what his life was like prior to the accident along with the challenges and problems resulting from a closed head injury. He relies on what other people tell him about himself and said that people say he was a good person.

Though he comes from a religious family, he was not religious until after moving to an assisted care facility after his accident. Much of his life story is about his spiritual and religious journey during his recovery from his injuries. At the time of our interview he recently left the assisted living facility and was living independently for the first time since his accident. He talked about struggling to pay the bills and dealing with the finances of living independently but also described loving his neighborhood and living on his own. The facility where he was living was hampering on his independence. Melvin talked about being reserved and not opening himself up to others (“building up a wall”). It wasn’t clear if that was because he didn’t really know who he was from the closed head injury or if he had always been that way. His becoming a preacher was a major part of his life and identity. He discussed how many people relied on him for advice and he helped them with their problems. He would often counsel people but

would not reveal his status. Becoming a minister was a way for him to receive status and authority especially since he could not return to his former career as a master mechanic due to dexterity and pain problems from his accident. No one really knows his status, not even his “wife”. It was unclear to what extent his wife was a companion or if they were sexually intimate. I do not think she knew his status. He did talk about how much he loved her and would have married her if they met earlier on in life. In response to HIV disruption questions he replied “yes and no”. He said that HIV prevented him from doing certain things (intimacy with others), but by not letting others know his status and not harming others by giving them HIV it didn’t disrupt his life. Melvin passed away about a year after our interview.

Mildred

Mildred was 56 years old when we met and had been living with HIV for seven years. She was waiting by the door for me as I pulled into the parking lot for her apartment building. She gave me a pass to put in my car so that I wouldn’t get a ticket. Her parking lot was monitored by security and was located across the street from a major hospital in Detroit. She was a petite woman and wore casual clothes (jeans and T-shirt). When I arrived she told me that she had a roommate/guest sleeping in another room and that they didn’t know her status. She spoke softly, perhaps because the guest was staying at her house. I asked if she wanted me to come back another time, but she wanted to go through with the interview. We talked softly and I referred to HIV as her “illness” because I didn’t want the other person to overhear us talking.

She talked about experiencing many losses to her family and appeared to be depressed. She talked about wanting to find work, but it was difficult due to her status and the lack of jobs in the Detroit area. She was recently diagnosed with diabetes and talked about how many people she knew were very ill or died from diabetes complications. Her eyesight is not very good because of her diabetes and she is in need of new glasses. She has a difficult time reading now because of her vision and reading is something she finds very enjoyable. I told her that the consent form had information about HIV on it and that she should put the form in a place where her guest would not see it. She said that she would fold it and put it in a locked place. I think the interview went well overall but I wondered to what extent she might have been more reserved because of the roommate.

She lived in a small subsidized apartment. It was clean and tidy and we talked at her kitchen table. She did not have a car. She talked about searching for janitorial jobs or care-giving jobs. She considers herself a fighter and a survivor and takes everything day by day, one day at a time. She mentioned she saw a family member at the HIV

clinic who didn't know her status. They just said "Hi," but that was about it. Only her sister and neighbor really know her status. They are a resource for her to take her places and help her out. She doesn't want to burden others by telling them about her status and is also worried about being talked about badly because of her status. She is on food stamps and tries to buy all the food she needs at the beginning of the month and plans out her meals to try to make it last for the month. She also said she takes her blood sugar monitor with her and orange juice in case she needs it. She said when she was first diagnosed with diabetes she was afraid to leave the house, but now she is learning the warning signs so she can take care of herself. She said she is tired of pricking herself but is afraid of the diabetes. Many people she knows that are younger than her are dying of diabetes or have had body parts amputated.

She doesn't really know how she got HIV but thinks it was from sex. Her husband died four years ago and she thinks that he had HIV. They had been separated and did not discuss having HIV with each other. Her faith helps to keep her going and keeps her strong. But she does have days where she gets depressed. She has established a routine of planning her meals around her meds and tries to walk for exercise. Other than not being able to communicate with others or not being intimate with other people she said HIV hasn't disrupted her life that much and that she lives life like a normal person. She goes out with girlfriends but avoids talking about her sex life and HIV status.

Patrice

I interviewed Patrice in her home. She lived in a big home on the east side of Detroit but the neighborhood was rundown. Her home was clean and nicely decorated. She was 51 years old and had been living with HIV for 8 years. When I went up to her door her son told me that she wasn't home. But then I heard her in the background telling me that she was home. She lived in a large home with her son. While I was there, her sister and sister's boyfriend were staying in her home. Her sister knew of her status but the boyfriend did not. Our interview was three hours long and it was quite emotional. She was a heavier woman. She was very nice, and at the end we gave each other a hug. She was getting tired so I had to wrap things up towards the end of the interview. She got emotional a few times and cried. I even started to get teary-eyed. She was very open with me and said the questions unlocked various emotions.

She had a history of drug use but changed her life around. She was adamant that she never sold her body for drugs. She talked a lot about being a "good" person and sharing her "smartness" with her grandson she helped raise. She talked a lot about being poor and black and having "the stuff" (HIV) and how her life turned out very

different than she expected. Her common law husband died about a year before our interview. She talked about how she loved him but at the same time she was very angry at him for a while for giving her HIV. She said she wanted to get working again (she liked doing housekeeping, cooking for “rich white” people). She accidentally said white people, but then she was embarrassed because she thought she offended me.

She was dating someone new now that didn’t have HIV but they do use condoms. She said they use two condoms. She also said that sometimes her boyfriend gets jealous of the time she spends with her grandkids. Prior to dating her boyfriend she thought she was going to be a leper because of her HIV status. She was afraid of getting rejected but eventually decided to tell her boyfriend and he accepted her.

Overall she’s doing well but sometimes she gets tired or depressed and suffers from neuropathy. She talked about sharing her testimony at church, but she did not want to share or publicize her HIV status. She talked about how her life turned out totally different than she expected. She thought it was going to be like the “Leave it to Beaver” show but it didn’t turn out that way. HIV disrupted her ability to date, but she has recently been able to open up to her boyfriend. She described experiencing rejection because of her HIV status from an aunt who she used to be close with (the aunt will no longer hug or kiss her).

Sheila

Sheila was 53 and had been living with HIV for ten years at the time of our interview. She was a very tall and was a larger framed woman. She lived in a home with her husband on the eastside of Detroit. She was blind from a gunshot wound from attempting to commit suicide prior to her HIV diagnosis. She had many other health problems due to a drug history and also had severe arthritis to the point that she could no longer braid her hair or do other tasks of daily living. She had some leg problems so she walked on a treadmill for exercise. She did not use assistive devices for blind people. She said that being blind helped her get services like Meals On Wheels and that her HIV would not have provided her with access to these services. Her arthritis was getting progressively worse and she fell down the stairs a year or so ago and broke both wrists. She still smoked but had been trying to quit. Her husband provided much support for her and was very helpful during our interview. He offered me a beverage and then gave us privacy to talk.

She said that HIV took a second seat to her blindness and various other health problems. She had a long history of drug abuse but changed her life around and had since enjoyed being a housewife and prided herself in keeping a clean home.

She did not have a former career because she was using drugs. She talked about being the first blind person to take and pass a substance abuse counseling test. She was very happy about receiving the counseling certificate.

She was a very positive person and seemed to handle her hardships very well. She described herself as a homebody and was not close with her family but loved them from afar. She did not have friendships, she had associates. She knew a lot of other people with HIV but they were all dead. She talked about how she was bullied her entire life by other people. She would find a quiet place to pray to deal with the bullying. Praying also helped her deal with drug addiction and HIV.

She had had a long history of IV drug use but was clean. She got clean when she met her husband. Prior to finding out about HIV she was a “train wreck”. She didn’t have any life course expectations because she was an addict and didn’t think about the future. She described how her HIV positive status has “slowed her train down” and made her “more aware”. She knew she was HIV positive when she met her husband but didn’t tell him at first. She didn’t tell him until after they had been married for five years. She pretended that she was surprised when they went in for testing together. She felt bad about lying to her husband but asked the Lord for forgiveness. She said the Lord had forgiven her because her husband did not have HIV. She tried to have her husband use condoms to protect him, but she could not force him to use them.

She was spiritual but didn’t like the church. Her husband was supportive but he didn’t know that she had HIV all along. She tried to talk about how she lied to her husband but it was difficult because her husband was home and in a different room, but sometimes he walked by us. Since she was blind, I tried to tell her or let her know when he was in the room. She seemed surprised when I told her that we had talked for three hours. She must not have thought it lasted that long but it was a long interview. She considered her blindness and arthritis to be more of a disruption to her life than HIV; she did not think of HIV as being a disruption. Her pills were a daily reminder of her HIV status and she mentioned that she sometimes forgot to take her pills. Sheila passed away a few months after our interview.

Wally

Wally was 51 years old and had been living with HIV for 12 years. He took the bus and met me on campus for our interview. He was a very nice person and mentioned that my sister, his former interviewer, was his “buddy”. He has been doing pretty good the last few years but still battles alcoholism and has gone to rehab in the past. He told me how he passed out on the street after drinking too much last Christmas Eve. He almost died and was in a coma for a few days. A good friend helped him through this difficult period

in his life. He is on disability and has been concerned being able to pay the copay for medications. He enjoys painting houses for people as a way to make extra money. He talked about getting depressed sometimes when he reflects back on his life. He wonders if he was less carefree and more responsible if that would have prevented him from acquiring HIV.

He talked about wanting to see his grandchildren grow up, and he wanted to have many more grandchildren. He finally has granddaughters which he is really happy about. He talked about running with the wrong crowds and being with lots of women (with 80 to 90 partners and three different mothers of his children). Since being HIV positive he says he is a better and more thoughtful person. He still struggles with alcoholism but tries to be a good person and to be a good dad to his kids. He told me how his ex-wife told him that he changed for the better and wondered why he wasn't like that when they were together. He told me how he was helping his ex build furniture for her new apartment and how happy he was to be around his children and grandchildren.

He was currently in a relationship with a woman who accepted his HIV status even though he did not tell her at first. She found out from someone else. He said his relationship with his current girlfriend was a good relationship and he wants to get married again. He used to be with a lot of women, but he is okay with being monogamous now.

His father died when he was 11, and he talked about being spoiled by his mom and grandmother. He had a normal life until he became friends with the rowdy crowd at school. He was stabbed in an alley when he was a teenager; he said he was in the wrong place at the wrong time. He thought he was going to be a professional baseball player but then he got involved with the wrong crowd.

After finding out about his HIV results he cried all day and said it was the worst thing that ever happened to him. He focused on taking medications to survive after seeing other people around him die from having HIV. He tries to live life one day at a time. He experiences side effects from the medications (itchy skin, thrush, insomnia). He talked about feeling like a guinea pig by having to take the medications. He wishes that he would have used condoms. He has only told one of his children about his status. HIV has disrupted his life because he doesn't have as many girlfriends as he used to have. He didn't always reveal his HIV status to women that he hooked up with, but he is trying to be a better person. He went to some group therapy sessions, but felt he couldn't relate to the other men in the group because they were gay.

Willie

Willie was 53 and had been living with HIV for 18 years. Willie was a tall and thin man. He was very expressive and emotional. When I showed up at his upper flat, he was surprised that I came alone. He jokingly asked if I had a bodyguard. He said not to worry about being in his place because no one would mess with us. He left the front

door open. His mother lived below him. He was a former health technician for elderly people and always dreamed of being a nurse. He was on disability. He opened up to me about his emotions and described himself as being “touched” (different, having mental health issues). He was very lonely and did not have many friends or a boyfriend.

He talked about roller skating around the neighborhood for exercise and how music, especially gospel, was “his weed”. He really enjoyed decorating his upper flat like a museum with unique finds from thrift stores and elsewhere. He talked about being poor but that he was getting more support from AIDS Partnership Michigan, so he was doing better financially. We talked at his dining room table. His table was black with glass top and had gold trim. There was birdcage with five chirping finches. He also had a snake and two dogs. The walls were painted red with ornate wall decorations and he had incense burning. There was a lot of stuff in his place but it was clean. His bathroom plumbing was old and in need of repairs. He showed me his new computer and he said he was enjoying learning how to use it. He said it was a “street” computer (perhaps bits and pieces received from stolen merchandise and then sold to people at a low price). He was quite friendly and open with me despite describing himself as a loner and feeling so isolated. He told me that he felt comfortable around me and that our interview was better than any therapy session that he ever had.

He talked about being a “late bloomer”. He only really had one boyfriend, the one who abandoned him about 14 years ago. He came home and his stuff was gone, half of his bank account was gone, and he never saw the boyfriend again. He tried to get closure by contacting him but was unsuccessful. No one knew about his HIV status or his sexual orientation. He felt disgraced because of his HIV status. He said that he would never have a loving, intimate relationship because of his HIV, and that he would have to rely on fantasy and masturbation. He was very upset about the loss of intimacy and love. He talked about the differences between sex and love and how important love was to him. He really wanted to be in a loving and caring relationship. He is afraid to give HIV to someone else and was afraid of being rejected if he were to reveal his status. He worries about his nephew whom he is very close to will find out he is gay. He also worries about putting on a façade that he is a “manly man” when really he is gay. He has to hide his medications from younger family members who snoop through his house. Despite the major disruptions to intimacy and sexuality, he talked about becoming more accepting of his condition, and that it was not as bad as he thought. Willie died about a year after our interview.

APPENDIX B:
RESEARCH DOMAIN, DATA SOURCES, AND MEASURES/METHODS

Domain Variable: Life Course	Source	Measure or Method
Life Course Reorganization/Disruption	Dissertation Interview HAART Project Data	Open ended questions ⁶⁷ <ul style="list-style-type: none"> • Life history narrative • HIV narrative
Timing of HIV Diagnosis	Dissertation Interviews HAART Project Data Demographic Data	Open ended questions Demographic questions <ul style="list-style-type: none"> • Age at HIV diagnosis, Length of time with HIV, Timing of HIV diagnosis
Aging with HIV	Dissertation Interview Health Professional Interview HAART Project Data	Open ended questions <ul style="list-style-type: none"> • Aging with HIV narrative • Challenges to aging with HIV • What's important to know about older adults with HIV Demographic, clinic, and psychosocial measures (e.g. Beck's Depression, cd4/viral load count, social support)
Ethnographic Setting of Aging with HIV in Detroit	Dissertation Interview	-Open ended questions -Demographic Questions

⁶⁷ Questions were based off of research and guidance from advisors Andrea Sankar and Mark Luborsky.

	<p>Health Professional Interview Text</p> <p>HAART Project Data</p> <p>Archival Data</p>	<p>(e.g. financial status, sources of support)</p> <p>-Psychosocial measures</p> <p>-Description of the city of Detroit in relation to older adults with HIV (e.g. access to care, bus routes, neighborhoods).</p>
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APPENDIX C: HEALTHCARE PROFESIONAL QUESTIONNAIREBackground information about HIV and Aging/Older Adults

1. What is important to know about HIV among older adults?
2. Can you tell me what you think about the use of age 50 to represent older adults with HIV?
3. What are some areas of interest/concern in relation to older African Americans with HIV?
4. What do you think general population or patients should know about being older with HIV?
5. Are there particular challenges for older African Americans with HIV?
6. Can you share any case studies about older adults with HIV?
7. Why do you think older adults are not usually testing until much later than older adults?
8. Do you think the context of Detroit may influence the experience of health and illness for older people with HIV?
9. Research suggests older adults have worse health outcomes than younger adults due to process of aging. To what extent does a late diagnosis and/or process of aging influence HIV prognosis?
10. Do you have any reservations about talking about HIV with older adults?

APPENDIX D: OLDER ADULT QUESTIONNAIRE

1. Life Disruption/expectations

- Tell me what's been going on with you since your last interview?
 - What changes in your life or updates you would like to discuss since your last interview?
 - How has your health been since your last interview?
- How did you expect your life with HIV would have been going?
- At what point in life were you diagnosed with HIV?
- How has HIV impacted your life?
- In what ways has HIV disrupted your life?
- To what extent have you experienced challenges to living with HIV?
- Can you talk about how and to what extent has HIV influenced your:
 - Day-to-day life
 - Goals
 - Relationships
 - Sexual relationships
 - Career
 - Family
 - Future
- How might being diagnosed at a different point in your life have affected your experience with HIV?

2. Life Reorganization

- During the HAART project interviews you were asked to share your life story. Is there anything you would like to add or change about your life story?
- During a HAART project interview you were asked to talk about living with HIV. Is there anything you would like to add or change about your life with HIV?
 - How might your experiences with HIV change overtime?
- How have you responded to living with HIV?
- In what ways has HIV made you think about your life?
- What did you think life was going to be like when you were diagnosed with HIV?
- In what ways have your perceptions of HIV changed overtime?

3. Aging with HIV

- Tell me about your experiences of living with HIV as you've gotten older?

4. Health Update

- Any changes in your health since you were last interviewed?
- Are you currently taking medications? Any changes with your medications or experiences taking medications since you were last interviewed?

- Do you have any other health problems?
- If so, what are they?
- Are there certain health conditions that are more difficult to manage or affect your life on a daily basis?
- Are you going to your doctor regularly?

5. Aging with HIV in the city of Detroit

- Please tell me about living in the city of Detroit?
 - In what ways does living in this area make it easier or harder to live with HIV?

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ABSTRACT**“STILL HERE, TRYING TO FIND MY WAY”:
UNDERSTANDING HIV DISRUPTION AND REORGANIZATION AMONG OLDER
AFRICAN AMERICANS IN DETROIT**

by

ANDREA NEVEDAL**December 2012****Advisor:** Dr. Andrea Sankar**Major:** Anthropology**Degree:** Doctor of Philosophy

Adults aged fifty and older are the fastest growing age group with HIV/AIDS. Research on older adults with HIV has focused primarily on health status and physiological changes that occur as people age with HIV. However, little is known about the socio-cultural consequences that occur when older adults are diagnosed with HIV and as they age with HIV. Drawing from an anthropological approach to the life course and Becker's (1997) framework of life disruption, this dissertation research explored to what extent people experienced disruption from living with HIV and reorganized their lives after experiencing disruption.

The specific aims included identifying and describing (1) how experiences of living with HIV map onto Becker's (1997) framework of life disruption and (2) the major disruptions and socio-cultural consequences of aging with HIV. This dissertation study took place from January to September 2009. The dataset consisted of data previously collected from a larger parent study (2002-2006) and in-depth interviews with older

African Americans living with HIV (N=14) and health care professionals (N=3) collected in 2009.

Findings from the qualitative analysis of interviews reveal patterns of living with HIV that support and conflict with Becker's framework of life course disruption and reorganization. Participants described experiencing major disruptions to sexuality and intimacy since living with HIV. This dissertation research provides insight into understanding how HIV impacts the expectations and experiences of older adults living with HIV and the ongoing importance of sexuality and intimacy throughout the life course.

AUTOBIOGRAPHICAL STATEMENT

Andrea Nevedal graduated from Wayne State University's Department of Anthropology doctoral program in December 2012. Ms. Nevedal was a former pre-doctoral trainee of the Wayne State University Institute of Gerontology National Institutes on Aging Pre-doctoral fellowship program. She received her M.A. and B.A. in Anthropology and a Graduate Certificate in Public Health Practice from Wayne State University. For the last ten years, Ms. Nevedal has worked on individual and team research projects exploring the socio-cultural consequences of health and illness (e.g., HIV/AIDS, cancer). Ms. Nevedal has utilized her multidisciplinary training to conduct research using multiple methods and to develop datasets using software programs ATLAS.ti, NVivo and SPSS. She has presented at regional and national conferences, including the American Anthropological Association, the Gerontological Society of America, and the Society for Applied Anthropology. She is co-author of the article "What do we know about older adults and HIV?: a review of social and behavioral literature," which was the third most-read article in the Journal of AIDS Care in 2012.