Older Adults with HIV/AIDS:

Experiences of Stigma-The Use of Personal Strengths

By

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ABSTRACT

This dissertation explores the stigma experiences of older adults who have HIV/AIDS, the personal strengths and other responses they have to these experiences, and whether they experienced personal growth as a result of their responses to stigma. A qualitative, phenomenological approach has been used in this dissertation. Older adults experienced stigma from family and friends and in the workplace. Some older adults responded to stigma by being resilient and empowering themselves with the support of family and friends. Older adults also had other responses to stigma such as non- disclosure of HIV/AIDS status and isolation. Some older adults experienced personal growth, for instance where they wished to give back some of their time and skills to the community. The results support the use of older adults and their families as key resources in the planning and implementation of stigma prevention programs.

Key words: Older adults, stigma, strengths responses, other responses, personal growth, HIV/AIDS.

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CHAPTER 1: INTRODUCTION

Overview of the Study

HIV/AIDS is a life threatening disease that affects people across all spheres of life. Stigma associated with HIV/AIDS has been acknowledged ever since the disease was first identified. Stigma has been a major impediment to identification, treatment, and prevention efforts (Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006). Stigma occurs across a cross section of people who are affected by HIV/AIDS (Emlet, 2005). The experience of stigma has been associated with clinical depression, shame, guilt, fear, anger, lesser chances of disclosure , and lower adherence to a medication regime (Fesko, 2001; Heckman, Kochman, Sikkema, & Kalichman, 2002; Vanable, Carey, Blair, & Littlewood, 2006). Stigma has often been viewed as a phenomenon that exists in the background of the AIDS epidemic rather than something that warrants study in its own right (Emlet, 2005). The individual facing stigma is largely viewed as being disempowered and weakened by the experience of stigma (Ayres et al., 2006; Fesko, 2001; Vanable et al., 2006).

Popular perception views HIV/AIDS as a disease that affects younger populations. However, a significant number of older adults have HIV/AIDS. According to the Centers for Disease Control (CDC), the number of older adults living with HIV/AIDS in the United States has risen from 65,655 in 2001 to 104,260 in 2004, a fifty-nine percent increase (Centers for Disease Control [CDC], 2005). New antiretroviral treatments are extending the lifespan of many middle aged adults diagnosed with HIV who are now living into old age. Concerns about the aging population within the HIV epidemic and the stigma older adults with the disease may face, have made it increasingly important to study the various experiences and pressures that older adults with HIV/AIDS experience. It is also important to examine the strengths they may be utilizing to deal with experiences of stigma associated with having HIV/AIDS. This information can then be analyzed to gain further insight into how these experiences may be understood to plan effective prevention options, treatment interventions, and policy measures.

Purpose of the Study

The purpose of the study was to examine how stigma experiences affected the lives of older adults with HIV/AIDS. The study examined their experiences of stigma, their strengths and other responses to stigma, and personal growth that they experienced as a result of their responses to stigma experiences. In this study, I made use of a phenomenological inquiry to understand stigma. Previous research in the field has concentrated on the negative implications of stigma on HIV/AIDS prevention and treatment (Emlet, 2003; Heckman et al., 2002). This study was aimed at gaining a detailed understanding of both the negative consequences of stigma as well as the positive use of personal strengths in dealing with stigma and deriving meaning from the stigma experience.

Studies have found that older populations have made use of personal strengths to deal with health problems (Chapin, Nelson-Becker, & Macmillan, 2006; Green & Cohen, 2005; Langer, 2004; Lewis, 1996; Perkins & Tice, 1999; Perkins & Tice, 1994). Other vulnerable populations such as injection drug users (Dickson-Gomez, Knowlton, & Larkin, 2004) and African American women with HIV/AIDS (Miller, 2005; Shambley-Ebron, & Boyle, 2006) have also made use of personal strengths in dealing with the stigma associated with a HIV/AIDS diagnosis.

In the past, social work practice had viewed old age and disease through the lens of the medical model and sought solutions accordingly (Weick, Rapp, Sullivan, & Kisthardtt, 1989). In the field of HIV/AIDS research, stigma has been viewed as a by-product of the disease. Social work practitioners have tried to contain the negative impact of stigma on the lives of their clients. Social work research has begun to focus on the stigma experiences of older adults with HIV/AIDS. However, most research in this area has examined the negative implications of stigma. Studies have not examined the use of personal strengths by older adults with HIV/AIDS to manage stigma and the growth that they may experience as a result of dealing with stigma on a day to day basis.

In this study, I examined the experiences of stigma faced by older adults with HIV/AIDS. I explored older adults' use of personal strengths to deal with stigma, if they demonstrated any positive response to their stigma experiences or if they did not demonstrate these responses; and their experiences of personal growth which may have resulted from their responses to stigma experiences. In this dissertation, I provide practitioners with in-depth knowledge of stigma and how it affects the lives of older people with HIV/AIDS while reflecting the voices of older adults who experience stigma.

Motivations for Conducting the Study

The study of stigma faced by older adults with HIV/AIDS and their use of personal strengths appealed to me because of my personal experiences dealing with stigma as a woman of color, my personal fear of an HIV/AIDS diagnosis, and because of questions that emerged as a result of my professional experience working with older adults. As a social work professional, I had the experience of working with older adults and their health issues. The difficulty of navigating social scenarios with advancing age was made clear to me through my work. As a researcher, I was interested in understanding the different dimensions of the stigma experience. In this study, I examined both the negative and positive faces of stigma as it was experienced by older adults with HIV/AIDS. I also explored the weaknesses and the strengths it may induce.

Previous research studies have identified stigma as a debilitating experience which robs those who experience it of the freedom of choice (Ayres et al. 2006; Fesko, 2001; Vanable et al., 2006). It also places those who experience stigma in poor mental health scenarios and risk situations. HIV/AIDS is perceived as a sexualized disease and popular perception largely considers young adults to be at the highest risk of contracting the disease. Even among these populations, stigma as a phenomenon has largely been studied as a problem faced by young people with HIV/AIDS. Little has been done to examine the personal strengths that may arise as a result of experiencing stigma. There is clearly a need for greater research in this area. I was motivated to carry out this study because of personal and professional reasons and because there is a gap in the research in this area.

Relevance to Social Work

Social work has been actively involved with people who have HIV/AIDS, but the profession has only turned its focus to older populations with the disease very recently (Emlet, 2006a; Emlet, 2006b; Emlet, 2005). This lack of attention to older populations living with the disease may be due to perceptions of younger age groups as being at greater risk and in need of greater intervention. While it cannot be denied that young adults have the greatest incidence of the disease, changing population demographics show that the percentage of older adults with this disease in most industrialized societies is growing (Emlet, 2006a; Emlet, 2006b; Emlet, 2005). This has made it extremely important for social work to focus on the aging face of the epidemic. The unique combination of old age and HIV/AIDS may place this group at a greater risk of experiencing stigma. Consequently, it is extremely important for social workers to understand the very nature of stigma as it is experienced by older adults and to plan treatment and prevention efforts that are tailored for them.

Needs Statement

Historical Context

HIV/AIDS was first discovered in the United Sates in the 1980s. At the time, it was associated with the deaths of young gay men from a disease called *Pneumocystis carinii* pneumonia. It was also found that there was an unusually high incidence of the disease, Kaposis' Sarcoma, among gay men from the ages of 20 to

50. The medical community took note of these deaths and of the other symptoms of the disease that they named Gay Related Immune Deficiency (GRID). Soon, it was clear that the disease was affecting all sections of society. In 1982, the CDC named the disease AIDS or Acquired Immune Deficiency Syndrome. In 1987, AZT became the first FDA approved drug used to treat HIV/AIDS. The government approved medication to contain AIDS through the AIDS Drug Assistance Program. In 1988, eleven states were granted HIV planning grants (AIDS Education Global Information System [AEGIS], 1998).

In 1990, the Ryan White Care Act was passed. The Act provided treatment to the poor and uninsured survivors of HIV/AIDS in the country (Abramowitz & Greene, 2005). The year 1990 also saw the inclusion of provisions against discrimination in the workplace for people with HIV/AIDS in the Americans with Disabilities Act (AEGIS, 1999). Further, legislation and policies passed by the federal and state governments as well as advances in medicine have prolonged the lives of many people with HIV/AIDS, giving rise to a concern that the epidemic is now aging.

The Aging HIV/AIDS Epidemic

HIV/AIDS is one of the most dangerous diseases of our times. Research indicates that no age group is safe from the threat of AIDS (Emlet, 2005). Though it has often been considered a younger persons' disease, growing numbers of adults 50 years and older are being diagnosed with HIV/AIDS. From 1990 to December 2001, the number of cases reported to the CDC in adults 50 years and older went up five fold (Mack & Ory, 2003). Current estimates indicate that in 2003, over 60,000 older

Americans were living with AIDS and more than 50,000 in this age group had died since the inception of the HIV/AIDS epidemic (Mack & Ory, 2003). Around twelve percent of patients with AIDS and eleven percent of those with HIV are adults 50 years and older (Zingmond et al., 2003). Although most studies would classify older adults as those who are 60 years and older (Fried et al., 2001), studies that have examined aging in people with HIV/AIDS have done so with adults 50 years and older (Mack & Ory, 2003; Zingmond et al., 2003). The reason behind altering the definition of older adults in these studies is primarily because most people with HIV/AIDS do not live into advanced ages, and adults who are 50 years and older form the aged population in this group. Orsulic-Jeras, Shepherd, and Briton (2003) suggest that older adults with HIV/AIDS fall into two categories: “long term survivors” (p. 234), that is those who have aged with HIV/AIDS, and adults who contract HIV/AIDS at an older age.

What It Means To Be Older and Living with HIV/AIDS

Being older and living with HIV/AIDS brings up a number of challenges. Not only is this population affected by the spread of HIV, the more vulnerable such as racial or ethnic minorities, among them are disproportionately affected by the disease (CDC, 2002). According to the 2000 Public AIDS Data set, ethnic minorities aged 50 years and older constituted 69% of cases among older adults reported in 1999, while these groups collectively form only 25% of the US population (CDC, 2002).

Older adults are more likely to report having absolutely no knowledge about HIV than are younger populations (Mack & Ory, 2003). This lack of knowledge may lead to a lack of awareness that they may be HIV positive. Many adults who are 50 years and older are diagnosed with HIV/AIDS later in the disease trajectory and could thus be less receptive to treatment (Funnye, Akhtar, & Biamby, 2002). The progression from HIV to AIDS is much faster in this age group. Chronic health problems are often accelerated, and ageist assumptions among medical staff regarding sexual and drug use behaviors by older adults may lead to a late diagnosis in this group (Mack & Bland, 1999). There is a greater vulnerability to HIV-related infections (Funnye et al., 2002) and a lack of programs that target their prevention needs specifically.

Older adults who may be HIV positive also face a unique social situation because of the views that society has on age appropriate behavior and health practices. Current research has shown a number of areas where older adults may find it more difficult to adjust to their HIV/AIDS diagnosis in comparison to other groups (Nichols et al., 2002). Older adults are less likely to seek out community supports and to have family members or siblings who could care for them (Heckman et al., 2002). They may find it harder to disclose their diagnosis than younger adults living with the disease (Emlet, 2008) and may face depression if they are stigmatized when they disclose their diagnosis (Kalichman et al., 2000). It has been found that older adults who received inadequate social supports had greater problems with issues of stigma and isolation (Nichols et al., 2002). They also face a number of dilemmas in telling their children about their HIV positive status. They may also find it difficult to seek support from the staff of service organizations who are not trained to manage issues associated with aging, sexuality, and HIV/AIDS (Linsk, Fowler, & Susan, 2003; Thorogood, 2002). HIV positive elders were less likely to access formal supports if they did not receive support from family and friends (Heckman et al., 2002). Older adults who did manage to access support networks were able to utilize these networks to replace those they lost as a result of stigma associated with their diagnosis (Poindexter & Shippy, 2008).

Older adults who belong to minority groups such as older gay men and African American men may be at greater risk of contracting the virus than other groups of older adults (Siegel, Schrimshaw, & Karus, 2004). They may also hide their sexual identities because of the fear of stigma associated with being gay (Morrow, 2001). Older gay men living with HIV/AIDS face stigma for having HIV/AIDS as well as for being gay (Emlet, 2006c). In addition, older gay men also face age related stigma from younger gay men (Gorman & Nelson, 2004; Schrimshaw & Siegel, 2003).

Another group of older adults who need special attention are older women living with HIV/AIDS. Studies have shown that older women were not adequately represented in prevention efforts (Binson, Pollack, & Catiana, 1997). They are unaware of the sexual risks that expose them to HIV/AIDS (Henderson, Bernstein, St. George, Doyle, Paranjape, Codie-Smith, 2004; Lindau, Leitsch, Lundberg, & Jerome, 2006; LeBlanc, 1993; Neundorfer, Harris, Brinton, & Lynch, 2005; Schable, Chu, & Diaz, 1996). They may also find it difficult to negotiate the use of protective measures such as condoms with their partners (Zablotsky, 1998; Zablotsky & Kennedy, 2003)

A growing number of older adults are getting HIV/AIDS and are facing a number of socio-economic and health problems that are unique to their situation. There are clearly a number of questions social workers need to explore in order to effectively meet the needs of this population, for instance: How do older adults who have HIV/AIDS deal with their diagnosis? Is there a great deal of shame and isolation that may be associated with this diagnosis? May this shame, this stigma, stop them from accessing the services that are essential to maintain their health and stop the further spread of the disease? Are factors such as time of diagnosis (contracting the virus at an age younger than 50 and living with it vis-à-vis getting it when they were 50 years and older), race, class, or gender additionally stigmatizing? Alternatively, are earlier experiences of stigma related to race, class, and gender associated with more positive growth and empowerment when they face stigma the next time as older adults with HIV/AIDS? What are the personal strengths that older adults with HIV/AIDS use to deal with their diagnosis? Is there any personal growth associated with the experience of HIV/AIDS related stigma and how older adults respond to it? These are important questions and they set the stage for this study.

Summary

In this chapter, I explored the aging of the HIV/AIDS epidemic. Facts were presented that support the need to conduct research with this population and the need for social workers to become more active in the field of aging and HIV/AIDS. I examined my own motivations: personal, professional, and academic for conducting this research. Finally, I identified issues faced by older adults with HIV/AIDS such as ethnic disparities, socio-economic problems, and medical vulnerability. Older adults experience stigma in different contexts. Their responses to stigma are determined by social and economic factors that influence their lives. It is extremely important to understand these factors in order to gain an in-depth understanding of stigma experiences of older adults living with HIV/AIDS.

CHAPTER 2: REVIEW OF THE LITERATURE

In the previous chapter, I discussed the needs of older adults with HIV/AIDS and the importance of conducting research with this population. Considering their medical and social vulnerability, it is extremely important to explore factors that may prevent older adults from accessing the services and medical help that they may require. In this chapter, I present two theoretical frameworks that can help to support the exploration of stigma experiences, responses to stigma, and experiences of personal growth by older adults who have been diagnosed with HIV/AIDS. These include Goffmans' theory of stigma and the strengths perspective. I also explore existing literature on stigma associated with HIV/AIDS and examine studies that have specifically looked at how older adults with HIV/AIDS may experience stigma and the use of personal strengths by older adults with HIV/AIDS.

Theoretical Frameworks

This dissertation has its theoretical underpinnings in the theory of stigma described by Ervin Goffman in his book '*Stigma: Notes on the Management of Spoiled Identity*' (1963) and in the strengths perspective described by Dennis Saleebey in his book '*The Strengths Perspective in Social Work Practice'* (2006). Both of these frameworks have been used to inform the study. It must, however, be clarified that I have not tested the effectiveness of either the theory of stigma or the strengths perspective within this dissertation. Rather, both of these frameworks have be used to provide the reader with a better understanding of participants' experiences of stigma, their responses to stigma, and the personal growth they may have experienced as a part of the stigma experience.

Goffman's theory of stigma has been cited extensively in qualitative and quantitative studies (Castro & Farmer, 2005; Herek & Capatino, 1997; Ingram & Hutchinson, 1999). These studies have examined the stigma experiences of various groups. It has also been cited in literature specific to the stigma experiences of individuals with HIV/AIDS including a few studies which explored issues surrounding aging with HIV/AIDS (Castro & Farmer, 2005; Herek & Capatino, 1997; Ingram & Hutchinson, 1999). The strengths perspective, on the other hand, has been used extensively in a number of qualitative studies and in a few quantitative studies of vulnerable populations with various health related issues. Among these, it has been used as a framework in studies which have examined issues of aging and health (Chapin et al., 2006; Green & Cohen, 2005; Langer, 2004; Lewis, 1996; Nelson-Becker, Chapin, & Fast, 2006; Perkins & Tice, 1999; Perkins & Tice, 1994).

Goffman's Theory of Stigma

Stigma and the stigmatized. I have used Goffman's theory of stigma as one of the theoretical frameworks that could provide the reader with an initial understanding of the stigma experiences of older adults with HIV/AIDS. Even though Goffman's theory has not been tested in this study, his conceptualization of stigma can still provide the reader with insights on how older adults experience stigma. According to Goffman (1963), stigma is an "attribute that is deeply discrediting" and which reduces someone from a "whole and usual person to a tainted and discounted one" (p.3). Stigma has also been described as a relationship between an attitude and a stereotype (Goffman, 1963). It is a phenomenon which is caused by an individual possessing an undesirable trait (in this case the HIV/AIDS diagnosis and old age) which is so overwhelming that it overshadows every positive trait that the individual may possess. Under normal circumstances, these positive traits would promote greater social interaction.

According to Goffman (1963), society consists of two kinds of people: the normal and the stigmatized (p.130). Normal people are those who do not have the underlying cause or factor of the stigma. Among the normal people, there are people who are associated with a stigmatized person, for example their family members. These associated people may experience a different kind of stigma by association.

Discredited and the discreditable. Goffman (1963) categorizes those who have stigma into two groups, ‘the discredited and the discreditable’ (p. 41). Individuals whose stigma conditions are apparent are called discredited individuals. In the case of older adults with HIV/AIDS, these may be individuals whose illness is physically apparent. On the other hand, the stigmatizing conditions of discreditable individuals are not apparent. These individuals often have to make the choice about whether they wish to disclose their stigmatizing condition and if they choose to do so, to whom and where they may make this disclosure.

Passing behavior. Goffman (1963) describes a lack of disclosure as “passing” (p. 73). If an individual chooses not to disclose his or her stigmatizing condition, he or she may have to carry out passing behavior. This is behavior where an individual pretends to be a member of the normal group but secretly belongs to a stigmatized group. In the case of older adults with HIV/AIDS, older adults may not disclose their HIV status to loved ones and friends.

Covering. An individual whose stigmatizing condition is very apparent may indulge in “covering behavior” (Goffman, 1963, p.102) to draw attention away from them and their condition. In the case of older adults, this would include behavior that may assign HIV symptoms to other diseases which are associated with old age.

The own and the wise. It is often the case that those with HIV/AIDS are stigmatized, yet there are individuals who are accepting of the condition and supportive despite it. These are referred to by Goffman (1963) as the “own and the wise” (p.19). Individuals in the “own” category actually share the stigma that the person has and are empathetic and sympathetic to their condition. The individuals in the “wise” category do not have the condition but still treat people living with HIV/AIDS with respect. Examples of wise individuals are supportive family members and friends.

Application of Goffman’s conceptualization of stigma. Ervin Goffman’s explanation of stigma and the different aspects of his conceptual framework have been used to understand how stigma affects the lives of people with different conditions. According to Byrne (2000), Goffman’s (1963) conceptualization of stigma can be applied to the mentally ill. Byrne (2000) refers to Goffman’s thought that the difference between a normal and a stigmatized person is a question of perspective. According to Byrne (2000), stigma associated with mental illness is promoted by existing stereotypes of people with mental illness as being weak and unable to take care of their own health. People with mental illness feel a sense of shame, isolation, and discrimination. Byrne (2000) suggests that improving interpersonal skills, transforming the patient into an advocate, and change within service systems will help a stigmatized person deal with the stigma.

Goffman's (1963) conception of stigma has also been applied to understand how people with chronic conditions such as physical disabilities or diabetes deal with their stigma. Goffman himself has discussed how people with physical conditions such as epilepsy are stigmatized as they cannot be accepted into "normal" society due to their unexpected seizures (Goffman, 1963, p.19). Joachim and Acorn (2000) describe how Goffman's stigma classification may be applied to people living with chronic conditions. They state that the way people with chronic conditions disclose their stigma is directly related to whether their illness or disability is visible or not.

According to Joachim and Acorn (2000), people with visible disabilities are considered to be more "discredited" as per Goffman's (1963) classification than those individuals whose stigmatizing conditions may not be apparent to the naked eye (p.41). People with illnesses such as diabetes on the other hand may not be as stigmatized as people with a physical disability as they may appear normal and their condition may not be apparent (Joachim & Acorn, 2000). They may also try to hide their condition and pass for "normal" (Goffman, 1963, p. 19). Younger people with diabetes may eat food or drink beverages that may be harmful to them in order to hide their condition from their peers. Joachim and Acorn (2000) also state that individuals with chronic conditions may choose to disclose their condition, however, if their disclosure is not well received then they are likely to spiral into depression or lose control of their lives. Stigma has also been related to physical conditions such as leprosy. Conditions such as leprosy fit Goffman's conception of a stigmatizing condition that leads to social isolation (Wong & Subramanian, 2002).

Goffman's conceptualization of stigma has also been applied to older adults. According to Martin, Leary, & Rejeski (2000), older adults have many similar characteristics to other stigmatized individuals. The use of hearing or other aids by older adults can be seen as attributes that make them different from "normal" individuals as per Goffman's (1963) classification (Martin et al., 2000). Older people with dementia are also stigmatized (Corner & Bond, 2004). Older adults with dementia are often assigned stigmatizing labels and are treated the same way as very young children. They also fit Goffman's (1963) assertion of a stigmatized individual not being viewed as "normal" by society (p. 19).

Critique of Goffman's stigma. Goffman's theory provides a clear definition of stigma (Link and Phelan, 2001). He also examines both individual and social characteristics of stigma (Camevale, 2007). However; this theory has been critiqued in the stigma literature. According to some authors, Goffman, in his theory of stigma, assigns a helpless role to the person facing stigma and does not acknowledge that stigmatized individuals may make valuable contributions to society (Fine & Asch, 1988; Gill, 2001). According to Anspach (1979), Goffman's conceptualization of stigma dooms people experiencing stigma to a lifetime of unhappiness in which they are unable to relieve themselves of their internalized perceptions that they are not normal. Parker and Aggleton (2003) have critiqued Goffman's conception of stigma as being too "static" (p. 14). According to them, stigma, particularly stigma associated with HIV/AIDS, is a phenomenon which changes according to the stage of HIV/AIDS disease. Despite these critiques of his theory, Goffman's conceptualization of the difficulties that stigmatized people face has been considered to be very relevant and his theory is still a dominant one in explaining stigma experiences. One of the main gaps in Goffman's theory of stigma is that it does not address the possible positive responses or growth that may result from the stigma experience. In this dissertation, I examine some of the key concepts of the strengths perspective so that there is a theoretical space in which older adults with HIV/AIDS can express the positive learning and growth that resulted from their stigma experience. I also discuss the literature on stigma and HIV/AIDS, older adults and HIV/AIDS, and the use of the personal strengths by older adults with HIV/AIDS.

The Strengths Perspective

The strengths perspective rose as a contrast to the pathology focus within the helping professions which labeled human nature as negative and consequently tailored interventions to suit that perception (Weick et al., 1989). The proponents of the strengths perspective have looked at the positive side of human nature and the strengths within human beings to solve problems. This approach is more in consonance with the value framework of social work and is likely to provide a more positive direction for the growth of the profession in general.

Key concepts of the strengths perspective. According to Saleebey (2006), there are seven key concepts to the strengths perspective: empowerment, membership, resilience, regeneration and healing from within, synergy, dialogue and collaboration, and suspension of disbelief. When these key concepts operate in unison, they place clients in a position of power throughout the planning and decision-making process and formulate unique relationships between the caseworker, family, and community resources to help the clients realize their goals.

Empowerment “indicates the intent to, and the processes of, assisting individuals, groups, families, and communities to discover and expend the resources and tools within and around them” (Saleebey, 2006, p. 11). Membership means that “people must band together to make their voices heard, get their needs met, to redress inequities, to reach their dreams” (p. 12). Resilience refers to peoples’ capabilities to positively adapt to their circumstances despite significant adversity they may have faced (Saleebey, 2006). The literature on resilience has also defined resilience as people’s capacity to transform negative experiences into positive learning opportunities (Adger, 2000; Benard, 2004; Farber, Schwartz, Schaper, Moonen, & McDaniel, 2000; Holling & Golling, 2002; Langer, 2004).

According to Saleebey, individuals are born with the capacity to “regenerate and resist when faced with disorder, disease, and disruption” (Saleebey, 2006, p.14). The process of healing and regeneration requires that there be collaboration between professionals and individuals facing a problem. It also requires professionals to believe in their clients and to help clients solve their problems on “their own terms” (p.16).

Unlike the problem-solving approach, which focuses on identifying a problem and finding a solution, the strengths perspective concentrates on the resources of both the person as well as the environment in which the individual resides. Problems are not denied, but they do not get center stage. The strengths perspective recognizes that illness may be a traumatic experience, but it may give rise to inner strengths. Further, it proposes that individuals, communities, and families have infinite capacity for growth and change. Collaboration with clients is viewed as leading to greater success in bringing about required changes. Finally, Saleebey (2006) contests that; the environment is full of resources that can aid recovery and treatment.

Literature Review

Stigma and HIV/AIDS

Various groups of people with HIV/AIDS have undergone different experiences of stigma. Some responses to stigma that have been identified in the literature are discussed below. Vanable et al. (2006) conducted a study with 221 men and women to evaluate the relationship between stigma and health behaviors needed to keep HIV/AIDS in check. It was found that greater stigma could lead to lower adherence in medication regimens and poor disclosure of HIV/AIDS status to partners. People living with HIV/AIDS are often socially isolated when their disease is made public (Ayres et al., 2006; Fesko, 2001). In a qualitative study conducted by Fesko (2001), it was found that people with HIV/AIDS faced increased stigmatization at the workplace. While the effects of stigma can be detrimental in the prevention and treatment of HIV/AIDS, adults who face stigma often find ways and means to deal with it and carry on with their lives. A meta-synthesis of 56 reports carried out by Sandelowski and Barraso (2003) found that mothers with HIV/AIDS developed unique mechanisms which allowed them to maintain their maternal bond with their children, protect themselves, and shield their children from the negative impact of social stigma.

The impact of stigma on individuals living with HIV/AIDS is profound (Lee, Kochman, & Sikkema, 2004). Though the overt stigmatization of people with HIV/AIDS has reduced in the United States, many people would still prefer to avoid those with the disease. According to Devine, Plant, and Harrison (1999), most people without HIV/AIDS have a strong “us” and “them” (p. 1208) ideology when they think or react to people who have HIV/AIDS. This is the root of all stigmatizing behavior towards the group of individuals with HIV/AIDS (Devine et al., 1999). Some people who do not have the disease find it hard to associate with people living with HIV/AIDS. They believe that the disease was caused by the individual’s deviant behavior or lifestyle trait. Studies on stigma faced by people living with HIV/AIDS have also concentrated on the people who stigmatize others and why they do so (Lee et al., 2004).

There are also several other reasons why HIV/AIDS is associated with a large amount of stigma. An HIV/AIDS diagnosis is associated with unprotected sex, homosexuality, and IV drug use. In some ways, the stigma associated with HIV/AIDS is considered to be a layered stigma as it is stigma added to the stigma associated with the above mentioned deviant behaviors (Lee et al., 2004). For example, gay men who are also HIV positive face the stigma both with being gay and having an HIV/AIDS diagnosis (Grossman, 1991). According to Parker and Aggleton (2003), stigma “feeds upon, strengthens, and reproduces existing inequalities of race, class, gender, and sexuality” (p. 13). There are, however, some individuals who may not be as stigmatized by an HIV/AIDS diagnosis as others. These are people who are perceived to be innocents such as hemophiliacs, babies, and young children (Taylor, 2001). It is also considered to be a disease that an individual is responsible for contracting in comparison to other diseases like cancer which are perceived to have more biological causes. It is also a contagious disease and is considered to be dangerous to society in general. Different groups may also be stigmatized differently. For example, Herek and Capatino (1999) state that African Americans are less judgmental of HIV/AIDS survivors who are injection drug users than a white population may be.

Studies on stigma and HIV/AIDS have found that an individuals’ perception of stigma may actually account for the impact of the disease on the individual (Fife & Wright, 2002). An individual’s perception of how loved ones or members of the general public may react to their diagnosis may also influence to whom they disclose or whether they choose to disclose their HIV/AIDS status at all (Derlega, Winstead, Greene, Serovich, & Elwood, 2002).

Older adults with HIV/AIDS, particularly those who may have been diagnosed at a younger age have therefore had a longer time to internalize their notions of the stigma associated with the disease and may find it more difficult to break out of those boundaries. One of the internalized reactions to stigma associated with HIV/AIDS is a feeling of shame (Fortenberry et al., 2002). However, it is also possible that if older adults with HIV/AIDS had earlier stigmatizing conditions, then they may have had more time and experience in learning how to deal with stigma.

Internalized stigma is likely to affect the mental health of individuals and their effective management of the disease (Lee et al., 2004). Individuals with HIV/AIDS may also find it difficult to receive support from organizations that normally provide support to individuals who are ill. In fact, many individuals feel that they must exercise extreme caution in revealing their HIV/AIDS status within the religious context (Fife & Wright, 2002). HIV/AIDS related stigma has also been associated with delays in timely testing which is required for appropriate care and treatment (Chesney & Smith, 1999; Fortenberry et al., 2002). People at risk of HIV/AIDS are often fearful of social consequences of having the disease. They may be fearful of many things such as family disapproval or a loss of health insurance. They may delay testing for these reasons. HIV/AIDS stigma is not felt just by the person who has the disease. Very often, the seronegative partner or the person who does not have HIV/AIDS is also likely to face stigmatization because of their partners' seropositive status (Straten, Vernon, Knight, Gomez, & Padian, 1998).

According to Siegel, Lune, and Meyer (1998), people facing stigma associated with HIV/AIDS can respond in a number of ways. Some people may try to hide their stigmatizing condition or pass it off as something less stigmatizing like cancer. Others may actively fight the stigma and reconfigure their environment to include people who are supportive and remove those who actively stigmatize them.

Research studies have also made an attempt to measure stigma associated with HIV/AIDS. One of the more popular scales that are used to measure stigma has been developed by Barbara Berger and measures aspects such as social affect, social support, and social conflict (Berger, Ferrans, & Lashley, 2001). When the scale was used among populations with HIV/AIDS, it was found that fears of disclosure and concern about public reactions were some of the primary stigmatizing factors. Such scales have also been adapted to measure the stigma felt by specific groups such as older adults (Emlet, 2005). According to Alonzo and Reynolds (1995), people with HIV/AIDS also experience different forms of stigma at different stages of the disease. Even though most people living with HIV/AIDS are fearful of contact with social groups, it has been found that the more contact a non- HIV positive population has with people living with HIV/AIDS, the more likely they are to be supportive and less stigmatizing of this group in general (Herek & Capatino, 1997).

Older Adults with HIV/AIDS and Stigma

In this dissertation, I explore the phenomenon of stigma experienced by older adults with HIV/AIDS. Existing literature on stigma and older adults with HIV/AIDS is not very comprehensive (Genke, 2000). A few studies have found that older adults are likely to experience stigma as a result of their HIV/AIDS status (Emlet & Farkas, 2002; Emlet, 2003). In a study conducted to evaluate how older adults (N=88) responded to a HIV Stigma Scale as opposed to younger adults who had been measured by the same scale, it was found that stigma exists across various dimensions. Even within the population of older adults, being an older woman and of any sexual orientation other than heterosexual was more likely to increase stigma associated with the disease (Emlet, 2005).

A study conducted with 113 middle-aged and older adults found that older adults with HIV/AIDS often felt suicidal. Often stigma that was associated with the disease further exacerbated the situation (Kalichman, Heckman, Kochman, Sikkema, & Bergholte, 2000). Older adults with HIV/AIDS are at increased risk of social isolation. Stigma experiences prevent older adults from seeking the informal support and help they need to deal with HIV/AIDS (Emlet, 2003; Heckman et al., 2002; Shippy et al., 2005). They lean more on formal support systems to deal with the disease (Heckman et al., 2002). Older adults are less likely to disclose their HIV status to family members and social networks due to a fear of stigma and isolation (Emlet, 2006b). However, having a close friend or other forms of social support may lead to reduced stigma (Emlet, 2006a). Spirituality may also have a role to play in how older adults deal with stigma. Siegel and Schrimshaw (2002) conducted interviews with 63 participants in which they examined the role of spirituality in the lives of older adults with HIV/AIDS. Spirituality was found to increase the feeling of empowerment, resilience, and strength among older adults living with HIV/AIDS (Siegel & Schrimshaw, 2002).

Older Adults, Strengths and HIV/AIDS

In the studies above, older adults used social support and spirituality in dealing with their stigma. These concepts are also discussed as a part of the strengths perspective within social work literature. This section examines studies within social work literature which have explored the use of personal strengths by older adults with HIV/AIDS. Siegel and Schrimshaw (2002) examined the role of spirituality with older adults who had HIV/AIDS and noted an increase in strengths and resilience in more spiritual older adults. A study conducted by Vance and Woodley (2005) identified fear of death, financial worries, fear of disclosure, and long-term coping as potential sources of stress for adults who were aging with HIV/AIDS. Participants in their study made use of strengths such as spirituality and community support to deal with their diagnosis.

Though not much of the strengths literature deals exclusively with older adults with HIV/AIDS, personal strengths have been used extensively by older populations in other health and social settings (Chapin, et al., 2006; Green & Cohen, 2005; Langer, 2004; Lewis, 1996; Nelson-Becker et al., 2006; Perkins & Tice, 1999; Perkins & Tice, 1994). In all the above studies, the use of strengths has enabled older adults and their families to deal with difficult health situations from a position of empowerment and control. The strengths perspective encourages a shift in this view. According to this perspective, a life changing medical diagnosis is no longer considered a threat but rather an opportunity to tap hidden strengths and resources.

The strengths literature has also been used to understand how other vulnerable populations deal with stigma. A case in point is the use of cultural strengths by the African American community to deal with the stigma associated with HIV/AIDS. In a study conducted with African American women with HIV/AIDS, it was found that the strength that they derived from their cultural heritage of being strong black women helped them to deal with the stigma associated with being HIV positive (Shambley-Ebron, & Boyle, 2006). African American men have also accessed their spiritual resources to deal with the stigma associated with being HIV positive (Miller, 2005). In general, it has been found that the use of cultural strengths in the African American community helps them to deal with the stigma associated with having HIV/AIDS (Dickson-Gomez et al., 2004).

The above mentioned studies demonstrate that the use of personal strengths were an integral part of an older adults' experience of dealing with a health crisis. Strengths have also clearly been used by vulnerable populations with HIV/AIDS to deal with stigma and discrimination. The experience of generating and utilizing strengths is an important part of both health and stigma experiences for adults with HIV/AIDS. It is therefore important to explore not just the negative consequences of stigma for older adults with HIV/AIDS, but also the use of personal strengths in dealing with stigma. The use of personal strengths has been emphasized in the research questions so that older adults who have experienced stigma would have the opportunity to voice whether there have been any positive changes, experiences, or growth due to dealing with the difficult diagnosis of HIV/AIDS and the stigma that may follow.

Summary

In this chapter, I have explored two theoretical models as well as the literature that examines various stigma and strengths experiences of older adults living with HIV/AIDS. The literature has mainly explored the negative effects of stigma associated with HIV/AIDS and has not examined how older adults' experiences of stigma may give rise to positive growth and experiences. This study aims to address this gap in the literature by examining not just the stigma experiences of older adults but also their experiences of strengths and personal growth. In the following chapter, I will lay out the methodology that was used in this study in order to provide the participants in the study with the opportunity to voice their experiences.

CHAPTER 3: METHODOLOGY

Previous chapters in this dissertation have examined the need to understand the experiences of older adults living with HIV/AIDS. It is extremely important that researchers examine not just the negative connotations of a stigma experience but also explore the positive growth that may result from stigma experiences associated with HIV/AIDS. Because this study sought to examine a wider range of responses to stigma than most previous researchers had explored, it was extremely important to make use of a methodology which allowed older participants in the study maximum freedom to voice their experiences without binding their responses in a rigid conceptual or methodological framework. After exploring possible methods, I decided to use Clark Moustakas's phenomenological method (Moustakas, 1994) as one that would allow me to explore stigma, strengths and other responses to stigma, and personal growth in an in-depth manner and would give the participants space to share the full range of their experiences.

Rationale for the Research Design

The rationale section of this chapter includes: the rationale for the paradigm of inquiry, the justification for the use of certain methods within the design, the method of sampling used, the use of concepts within the research design, phases of inquiry, and the role of the dissertation committee in enhancing study findings and in the preparation of the final report. Current research on stigma experiences of older adults living with HIV/AIDS is quantitative (Emlet, 2006a, 2006b; Shippy et al., 2005) and qualitative (Poindexter & Linsk, 1999) in nature. Qualitative inquiry has been used in this dissertation. According to Patton (2002), a quantitative analysis would assign a limited set of questions to a large number of people. The results of such a study are largely generalizable. Qualitative studies on the other hand, provide a “wealth of detailed information about a much smaller number of people and cases” (Patton, 2002, p.14).

I carried out a detailed examination of stigma as it was experienced by older adults with HIV/AIDS in this dissertation. In-depth qualitative interviews were conducted with 21 participants. The use of qualitative methodology permitted me to extract the richest and most meaningful understanding of stigma from older adults’ experiences. A quantitative design would not have provided an intimacy with the participants and the data which was essential in gaining an understanding of the richness and meaning within the stigma experience for older adults with HIV/AIDS.

A phenomenological perspective has been used in this dissertation. According to Patton (2002), phenomenology explores the “meaning, structure, and essence of the lived experience” of a certain phenomenon, for a “person or a group of people” (p. 104). A phenomenological paradigm is appropriate for those issues, which have their roots in the researcher’s “autobiographical” experience and which also have a deeper social significance (Moustakas, 1994, p.103). This dissertation was based on my personal experience with HIV/AIDS, my professional work with older adults and their health issues, and my conviction that the issue of aging and HIV/AIDS is socially relevant and significant to the social work profession. The use of a phenomenological inquiry allowed me to carry out an in-depth and intimate examination of stigma as a phenomenon.

Within the broader paradigm of phenomenology, I made use of a transcendental phenomenological method of analysis as presented by Clark E. Moustakas (1994). According to Moustakas, the word phenomenological is used to describe a process where the researcher uses the richness of the participants' experience to gain a deeper understanding of a phenomenon. Though Moustakas had laid out his method very clearly, he had not specified techniques to fulfill certain procedures in his method. Patton's (2002) generic qualitative method was used throughout the research design to compensate for gaps in Moustakas' phenomenological method. Instances where Patton's work was used to address these gaps are found in the sampling, formation of the interview guide, coding and deriving themes, and trustworthiness (credibility and transferability) sections of the research design. Patton's method is generic and not affiliated with any particular qualitative paradigm. Thus, it was easier to merge the work of these two authors, and maintain the phenomenological focus of this design.

Sampling in qualitative studies is largely purposive. Purposive sampling allows the researcher to gather information-rich, in-depth data that are required to make a qualitative study effective. While Moustakas (1994) states that criteria must be developed for the selection of participants, he does not lay down any particular steps to establish these criteria. In this dissertation, I utilized Patton's (2002) criterion sampling to gather information from study participants. A certain set of criteria were identified. These criteria, for the selection of participants in this study, were the age of the participant (50 years and older), their diagnosis (HIV/AIDS), and their identifying an experience of stigma.

A broad overview of concepts is given in the next section of the chapter to further enhance the understanding of stigma for any reader of this dissertation. In this study, I focused on how these concepts emerged from the data and findings of the study. The definitions of the phenomenon of stigma are flexible. These definitions have undergone changes based on the data derived from this study. Before actually carrying out the research, I formed a dissertation committee. The chair of my dissertation committee and the methodologist reviewed my work through the research process. They also provided their expertise in the areas of carrying out the methodology and writing up the report.

Research Questions

Previous research studies have identified stigma as a debilitating experience that robs those who experience it of the freedom of choice (Ayres et al. 2006; Fesko, 2001; Vanable et al., 2006). These studies also imply that people who experience stigma are more likely to experience poor mental health and be prone to risk situations. HIV/AIDS is perceived as a sexualized disease and popular perception largely considers young adults to be at greater risk. Even among these populations, stigma as a phenomenon producing largely negative consequences has largely been studied as a problem faced by people with HIV/AIDS. Little has been done to examine the personal strengths that may arise as a result of experiencing stigma and may be used to deal with it. The following research questions have been formulated as a result of my personal interest in stigma and HIV/AIDS and the social significance that this issue has to the field of health and social work.

The research questions are:

- What are the experiences of stigma that older adults with HIV/AIDS encounter?
- How do older adults employ personal strengths when responding to the stigma associated with the disease?
- What other responses do they have to stigma?
- How do these responses, both strengths related and other, contribute to personal growth?

Key Concepts

According to Moustakas (1994), once the researcher has formed the research question, he/she should define the key terms of the question. According to Kelle (1997), inductive qualitative reasoning describes a phenomenon by "subsuming it under an already existing category or rule" (p. 10). These categories may be based on the researcher's existing knowledge of theory and practice. However, all pre-existing knowledge and prejudice undergoes a change through the process of conducting the research. The researcher may be forced to revise his or her pre-conceived concepts or even abandon them on the basis of themes that may emerge from the data. The key terms in the research questions are: stigma, older adults, personal strengths, and personal growth. These terms are further explained below.

Stigma

According to Green and Platt (1997), stigma experiences or how adults with HIV/AIDS undergo stigma can be placed in two categories. These are “enacted” stigma (discriminatory practices applied to people with HIV/AIDS) and “felt” or perceived stigma (the fear that people with HIV/AIDS have of enacted stigma) (Green & Platt, 1997, p.72). Within this dissertation, I have examined both perceived and enacted stigma experiences of older adults. Responses to stigma refer to how older adults with HIV/AIDS are likely to react to stigma. This refers to both positive and negative responses. Older adults may develop positive responses to stigma and may emerge stronger as a result of exposure to stigma. The literature, however, has popularly noted negative responses to stigma. Some of these responses are: lesser adherence to medication (Bennett, Kelaher, & Ross, 1994), social withdrawal, and increased risk behavior (Vannable et al., 2006). One of the limitations within this concept is that the development of positive strengths by older adults as a response to stigma has never been studied. Therefore, there is not much literature to support the use of personal strengths as a response to stigma within this population.

Older Adult

Older adults have been defined by many gerontologists as adults who are 60 years and older. However, according to the American Psychological Association [APA], the definition of age varies according to the population that is being studied (2007). The older population among people with HIV/AIDS can be defined as those who are in the older subgroup in terms of having the disease. For the purpose of this dissertation, older adults are defined as those who have HIV/AIDS when they are 50 years or older. This definition is based on other studies that have stated that the older population in this group is 50 years and older (Emlet, 2005, 2006a, 2006b). One of the weaknesses of this concept is that the information derived from this age group is hard to synchronize with other studies of health and older populations, as other studies largely define an older adult as someone over the age of 60. Another area to consider is that there are two categories of older adults who have HIV/AIDS. These are people who have been diagnosed with HIV/AIDS when they were 50 years or older and adults who may have contracted the HIV/AIDS virus when they were younger than 50 and have grown older with the disease. Considering that forms of stigma and discrimination may have changed and lessened in intensity since the inception of the HIV/AIDS epidemic, it was important to note the changes in the experiences of stigma that older adults who had aged with the epidemic describe and compare them with those older adults who had received their diagnosis at a more recent date.

Personal Strengths

An important concept in the research design is the concept of personal strengths used by older adults to deal with stigma. I made use of a phenomenological perspective in order to understand how older adults with HIV/AIDS derive meaning from their stigma experiences. As discussed in the previous chapter, personal strengths refers to responses to stigma by individuals where they demonstrate the use of empowerment approaches, seek membership in support groups, use spiritual resources, and/or engage in collaborative dialogue with medical and service professionals to access effective care despite their stigmatizing condition. An understanding of how older adults may use personal strengths is an integral part of the dissertation.

Personal Growth

As discussed in Chapter Two, not many studies have demonstrated that people respond to stigma in positive ways. However, some studies have stated that experiences of stigma may actually lead to new experiences such as a change of jobs or stronger relationships within the family (Hermann & Miall, 1990). People who experience positive growth from stigma are generally more assertive and make greater efforts at social interaction. Personal growth within this study refers to positive changes in habit, temperament, or lifestyle that may have occurred as a result of older adults' use of personal strengths and other empowering changes that older adults may have made in their lives as a response to the stigma of being older and having an HIV/AIDS diagnosis.

Protection of Human Subjects

The Human Subjects Review process was completed to ensure that the method and motives for the research were ethical, and that participant rights were protected. Respondents in the study were allowed to withdraw at any point of time in the study. Participants were fully informed about the nature of the study, that it would be tape-recorded, and about the procedures that were used use to keep this these data private and confidential. Interviews with the participants were stored in digital files in my computer. I assigned numbers to the transcripts so they could not be traced back to participants by their names. Participant addresses and other personal information were printed and stored in a locked file cabinet in my home. All identifying information such as names, addresses etc. have been removed from this dissertation. Transcripts will be stored in a secure location at my home for future research and publication. Tapes will be erased at the end of this study. Participants were sent an initial report and I have incorporated their feedback and suggestions in this dissertation.

Methodology for Data Collection

The study methodology is a combination of the methods suggested by Moustakas (1994) and Patton (2002). I primarily made use of Moustakas' phenomenological method. I utilized Patton's methodology to fill perceived gaps in Moustakas' method. According to Moustakas (1994), the researcher has to carry out a "series of methods and procedures that satisfy the requirements of an organized, disciplined, and systematic study" in order to derive "scientific evidence in phenomenological investigations" (p. 103). These include: "discovering a topic rooted in autobiographical meanings" as well as in "social meanings and significance," "conducting a comprehensive review of the literature," "constructing a set of criteria to locate appropriate co-researchers" (participants), developing an agreement of "informed consent," and "developing a set of questions or topics to guide the interview process" (p. 103). In this dissertation, I constructed a set of criteria to locate the participants for this study. I planned provisions for informed consent and protection of human subjects. I also constructed a set of questions with probes to guide the interview process (See Appendix B).

Data Sources

The participants were contacted through local organizations that work with clients who have HIV/AIDS within Kansas and Missouri. After initial contact was established, I sent letters and emails with a summary of my proposed study to executive directors or program heads and asked them to allow me access to older clients with HIV/AIDS. I also made phone calls to program coordinators to further explain the nature of the study.

Participants/Sampling (Locating Co-Researchers)

Moustakas (1994) has identified this process of selection as finding “appropriate co-researchers” (p. 103). Moustakas lays out no specific criteria to actually locate participants. He states that the participant in the study should have experienced the phenomenon, should be interested in exploring it with the researcher, and should be willing to allow the researcher to publish findings in a thesis or dissertation. This method of sampling is in keeping with Moustakas’ (1994) instructions for “constructing a set of criteria to locate co-researchers” (p. 103). As the range of experiences of those dealing with HIV/AIDS is so wide, this form of sampling allowed me to access adults with HIV/AIDS who met the following criteria: 1) participants should be 50 years or older; 2) participants should have HIV/AIDS.

Recruitment

Program directors in the organizations suggested that I frame a letter to potential participants explaining the nature of the study and requesting them to participate in the study. This letter, which was sent by the organizations to their older clients, contained my contact information. Twenty-one older adults called me back and agreed to participate in the study. This procedure was followed to maintain the confidentiality of clients. Only the persons within the organization who helped me gain initial access and I know the identities of clients who participated in the study. The confidentiality clause in the document of informed consent will ensure that no other person is informed of the participant's HIV/AIDS status, or that the participant is taking part in the study.

Data Collection Strategy

I used the "long interview" which is the most frequently used tool of data collection in a phenomenological analysis (Moustakas, 1994, p. 114) in this study. A phenomenological interview is informal and makes use of open-ended questions. While the researcher may make use of an interview guide to elicit "a comprehensive account" (Moustakas, p. 114) of the phenomenon, these questions are flexible, and may be changed or not used at all when the participant is sharing their experience of a particular aspect of the phenomenon.

In keeping with the phenomenological method of interviewing, I made use of Patton's (2002) interview guide method. This method ensured "that the basic lines of questioning" was "pursued" with every participant (Patton, p. 343). It also provided me with a framework within which questions were "developed and sequenced"

(Patton, p. 344). However, interview questions were open- ended. The interview guide was flexible and went through changes depending on the experience of the older adult being interviewed. A preliminary interview guide was prepared and discussed with members of the doctoral committee. I pilot-tested the preliminary interview guide with one older adult living with HIV/AIDS. The interview guide was finalized after I incorporated the feedback given by all of the above sources.

Informed Consent

According to Moustakas (1994), it is the responsibility of the researcher to "develop procedures for insuring full disclosure of the nature, purpose, and requirements of the research project" (p. 109). Before collecting data, I informed participants about the nature of the study. Appropriate informed consent and confidentiality measures were used and the responsibilities of both the participant and the researcher were clearly outlined.

Procedure for Collecting Data

In-depth, semi-structured, face-to-face interviews were conducted with the participants. I introduced myself and informed the participant about the nature of the study. I also informed participants about procedures that were in place to protect their privacy and safety. Once the participant being interviewed was relaxed, I conducted the interview. The interviews lasted for 60-80 minutes and were recorded on tape. Flexibility of time was allowed for those participants who wished to elaborate on their experiences.

According to Moustakas (1994), the interviewer is “responsible for creating a climate in which the research participant will feel comfortable and will respond honestly and comprehensively” (p. 114). The venues in which interviews were conducted were the participant’s home, an HIV/AIDS organization, or any other venue that was convenient for both the participant and the researcher. The venues met the requirements for privacy, confidentiality, and a quiet atmosphere where interviews could be taped without interference.

Data Analysis

Inductive and Deductive Qualitative Analysis

According to Patton (2002), deductive analysis refers to data that can be “analyzed according to an existing framework,” while inductive analysis “involves discovering patterns, themes, and categories in one’s data” (p. 453). In this study, I made use of Clark Moustakas’ (1994) and Patton’s methods of analysis. Both Moustakas (1994) and Patton (2002) make use of themes in analyzing information from the transcribed interviews of participants. The final goal of Moustakas’ phenomenological method is to derive a core understanding of the phenomenon from the experiences of individual participants in a study. In this study, I analyzed themes that emerged from the data that were gathered from the participants in the study. My understanding of the phenomenon of stigma experienced by older adults with HIV/AIDS was based on their stories and discussions.

Transcribing the Interviews

Organization of the data can only begin once the "primary researcher places the transcribed interviews before him or her, and studies the material through the methods of phenomenological analysis" (Moustakas, 1994, p.118). After conducting the interviews, I transcribed each interview. Once the data were transcribed, I continued with the procedures of the phenomenological analysis, also known as a phenomenological reduction.

Phenomenological Reduction

Phenomenological reduction uses "textural language" to describe both the actual experience of the participant, as well as the researcher's thoughts, feelings, and intuition about the phenomenon that is being explored (Moustakas, 1994, p.118). I examined the data in great detail. This process allowed me to establish an intimate relationship with the phenomenon, and to examine the participants' experiences of the phenomenon in the context of my own beliefs and attitudes.

According to Moustakas (1994):

> The procedures include horizonalizing the data and regarding every question and regarding every horizon or statement relevant to the topic as having equaled value. From the horizonalized statements, the meaning or meaning units are listed. They are clustered into common categories or themes, removing overlapping and repetitive statements. The clustered themes and meanings are used to develop the textural descriptions of the experience. From the textural descriptions, structural descriptions and an

> integration of textures and structures into the meanings and essences of the phenomenon are constructed (p.118-119).

Horizonalizing the data (data units). The first procedure in phenomenological analysis is “horizonalizing the data” (Moustakas, 1994, p.123). This is done so that “every horizon or statement having relevance to the topic” is regarded as having “equal value” (Moustakas, 1994, p. 123). According to Moustakas, the researcher must carefully consider “each statement in the transcript,” record all relevant units,” and “list each non-repetitive, non overlapping statement” (Moustakas, p.122). These can be described as “invariant horizons or meaning units of the experience” (Moustakas, p.122).

I examined each transcript gathered from the participants in the study for remarks and sentences that were relevant to the study and described experiences of stigma, responses to stigma, personal strengths, or any experience of growth and noted them separately onto index cards. The transcripts were imported into a file in Atlas Ti software. Coding tools within Atlas Ti were used to separate and organize these data. I listed every expression relevant to the experience of stigma faced by older adults in the computer. Atlas Ti software was used to organize the data in the computer. This aided in the process of horizonalization.

Relating and clustering meaning units into themes. Once the data were horizonalized, I related and clustered meaning units into themes. Though Moustakas (1994) has stated that deriving themes from the meaning units are a step in the phenomenological methodology, he also stated that the researcher has the flexibility in choosing how to organize data to recognize emerging themes. I followed Patton's (2002) method of organizing data into themes. According to Patton, there are two steps involved in deriving themes from the data. These are coding the meaning units and conducting a pattern and theme recognition.

After transcribing the interviews and preparing the meaning units, I conducted the first step in analysis which is coding the data. According to Patton (2002), "developing some manageable classification or coding scheme is the first step of analysis" (p. 463). Patton (2002) thoroughly reviews all the transcripts and notes. He prepares notes on various passages, and makes note of various topics the data may be organized into. This is called indexing the data. He then prepares a list of "shorthand codes" which he pastes in various "data passages" (p. 463). Finally, after several readings of the transcripts, a final coding guide is prepared and the data can be indexed and coded.

Following this method, I thoroughly reviewed the interview transcripts. Once the transcripts were reviewed and organized into meaning units, I developed preliminary coding categories (shorthand codes) and index categories as I saw them emerge from the transcripts and data units. This initial analysis was discussed with the chair and the methodologist. Their feedback was incorporated to form a final coding guide.

Pattern and theme analysis. After the final coding guide was ready, I reviewed the data derived from transcripts and data units and coded all the data. Once this process was completed, I conducted a pattern and theme analysis. According to

Patton (2002), the ability to recognize themes requires the researcher to identify patterns (p. 452). Patton refers to this analysis as content analysis. Before beginning this content analysis, I identified the sensitizing concepts of stigma. According to Patton (2002), these refer to knowledge and biases that I may bring to the research. For the purpose of this study, I made a list of the facts about stigma derived from my review of the literature. I also made note of my own biases regarding aging and HIV/AIDS. These notes helped me make clear distinctions between what current research may say about stigma, and the information that was derived from the actual data that I gathered. Once the sensitizing concepts were identified, I conducted the content analysis.

Content analysis. In the first step of content analysis, I reviewed the sensitizing concepts of stigma, interviews, the coding guide, and the meaning units to form a broad framework. This allowed me to formulate an overview of what the data portrayed. This framework was reviewed and underwent changes many times as further analysis of data was conducted.

In the second step of analysis, I identified indigenous concepts that describe stigma experiences of older adults. An emic analysis was utilized for this purpose. Within an emic analysis, the researcher attempts to gain an understanding of "indigenous categories that people interviewed have created to make sense of their world" (Patton, 2002, p. 454). This is opposed to etic analysis, where "labels used by the researcher" are the primary basis of analysis (Patton, 2002, p. 454). The data were examined for any language, symbols, words, or gestures that older adults used to describe their experiences of stigma. I also constantly reviewed transcripts of the interviews to make sure that the context of any coded data was not missed.

After the indigenous concepts were identified, I brought these concepts together in my analysis in the form of indigenous typologies. Indigenous typologies refer to the special language given by a group to identify their experiences (Patton, 2002). I constructed indigenous typologies by grouping commonalities and differences in the language used by older adults to describe their stigma experiences. The themes derived from indigenous concepts and typologies were utilized in constructing individual and composite textural descriptions, which is the next step in phenomenological reduction.

Individual textural descriptions. Once the themes for individual participants and the group were identified, I conducted the next step in the phenomenological analysis, constructing an individual textural description and a composite textural description. According to Moustakas (1994), an individual textural description contains a written account of the individual participants in a phenomenological study. An individual textural experience would contain a description of the experience of stigma of each individual participant. I explored themes for a description of each individual older adult's experiences of stigma and prepared a text that contained a description of these individual experiences.

*Composite textural descriptions. C*omposite textural descriptions are written accounts of how a group of participants experience a phenomenon (Moustakas, 1994). I examined the themes and data for any information of the group experience of stigma and constructed a textural description of the personal experiences of the entire group of older adults who experienced stigma.

Imaginative variation. I engaged in the process of imaginative variation. Imaginative variation refers to viewing the phenomenon (freely, using all the faculties of one's imagination), from different perspectives and roles (Moustakas, 1994). This was done after I read the textural descriptions. For example, I tried to understand how the phenomenon of stigma could vary for different classes or for different genders, or how older adults who have HIV/AIDS would have responded to other HIV positive individuals if situations had been reversed and they were HIV free. I also explored if the experiences of individuals who had HIV/AIDS earlier in their life were any different from the experiences of those individuals who were diagnosed later. I made notes of my views that emerged from the process of imaginative variation.

Listing structural qualities. I then constructed a list of structural qualities of the stigma experiences. Structural qualities were derived from the individual and composite textural descriptions of the stigma experiences of older adults with HIV/AIDS, as well as through the process of imaginative variation. Structural qualities refer to structures that influence the experience of the phenomenon (Moustakas, 1994). I examined the textural descriptions of the gathered data to identify societal, familial, and other structures that influenced the experience of stigma faced by older adults with HIV/AIDS. Last, I made a note of these structures.

Individual and composite structural descriptions. After I constructed a list of structures that may influence the stigma experiences of older adults with HIV/AIDS, I constructed an individual structural description. An individual structural description is a description of structural themes in the data (Moustakas, 1994). These themes point to what structures can trigger a stigma experience for individual participants. I also examined how participants responded to stigma and if they have experienced any growth and empowerment as a result of this experience.

Following the construction of an individual structural description, I constructed a composite structural description of the participants' experiences of stigma. A composite structural description illustrates "how co-researchers as a group experience what they experience" (Moustakas, 1994, p. 144). I examined the themes for any factors or structures that influenced the stigma experience of the group of older adults with HIV/AIDS.

Textural-structural synthesis. Finally, a synthesis of the textural and structural descriptions of the experience of stigma and strengths by older adults was developed. This provided a "synthesis of the meanings and essences" of the stigma experience (Moustakas, 1994, p.144) for older adults with HIV/AIDS.

Specialized Plot Analysis

Besides conducting a thematic analysis which aimed to answer the research questions in the study which explored the stigma experiences of older adults, their responses to stigma, and experiences of personal growth; I also conducted a specialized plot analysis (See Table 2, Appendix D) for additional information on the effect that the processes of disclosure and non-disclosure had on the stigma, strengths and other responses, and personal growth experiences of older adults living with

HIV/AIDS. This work builds on the model of analysis conducted by Kapp (2000). Each participant in this dissertation had a story to tell and each of these stories had a plot which described how they experienced stigma, their responses to stigma, and personal growth. Each plot was further analyzed to gain a deeper understanding of how the events of disclosure and non-disclosure impacted older adults' experiences of stigma, their responses to stigma, and their experiences of personal growth. I then compared and contrasted the plot summaries of individual participants in the study to understand how these events work among a group of older adults who are living with HIV/AIDS. Refer to Appendix D for Table 2 which illustrates the plot summaries for individual participants in the study

Testing for Completeness

Once the specialized plot analysis was conducted, I tested for the completeness of the study. I applied Moustakas' (1994) method of "application validation" (p.121) where I checked whether themes identified were expressly mentioned in the transcripts. If they were not mentioned in the transcripts, I checked if the themes were consistent with the study question, and if they were not, I determined if any of the themes should be deleted from the initial report. Once I tested for completeness, I prepared the initial report. Participants, the dissertation committee chair, and the methodologist reviewed the initial report. They checked the report to see if the whole picture was presented and if the data had been accurately represented.

Member Check

The initial report was prepared and mailed to fifteen participants. Six participants could not be located as they had changed addresses and phone numbers since the time of the interview. I prepared and sent copies of the initial report to case management supervisors of organizations so that they could forward the report to participants who I was unable to locate. Two participants emailed their member check responses to me while two others sent in their responses by regular post. Four participants conveyed their feedback through telephone conversations. Further discussion of participant feedback will be further examined in Chapter Four.

Final Report

After the process of reviewing the initial report was completed, I prepared the final report. According to Moustakas (1994), this report contains a summary of the study, the connection of the findings to the literature review, and the "personal" and "professional" outcomes of the study. It contains the study's "social meaning and relevance" (p.182). The final report contains a "composite description of the meanings and essences" (Moustakas, p. 121) of the stigma experiences for the group of older adults with HIV/AIDS.

Trustworthiness

Qualitative researchers build in a number of measures throughout the study to ensure that the study is trustworthy. The measures for trustworthiness (credibility and transferability) in the research design in this study were established according to Patton's (2002) criteria for trustworthiness. Measures for dependability and confirmability were established according to the procedures established by Lincoln and Guba (1985), as these measures had not been elaborated in Moustakas's (1994) phenomenological methodology or in Patton's (2002) work.

Credibility. Credibility refers to the confidence that various stakeholders have in the researcher's findings and whether they find the process credible. According to Patton (2002), the credibility of a study depends on three elements. These are, the use of "rigorous methods" which would "yield high quality data" (Patton, p. 552), credibility of the researcher, and the philosophical belief in the value of qualitative inquiry. To ensure the above, I made use of certain techniques such as triangulation to enhance the credibility of the study. Triangulation refers to the researcher verifying the information in the study from sources other than the researcher. I made use of the "analyst triangulation" method (Patton, p. 556). According to this method, the researcher should use multiple analysts to review findings. The chair and methodologist of the dissertation committee reviewed this report and other material throughout the research process thereby ensuring that the study is credible. I made use of a "review by inquiry participants" (Patton, p. 561). According to Patton, a great deal can be learned about the "completeness, fairness, and perceived validity of data" (p. 560) from the participants of the study. All participants were mailed a copy of the initial report. The feedback from participants who responded to my request to review the report is included in the following chapter.

Transferability. Transferability refers to whether the findings in a study can be generalized in another. According to Patton (2002), findings from a qualitative study are difficult to generalize. Qualitative studies are not causal in nature. Instead, they are supposed to provide rich and detailed information on the subject of study. Also, the individual nature of participants in a study would make it difficult to get identical results in another similar study. However, I maintained a “thick description” (Patton, p. 438) of sample size, selection, analysis, and findings so that another researcher who reads this research should be able to judge whether these findings may be transferable to similar populations even though the findings of another study may not prove identical to this study. The term thick description is used by anthropologists to refer to an in-depth, literal description of a phenomenon (Merriam, 1988). The thick description that I maintained included notes on the observation of the participants in their natural settings, interviews with the participants, and review of all material from the process such as personal notes that I prepared during the course of the process.

Dependability. Dependability refers to whether another researcher using the same instruments and techniques would reach similar results in a similar population (Lincoln & Guba, 1985). The dependability of a study can be enhanced by constantly reviewing the research design and process. As the design is emergent, it was reviewed through the research process by the chair and the methodologist.

Confirmability. Confirmability is established if the data and findings can be traced back to the participants. During the course of my study, the methodologist reviewed my first pilot interview, my transcripts from other interviews, and the coding guide at various stages. I also carried out an ongoing discussion with the methodologist about the interview process and the process of analysis. These processes ensured that I was truly reflecting the voice of my participants and that the findings represented what was shared by participants. This process also helped to ensure that my biases would not color the findings and are accurate in their representation.

Timeline (Phases of the Research Study)

The current study took approximately eight months to complete. There were three phases in this research study. Phase 1 consisted of obtaining the HSCL approval, refining the research design and conducting any preliminary tasks suggested by the dissertation committee, and making changes in the research design, interview guide, or sampling procedures that were recommended by the committee. I also contacted potential participants in this phase of the research; pilot tested an interview instrument and carried out an initial analysis on Atlas Ti to familiarize myself with the software which lasted for a period of one month. Through this process, I recorded any decisions and changes made in the design process and the reasons thereof in the methodological log.

In the second phase of the research, I recruited participants for the study and conducted semi structured in-depth interviews with the participants of the study. I transcribed the interviews. I thoroughly reviewed the interviews and began the preliminary coding and analysis process. This phase lasted for three months.

I carried out the final analysis and the write-up in the third phase of the research study. This phase lasted for four to five months. In this phase, I completed the preliminary analysis. Final coding categories were formed; themes were identified; and the final analysis was written. I synthesized my findings into a preliminary report. Participants in the study, the chair, and the methodologist reviewed the report. After incorporating the feedback from all these groups, with special emphasis on older adults who participated in the study, I prepared the final report.

Summary

In this chapter, I have laid out the methodology that has been used in the study. The methodology was chosen to allow older adults to express the full range of their experiences and to explore areas which other researchers had overlooked. Many parts of the methodology such as the research questions, key concepts, sampling and recruitment methods, procedures for data collection and analysis were constantly reviewed through the entire dissertation process to ensure that the voices of the participants were heard and accurately represented. In the next chapter, I will discuss analysis techniques and the findings that emerged as a result of the data collection.

CHAPTER 4: DESCRIPTIVE FINDINGS

The findings presented in this chapter are based on interviews conducted with adults 50 years and older living with HIV/AIDS. The sample included participants who were living in Kansas City, Topeka, and Lawrence, Kansas. Participants were identified for the study through case managers at three HIV/AIDS organizations, two of which were in Kansas City and a third that was in Lawrence. The participants were selected because they were 50 years and older and had been diagnosed with HIV/AIDS.

In this chapter, I will discuss 1) demographic characteristics of participants in the study; 2) individual participants' experiences of stigma as well as their responses and possible personal growth; 3) descriptive findings that answer the research questions of the study; 4) findings that emerged from the specialized plot analysis that was conducted to examine the impact of disclosure and non-disclosure decisions on participants' stigma experiences, responses to stigma, and personal growth; 5) findings that emerged from member checks with participants; 6) and additional findings that describe the experiences of women 50 years and older living with HIV/AIDS.

This chapter begins by detailing the demographic characteristics of the participants in the study (See Table 1). These demographics provide an understanding of the social and economic background of the participants in this study. The findings are organized in a manner that will allow the reader to understand the depth of the stigma experiences of adults 50 years and older living with HIV/AIDS. The literature has defined adults 50 years and older as the aging subpopulation who have HIV/AIDS.

Second, in this chapter**,** I examine individual participants' experiences of stigma, their strengths and other responses to stigma, and their personal growth. Through the analysis of interviews, I provide a description of the group experiences of respondents. However, it is also important to convey the individual experiences of each participant in the study as each experience is valuable and adds depth to the findings that are presented in this dissertation.

Third, in the section on descriptive findings, I discuss the themes that emerged from my analysis of the interviews. These themes explain the respondents' collective experiences of stigma, their strengths and other responses to stigma, and their personal growth. In this chapter, I directly address the research questions that the study seeks to answer. The first set of themes relates to research question one, which examines the experiences of stigma faced by adults 50 years and older living with HIV/AIDS.

I also examine how adults 50 years and older respond to stigma. My findings reflect various strengths that respondents employed to manage stigma. Some of these were personal strengths, such as membership in support groups and greater personal resilience. Participants also gained support and strength from family members, from employers, and from their churches. I also present responses to stigma that were not strengths-related such as non-disclosure of HIV/AIDS diagnosis, and social isolation and withdrawal. These findings relate to research question three, which seeks to understand participants’ other responses to the stigma associated with having and living with HIV/AIDS. In the discussion of findings, I examine the personal growth that adults 50 years and older may have experienced as result of their response to stigma. These findings relate to research question four, which explores whether strengths and other responses to stigma contribute to personal growth. Fourth, I explore findings that emerged from the specialized plot analysis, which was conducted to further examine the impact that the processes of disclosure and non-disclosure had on the stigma experiences, responses to stigma, and personal growth experiences of participants in the study.

Fifth, I discuss the impact of the member check process on findings. I examined participant feedback to see if they confirmed the findings. I also examined feedback to explore whether any participants disagreed with the findings or had any further information they wished to add to the report. Finally, I present additional findings that describe the experiences of female participants.

Demographic Characteristics of Study Participants

This study included 21 adults 50 years and older who living with HIV/AIDS. Of these, 15 participants were men and 6 participants were women. The demographic characteristics of the participants who were interviewed in the study are summarized in Table 1. Given that a large proportion of the participants were men, Table 1 has been organized according to the participants’ gender. The order in which a participant was interviewed is noted above that participant’s name. For example, Shana was the fourteenth participant to be interviewed in the study.

All of the women who participated in the study described their sexual orientation as heterosexual. Nine men said that they were gay, five described their sexual orientation as bisexual, and one participant in the study described his sexual orientation as heterosexual. Six participants were in a relationship or partnership while the remainder had no partners at the time of the interview.

The participants in this study were either African American or Caucasian. Of the 21 respondents in the study, 7 were African American while the rest described their ethnicity as Caucasian. One participant had some high school experience. Three participants had completed high school. Twelve participants said they had some college experience. Five participants in this study were college graduates.

With regards to income level, 10 participants had an income level of $10,000 or below, while10 others had an income level between $10,000 and $20,000 dollars. Only one participant described his income level as being between $30,000 and $ 40,000. Most participants in the study were from low income households.

Eight respondents had been diagnosed with HIV/AIDS in their thirties, seven between the ages of 41 and 50, five had been diagnosed when they were between the ages of 51 and 60 and one participant had been diagnosed when they were over 60 years old. Of the six women who participated in the study, only one had been diagnosed with HIV/AIDS in her thirties. Three women had been diagnosed when they were between the ages of 40 and 50 and two women had been diagnosed when they were 50 and older. Findings reveal that many men who participated in this study had received their diagnosis between the ages of 30 and 40, while most women who participated in the study had been diagnosed at a later age.

Demographics also revealed that nine participants had been diagnosed before the passing of protective legislation such as Ryan White Care Act and the Americans with Disabilities Act which include provisions to protect people living with HIV/AIDS from social stigma.

Table 1: Study Participants: Demographic Profile

Number	Age	Gender	Sexual Orientation	Relationship	Ethnicity	Education	Income	Age at Diagnosis	Diagnosed Before the Passage of Protective Legislation (Pre-Legislation
003 Martha	53	F	Hetero-sexual	Partnership	African American	Some College	10,001-20,000	41-50	----------
004 Jacque	72	F	Hetero-sexual	Single	Caucasian	College Graduate	10,001-20,000	Over 50	Pre-Leg
007 Sarah	57	F	Hetero-sexual	Widowed	Caucasian	Some College	0-10,000	41-50	---------
014 Shana	66	F	Hetero-sexual	Separated	Caucasian	High School Grad	10,001-20,000	Over 60	-----------

Number	Age	Gender	Sexual Orientation	Relationship	Ethnicity	Education	Income	Age at Diagnosis	Diagnosed Before the Passage of Protective Legislation (Pre-Legislation
017 Caitlin	50	F	Hetero sexual	Single	African American	Some High School	0-10,000	41-50	---------
021 Sabrina	52	F	Hetero-sexual	Divorced	Caucasian	Some College	10,000-20,000	31-40	Pre-Leg
001 Arnold	52	M	Gay	Single	African Amer.	Some College	0-10,000	31-40	Pre-Leg
002 Hank	53	M	Bisexual	Single	African American	Some College	0-10,000	31-40	Pre-Leg
005 Patrick	53	M	Bisexual	Same Sex	Caucasian	College Graduate	10,001-20,000	Over 50	----------
006 Jonathan	59	M	Gay	Same Sex	Caucasian	Some College	0-10,000	41-50	----------

Number	Age	Gender	Sexual Orientation	Relationship	Ethnicity	Education	Income	Age at Diagnosis	Diagnosed Before the Passage of Protective Legislation (Pre-Legislation
008 Richard	56	M	Gay	Single	African American	High School	0-10,000	41-50	----------
009 Matthew	56	M	Gay	Partnership	Caucasian	College Grad	10,001-20,000	31-40	----------
010 Chris	65	M	Gay	Single	African American	Some College	10,001-20,000	31-40	Pre-Leg
011 Cory	51	M	Bisexual	Single	Caucasian	High School	0-10,000	31-40	---------
012 Andrew	72	M	Bisexual	Divorced	African American	Some College	0-10,000	Over 50	Pre-Leg
013 Keegan	54	M	Gay	Single	Caucasian	Some College	10,001-20,000	41-50	----------

Number	Age	Gender	Sexual Orientation	Relationship	Ethnicity	Education	Income	Age at Diagnosis	Diagnosed Before the Passage of Protective Legislation (Pre-Legislation
015 Bailey	52	M	Gay	Same Sex	Caucasian	Some College	30,001-40,000	31-40	Pre-Leg
016 Wallis	67	M	Bisexual	Single	Caucasian	Some College	10,001-20,000	Over 50	---------
018 Lincoln	62	M	Gay	Same sex	Caucasian	College Graduate	0-10,000	Over 50	----------
019 Toby	58	M	Gay	Single	Caucasian	College Graduate	10,000-20,000	41-50	---------
020 Phillip	54	M	Heterosexual	Divorced	Caucasian	Some College	10,000-20,000	31-40	Pre-Leg

Individual Experiences of Stigma, Responses to Stigma, and Personal Growth

In this section, I discuss the individual experiences of participants in the study. I aim to emphasize the stigma experiences, responses to stigma, and personal growth experiences that are unique to each respondent. My intent was to provide the reader with a sense of greater intimacy and connection with the stories of individual participants. Participants in this study shared deeply personal and traumatic experiences, and it is important that all of their voices be heard and acknowledged in this report.

These snapshots have been derived from the notes on indigenous concepts and individual textural and structural descriptions of participants' experiences. These notes were prepared after analysis of transcripts of taped interviews. The names of the participants in the study have been changed to protect their confidentiality. Individual experiences have been organized according to the gender of the participants. I first describe the experiences of women in the study and then the experiences of men who participated in the study.

Martha

Martha was an African American female participant. Martha described various experiences of stigma. She felt stigmatized by the conservative neighborhood where she lived. She also reported that she was stigmatized by family and friends to whom she revealed her diagnosis. While Martha had these direct experiences of stigma from people to whom she revealed her diagnosis, she also anticipated stigma from certain sources such as churches. This was because she had had a bad experience with a previous church pastor with whom she had shared her diagnosis. As a result of the stigma she faced from him and his family, she chose not to reveal her diagnosis to the members of the church she was currently attending.

She actively resisted being stigmatized. She overcame her own misgivings about her diagnosis by attending meetings and support groups so that she could get the information that she required for combating the stigma associated with the disease. She refused to let friends and family members label her because of her diagnosis. She became a peer counselor and used her experience to help others with the disease combat the stigma associated with it. The stigma that she experienced led her to become a more spiritual person. The help that she received made her decide to give back to the community and help others who have HIV/AIDS.

Jacque

Jacque, a white female, was one of the few participants who had been diagnosed with HIV/AIDS after she turned 50 years old. It is very interesting to note that unlike many participants, she felt little guilt or shame about her diagnosis. She also reported fewer experiences of stigma compared to other participants in the study. Unlike a lot of other participants, she also actively sought support from family and friends from the very moment she found out she was HIV positive. She shared her diagnosis with family and friends, all of whom supported her and helped her. Jacque sought to learn as much as possible about her diagnosis. After an initial period of feeling low, she publicly came out with her diagnosis and chose to be an active advocate for the cause of older women living with HIV/AIDS. She spoke about what makes this group more vulnerable to contracting the virus, such as lack of information available to post menopausal women on how HIV/AIDS is spread.

Sarah

Sarah was a Caucasian female respondent in the study. She faced stigma from family and friends, however, she found support from her children. Sarah found it difficult to negotiate friendships and sexual relationships because of her diagnosis. She expected to be stigmatized by people to whom she revealed her diagnosis. She chose to isolate herself rather than share the details of her diagnosis with other people. Another place that Sarah experienced stigma was from colleagues at her workplace. She received support in the workplace from her boss, who helped her combat the stigma. Sarah also made use of humor when she was stigmatized by older members of her family who sometimes stopped her from sharing plates or touching objects in their house. While Sarah chose to isolate herself rather than speak about her diagnosis in intimate relationships, she sought help and guidance in support groups and was an active member of these groups until her health prevented her from attending these groups.

Shana

Shana, a Caucasian female respondent in the study had been diagnosed with HIV/AIDS when she was over 50 years old. She described her shock when she discovered her diagnosis. Shana felt that she was all alone and that it was probably rare for a woman her age to be diagnosed with the disease. She was stigmatized by her partner, from whom she contracted the disease. She also feared sharing the news of her diagnosis in her church, in which she was actively involved, because she expected to be stigmatized in the church. She had experiences of stigma in which strangers with whom she shared her diagnosis moved away from her because they were scared that they would contract the disease from her.

She was able to share her diagnosis with her children, and with their support she got over her dismay at having HIV/AIDS. She also spoke about how post menopausal women were unaware that they were at risk of contracting HIV/AIDS. Shana felt that medical professionals were often unaware that older women were contracting the disease or that they were embarrassed about talking to older women about their potential risk of contracting the HIV/AIDS virus. Shana had been a peer counselor and was an advocate who educated medical professionals about the need to educate older women regarding their risk of contracting HIV/AIDS.

Caitlin

Caitlin was a 50 year old African American who had been diagnosed with HIV/AIDS in her forties. She described a feeling of ‘numbness’ when she heard of her diagnosis but also said that she knew she had to live with it and do whatever was necessary to deal with it. She disclosed her HIV/AIDS status to family and friends. She found support from most family members and friends. She noted however, that a few friends were uncomfortable with her diagnosis because they felt that she might spread the disease to their children. They cleaned toilets after she used them and handed out special plates for her. She took these friends to meet her doctor, who educated them on how HIV could be spread. The doctor helped them understand the disease, and they stopped stigmatizing her. She also has had friends who read about the disease so that they were better informed and could help her. Caitlin disclosed her

HIV/AIDS status in her church and was supported by her pastor, who came to her HIV meetings to gain more knowledge about the disease and to provide her with support. While many people to whom she disclosed her HIV/AIDS status supported Caitlin, she met many other people living with HIV/AIDS who had not disclosed their HIV status to family members because they expected to be stigmatized by them. Caitlin stopped all drug use after her diagnosis. She attended support groups to get information and meet other people who had HIV/AIDS.

Sabrina

Sabrina was a 52 year old straight Caucasian respondent who had been diagnosed with HIV/AIDS between the ages of 30 and 40. She disclosed her diagnosis to her husband, family, and close friends. Her best friend stopped speaking to her and never contacted her again. This prevented her from speaking about her diagnosis to other friends for a long time. She also publicly revealed her diagnosis to members of her church and had to leave the church as a result of the stigma that she had to endure. She was however, proud that she had spoken publicly about her diagnosis.

Sabrina received guidance from members of an HIV/AIDS support group regarding how to disclose to close family and friends. Her spouse revealed her diagnosis, without her consent to her sister. Her sister acted as an intermediary and helped her reveal her diagnosis to their parents. Her sister also helped their parents process the news so that they did not say anything hurtful to Sabrina when they were with Sabrina. Sabrina also received support from her friends, who educated other people on how the disease was spread. At the time of the interview, she was acting as an advocate for women living with HIV/AIDS. She spoke publicly about her experiences and hoped to encourage other women to seek help. She also reported becoming more religious as a result of her experience.

Arnold

Arnold was an African American gay male who had been diagnosed with HIV/AIDS when he was between the ages of 30 and 40. At the time of the interview, he had lived with the disease for a long time. Arnold spoke about his experiences of stigma associated with the disease. He observed the negative manner in which his family members treated his younger brother, who was also gay and HIV positive, and consequently decided not to disclose his diagnosis to them.

He also faced stigma within organizations that should have provided him with help and encouragement, such as the support groups that he attended. He felt he was largely discriminated against because he was black, older, and not sexually available. Arnold responded to the stigma that he felt within support groups by withdrawing from the groups and not seeking help. Arnold also indicated that he was stigmatized at his workplace. He spoke about how he had to eat at odd hours at his place of work because of his HIV medication regimen and how office staff complained about his food habits. When he discussed his diagnosis with his superiors, he was fired. Arnold felt that he had done the right thing by standing up for himself and against the discrimination he had faced from office staff before he was fired. Having had HIV for so long, Arnold also recalled how adults living with HIV/AIDS were stigmatized in the past. He described the historical context of stigma experiences associated with HIV/AIDS. He recalled a time when doctors would not treat AIDS patients and mortuaries would not prepare the dead bodies of those who had died of AIDS.

Arnold also experienced personal discomfort about his diagnosis and shame that he had allowed it to occur. Stigma associated with HIV/AIDS had a detrimental effect on Arnold's life. He had often responded to stigma by isolating himself and not disclosing his HIV/AIDS status to family and friends. One of the questions in this study examined the personal growth that participants may have experienced when they had a strengths response to stigma. Arnold was able to stand up for himself at his workplace. Although he was fired and was bitter about the experience, he felt that he had faced the situation with courage. In that situation, he stood up for himself, something he had been unable to do in the past. While Arnold had a strengths response to the stigma he experienced at work, he was unable to consistently demonstrate strengths responses to all stigma experiences and did not make significant life changes. Overall, his stigma experiences made him suspicious and bitter. The interview with Arnold was the first interview that I conducted as a part of this study. It was also the longest interview, which is why the description of Arnold's experiences is perhaps the longest one in this section.

Hank

Hank was an African American participant in the study. Hank identified himself as bisexual. He had been diagnosed with HIV/AIDS when he was between the ages of 31 and 40 and, like Arnold, was a long-term survivor. He had no immediate family with whom he could share his diagnosis and chose not to share the news with extended members of the family because he felt that he would be judged for his bisexuality and that some might even feel that he had used drugs.

He sought companionship within support groups but did not speak about his diagnosis within these groups. He was fearful that members within the support group would disclose his diagnosis to others. He was also fearful of disclosing his diagnosis to potential sexual partners for the same reason. Hank had seen other people with HIV/AIDS being stigmatized in the workplace.

Hank responded to the stigma that he experienced in two ways. His own expectation of stigma prevented him from disclosing his HIV/AIDS status to family members and friends and in support groups. On the other hand, he actively attended support groups in order to increase his knowledge. He wished to be able to help others living with HIV/AIDS and hoped that one day he would be able to overcome his fear and help others. He also felt secure within these groups and looked at them as potential avenues to meet other people with HIV/AIDS.

Patrick

Patrick is a Caucasian adult who had been diagnosed with HIV/AIDS when he over 50. Patrick experienced a sense of shame about his diagnosis and dealt with his feelings that he should have been able to avoid contracting HIV. He responded to this feeling by actively seeking help and support from organizations and friends. Prior to his diagnosis, his family members had stigmatized him for being gay. This previous experience of stigma stopped him from disclosing his HIV/AIDS status to his family as he expected to be stigmatized by them. He received support from members of the medical community and from staff at the organization where he was tested. He also received support from his partner. Patrick sought support from a group of partners of people dying of HIV/AIDS. At the time of the interview, he was a peer counselor. He spoke about how he had received compassion and guidance from professionals when he was diagnosed. Many people had helped him combat stigma and manage his diagnosis. He wished to express his gratitude for the support he had received by helping others living with HIV/AIDS in the same way that he had been helped. His experiences made him more religious which helped him to forgive those who stigmatized him.

Jonathan

Jonathan was a gay participant who had been diagnosed with HIV/AIDS when he was in his forties. He disclosed his HIV/AIDS status to family members and friends. He spoke about how he faced stigma at the hands of medical professionals in the early 1990s. He recalled how HIV/AIDS had been considered a gay man’s disease in the 1980s and early 1990s and how many gay men with HIV had had to face stigma from society. He also felt that he should have been able to avoid getting the disease. He reported that he was taking better care of himself after having been diagnosed. He also reported that people were rapidly realizing that HIV/AIDS was not a gay man’s disease but that it affected all populations.

Richard

Richard was a 56 year old African American participant who had been diagnosed with HIV/AIDS between the ages of 40 and 50. Richard shared that he had chosen not to reveal his diagnosis in his workplace because he had expected a negative reaction from his employers. He also spoke about historical experiences in the 1980s and early 1990s, when HIV/AIDS was viewed as a gay man's disease and gay men with the disease faced societal disapproval and discrimination. Richard also faced direct experiences of stigma from family members who were uncomfortable about his using common silverware once they knew about his diagnosis. He responded to this stigma by refusing to let it affect his life and by avoiding those who stigmatized him. He received support from his church, where he revealed his diagnosis and from medical professionals to whom he went for treatment. Richard also spoke of a greater spiritual connection with God after his diagnosis, which helped him manage his diagnosis.

Matthew

Matthew was a 56 year old Caucasian male participant. Before his diagnosis, Matthew had experienced stigma after his uncle revealed to Matthew's family that Matthew was gay. This experience made him initially wary of disclosing his HIV/AIDS status to family members. Matthew did not disclose his HIV/AIDS status at his workplace because he feared that he would have lost his business as a result of the disclosure. When his partner died of AIDS, Matthew faced stigma as he arranged his partner's funeral. The funeral home representative resisted making arrangements for someone who had died of HIV/AIDS. Matthew had a direct experience of stigma at the hands of a medical professional where he was discriminated against because of his HIV/AIDS diagnosis.

Matthew also spoke about how people with HIV/AIDS are stigmatized in the gay community. According to him, the gay community shuns people who have HIV/AIDS and are sexually active. Matthew observed that, in response to this kind of stigma, many people with HIV/AIDS do not disclose their HIV status in community gatherings or to potential sexual partners.

After his diagnosis, Matthew and his current partner made themselves financially secure. They had also helped other adults with HIV/AIDS because they considered themselves fortunate to be in a positive personal and financial situation. At the time of the interview, Matthew was an active member in support groups. He was also an advocate for the rights of patients living with HIV/AIDS and was active in community organizations.

Chris

Chris, an African American respondent had been diagnosed with HIV/AIDS between the ages of 30 and 40. Chris recounted the historical context of stigma. He spoke about how scared he was about having HIV/AIDS when he was diagnosed in the late 1980s. Chris recalled that this was the era when HIV/AIDS was called GRID (Gay related immune-deficiency) and many of his gay friends were dying of the disease all over the country. He, however, faced no discrimination from family and friends to whom he revealed his diagnosis. He also disclosed his HIV/AIDS status to people within his church, where he received support. Chris also received support at his workplace, where he disclosed his diagnosis. When asked if he had ever experienced any overt stigma, he said that he did not allow anyone to stigmatize him and did not put himself in a position where it was likely to occur.

Cory

Cory was a bisexual, Caucasian, male participant who had been diagnosed with HIV/AIDS between the ages of 30 and 40. He was very reticent to talk about his experiences. He said that he had disclosed his diagnosis to family and friends and had not faced any discrimination from them. When he was first diagnosed, he faced some initial depression and suicidal thoughts, as well a sense of shame. Cory also shared that he had not disclosed his diagnosis within his church because he expected to be stigmatized by members of his church. He received support from medical professionals to whom he went for treatment.

Andrew

Andrew was a 72 year old African American and was one of the oldest respondents in the study. He had been diagnosed with HIV/AIDS when was over 50 years old and learned of his diagnosis from a volunteer. The news was not delivered in a sympathetic manner and he felt stigmatized at the time. Andrew’s family was shocked when they learned of his diagnosis and they withdrew from him for some time. One example he gave was that his brother was not comfortable handling tools that Andrew was using. Andrew responded to the stigma with patience and forgave those who stigmatized him. He received support from medical professionals to whom he went for treatment. He wanted to tell patients the news of their diagnosis in a compassionate and supportive manner. This led him to volunteer at the clinic where he was diagnosed.

Keegan

Keegan was a 54 year old Caucasian male respondent in the study. He had been diagnosed with HIV/AIDS between the ages of 40 and 50. Keegan was stigmatized by certain people in his workplace. He was stigmatized for being gay and for having HIV/AIDS. He responded to the stigma by seeking the support of his boss, who helped him combat the stigma that he was facing by confronting the employee who had stigmatized Keegan. He also joined support groups in order to be with other adults living with HIV/AIDS. In those support groups, he heard the stories of many people who had been disowned by their families and ignored by their friends.

Keegan received the support of his family when he disclosed his diagnosis to them. He said that he felt incredibly fortunate that he had received their support. At the time of the interview, Keegan volunteered at an HIV clinic to help others who had been diagnosed with HIV/AIDS. He had also stopped taking drugs and said that he had started taking better care of himself after being diagnosed.

Bailey

Bailey, a gay Caucasian participant had been diagnosed with HIV/AIDS between the ages of 30 and 40. He was devastated when he found out that he had HIV/AIDS. He described his guilt because he had infected the man who was his partner at the time and who was still his partner at the time of the interview. He also spoke about how gay people with HIV/AIDS had faced stigma in the 1980s and early 1990s and how that could be attributed to people's lack of knowledge about how the disease was spread. While he had not had many experiences of stigma from family members, he attributed this to the fact that he walked away from situations where he was likely to be stigmatized. He received support from medical professionals, to whom he had disclosed his diagnosis. He also received support from his employers, to whom he disclosed his HIV/AIDS status. They allowed him to take sick leave and to modify work hours to suit his medication regimen. Bailey felt that in the future he wanted to pursue a career in the medical profession as he could help others who had HIV/AIDS in that field.

Wallis

Wallis was a 67 year old bisexual, male respondent who had been diagnosed with HIV/AIDS when he was over 50 years old. He did not have any family. His one experience of stigma resulted when he disclosed his diagnosis to his sexual partner who disappeared from his life after hearing that Wallis was HIV positive. He disclosed his HIV/AIDS status to medical professionals, whom he found supportive. Wallis relied on his case manager for support and information on managing his diagnosis. He also received support at his workplace. He spoke about how he did not allow stigma to affect his life and went through life as if he were not affected by HIV/AIDS. Finally, he said that he had become more careful about taking care of his health after learning about his diagnosis.

Lincoln

Lincoln was a 62 year old gay man who had been diagnosed with HIV/AIDS when he was over 50 years old. He said he was not shocked when he found out about his diagnosis because he had been sexually active with a partner who had HIV/AIDS and who had died of the disease. His one experience of stigma had been in the 1980s, when a medical professional to whom he had disclosed his diagnosis responded with anti gay sentiments. He had also known other people with HIV/AIDS who had been stigmatized by their family and friends.

He disclosed his diagnosis to his sexual partner and his family members and received support from both his partner and his family. He disclosed his status because he wanted his family's support if he were to ever to fall ill. He felt that support groups were some of the most significant avenues of support that he had accessed. He felt he was able to get information from these groups, overcome his shyness, and even form a social circle with members of the groups.

Toby

Toby was a 58 year old, Caucasian respondent in the study who had disclosed his diagnosis at his workplace as well as to close friends and family. He did not experience stigma from these family and friends. Toby spoke about how society stigmatized people who were living with HIV/AIDS and remained sexually active. He said that this stigma did not prevent people from being sexually active, but it stopped adults living with HIV/AIDS from disclosing their status to potential sexual partners.

He was supported by members of his professional group as well as by his family. However, he was careful about disclosing his diagnosis in wider circles because he expected to be stigmatized by society.

Phillip

Phillip was a heterosexual, Caucasian respondent who had been diagnosed with HIV/AIDS between the ages of 30 and 40. He was the only respondent in the study who had contracted the virus through drug use and not through sexual contact. Phillip spoke about how difficult it was to negotiate sexual encounters once he was diagnosed with HIV/AIDS. Potential sexual partners responded to the news that he was HIV positive with sympathy or shock and often withdrew from the relationship. Despite the expectation that potential sexual partners may stigmatize him, Phillip continued to disclose his diagnosis to them. Phillip's diagnosis was disclosed at work by someone other than himself. He was asked to leave his job, which required the use of tools because his employers feared that he might cut himself and spread the disease. He was not upset with his employers and said that he could understand why they had asked him to leave even if he did not agree with it. He said that he had stopped using drugs and had become more religious after his diagnosis.

In the previous section, I presented a summary of participant experiences. These experiences were organized according to the gender of the participants. In the next section, I review my definitions of stigma and discuss the themes that emerged from the thematic analysis of the data. These themes, and the narrative that elaborates on them, seek to answer the research questions. The themes that are discussed in the next section emerged after a careful analysis of the interviews of respondents. The first set of themes discussed in the next section are related to the experiences of stigma of adults 50 years and older who participated in the study. Some of these themes relate to stigma from family and friends, stigma in the workplace, anticipation of stigma, and internalized stigma.

Experiences of Stigma of Adults 50 Years and Older Living with HIV/AIDS

This section relates to the first research question in the study: What are the experiences of stigma that older adults living with HIV/AIDS encounter? The literature that I presented in previous chapters revealed that adults 50 years and older living with HIV/AIDS do frequently experience stigma, however, the literature did not extensively describe the exact experiences of stigma of adults who were 50 years and older and living with HIV/AIDS (Emlet, 2006a; Genke, 2000). Theoretical models that examined the stigma experiences of adults living with stigmatizing conditions such as HIV/AIDS have provided possible explanations of how these adults actually experienced stigma.

Based on my sample, it appears that adults 50 years and older have had a broad range of stigma experiences. While some participants had been diagnosed relatively recently, many had been diagnosed in the 80s and 90s when stigma associated with the disease was strongest. Some participants who had lived with the disease for a long time, most of whom were diagnosed before they were fifty years old, described stigma experiences that occurred across the course of their illness. Themes that emerged from the analysis of data include stigma experiences of those who had been diagnosed early and who had aged with the disease as well as the experiences of those who had been diagnosed when they were age 50 and older.

Some examples of stigma experiences are direct experiences of stigma, such as family members avoiding them due to their condition as well as experiences of internalized stigma where older adults stigmatized themselves (Fortenberry et al., 2002; Lee et al., 2004) and felt distressed or ashamed of their own diagnosis. Terms such as enacted stigma and felt stigma (Green & Platt; 1997) were also discussed in the review of literature. In order to clearly delineate the major categories used when discussing findings on stigma experiences, I provide a review of the concepts of felt and enacted stigma.

Thematic analysis of stigma experiences shows that some findings are consistent with existing definitions of stigma in the stigma literature. All stigma experiences that are described in this section fall under the broad categories of "enacted stigma" and "felt stigma". However, the definitions have been further extended to fit with the experiences of participants in this study.

Enacted stigma refers to actual experiences of discrimination that people living with HIV/AIDS may experience at the hands of family, friends, or any social organization (Green & Platt, 1997). Felt or perceived stigma refers to a real or imaginary fear that a person may feel of being stigmatized by society, family, and friends about a particular undesirable trait (Green & Platt, 1997). In this sample, the undesirable traits include being 50 years and older and living with HIV/AIDS.

Very often, felt stigma is used as a survival strategy to prevent the occurrence of enacted stigma (Green & Platt, 1997). For example, adults 50 years and older who are fearful of enacted stigma from family or friends undergo felt stigma. Findings that describe the felt and enacted stigma experiences of respondents have been discussed in this chapter and in Chapter Five of this dissertation.

Enacted Experiences of Stigma

In this section, I present findings on enacted stigma experienced by participants. Two major themes emerged that describe the enacted stigma experiences of respondents living with HIV/AIDS. These are 1) stigma from family and friends and 2) stigma at the workplace.

Stigma from family and friends. Family and friends often responded with shock and confusion when participants revealed their diagnosis. This was an extremely important theme. A number of respondents in the study had been stigmatized by family and friends. According to participants their family and friends felt that their loved one might die soon and often disassociated themselves from their loved one due to their own inability to cope with the news. Respondents in this study described how they had lost friends they had had for a number of years when their friends found out they had HIV/AIDS. Sabrina described how her best friend abandoned her when she found out that Sabrina had HIV/AIDS.

Researcher: Did he say anything or did she just disappear?

> Sabrina: She just changed her calling number and didn’t call me anymore. I just figured out, she didn’t want anything more to do with me.
>
> Researcher: Did you ever talk to her?
>
> Sabrina: No, I can’t remember exactly what she said but she made it very clear, she wanted nothing to do with me. That hurt the most.

Participants in this study described how family and friends often felt that the participants were responsible for contracting HIV/AIDS and that they deserved their diagnosis. Other forms of judgment passed by family members were negative reactions to perceived lifestyle choices that were made by respondents, such as being gay. Bailey, a Caucasian male respondent spoke about how his family thought that his diagnosis was a punishment from God for living an abnormal lifestyle.

> I have a nephew in (place) and he thinks because I am gay, it’s my choice which is not true……. (Nephew said), ‘Yes, because you are HIV positive, God is after you’.

Family and friends were also afraid that they would contract the HIV/AIDS virus from the respondents. Participants in the study described the measures that were taken by family and friends to protect themselves from the disease such as using silverware that could not be reused or cleaning a bathroom immediately after participants had used it. Findings also show that there appears to be a lack of knowledge about how HIV/AIDS is transmitted (through sexual contact, contaminated blood, and sharing syringes). Richard, an African American respondent, spoke about how his friends used plastic plates instead of regular silverware when he had dinner with them.

> You know, you go to someone's house and they put out plastic plates. Everyone is trying to pretend that's the way they have always eaten.

Family and friends to whom respondents revealed their diagnosis were afraid of contamination through bodily fluids that may be shared by using a common bathroom or actual contact with any tools or equipment that participants may have used. Many family members and friends were fearful of contracting the HIV/AIDS virus. There was a perception that the virus could be contracted through the use of common silverware or restrooms and that the disease was spread through touch. Both of these perceptions are inaccurate as HIV/AIDS is not spread through touch or through using a common restroom. It is spread through sexual contact, contaminated blood, and the sharing of needles.

Stigma in the workplace. Another area where participants experienced enacted stigma and were ostracized was in their workplace. Some respondents described how they lost their jobs when bosses in their workplace found out that they had

HIV/AIDS. One respondent gave a poignant description of how he disclosed his HIV/AIDS status in the workplace and how he lost his job as a result.

> I said, ‘I have never told this to anyone before because I have never felt it necessary’, but I was quite emotional about it. I said, ‘I am HIV positive, have been for years’. I said, ‘fortunately, I am healthy. I have good medical care but in order to keep up, I have to eat a lot. I have to keep my calories up. I have to eat six or seven times a day, munch on an apple or have to have my oatmeal. I take medication. It’s difficult with the medication which is why I eat at such and such time, which is why if I get to work at 9:00 [a.m.] and have to take my medications at 9:30 [a.m.]. Then I need to have a bowl of oatmeal or something. It’s not stopping me from doing my work… I am not just being a pig on this….. ’. I mean there was no problem with my work performance. These little things were getting on the nerves of somebody apparently, that I am eating at my desk, or I am taking a nap at lunch which is my free time and I don’t see what difference it made to anybody so I felt I can explain this. So I did, and I was fired the next day, the very next day and so I don’t know. You tell me, it seemed coincidental to me.

Keegan, another male participant also described a similar stigmatizing experience in the workplace, where a colleague disclosed his HIV status to his corporate office and refused to work with him because he was gay and HIV positive.

> Researcher: And remember, when we started this conversation………….. This one person who was sweet as candy but was really vicious. So could you just tell me what happened?
> Keegan: Bitch (laughs). It was my last job and I had moved from working outside dealing with the patients to customer service. She was the (position). There were three of us, four of us, in the big office. She was in sales. Two or three of them were in sales. We were all there. The fax machine went off. You never knew who it was for so you went and picked it up. So I went and picked it up one day. It was a letter from corporate and there was a copy of the letter she sent to them about being forced to work with an AIDS infected faggot.

Participants had different enacted stigma experiences. Family members and friends stigmatized respondents by stopping contact with them. They expressed that they felt participants were leading a risky lifestyle and consequently, they deserved their diagnosis. They were also fearful of contracting the AIDS virus and sought to minimize physical contact and touching of bodily fluids.

In the workplace, some participants were either fired by their bosses or faced overt discrimination from fellow employees. These were experiences where participants were stigmatized by other people. Next, I discuss the experiences of stigma where respondents were fearful that they would be stigmatized but did not actually face stigma from external sources. Such experiences are discussed under the heading of felt experiences of stigma.

Felt Experiences of Stigma

Many respondents in the study experienced enacted stigma when family members and people in the workplace became aware of their diagnosis. However, not all respondents who participated in the study had direct experiences of stigma. Several participants anticipated stigma from family and friends as well as other sources. Sometimes, felt stigma, or a fear of possible stigma was a result of a previous experience of enacted stigma where respondents had actually experienced stigma from someone. More respondents who were diagnosed with HIV/AIDS before they were 50 had experienced enacted stigma over the course of their illness. Repeated experiences of enacted stigma over many years led to felt stigma. Felt stigma was more common among participants who were diagnosed before the age of 50 as opposed to those who were diagnosed when they were 50 or older. Two key themes emerged from the findings that fall under the category of felt experiences of stigma. These are 1) anticipation of stigma and 2) internalized stigma.

Anticipation of stigma. Some participants who had HIV/AIDS and who participated in the study expected that they would be stigmatized by family or friends or at venues such as the workplace and their churches if people in these venues ever found out about their diagnosis. A few respondents in the study even anticipated stigma in support groups, which are supposed to be safe spaces for infected adults to share their experiences and receive help and guidance.

A number of respondents anticipated that they would face stigmatizing reactions from potential sexual partners. By its very nature, living with the disease raises questions related to sex and sexuality for respondents. Adults 50 years and older felt that the stigma surrounding being sexual after receiving an HIV/AIDS diagnosis made it difficult for them to negotiate sexual encounters even if they wanted to remain sexually active. They also faced their own doubts about their diagnosis and their discomfort about having sex with other HIV positive adults. Arnold described his experience of negotiating sexual encounters while facing the fear of his diagnosis, as well as the fact that his potential sexual partner could also be HIV positive.

> In the beginning, it was like, ‘who would want to have sex with me’, then it changed to like, ‘I don’t want to have sex unless it’s consensual and someone who knows everything about me’, and then it was like, ‘no, I don’t have to have sex unless someone is HIV positive’, and then it was like, ‘no I don’t want to have sex with someone who is HIV positive because that’s yuck’.

Adults 50 years and older may also experience a lack of desire and may find it difficult to talk about their diagnosis with a potential sexual partner. Besides the doubts and fears that respondents had about being sexually active after being diagnosed, they were also aware of social disapproval associated with being HIV positive and having sex. Toby a gay man stated:

> I didn’t want to be seen out there having sex.

Another participant, Matthew, also emphasized that sexual expression and desire were natural things and that adults 50 years and older living with HIV/AIDS should not be forced by stigma to hide their identities as sexual beings.

> There are forty percent that are so stigmatized and so afraid of giving someone AIDS that they would rather have no contact and I know a few like that. [They are] my friends. And to tell you the truth, I try to talk to them about that because that’s no life. Everyone needs someone and everyone has needs. I don’t care what the situation is. So the stigma is there and they are just not being truthful.

While the literature has shown that older adults are perceived to be asexual by medical professionals and society at large (Maes & Louis, 2003; Skiest & Keiser, 1997), the analysis of interviews shows that not only were some respondents in the study sexually active at the time of diagnosis, but also continued to be sexually active post diagnosis and were continually negotiating how to express their sexuality after learning they had HIV/AIDS.

Adults 50 years and older also anticipated stigma because they observed stigma experiences of other people who were living with HIV/AIDS. These people included friends, people in social organizations, or members of support groups that they attended. They vicariously experienced the stigma that was felt by other people living with the disease and felt a deep sense of empathy because of their own experiences of living with the disease. Arnold spoke about how he saw his brother (also gay and HIV positive) face stigma because of his homosexuality and HIV/AIDS status.

> My father said to me, ‘your brother has VD and I want you to talk to him about it’. And I kept thinking, ‘what am I supposed to say to him?’ [I was] getting the whole situation that had gone on with them, which I knew very well about. [His father told his brother], ‘get out of the house, you fag, you no son of mine.’

Lincoln spoke about how he had heard members of his support group share experiences of stigma from their families.

> And people have had all kinds of experiences. Some really virtually excluded from the family to the point where you can tell some of the younger generation absolutely will not tell grandma and you will not tell mother.

Many of the participants in this study had been diagnosed in the early years of the epidemic and some participants were long-term survivors. Over the years, some respondents had seen a number of other adults being stigmatized by different people. In their interviews, participants shared how terrible the stigma associated with HIV had been in the early years of the epidemic. In the 80s and the early 90s, HIV/AIDS had been perceived to be a gay man’s epidemic. Several participants in the study recalled how HIV/AIDS was perceived as an exclusively gay disease and how gay men were held responsible for spreading it. Hank described how people were afraid of being infected with HIV/AIDS.

> In 88, when I was first diagnosed, they were burning down people’s houses. That kind of stigma, there is a history of it.

Participants in the study reported that having HIV/AIDS in the 80s and 90s was ‘a scary place to be in’. Arnold described how getting medical care had been very hard as doctors were terrified of being infected by their patients. Further, spiritual solace was denied even after the death of an individual who had died of infections related to HIV/AIDS.

> Arnold: Well, I can only go back to early days where doctors and health care professionals would refuse to treat you period.
>
> Researcher: Exactly, did you ever go through that?
>
> Arnold: No, I didn’t but I did know a couple of people who did. You know back in the day when they said that they were going to quarantine you and this and that, this and that. So it’s not foreign to me, in much the same way the minister at your church wouldn’t perform your ceremony, or the mortuary wouldn’t handle your remains. That was not remote for me in the sense of, ‘oh, I have never heard of that’, but it was close enough for me, for people two times removed, something like that happening. So, when I would get that kind of vibe from somebody at the hospital, I would kind of like say, ‘I can kind of tell what you are’…. Or the doctor would be very patronizing and condescending towards you sort of like, ‘now you are a fag’. Not in those words but that kind of attitude.

Anticipation of stigma prevented participants in this study from revealing their diagnosis to family, friends, and potential sexual partners. It also prevented them from fully utilizing support groups and seeking help. There is a history of people living with HIV/AIDS being stigmatized and adults who were diagnosed when the stigma was really strong such as the late 80s and early 90s remember the times when social stigma was very apparent and painful.

Internalized stigma. The second recurrent theme that emerged was that participants felt internalized stigma. Internalized stigma consists of feelings of discomfort and shame that respondents felt about being HIV positive. I have included this theme under the broad category of "felt" stigma. The broad definition of felt stigma indicates that felt stigma is the fear that participants have of enacted stigma or direct experiences of stigma. I have expanded the definition of "felt stigma" to include the sense of personal shame and responsibility that some respondents had about their diagnosis.

It is often assumed that people living with HIV/AIDS contract the disease as a result of unsafe sex and irresponsible behavior. Drugs and unprotected sex are the primary modes of HIV transmission. People may engage in risk behaviors in times of crisis and the result maybe contracting HIV. This does not necessarily represent a lifelong habit of risk behavior. Jonathan, a male Caucasian participant describes the circumstances in his life when he contracted HIV/AIDS.

> Oh yes, I was really mad at myself for thinking that I wouldn't get it, you know. And I should have practiced safe sex. But at the time, I had just broken up with someone. We had been together for ten years. And he just upped and told me one day that he didn't love me anymore and

> he wanted me to move back. I didn’t even know this was coming and I was devastated. I hated my job and that’s when I had the nerve damage to my feet so I couldn’t work any longer. I was working as a meter reader for (name of county) so I had to sue them because they wanted money for the operation [and] because I didn’t want to pay them for the operation. I had just lost my partner, my sister took me in. But, I was just real despondent, real disappointed so I started behaving badly because I had low self esteem at the time. And I was going out and not having safe sex because I didn’t care about myself anymore. And by the time I did, it was too late. How could you be so stupid? How could you be so dumb?

Some participants found it difficult to overcome their feelings of self shame. Even respondents who were socially active and aware of the stigma that existed in society towards individuals who have HIV/AIDS found it difficult not to feel an internalized stigma because of their diagnosis. Some participants felt that they had contracted the virus despite having the knowledge of how it was transmitted and how they could protect themselves. This knowledge added to their sense of disappointment in themselves. Patrick, an older peer counselor described how he could not resist stigmatizing himself despite having knowledge about the disease.

> I know a lot of HIV positive people that are living in this community. You would never know, like Magic Johnson you know. You would never know because there is no visible sign. And I know if you stand here one hundred percent of the time that’s the best thing that you can do. To eat right, exercise, all of that stuff, and I knew all that stuff and it still floored me for a month. I was left going, ‘what am I going to do?’ This has changed everything now. And the stigma of it sat there and crept up. And I couldn’t believe it. After all that I knew, after living through 1981, 1982, 1983 with my friends at the college, all the gay and bisexual guys I knew, that we were going to die and stuff and having had to live through the stigma of ‘you’re queer’ and all that crap that people throw at you, I felt it creep up inside of me. The stigma towards myself, I still wrestle with it, I think I always will. I don’t know why, well I don’t. I have a real high IQ, a real high intelligence and I sit here and I wrestle with the fact that I allowed myself to be stupid enough to let this happen to me.

In summary, participants in this study faced a number of stigma experiences. Some adults had been diagnosed at younger ages and described stigma experiences over the course of their life since diagnosis, while others had been diagnosed when they were aged 50 and over and had had different experiences of stigma. Long term survivors were more likely to have experienced felt stigma as a result of having experienced enacted stigma for a number of years, when compared to those participants who had been recently diagnosed.

Participants had also been stigmatized by family and friends and at the workplace. While these were direct or enacted experiences of stigma, they also faced felt stigma. Felt stigma has been defined as a fear of enacted stigma. Adults 50 years and older anticipated stigma from family, friends, and in support groups. They also anticipated stigma from potential sexual partners.

Some participants also anticipated stigma because they had seen other adults living with HIV/AIDS being stigmatized by their family and friends. Some participants who had been diagnosed in the late 80s and early 90s had seen how badly people diagnosed with HIV/AIDS were treated in those decades. These experiences made them anticipate stigma from various sources.

Both forms of felt stigma: anticipated stigma and internalized stigma, prevented respondents from disclosing their diagnosis to family and friends and from seeking help. This response to stigma, non-disclosure, will be discussed in the section on other responses to stigma. In the next section, I discuss the strengths responses that participants had to stigma experiences.

Strengths Responses to Stigma

This section relates to the second research question in the study: How do older adults employ personal strengths when responding to the stigma associated with the disease? Findings show that participants had a range of strengths responses to the stigma that they faced. According to literature on the strengths perspective, strengths are often developed or cultivated in the face of trauma and stress (Saleebey, 2006). Some of the personal strengths that participants living with HIV/AIDS demonstrated were, 1) empowering themselves with the help of supportive people in their lives; 2) seeking membership in support groups; 3) developing resilience in the face of stigma experiences; and 4) educating themselves and others about stigma associated with HIV/AIDS.

Empowering themselves with the help of supportive people. The participants in this study responded to stigma in many ways. Some participants felt overwhelmed by the stigma they experienced and isolated themselves or did not disclose their HIV status as a result of their stigma experiences. These responses are discussed in the next section on other responses to stigma. However, findings show that these are not the only interactions that occurred in the stigma process.

While participants' anticipation of stigma and internalized stigma may have prevented them from disclosing their HIV status and seeking help, respondents who did manage to judiciously disclose their status to trusted friends, family, and other members of their social circle, received support from them. These sources acted as intermediaries who helped stop "enacted" stigma (actual discrimination and stigma) helped participants overcome "felt" stigma or their fear of "enacted" stigma. They encouraged respondents to develop personal strengths responses to stigma. While the literature on the strengths perspective has focused on how professionals may help clients empower themselves and free themselves from self doubts and tensions associated with their respective conditions; analysis of interviews conducted with participants in this study showed that respondents often disclosed their HIV/AIDS status to family and friends and that these were the people who helped them empower themselves to manage and combat stigma.

Respondents received different kind of support from sources to whom they revealed their diagnosis. This support ranged from a simple acceptance of their diagnosis, an acceptance that was free of any stigmatizing reaction; to more active support in helping them access resources and combat stigma that they may have faced from other sources. Several participants in the study said that the sources to whom they revealed their diagnosis either simply accepted the diagnosis or sometimes actively extended support to them. Caitlin, an African American woman, described how she felt that she could handle her diagnosis as long as she had her daughter's support and love.

> Researcher: Was there anyone who came out and supported you at the time?
>
> Caitlin: My daughter, my main support was my daughter. As long as she supports me it's all right. That's my life right there, my daughter.

Participants in the study also described how important it was for them that family and friends continued to treat them normally and that there was no significant change in behavior after they had revealed their diagnosis to them. Chris spoke about the fact that although family and friends were concerned about his illness, there was no overt stigma.

> I guess there was the same amount of dismay just as if I had cancer or any other chronic condition but I have never seen any ostracism from my close friends or associates because of it.

Findings show that, while some participants in the study experienced stigma in the workplace, some did not. Jonathan stated that he had never experienced any overt form of stigma at the workplace.

> There was never any stigma that I noticed. [Nobody] ever made a comment to me or was strange around me or wouldn't eat after me, or go to the drinking fountain after me so I never felt stigmatized at work.

It was also important for respondents that their intimate partners did not react negatively to their diagnosis. Patrick, a respondent in the study said that his partner's support was extremely important and helped him through his diagnosis.

> Researcher: So how did your partner respond to it? You told your partner that you had HIV, how did that go?

> Patrick: He dealt with it really well. I told him one time when we were really connecting. I said, 'that was one of the greatest things that ever happened'.

Participants in the study reported that they had wanted a sense of normalcy when they disclosed their diagnosis. They did not appear to be disappointed if more active support was not extended to them but rather appeared relieved if their diagnosis was accepted and disclosure did not result in stigma. Participants also described how some sources with whom they shared their experiences, made an effort to find out more about the disease so that they were able to help participants manage stigma associated with the disease. Sabrina spoke about how her sister gathered information on the disease.

> I think she went and worked for an AIDS organization in the town or in the next town or something. ……. So she could understand more about what I had.

Sabrina went on to share how her sister's support helped her cope with her diagnosis more effectively. Similarly, Caitlin described how she received support from her church and how her pastor supported her by attending meetings with her.

> Researcher: Who did you tell, the pastor?
>
> Caitlin: I told the congregation, I stood up and told them.
>
> Researcher: It's like a meeting?
>
> Caitlin: You know its like; if I have anything to say you stand up. I talked about it.
>
> Researcher: What did people say to you?
>
> Caitlin: I get supported. My pastor goes to all my HIV things.

Finally, some people with whom participants shared their diagnosis helped them combat the stigma that they faced from other sources to whom they disclosed their diagnosis. In some ways, these supportive friends and family members helped participants deal with their felt anticipation of stigma and stopped enacted or actual stigma experience from occurring or at least minimized the amount of stigma that could have been manifested by other sources who found out about the respondents' HIV status. Sabrina, a female respondent, shared how her sister broke the news of her illness to their parents. She also described the strategies used by her sister to stop any stigma that Sabrina may have faced from their parents.

> [Her sister said] 'Well the next year in spring vacation, the kids and I are going to visit Mom and Dad', she says. 'And there is going to be a day when the kids are going to be with Tamy and VJ and their girls. They are going to take all of my kids with them. So I am going to be alone with Mom and Dad and I want them to find out about your

> status'. And she says, 'I want you to write a letter, send it to me and I will share this with them'. I said, 'you sure'. She says, 'you got to tell them sooner or later and if you don't I will'. I said, 'OK' (laughs). So I wrote a letter so she shared it with them. She shared it with them and mom wanted to pick up the phone and call me and Sandra (the sister) says, 'oh no you are not going to pick up the phone and you are not going to tell Sabrina (the respondent) what you just told me which was something about, she deserves this'.

Sarah, a respondent who had lost her husband to HIV/AIDS, described how the supervisor at her workplace helped her combat the stigma she was facing from her co-workers.

> I would hear all this other stuff between all these other girls in the office. 'I wonder if she's got it'. A couple of them went to the supervisor and the supervisor told them, 'Well are you having sex with her? If you are not having sex with her and if you work here, you don't do drugs because we don't allow it, so what's your problem?' So the supervisor handled it very well.

In summary, family, friends, and members in the workplace aided participants in the process of empowering themselves. Sometimes, they were accepting of the respondents' diagnosis and supportive of them despite it. At other times, they played a more active role, acting as intermediaries who prevented people who could have stigmatized participants from saying or doing hurtful things. Intermediaries can significantly impact both felt and enacted stigma experiences of adults. Respondents indicated that they were able to empower themselves and manage stigma effectively because of the help they received from supportive family members, friends, employers, and partners all of who supported them and sometimes intervened on their behalf when they were about to be stigmatized.

Membership in support groups. Participants sought out membership in various support groups and received guidance and advice from members of these groups on how to deal with possible stigma. Support groups consist of people who share the same diagnosis as the participants. Respondents went to support groups to discuss their problems and experiences of stigma. They sought advice from members of the support groups on how to face stigma and to minimize its impact. Sabrina described how members in her support group offered her help on how to carry out the disclosure process.

> And then about six months later, I started going to Kansas City to see the doctor, [and] the support group. Chuck was the one who happened to talk to me after that group and suggested that, you know, that he would be happy to sit down with me and talk to me about how to share with people when I was ready.

Support groups also helped participants overcome stigma by providing them with skills such as public speaking and advocacy. Lincoln said that he had always found it difficult to speak to people and being a part of a support group helped him overcome his shyness.

> Researcher: So you think that these groups have been really helpful?
>
> Lincoln: Absolutely.
>
> Researcher: What have they helped you do?
>
> Lincoln: They have helped me speak my mind in public. They have helped me be open to other people, like actually making an effort to make contact with somebody else which I had successfully avoided for 57 years.

Respondents also felt that their confidentiality would be protected within support groups, which made it easier for them to share their experiences. Hank described how members of support groups had similar experiences to his and how these shared experiences helped him establish bonds with other people in the support groups.

> Researcher: So how does it work?
>
> Hank: People talk about their problem, it's a social group. Also, the real reason about groups like this, people who are in the positive group

> don’t date the general population so these are people who have disclosed to each other, they have common problems.
>
> Researcher: So you think it helps them combat the stigma a little bit?
>
> Hank: It does.

Seeking membership in support groups is an extremely important personal strengths response to stigma. Participants who were members of support groups were able to access an organized network that gave them guidance and advice on managing stigma associated with HIV/AIDS.

Resilience in the face of stigma. Resilience has been defined as people’s capabilities to positively adapt to their circumstances despite significant adversity they may have faced. Respondents demonstrated resilience in the face of the stigma they faced and became stronger in the process. One form of resilience demonstrated by participants was their ability to forgive those who stigmatized them. When participants faced stigma from family or friends, some did not isolate themselves but rather chose to forgive the person who was stigmatizing them and continue their relationship with them. Andrew, a bisexual respondent, described the stigma he experienced at the hands of his brother and how he forgave him for that stigma.

> Andrew: He was a grown man and I thought he would accept it better but here is how I found out his true feelings about it. I had another car and, as I said, he knew a lot about cars. I was about to tear it down, get

> an automatic and I said ‘do me a favor check if all is right. I can’t do it today’. He said, ‘Okay’. I gave him a wrench, I said, ‘here, take this and do it’, and he said, ‘I’ll get another one’ and he took another one and used it and the guy I have been involved with …said, ‘did you see what he did? He wouldn’t take the one that you gave him but he went and got another one’. And I knew then how he felt about it.
>
> Researcher: Did you do anything about it or did you just accept it?
>
> Andrew: No, I didn’t go too much into it. I thought, he was my brother and I love my brother very much. He is three years younger than I am and I still love him.

Some participants who faced stigma from family and friends used the love they had for them to forgive them and continue their relationships despite the stigma that they had faced. Martha had been infected by her partner. She spoke about how forgiveness and love played a key role in reconciling with her partner.

> The guy who gave it to me, we are still together, I am still with him. I forgave him you know, [be] cause I loved him.

Resilience is an important strengths response to stigma. Participants who showed resilience recognized that they could not completely isolate themselves from family members and friends who stigmatized them. Finding ways to reconcile with society is an important tool in managing stigma. Respondents in the study used a variety of tools to manage the stigma that they were facing. Sarah spoke about the use of humor in dealing with the stigma that she faced.

> Well my mom. ….. Every family dinner getting out the china and you know having dinner, it was like well plastic silverware and mum used to get the Styrofoam plates and wash them and reuse them but now everything went in the trash and she was a nurse and she's 80, you know, so she's kind of older and we kind of laugh at her behind her back and say, 'that's just granny'. She saw me drinking out of [sons' cup] at one time and she reached over and grabbed the cup out of [sons] hand and said, 'here let me get you a new cup' (laughs) and I looked at her and [said], 'we do this all the time you know.'

Participants refused to be labeled and to let the diagnosis define who they were. Martha spoke about how her girlfriends tried to label her and how she refused to let them do so.

> You know even my girlfriends stigmatized me once. [They said], 'You know you are labeled'. I'm not labeled. You know I am not labeled at

> all. I may be HIV positive but I do not wear a label on my head saying that I am HIV positive. You know things like that.

Participants in the study refused to let HIV/AIDS define who they were. While they accepted their diagnosis, many did not accept the stigma that came with the diagnosis. They took active measures to minimize the stigma in their lives such as avoiding the sources of stigma or dealing with it with a sense of humor and not letting it affect their lives. As Shana a Caucasian respondent in the study stated:

> I say, ‘you know what, I have HIV. HIV doesn’t have me.’

To summarize, some respondents developed resilience in the face of stigma. Very often, the people who stigmatized them were family members or friends. They forgave these friends and continued to love them. They also laughed at hurtful comments. Other forms of resilience included refusing to accept stigma and labeling from anyone. Participants maintained their integrity and dignity despite facing stigma from a range of sources.

Education of self and others and volunteering. Another personal strengths response that emerged from the findings was that respondents volunteered to educate people about HIV/AIDS in order to minimize stigma associated with the disease. Some adults 50 years and older responded to the stigma that they faced from various sources, by either educating the sources from which they experienced stigma or by channeling what they learned from this experience into educating and helping others. Participants made an effort to educate the people to whom they revealed their diagnosis.

Several participants spoke about the importance of education in managing stigma that they faced. Sometimes they took family and friends to doctors or caseworkers to help them get a better understanding of the disease. Caitlin said that she had taken her friends to the doctors who were treating her.

> Researcher: So things got better. Did you have any conversations with them or did they find out on their own?
>
> Caitlin: I had conversations with them and I had doctors talk to them.

Respondents who had faced negative experiences when they received their diagnosis volunteered in clinics to give patients their test results. Andrew, an African American participant, had been given his test results as if it was a death sentence. He was determined to help others with HIV have a friendlier experience.

> I said, the young man who told me I was positive, I thought, did it in a manner that was very detrimental to people and I don’t want to ever

> have somebody tell someone like that as long as I am living. I explained to them, he said you are dying, go home and get your house in order or go out and have a good time. I don't think you should tell people that. They said who was it and I was like I am not going to tell any names who volunteered at the time to give information.

Shana, a participant in the study, shared her experiences with other women 50 years and older and disseminated information on how the disease affects women 50 years and older.

> I went to schools and talked to teachers and a lot of student doctors and I have talked to other women. I try to put out there as much knowledge about this disease. Just because you think you are a senior citizen doesn't mean you won't get it and what we try as senior citizens, I know I do and some my friends do, we try to emphasize, the regular MD, if he is asking you if you want to take a HIV test, you tell him you want to take it because even they are afraid they will lose their patients. I tell them if you don't offer to test them then you will turn around and lose them anyway.

Besides educating others about the disease, respondents also educated themselves about the disease, both to combat the stigma that they faced from external sources and to combat the internal stigma that they experienced. Martha, an African American respondent moved from one location to another because she felt that the stigma in a conservative city was harder to deal with. She spoke about how she educated herself once she had made the move to Kansas City.

> Martha: Back in the South it was kind of hard because stigma in the South is real bad for HIV.
>
> Researcher: You were in (location).
>
> Martha: I was in (location) at the time. And they did frown on me down there. They did frown on me real bad down there. And they don't have the same resources down there as they have down here that I could get out into. I was kind of stagnating because of the stigma out there. When I came back to Kansas City, I hit the ground running. I started attending everything. I attended the life program and I attended what they called the people to people, the peer program, and to self educate myself even more as to what was going on to see exactly how this disease has affected me.

Education is an important personal strengths response to stigma. It allowed participants to use their experiences for the greater benefit of others who were living with HIV/AIDS. It also empowered them to look beyond their diagnosis and become advocates for themselves as well as for others living with the disease.

In summary, respondents developed a number of strengths responses to stigma. They empowered themselves with the support of family and friends. They joined support groups and gathered information on how they could combat stigma. They also formed social networks. They developed resilience and used forgiveness and humor to manage stigma. Finally, they educated themselves and others about the disease so that people would not stigmatize them and others living with HIV/AIDS. However, there were times when the stigma associated with the disease weighed them down and had a negative impact on their lives. In the next section, I present other responses to stigma that were not strengths responses.

Other Responses to Stigma

In this section, I examine findings related to the third research question in the study: What other responses to stigma (besides strengths responses) do older adults have? While respondents had strengths responses to stigma, the stigma that they experienced sometimes overwhelmed them and had a negative impact on their lives. Some of the key themes that emerged from the analysis of data that describe the negative impact of stigma on the lives of adults 50 years and older living with HIV/AIDS are: 1) non-disclosure of HIV/AIDS status and 2) isolation.

Non-disclosure of HIV/AIDS diagnosis. A recurrent theme that emerged when I examined the data related to responses to stigma that were not strengths responses was the decision to not disclose their HIV/AIDS diagnosis. When faced with possible or felt stigma, some participants chose to conceal their HIV/AIDS status. Some respondents who had experienced enacted or direct forms of stigma also chose to not disclose their diagnosis because of fears that they would be stigmatized again. This is another example of how felt and enacted stigma can interact and how participants' responses are influenced by their experiences of felt and enacted stigma. Several respondents expected that they would experience stigma upon disclosing their HIV/AIDS status and chose not to reveal their diagnosis. Patrick, a gay male, stated that he could not disclose his diagnosis to his family for fear that they would react negatively to this news.

> It's sad. It is. I can't tell my daughter, I can't tell my grandsons. I can't tell (my sister). Oh God, if I told her family, they would just probably send an assassin to shoot me. I can't tell my family, I can't tell anybody in my family, I can't.

Sometimes respondents had previous experiences or enacted experiences of stigma or had seen others experience stigma (vicarious stigma) and this prevented them from revealing their diagnosis. Arnold, an African American respondent had seen his brother, who also had HIV/AIDS, being stigmatized by their parents. This prevented him from disclosing his diagnosis to his family.

> [Father said], so we're not going to have to go through this with you too are we? And at that point I knew that I could never give him the

> satisfaction of telling him. The way that he said it was so kind of evil that there was no way that I could give him the satisfaction. I was like, ‘go through what? I have seen the way you have gone through this, and please not me. No I would disappear first. I’ll go to the jungles of Guatemala and you’ll never see and hear from me again before you hear that’.

Sabrina also had an enacted experience of stigma. Sabrina’s friend never spoke to her again after she disclosed her diagnosis. This is an enacted experience of stigma. Sabrina did not share her diagnosis with anyone for some time because she feared that others might react the same way (felt stigma).

> Researcher: When you found out, did you tell anyone?
>
> Sabrina: When I found out, I told my husband of course, I told my best friend. He took off. We had known each other for several years.
>
> Researcher: He took off?
>
> Sabrina: Yeah.
>
> Researcher: Didn’t ever talk to you again, took off?
>
> Sabrina: Yeah, so I didn’t tell anyone else for six months.

These findings show that there is a constant interaction between enacted and felt stigma. Some respondents reacted to anticipated stigma, a felt stigma experience, by not disclosing their HIV/AIDS status. Richard, an African American participant, said that he had not shared his diagnosis in the workplace because he anticipated stigma there.

> Researcher: And is that because you thought it was none of their business or did you think there would be some kind of adverse reaction?
> Richard: At that time, yes, I thought it would be, it would be a bunch of mess. It could cause a lot of controversy and I didn't want to go through all that.

Participants in the study were also scared that the people to whom they disclosed their diagnosis would spread the news that they had HIV/AIDS, leaving them vulnerable to further stigma. Hank, a bisexual male who participated in the study, described how he feared disclosure at the hands of potential sexual partners and how this fear prevented him from revealing his HIV/AIDS diagnosis to them.

> You want to date somebody. I've been through this before and it goes through your mind. I know I should tell them but if I tell them …….they can tell anybody else my business.

Several participants in the study stated that they chose to conceal their HIV/AIDS status from others because of their stigma experiences. Non-disclosure prevented participants from accessing support mechanisms from other sources that could have helped them manage their diagnosis.

Isolation. Another theme that emerged from the analysis was that some respondents isolated themselves from society because of the stigma that they faced. Sarah said that it was difficult for her to share her symptoms and conditions associated with her diagnosis with other people. HIV/AIDS affected various facets of her life and was a lifelong illness. She found it easier to isolate herself rather than share these conditions with other people.

> It's one of the reasons I isolate because I don't want to have to deal with telling somebody why I don't want to go out, why I don't want to date. It's just easier to say, 'I don't period', than 'I don't because I don't want to deal with the issues of sex and all of that'. It's made a difference in what I think of the future, especially because I see this is what my future is right here in this house and it's not ever going to get better. They talk about, well, so many people are getting better and going on with their lives and going back to work. That's not going to happen to me.

One of the main reasons that study participants and older isolated themselves was that they felt they were unable to completely share their lives with others. Their diagnosis prevented them from having normal relationships and they felt a sense of hopelessness. Hank spoke about how he was unable to establish a really close relationship. This frustrated him and he isolated himself as a result.

In normal relationships with everyday people, I meet somebody I like. I can’t just go to bed with him. There is all this crap. Most people will say, ‘forget it. It’s totally professional, associate, there ain’t no deep relationship’. I know people 50 years and older who don’t go out at all.

Some other responses to stigma are non-adherence to medication and reluctance to visit medical professionals. Hank spoke about how he did not take his medication because he did not want his friends to find out he had HIV/AIDS.

> But then you have to have your medicine and stuff but you have to refrigerate it. I didn’t take it for four months because of the refrigerating. What’s this stuff about refrigerating and what’s this blah, blah, blah, so I didn’t take my medicine just for that reason.

Sarah found it difficult to discuss her condition even with a medical professional like a doctor.

> I hate even going to a new doctor because I don’t even want to go through that 20 questions thing you know. The 20 questions thing for a

> normal person is 20 questions. Twenty questions [for someone else] are 150 questions [for me].

Findings show that having HIV/AIDS can be an extremely lonely experience. Participants in the study shared how they isolated themselves from potential partners, friends, and medical professionals because they found it difficult to constantly negotiate a conversation about their illness. It seemed to exhaust them and they preferred to be on their own rather than navigate the dating scene or meet and socialize with people. In the next section, I present findings regarding personal growth experiences related to strengths responses to stigma.

Personal Growth

This section relates to the fourth research question in the study: How do these responses, both strengths related and other, contribute to personal growth? Findings have shown that participants experienced personal growth in the face of stigma. Personal growth in the context of this study is defined as significant and positive life changes experienced by respondents living with HIV/AIDS, which occur as a result of their responses to stigma. While a number of respondents in the study had strengths responses to stigma, some were able to build on these responses and use what they learned to make significant, positive changes in their daily lives. Their ability to make these changes has been recognized in this study as their personal growth experiences. A few respondents in the study did not demonstrate consistent strengths responses to stigma. Analysis of transcripts did not reveal content on personal growth for these adults. Some major themes that emerged through the analysis of data related to personal growth were 1) giving something back and 2) spiritual growth.

Giving something back. Many respondents who received positive support from others continued to have strengths responses to the stigma that they faced. As a result of this support, they consistently demonstrated strengths responses to stigma and made significant life changes. One instance of such a life change that some participants described was a decision to give something back to the community.

Patrick spoke about the internalized stigma that he faced when he heard his diagnosis. He also shared that the person who revealed his diagnosis helped him manage his diagnosis. This experience reduced his own sense of internal shame about his diagnosis. He was touched by how a total stranger had helped him deal with the stigma he experienced. He also felt that he was better able to deal with his feelings of loathing and shame after his diagnosis because of the support he had received from the volunteer at the community organization where he was tested. This experience made him want to give something back to the community.

> When you pride yourself on protecting yourself every time, how did this happen and I sat down and I just welled up with tears and just silently started crying my eyes out. And this guy I didn't know that was younger than my daughter sat there and just held on to me like a baby and I'll never forget that as long as I live. That's why I do this

> job. Because somebody loved me that much that they didn't even know who I was but they helped me and held onto me like you know.

Martha shared a similar experience where she decided to be a peer counselor because of the help that she had received to combat stigma.

> [I think] about giving back a lot. That's why I am into social work because so many people have helped me. There is so much out there for everybody else that I want to help somebody. It showed me a lot of things that were out there to get ahead you know so I want to give back what was given to me.

Spiritual growth: Respondents who had strengths responses to stigma also experienced spiritual growth. Some participants who decided to educate others about the epidemic and minimize social stigma found that they used their personal spirituality as a resource to help others manage stigma. Sabrina spoke about how she had conversations with God, which guided her efforts to help other people.

> Researcher: How did that work?
>
> Sabrina: Great.

> Researcher: Did you walk into a TV station and say I want to do this? How does it get set up I guess?
>
> Sabrina: Oh, (name of project) was the one I was with at the time and I went to them and I said, ‘OK, you know I have talked to small groups in churches and stuff like that’ and they said, ‘yeah, we sent you there’ and I said, ‘God and I have been in discussion all winter and God decided I needed to be speaking out more and I said, here I am and I am ready for whatever’ and they are going, ‘are you serious? And I am going, ‘yes I am serious’. And they said, ‘you would even be on the news’ and I said, ‘sure.’

Martha, a peer counselor who participated in the study, spoke about how she tried to have a connection with God that helped her deal with her diagnosis and to help others who come to her for guidance in her role as a peer counselor.

> Researcher: What do you tell people who come to you as a peer educator about stigma, disclose, not disclose?
>
> Martha: I cannot tell them not to (disclose). I cannot tell them to (disclose). You’ll know when it’s time, just take your time. You don’t have to disclose to anybody. As far as the stigma goes, it’s out there. I tell them, ‘it’s out there. But don’t let it dictate your life because nobody has to know you are HIV positive except you and God

> almighty'. So I try to give courage there. Not to look like they have a problem you know. I can't inject a spiritual dimension in it but I try to have a relationship with God.

Shana felt that her faith had helped her manage her diagnosis.

> Even now, I live with my daughter and my grandchildren and she'll find out if I am not feeling well and she'll check on me or call me and I say yes. [Daughter says], 'I don't know how you do it'. [Shana said], 'You do it with the grace of God one day at a time'. I think my faith has gotten me through this also.

Participants experienced personal growth as a direct result of their strengths responses to stigma. Findings revealed that adults 50 years and older who empowered themselves through the help of supportive people in their lives, sought membership in support groups, developed resilience in the face of stigma, and who made the effort to educate people and themselves about their diagnosis, were much more likely to experience spiritual growth and become advocates for the cause of adults fifty years and older living with HIV/AIDS than those who did not have strengths responses to stigma and let the stigma influence their lives in negative ways.

Next, I will discuss some other personal growth experiences that are related to how participants responded not just to stigma but also to their diagnosis as a whole.

Many respondents I interviewed had experienced personal growth that was not necessarily related to their stigma responses. I thought it was important to incorporate these findings, as they demonstrate how adults 50 years and older experienced growth despite living with a chronic condition.

Other Findings Related to Personal Growth

Some other personal growth experiences that participants went through cannot be linked directly to their experiences of stigma but rather they resulted from their overall experience of living with HIV/AIDS. These personal growth experiences are: 1) an increased appreciation of life and 2) stopping risk behavior.

Increased appreciation of life. Participants in this study described how having HIV/AIDS increased their appreciation for life. One participant, Martha, explained how being confronted with a chronic disease can change a person's perspective on life.

> We take things for granted. A lot of us take things for granted. It's nature. We have to stop trying to take things for granted. Make good money, shopping, this, that, and the other you know. But once you are faced with a life or death situation, it kind of makes you think about things.

Shana, another female respondent in the study, described how having HIV/AIDS increased her feelings of empathy towards others who had HIV/AIDS.

> Researcher: How has this experience changed you? Has it changed you as a person?
>
> Shana: I don't know, I think it has in a way (made me) appreciate life more. I don't think the person you have before you is the person I was before. I don't think I have become more compassionate because I think I was always compassionate. It brings you to a level that when you see somebody else with this disease and they are sitting there in front of you crying. My heart goes out to them. HIV is such a disease that the pain of it is unreal.

Stopping risk behavior. Respondents also stopped indulging in risk behavior such as drug use. Caitlin shared how she had stopped risk behavior such as drug use after being diagnosed.

> Researcher: Right, and can you talk a little bit about how this experience of having HIV has changed you? Has it changed you?
>
> Caitlin: It changed me in a way for the better because if I hadn't found out about HIV, if you could have seen me when I came here, you see how big I am right, I was like 80 pounds, that sick, not taking care of myself, doing drugs. When I woke up it was drugs, when I sleep it was drugs, drugs and drinking. That was my life. I got a check on the first

> of the month and it was gone (very soon). That’s how bad it was. Each day went by and all I thought about was drugs. Having HIV changed my life. I would have been dead.

Participants in the study demonstrated personal growth in the face of stigma. They had an increased appreciation for life and a desire to return something to society. They also experienced spiritual growth as response to the difficult circumstances in their lives. Some of the participants reported that being diagnosed with HIV/AIDS saved their lives and prevented them from further indulging in risk behavior that jeopardized their health.

In summary, findings show that participants experienced stigma. Some of this stigma was experienced as a result of enacted discrimination, while other cases involved fears of being stigmatized or even stigmatizing themselves. Some respondents experienced stigma from family, friends, and coworkers. Some participants responded to stigma with strengths responses and in other ways. Some of the strengths responses were: joining support groups, developing resilience in the face of stigma, and actively educating themselves and others about the disease. Some participants also received support from family, friends, and trusted members of society who helped them to face stigma in a positive manner. In contrast, some respondents were overwhelmed by the stigma and chose to not disclose their HIV/AIDS status and isolated themselves from family and friends.

Some participants in the study also experienced personal growth as a result of their stigma experience. Participants shared how their experiences of support during the stigma experiences had led them to educate others and give back to society. Participants also experienced spiritual growth as a result of stigma.

Findings in this chapter revealed a connection between the decisions to disclose or not disclose and respondents' experiences of stigma, their responses to stigma, and the personal growth that may result from their responses. These issues arose repeatedly in the findings discussed in this chapter and it is apparent that participants' responses to stigma are closely related to their disclosure and non-disclosure decisions.

Some participants in this study did not reveal or disclose their diagnosis either because they had experienced stigma in the past and anticipated it in the future or because they expected to be stigmatized despite having no direct experience of stigma before. Some respondents who chose to disclose their diagnosis were stigmatized by family members and friends and in the workplace. However, others who disclosed their HIV/AIDS to family members and friends, in workplaces and support groups, received support that encouraged them to empower themselves to manage stigma. It became clear that disclosure and non-disclosure decisions were central to older adults' experience of stigma. Therefore, I conducted a specialized plot analysis to further explore the impact of these processes on the experiences of respondents living with HIV/AIDS. In the next section, I describe findings that emerged from the specialized analysis.

Disclosure and Non-Disclosure

The review of literature showed that adults 50 years and older living with HIV/AIDS faced a number of stigma experiences triggered by a variety of events (Emlet, 2005; Emlet 2006a; Emlet, 2006b). The phenomenological analysis of participants' interviews showed that that many participants in the study faced a large amount of their stigma experiences when they disclosed their HIV status or as a result of choosing to not disclose their HIV/AIDS diagnosis. The decisions to disclose or to not disclose their HIV/AIDS diagnosis were ongoing events in the lives of participants in this study. This understanding of the decisions of disclosure and non-disclosure led me to focus more closely on participants' disclosure and non-disclosure decisions. Further, the time of the initial diagnosis and therefore initial decision to disclose, was also examined to explore potential effects of time period and age of respondent on stigma at time of initial diagnosis and disclosure decision.

Specialized Plot Analysis

A specialized plot analysis separate from my thematic analysis was conducted to examine the impact of participants' disclosure and non-disclosure decisions on their stigma experiences, their responses to stigma, and their personal growth experiences. The specialized plot analysis departed from the thematic analysis in that it examined the individual stories of participants in the study. It was clear that while some participants had similar experiences of stigma that influenced their decisions to disclose or to not disclose their diagnosis, the participants did not come from a single homogeneous group and certainly had a variety of stigma experiences.

Orsulic-Jeras et al., 2003, suggested that older adults with HIV/AIDS fall into two categories: “long term survivors” (p. 234), that is those who have aged with HIV/AIDS, and adults who contract HIV/AIDS at an older age. Other categories emerged from my study. Some participants in my study were diagnosed when they were 50 years and older while others were diagnosed before age 50. Some participants had been diagnosed before legislation protecting people living with HIV/AIDS from stigma, such as the Americans with Disabilities Act and the Ryan White Care Act were passed, while others were diagnosed after the legislation had been passed. These categories were included in Table 2 which contains plots which illustrate participants’ experiences after they had been diagnosed (See Table 2, Appendix D).

Each plot mapped the individual participant’s age at diagnosis, if they had been diagnosed before or after the passing of protective legislation, their ongoing decisions to disclose or to not disclose their diagnosis after they had been diagnosed, their stigma experiences, their responses to stigma, and their personal growth experiences. Plots revealed that there were multiple patterns of disclosure and non-disclosure. For example, some respondents chose to disclose their diagnosis immediately after they were diagnosed. As a result of this decision, some participants experienced support while others experienced stigma. Their experiences influenced their future disclosure and non-disclosure decisions. Findings showed that the decisions to disclose or to not disclose played differently for different participants in the study.

Once plots illustrating the participants' disclosure and non-disclosure decisions and their link to participants' stigma experiences, responses to stigma, and their personal growth experiences had been established, I prepared plot summaries for individual participants. Each plot summary contained a brief written description of individual participant's disclosure and non-disclosure decisions and the impact of these decisions on their stigma experiences, their responses to stigma, and their personal growth experiences. I then compared the plot summaries of all participants in order to gain an understanding of their collective experiences. In the next section, I present an overview of participants' disclosure experiences.

Overview of the Experience of Disclosure

Participants in this study disclosed their HIV status to different social groups. Some respondents who had been sexually active after they had been diagnosed said that they had disclosed their HIV status to intimate sexual partners. Some participants disclosed their status to family and friends while others had revealed their HIV/AIDS status within support groups and churches. Participants had informed medical professionals, employers and coworkers, and management staff of housing complexes where they lived, about their diagnosis. In rare circumstances, they disclosed their HIV/AIDS status to people who they did not know personally, who had no immediate influence on their lives, and who were in fact, strangers.

Some respondents reported that they had disclosed their diagnosis because they had been confident that they would receive the support of family and friends. Others respondents had not been sure of the reactions that they would face yet chose to risk disclosing their diagnosis. While some participants who disclosed their diagnosis received support, others were stigmatized by people to whom they revealed their diagnosis. Another pattern of disclosure that emerged was involuntary disclosure or disclosure by someone who was aware of a participant's diagnosis and disclosed the participant's diagnosis without their consent.

There were many reasons why respondents disclosed that they were HIV positive. They decided to inform sexual partners because they had the greatest risk of infection. They discussed their HIV/AIDS diagnosis with medical professionals who they sought out for treatment and help. Participants in this study revealed their diagnosis to family members, either, because they expected to die or, because they needed their family's support to survive their chronic illness. Patrick, a gay respondent, said that he revealed his HIV status to his family, after watching his partner die of the disease.

> I just told them just in case something did happen to me. After watching my lover die, you know, because all you had then was AZT. They didn't have cocktail therapy then. They came up with that just a few months after he died. That's when my T cells shot up and my viral load went down. Well, I just wanted people to know.

Some participants stressed that disclosure was a deeply personal experience and that people who found out that they had HIV/AIDS should disclose their

HIV/AIDS status only when they felt comfortable doing so. They also felt that their HIV status was ‘really not too many peoples’ business’. Participants in this study felt that they should not be expected to disclose their HIV status as most people with other chronic conditions besides HIV/AIDS were not generally expected to disclose their illness to society. Hank mentioned the importance of realizing that people diagnosed with HIV/AIDS often faced stigmatizing reactions from the people to whom they disclosed their HIV status.

> I told somebody, a student helper or something. ‘You tell somebody. It’s about clearing your mentality, your mind………. so go ahead and tell but they might not want you in their house anymore, in their toilet, in their kitchen.’ ‘You can’t touch this, you can’t touch that. It happens. So you can go ahead and tell if you want to ……….. But there are consequences.’

A few participants expressed how uncomfortable and unprepared they had felt when they had lost control of the disclosure process and their diagnosis was revealed to family members and friends by someone other than themselves. Arnold, a gay black man, described how upset he was when his brother who also had HIV/AIDS revealed Arnold’s HIV status to their parents in order to deflect their stigmatizing reactions from himself.

> Actually, my brother told them. I could kill him for that (laughs). What happened was that he has no support system here and apparently in one of their big fights, they said something to him like, ‘well, you are just a fag and you are just lying’. Well, he couldn’t take it anymore. And he said, ‘well, I don’t know why you are picking on me all the time. Arnold has HIV too’. And I just hated him for that but I understand where that was coming from.

To summarize, the process of disclosure is delicate and complex. Participants in the study wanted to have maximum control over this process. While some participants received support on disclosing their HIV/AIDS status to various people, others were stigmatized by the people to whom they revealed their HIV/AIDS status. Many of the respondents in this study had to make a choice regarding whether they wished to disclose or to not disclose their HIV/AIDS diagnosis. If they chose to disclose their diagnosis, they had to prepare themselves for the possible stigma that they might encounter when they disclosed their diagnosis. These decisions ultimately impacted the way they responded to stigma and their potential for personal growth.

As previously explained, I conducted the specialized plot analysis to further examine specific disclosure decisions of participants in this study. A different form of analysis from the thematic analysis provided a fresh perspective on the experiences of participants in the study. New findings emerged as a result of this analysis which had not emerged from the earlier thematic analysis. In the next section, I present summaries of 2 of the 21 plots that were constructed to illustrate the impact of disclosure and non-disclosure decisions on the experiences of the respondents living with HIV/AIDS.

Plot Summaries

Arnold's plot. Arnold disclosed his HIV/AIDS diagnosis in certain circumstances while he did not disclose his diagnosis in others. He saw that his family had stigmatized his brother who was also gay and HIV positive. He felt that he would also be stigmatized by his family if he revealed his diagnosis to them. He responded to this felt stigma by choosing, to not disclose his HIV/AIDS diagnosis to his family.

He disclosed his diagnosis in a support group. He was stigmatized by members of this support group. Arnold responded to this stigma by isolating himself from this group. Arnold also disclosed his diagnosis in his workplace. He was fired after disclosing his diagnosis at work.

Arnold experienced dual responses to stigma. One, he felt helpless in the face of stigma. On the other hand, he was glad he disclosed his diagnosis in his workplace and felt he stood up for himself. This participant had had a number of stigma experiences and was unable to experience personal growth as a result of his stigma experiences and his negative responses to stigma.

Caitlin's plot. Caitlin disclosed her diagnosis to family members and friends. She was supported by some family members and friends. She was stigmatized by other friends who were scared that they would contract the disease from her. She responded to the stigma by taking her friends to doctors who educated them about the disease. She also disclosed her diagnosis in church where she was supported by church members and by her pastor who attended all her HIV meetings and further educated himself about the disease. She was also a member of a support group. Caitlin said that disclosing of her diagnosis in a support group helped her access the services of social service organizations, become part of a social group of people living with HIV/AIDS, and manage stigma associated with the disease. In the next section, I present the impact of participants' disclosure and non-disclosure decisions on their stigma experiences, their responses to stigma, and their personal growth experiences.

Impact of Disclosure and Non-Disclosure Decisions

Disclosure, non- disclosure, and stigma. Some participants in this study who disclosed their diagnosis were directly stigmatized by people to whom they revealed their diagnosis. Plots showed that most participants experienced enacted stigma when they disclosed their diagnosis. This experience of enacted stigma can lead to felt stigma or a fear of being stigmatized again. While some participants experienced enacted' stigma on disclosure which led to 'felt' stigma, other participants had independent 'felt' stigma experiences which were not connected to enacted stigma experiences.

An example of enacted stigma leading to felt stigma can be seen in the plots illustrating the experiences of those participants who were diagnosed before the passing of protective legislation (See Table 2, Appendix D). Participants in this study who were diagnosed between the ages of 31-40 were long-term survivors of the disease. They were all diagnosed with the disease before legislative measures, such as the Americans with Disabilities Act and the Ryan White Care Act, were passed to protect adults living with HIV/AIDS from stigma and providing them access to health care. While gathered data does not establish a clear causal connection between greater stigma and being diagnosed before protective legislation was passed, it was clear that participants who had aged with the diagnosis had been exposed to stigma over a number of years. Even if their experience of enacted stigma had reduced, the impact of previous experiences of enacted stigma led them to have anticipatory stigma experiences in the present. This felt stigma sometimes prevented them from judiciously disclosing their diagnosis and accessing support services.

Six major findings on stigma have emerged from the analysis of the plots: 1) participant’s first experience of stigma after disclosure of their HIV/AIDS diagnosis is likely to be an enacted stigma experience; 2) an experience of enacted stigma on disclosure can lead to participants anticipating stigma in the future or having a felt experience of stigma; 3) participants who experienced felt stigma as a result of a previous enacted stigma experience were likely to respond to stigma by choosing to not disclose their diagnosis to other people they meet who could stigmatize them; 4) Most participants who chose to not disclose did so because they anticipated stigma on disclosure; 5) participants who had been diagnosed before the passing of protective legislation and who had aged with the disease had greater enacted stigma experiences than those who were diagnosed after the passing of protective legislation and who had been diagnosed more recently. At the time of the interviews, participants who had been diagnosed at younger ages reported a greater amount of felt stigma experiences that had resulted from previous enacted stigma experiences than those participants who had been diagnosed when they were older. Participants who were diagnosed at earlier ages and who had experienced stigma over a longer period of time were less likely to disclose their diagnosis than participants who had been diagnosed at older ages.

Disclosure, non-disclosure, and responses to stigma. The analysis of plots confirms findings from the thematic analysis that, though, many participants who disclosed their diagnosis were stigmatized by the people to whom they revealed their diagnosis; others received support and guidance from the people to whom they disclosed their diagnosis. A further look at the plots showed that respondents who chose to not disclose their HIV/AIDS diagnosis were far less likely to develop a strengths response to stigma than those who chose to disclose their diagnosis, face stigma, and continued to disclose despite the possibility of experiencing stigma. This is an extremely important finding because it revealed that engaging in the process of disclosure and facing stigma was crucial for participants to develop a strengths response to stigma. Participants who did not engage in this process or who stopped engaging in it because of previous experiences of stigma found find it harder to develop strengths responses to stigma than those participants who consistently and judiciously disclosed their diagnosis.

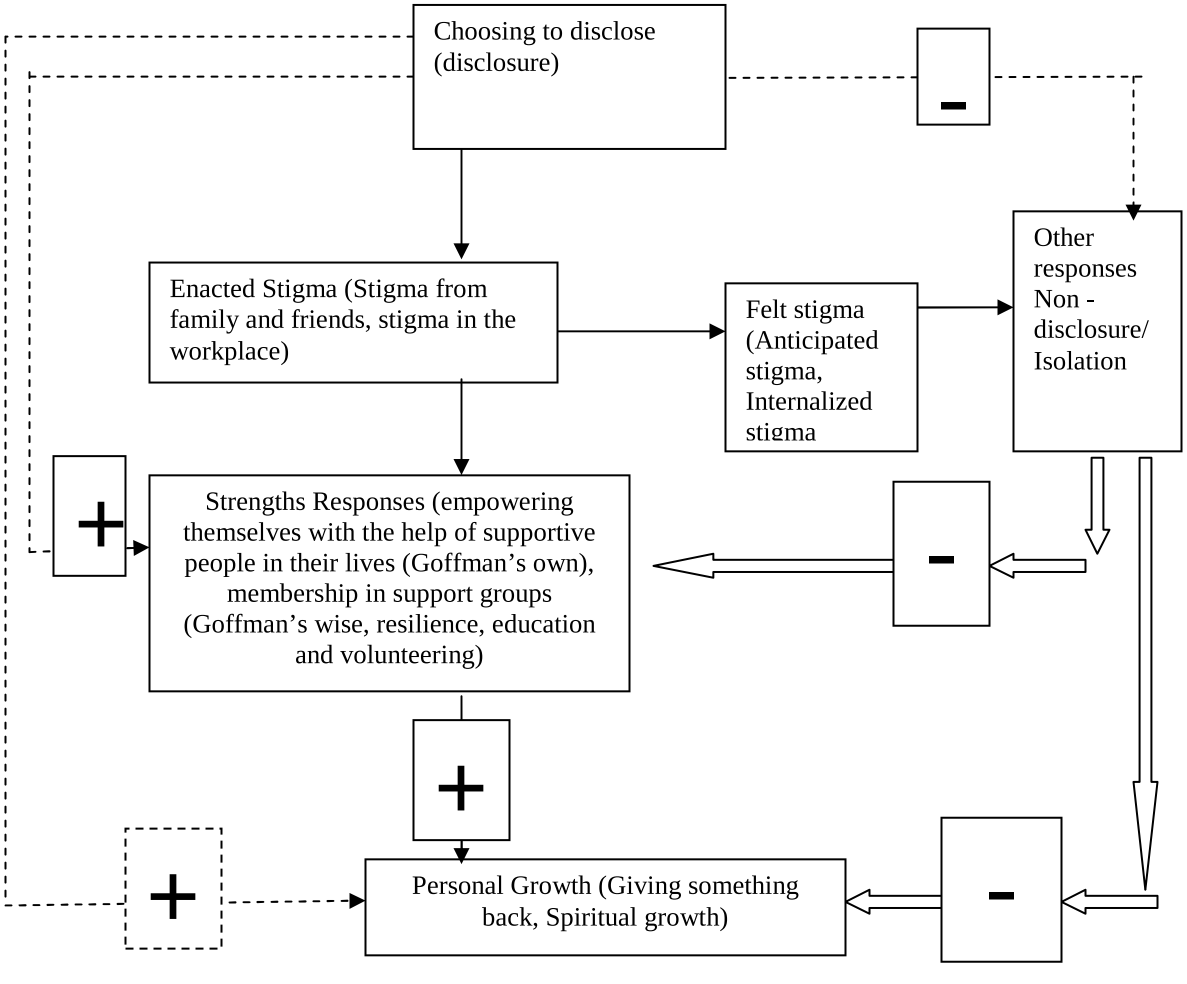
Disclosure, non-disclosure, and personal growth. The third analysis that I carried out was to see if disclosure and non-disclosure decisions impacted how participants in this study experienced personal growth. Specialized plot analysis revealed that participants in the study who consistently and judiciously disclosed their HIV/AIDS diagnosis developed strengths responses to stigma as opposed to those who chose to not disclose their diagnosis or stopped disclosing as a result of felt stigma which resulted from their previous enacted stigma experiences. Further analysis of the plots revealed that some respondents who consistently disclosed were also more likely to experience greater personal growth than those who did not disclose their diagnosis.

To summarize, specialized plot analysis revealed that disclosure and non-disclosure decisions played an important role in respondents' experiences. These decisions occurred on an ongoing basis in the lives of participants in this study. Participants in this study chose to disclose or to not disclose based on their personal inclinations and previous life and stigma experiences. Participants who were able to overcome their fear of stigma and consistently, yet judiciously, disclose were more likely to develop strengths responses and experience personal growth. Findings from the above analysis added to the depth of findings that emerged from the thematic analysis. In the next section, I present a model which illustrates the role of disclosure in shaping stigma experiences, responses to stigma, and personal growth experiences of participants in this study.

New Conceptual Model

A new conceptual model has emerged from the findings of this dissertation. As described earlier, the decisions to disclose or to not disclose their diagnosis impacted participants' experiences. Figure 1 illustrates how the decision to disclose can lead to strengths responses and personal growth and how non-disclosure decisions reduce the chances of strengths responses and personal growth.

Figure 1: The Role of Disclosure in Shaping Stigma Responses of Older Adults Living with HIV/AIDS.



Dotted lines with arrow tips and plus and minus signs demonstrate the impact of the decision to disclose on participants' experiences of stigma, their responses to stigma, and their experiences of personal growth. Block arrows in conjunction with plus and minus signs have been used to illustrate the impact of non-disclosure and isolation on the experiences of respondents' experiences. In the model, solid lines with arrows have been used to illustrate possible disclosure and non-disclosure pathways chosen by participants after they were diagnosed.

Experiences post disclosure. The decisions to disclose or to not disclose an HIV/AIDS diagnosis were ongoing events in participants' lives after they were diagnosed. Some participants who chose to disclose their diagnosis faced experiences of stigma while others received support. Those who faced stigma generally had an enacted or direct experience of stigma. Some participants overcame stigma and demonstrated strengths responses to stigma. Others carried the memory of the stigma experience with them. Their enacted experiences of stigma influenced their perceptions of people's possible reaction to their diagnosis. They developed felt stigma. Felt stigma was likely to lead to non-disclosure and isolation.

Experiences post non-disclosure. While some participants chose to disclose their diagnosis and then experienced different forms of stigma or support, others experienced felt stigma immediately after they learned of their diagnosis. Some of these participants never disclosed their HIV/AIDS diagnosis to anyone because of their fear of being stigmatized.

Impact of the decision to disclose on older adults' experiences. Findings show that some participants made a decision to reveal their HIV/AIDS. Some respondents who disclosed their diagnosis did not receive support and were stigmatized. Of the participants who were stigmatized, some developed resiliency and used their experience to educate others about the disease. In the model, dotted lines lead from the decision to disclose to strengths responses to stigma. A plus sign (+) placed in the dotted line illustrates the positive impact of the decision to disclose on the lives of participants. Participants who chose to disclose had a greater chance of developing strengths responses to stigma. Similarly a minus (-) sign has been placed on dotted lines leading to other responses to stigma. This signifies that respondents who made the decision to disclose had reduced chances of isolation in the future than those who did not disclose their diagnosis. Participants who disclosed their diagnosis also had greater chances of personal growth.

Impact of non-disclosure and isolation on older adults' experiences. Block arrows in the model illustrate the impact of non-disclosure and isolation on participants' experiences. Some respondents who chose to not disclose their HIV status after they were diagnosed or after they were stigmatized were less likely to develop strengths response to stigma. This negative impact has been illustrated using minus (-) signs in conjunction with block arrows.

To summarize, findings describe the stigma, responses to stigma, and personal growth experiences of participants in this study. Disclosure and non-disclosure decisions were found to impact the experiences of these respondents. An additional, specialized plot analysis was conducted to further examine these decisions. Preliminary findings from this study were compiled in a report and sent to the participants for feedback. In the next section, I will discuss the feedback received from participants through the process of member checking.

Member Check

A preliminary draft report was prepared which was sent to the participants in the study. I was unable to contact six participants because they had not sent their phone numbers or house addresses. Copies of their reports were sent to the HIV/AIDS organizations from which they were recruited and case management supervisors were requested to forward the report to the participants. Four participants responded to a request for feedback by email or mail. I was able to contact four other participants by telephone and gather feedback on the report from them. Participants were sent a form with three open ended questions. These questions were: 1) Does the report describe stigma, strengths and personal growth experiences that you have gone through or that you have seen others go through? ; 2) Are there any other experiences that you would like to share that have not been reflected in the report? and 3) Do you have any other feedback on the report?

Seven of the eight participants who responded to my request for feedback agreed with the findings of the report. Two of these respondents were women, four were gay Caucasian males, and two were black, gay men. Sabrina said that she agreed with the study findings and felt that the report accurately described her experiences as an older woman living with HIV/AIDS. She was moved by the description of the stigma experiences of participants in the study. This view was confirmed by Sarah. Sarah shared the findings of this report in a support group of women living with HIV/AIDS and said that women in the group felt that the findings accurately described stigma experiences, responses to stigma, and experiences of personal growth. An interesting note from Chris, a black gay man was that he felt that most adults in the study who had faced stigma had probably had both felt and enacted experiences of stigma and that further research would reveal that many adults fifty years and older living with the disease had experienced both these forms of stigma. He also shared that there is ‘universal’ stigma associated with HIV/AIDS and that the response to this stigma by adults fifty years and older living with HIV/AIDS has a ‘sophisticated’ and ‘matured manifestation’. Andrew, an African American bisexual respondent stated that he had enjoyed the report. He recognized himself in the report and was particularly moved by the description of stigma he had faced from his brother. Keegan, a Caucasian adult, said that the report confirmed his experience as well as the experiences of others around him living with HIV/AIDS. He expressed his sorrow that these experiences still occur. Patrick another Caucasian respondent who was also a peer counselor said that he appreciated the use of pseudonyms for participants and the efforts made to protect their confidentiality. All respondents made suggestions to improve readability. I have taken their suggestions into consideration in the preparation of the final report.

Additional Findings on Older Women Living with HIV/AIDS

Female participants in the study had unique experiences of living with HIV/AIDS which were different from the men. As a result of the phenomenological nature of the study, there were some findings related to older women which were not directly linked to their stigma experiences. However, these findings provided important insights into how older women live with HIV/AIDS and their needs. Women in the study reported they were diagnosed at older ages than men in the study. The primary mode of infection for women in the study was heterosexual transmission. As women grew older, they described that they became less careful about protection as their chances of getting pregnant went down. Some women spoke about how birth control had been the major issue for their generation and that they did not expect to be infected with HIV/AIDS. Older women had not developed sexual negotiation skills and did not speak to their partners about STDs and using condoms. They expressed a need for greater awareness of older women's vulnerability to the disease. Some women in the study worked as advocates who spread awareness about this issue and counseled other older women, youth, and medical professionals about how HIV/AIDS affects the lives of older women and the need for prevention efforts with this group.

Summary

Older adults living with HIV/AIDS described their experiences of stigma, responses to stigma, and personal growth. Experiences of stigma were organized under the categories of felt experiences of stigma and enacted experiences of stigma.

In this chapter, I have discussed themes that address these experiences. Findings also show that older adults developed strengths responses to stigma and experienced personal growth. The processes of disclosure and non-disclosure were found to impact participants’ experiences. A specialized plot analysis was conducted to further explore this impact from a fresh methodological perspective. This analysis added to the thematic analysis of participants’ experiences and examined individual stories for disclosure and non-disclosure decisions and the impact of these decisions on respondents’ experiences. New findings emerged as a result of this specialized analysis. A new model was presented which illustrated the impact that the process of disclosure had, on the participants’ stigma experiences, their responses to stigma, and their experiences of personal growth. Implications of the findings described in this chapter for social work theory, practice, and policy will be discussed in Chapter Five.

CHAPTER 5: DISCUSSION AND IMPLICATIONS FOR SOCIAL WORK

The purpose of this study was to examine how adults 50 years and older living with HIV/AIDS experience the stigma associated with the disease. Specifically, this dissertation explored respondents' experiences of stigma, the strengths responses and other responses they had to stigma, and the personal growth that may have taken place as a result of their responses to stigma experiences. Phenomenological methods were used to analyze the data of this study. Thematic analysis was completed. The data showed that participants experienced stigma from a variety of sources. Forms of stigma experienced by adults 50 years and older included; 1) enacted or direct experiences of stigma and 2) felt stigma or a fear of possible stigma.

The main themes presented in this dissertation center around respondents' enacted experiences of stigma and felt experiences of stigma. Some respondents of this study experienced enacted stigma from their families and in their workplaces, while other participants had additional felt experiences of stigma including anticipation of stigma and internalized stigma. The responses participants had to stigma varied. Some adults fifty years and older who reported strengths responses to stigma indicated that they empowered themselves with the help of supportive family and friends, sought membership in support groups, developed resilience in the face of stigma experiences, and educated themselves and others about stigma associated with HIV/AIDS. Other responses to stigma were non-disclosure of HIV/AIDS diagnosis and isolation. Interestingly, some participants also experienced personal growth as a result of their strengths responses to stigma. Examples of respondents' personal growth in this study included giving something back to the community and spiritual growth.

Further analysis of data showed that the decisions to disclose or not disclose their diagnosis played a central role in participants' experiences. A specialized plot analysis was conducted to examine the impact of these disclosure and non-disclosure decisions on respondents' experiences of stigma, their responses to stigma, and their experiences of personal growth. In this chapter, I discuss the implications of the findings that emerged from the analysis of data and more specifically, the implications of these findings for social work theory, practice, and policy.

The data includes 21 transcribed interviews, which were conducted and coded by me. Interviews were conducted with the participants who accessed the services of three community based health care organizations, two of which were in Kansas City and one of which was in Lawrence, Kansas. The preliminary findings were presented to participants in the study as a part of member checking. Findings were validated and refined on the basis of feedback received from participants during the process of member checking.

In this chapter, I initially discuss findings that answer the research questions in the study. Implications for social work practice, theory, and research are briefly discussed and then further explored in later sections of the chapter. Specifically, after discussing findings related to each research question, I present the theoretical implications of this study. This discussion is followed by social work practice implications, discussion of needed policy changes, limitations of the study, and areas for further research.

Discussion of Findings

Discussion on Findings Related to Research Question One

Stigma experiences of respondents living with HIV/AIDS. Research question one examined how respondents living with HIV/AIDS experienced stigma. Respondents experienced two different forms of stigma. The first was ‘felt’ stigma or the fear that they may be stigmatized and the other was ‘enacted’ stigma or an actual experience of stigma. For example, participants were overtly stigmatized by family, friends, in their places of work and in other venues.

Findings show that there appears to be a lack of knowledge among family members and employers about how HIV/AIDS is transmitted (through sexual contact, contaminated blood, and sharing syringes). This lack of knowledge makes family members and people in the workplace fearful of contracting the disease from older adults who are diagnosed with HIV/AIDS, and consequently they actively stigmatize the older adults. Examples of active stigmatization included avoiding respondents, stopping all communication, or firing respondents from their jobs. Findings in this dissertation support current research in the area of aging and HIV/AIDS which has indicated that adults 50 years and older living with HIV/AIDS experience difficulty in accessing community support and family care.

Thematic analysis of gathered data indicated that participants were stigmatized by family and friends. Respondents were hesitant about disclosing their diagnosis to family members because of previous experiences of stigma associated with having HIV/AIDS as well as other factors such as being gay or living a risky lifestyle.

Findings also support research that adults who are diagnosed when they are 50 years and older find it difficult to reveal their diagnosis to their children in particular (Heckman et al., 2002). Some respondents in the study stated that they found it difficult to reveal their diagnosis to their children, as they were fearful that their children would reject them. For some participants, this fear of rejection may have been the result of having seen other adults with HIV/AIDS experience stigma when they disclosed their diagnosis to their children. Existing studies have also indicated that adults 50 years and older living with HIV/AIDS were more likely to be stigmatized and isolated if they were unable to access the support of family members and friends (Heckman et al., 2002; Nichols et al., 2002). Adults 50 years and older who received family support were more likely to access formal support systems than those who received no support from their families (Heckman et al., 2002; Nichols et al., 2002). In this study, several respondents indicated that the help they received from supportive family members allowed them to further empower themselves and combat stigma from other sources. Supportive family members also acted as intermediaries who helped participants disclose their diagnosis in a judicious manner and minimize possible enacted stigma from the people to whom they revealed their diagnosis. Participants who were able to empower themselves with the help of supportive family members demonstrated greater personal growth than those who did not demonstrate a strengths response to the stigma they faced. The findings of this study as well as existing research point to the need for educating employers, family members, and community organizations about the possibility of adults 50 years and older living with HIV/AIDS. Family members should also be counseled on how they may be instrumental in helping older adults empower themselves and combat stigma.

It is also important to make adults 50 years and older more aware of their human and legal rights as people living with HIV/AIDS and inform them of the resources that they can access for support. Suggestions for possible practice and policy innovations that have emerged from this study are described in the next section.

Findings also show that respondents had other kinds of stigma experiences besides direct discrimination (enacted stigma) that they experienced from family, friends, and other social groups. Participants in the study spoke about a fear of possible stigma or felt stigma describing that they anticipated that the people to whom they revealed their diagnosis would stigmatize them. Respondents expressed fears that the people to whom they reveal their diagnosis may discuss their conditions with other members of society, making them even more vulnerable to possible stigma. Findings also indicated that fear of possible stigma prevented some participants from adequately accessing and utilizing support mechanisms.

Some respondents expected to be stigmatized by a number of sources. One source from whom they anticipated possible stigma was potential sexual partners. The fear of rejection and the fear that their sexual partners may reveal their diagnosis to other people made some of them extremely wary of discussing their diagnosis with them. These findings point to the need to work with older clients on the mental health issues that can arise from their fear of possible stigma from sexual partners.

Respondents in the study also shared how stigma experiences occurred over the history of the HIV/AIDS epidemic. Over the course of their disease, many respondents observed other adults who were living with HIV/AIDS experience stigma. These historical experiences and their own observation of other adults’ stigma experiences are an important part of how older adults experience stigma and how they respond to it.

The impact of historical experiences of stigma on participants’ lives is particularly evident in the stories of some gay men who participated in this study. Most of the respondents in this study were older gay men who had contracted the virus from other men. Research has established that older gay men are at risk of contracting HIV/AIDS (Seigel et al., 2004; Morrow, 2001). In particular, African American older gay men were more likely to report having unprotected sex than Caucasian men (Seigel et al., 2004). Additionally, many gay men report hiding their sexual identity for fear of stigma they would face (Morrow, 2001).

Several gay respondents in the study had been infected with the virus in the late 80s and early 90s when the stigma associated with the disease was the strongest. They were more likely to face the effects of layered stigma than participants who were straight. Layered stigma can be defined as experiencing many forms of stigma at once, which are the result of having different discrediting conditions like being gay, being of an older age, and having HIV/AIDS (Emlet, 2006c). One instance of ageism and HIV/AIDS interacting with each other was evident in an interview with one older gay male respondent who felt that the multiple stigmas of being black, older, and HIV positive made it difficult for him to attract a potential partner in the gay community which was youth centric. As men having sex with men continue to be at risk of contracting HIV/AIDS and as many adults in this group age with the disease, it is important to examine how aging is viewed within the gay community and how this community responds to the needs of older gay men with HIV/AIDS. Further research is also required to examine how layered stigma impacts the lives of older gay men living with HIV/AIDS.

Older gay men may also experience both enacted and felt stigma. Further analysis of findings reveals that the relationship between felt and enacted stigma was extremely fluid. Some respondents experienced only felt stigma or fear of possible stigma while other respondents had only direct or enacted experiences of stigma. There were also respondents who had experienced both felt and enacted stigma. In some cases, these experiences were linked to each other where a previous enacted experience of stigma could lead to felt stigma in the future. For example, older gay men may have experienced enacted or direct stigma in the early 1980s and 1990s when the stigma associated with being gay and HIV positive was very strong. This enacted experience of stigma which occurred in their past may make them fearful of experiencing stigma in the present which in turn may stop them from disclosing their diagnosis to people with whom they interact.

Some gay men who lived through the 80s and 90s faced both internalized as well as externalized homophobia. A number of participants in this study were gay men, so this study was able to examine what possible strengths older gay men living with HIV/AIDS may have developed over the years. Members of this group have also been described by Morrow (2001) as “resilient survivors” (p. 162). It is important that social work practitioners assess the clients’ identity of being gay, older and HIV positive so as to understand how multiple stigmas may impact the lives of older, gay, men living with HIV/AIDS.

Findings from this study show that the experience of stigma is very complex and influenced by a number of social factors. This further emphasizes the need for reexamining the models of stigma currently available in the literature. Other theoretical implications are described in the next section. To summarize the implications of findings related to research question one, respondents were stigmatized by family, friends, and at the workplace. They also anticipated stigma from a variety of sources and were aware of the history of the HIV/AIDS epidemic and of how people were stigmatized in the past. Participants also observed the stigma experiences of other adults living with HIV/AIDS and these experiences shaped how they currently respond to stigma. Some respondents in the study also expressed a sense of personal shame and distress about their diagnosis. These and other implications are further discussed in the implications section of this chapter.

Discussion of Findings Related to Research Question Two

Strengths responses to stigma. The second research question for this study was: How do respondents employ personal strengths when responding to the stigma associated with the disease? This question explored the strengths responses that some respondents had to the stigma that they experienced. Findings showed that some respondents empowered themselves and developed various ways of managing the stigma they experienced. This self-empowerment was further encouraged by the support of family members, friends, and other members of society such as bosses in the workplace who helped respondents' combat stigma by providing support and guidance. They also served as intermediaries who stopped other sources from stigmatizing respondents. These findings point to the need for practitioners to recognize the role family and friends may play in helping respondents' combat stigma so that they may further involve them in the interventions developed to help respondents manage the stigma that they face from various sources.

Participants also sought guidance on how to manage stigma from the support groups that they attended. Respondents who attended support groups shared how they had received advice and information on how to deal with stigma experiences from other support group members. They developed communication skills and confidence in these groups as well as gained access to friends and developed a social circle that included members of their support groups. Findings showed that seeking membership in support groups was an important strengths response to stigma. Membership in these groups helped respondents break the isolation that often resulted when respondents revealed their HIV/AIDS diagnosis in society. Suggestions for incorporating respondents and their issues in support group settings are discussed later under implications for social work practice.

Some respondents were clearly resilient in responding to stigma. Benard (2004) has defined resilience as an “innate capacity bolstered by environmental protective factors (p. 9).” Consensus in the literature defines resiliency as the ability to cope with unexpected and negative life circumstances (Adger, 2000; Holling & Gunderson, 2001). According to Langer (2004), when people transform negative experiences into positive opportunities, they are likely to experience personal growth. Adults living with HIV/AIDS who demonstrate greater resilience are also more likely to positively cope with their diagnosis than those who don’t demonstrate resilience (Farber et al., 2000). Some responses that demonstrated resiliency were the use of humor as a response to a stigma experience, forgiving those who stigmatized them, and refusing to be labeled because of their diagnosis. Findings point to the need to further explore respondents’ resilience in managing stigma associated with HIV/AIDS.

Several participants in the study became involved in volunteer efforts to educate society about the disease because they recognized education as an important tool in combating stigma. Participants also volunteered to provide support to others living with HIV/AIDS who had similar experiences of stigma. Research on the strengths of older adults living with chronic conditions has shown that they are able to build on basic survival skills and develop their own solutions to the problems they are facing (Perkins & Tice, 1994). Respondents living with HIV/AIDS are an important resource who can help others living with HIV/AIDS manage stigma. Implications of this finding for social work practice are discussed in a later section of this chapter.

To summarize, this study explored participants' use of strengths responses when faced with stigma. Findings showed that some respondents had empowered themselves with the support of family and friends, were resilient, sought membership in support groups, and most importantly used themselves as personal resources to combat stigma. Social work practice may be improved by recognizing the strengths that adults 50 years and older possess and using their skills in developing stigma management programs. Little research has been conducted on strengths responses to stigma and research on the strengths responses that the older adult population has to stigma, is even more limited. The findings of this study that respondents have strengths responses to stigma, further inform the already existing research on the strengths perspective and its role in social work practice.

Discussion of Findings Related to Research Question Three

Other responses to stigma. The third research question of this study explored alternate responses the participants had to stigma as opposed to strengths responses. Findings showed that participants responded to stigma experiences in different ways, the first of which was strengths responses to stigma. This was discussed in the previous section. Some respondents also responded to stigma in ways that did not utilize their strengths. One of these responses was a decision to not disclose their HIV status to people in their lives or society. Respondents who had experienced stigma either directly or expected to experience stigma often did not disclose their HIV status. This could be troublesome considering that disclosing their HIV status might have helped respondents acknowledge that they live with a chronic disease and ultimately seek out social support. Further discussion of possible measures that social workers can use to help respondents overcome stigma which is a major barrier to disclosure are presented in the implications section of this chapter.

Some respondents also stated that they isolated themselves either because of previous experience of stigma or because they feared that they may be stigmatized. Literature examining the experiences of adults 50 years and older living with HIV/AIDS has suggested that older adults are at greater risk of social isolation than younger adults living with the disease (Emlet, 2006c). Once again, their response prevented them from seeking support from family, friends, and social organizations. Social workers need to reach out to older adults who may have isolated themselves as a result of stigma experiences. Possible innovative methods of accessing older adults who have isolated themselves as a result of stigma are discussed in the next section.

Discussion of Findings related to Research Question Four

Personal growth resulting from stigma experiences. The fourth research question examined if respondents experienced personal growth as a result of their responses to the stigma they experienced. Findings revealed that some respondents experienced personal growth when they demonstrated strengths responses to stigma. Personal growth occurs when respondents consistently demonstrate strengths responses to stigma and then make significant life changes as a result of their strengths responses. Personal growth responses experienced by some respondents included a desire to give something back by helping others with the disease and spiritual growth. Findings show that respondents who demonstrated strengths responses to stigma were more likely to demonstrate personal growth. For example, some respondents said that they felt like giving back to the community because of the support that they had received from organizations or other people living with HIV/AIDS. Some respondents also stated that they had experienced spiritual growth as a result of their stigma experience. Literature that examines the use of spirituality by aging populations shows that spiritual beliefs lead to greater resilience and can help people build competence in new areas (Nelson-Becker et al., 2006). Current understanding of stigma has largely explored the negative consequences of stigma on the lives of the people experiencing it, but is more limited in its look at positive outcomes. These findings show the other side of the stigma experience where respondents are able to use their experiences to make positive changes not just in their own lives but also in the lives of others living with the disease. The next section of this chapter presents the theoretical, clinical practice, and policy implications of the findings of this dissertation.

Discussion of Findings from Specialized Analysis (Disclosure and Non-Disclosure)

Analysis of the interviews conducted with respondents revealed that their experiences of stigma were closely linked to the decision to disclose or to not disclose their diagnosis to family members, friends, and other people in their lives. Because of this finding related to the stigma experience, I conducted a specialized plot analysis to further investigate the role of disclosure and non-disclosure decisions. In this section, I integrate the implications of this plot analysis with the literature on disclosure. Emlet (2008) studied the disclosure concerns of older adults living with HIV/AIDS and found that older adults living with HIV/AIDS chose not to disclose for a number of reasons. With regards to parents, older adults felt that they may probably outlive their parents and did not want to upset them with their diagnosis. Emlet (2008) has called this lack of disclosure “protective silence” (p. 712). Participants in his study also went through a period of reflection where they weighed the positive and negative consequences of disclosing their diagnosis. While some participants who disclosed their diagnosis received the support of family members and friends, others experienced stigma from the people to whom they revealed their diagnosis. Findings point to the need for interventions which could help adults 50 years and older disclose their diagnosis in a judicious manner and minimize the stigma they may experience when they choose to disclose their diagnosis.

Emlet (2008) also identified fear of stigma related to disclosure to potential sexual partners. Participants in this study were scared that their confidentiality would be violated if they disclosed their diagnosis to potential sexual partners. Respondents in my study also discussed how difficult it was to negotiate sexual encounters. Some respondents expressed their fear that potential sexual partners might disclose their diagnosis without their consent. Participants were also afraid that sexual partners might reject them when they revealed that they were HIV positive. While several participants acknowledged that they had sexual needs, their fears of being stigmatized by their sexual partners made them wary about disclosing their diagnosis. These findings point to the need to counsel older adults with HIV/AIDS on how they may negotiate sexual encounters and what they can do to protect others from the risk of contracting HIV/AIDS.

Findings from this study adds to the limited research that examines the disclosure experiences of adults 50 years and older who are living with HIV/AIDS. An analysis of the data indicated that this decision had a great impact on their experiences of stigma, responses to stigma, and experiences of personal growth specialized plot analysis revealed some intriguing findings. For respondents' who experienced stigma on disclosing their diagnosis, their first experience of stigma was likely to be an 'enacted stigma' experience. An experience of enacted stigma on disclosure could lead to respondents anticipating stigma in the future or having a 'felt' experience of stigma. When 'enacted' stigma experiences lead to 'felt' stigma, participants were likely to respond to it by choosing not to disclose their diagnosis to other people they meet who were likely to stigmatize them. Most respondents who choose not to disclose did so because they anticipate stigma on disclosure.

In particular, adults who have aged with HIV/AIDS have faced stigma over a long period of time. Many of these adults experienced stigma in the 1980s and 1990s when the stigma associated with the disease was strongest. They also saw other people living with HIV/AIDS experience different forms of stigma. Over a period of time, social stigma associated with HIV has reduced when compared to the stigma felt by people living with HIV/AIDS in the 1980s and 1990s. and this was true for participants in this study, However, even if the frequency of their experiences of enacted stigma was reduced over time, participants who were diagnosed earlier and who aged with the epidemic were likely to either anticipate or have felt experiences of stigma caused by their previous experiences. These participants were, in fact, less likely to disclose their diagnoses than participants who had been diagnosed more recently. These findings point to the need for social workers to assess the historical experiences of stigma experienced by those adults who have aged with the disease. Implications of this finding are discussed in the practice implications of this study.

Further analysis also revealed that engaging in the process of disclosure and facing stigma could be a stimulus for persons living with HIV/AIDS to develop strengths responses to stigma. Respondents in the study who disclosed their diagnosis reported developing strengths responses to stigma more consistently than participants who had other responses to stigma. While a decision to disclose exposed respondents to possible stigma, it also allowed them to access support from family members, friends, support groups, and other people in society who wish to support them. Facing a stigma experience is also the only way to develop increased resilience in the face of stigma. When respondents chose not to disclose their diagnosis, they reduced the possibility of receiving support and developing increased resilience. This finding indicates that those respondents who disclosed their diagnosis and faced stigma were often able to move on and find positive ways to manage their stigma experiences.

While disclosure could lead to positive support, some respondents who disclosed their diagnosis also faced stigma as a result of their disclosure. Studies have shown that while disclosure may lead to positive support, indiscriminate disclosure may lead to distress, depression, and suicidal thoughts (Kalichman et al., 2000). Existing research in the area has also stated that adults 50 years and older living with HIV/AIDS are less likely to disclose their diagnosis to family, friends, and service professionals than younger adults (Emlet, 2006c). Findings from this study and existing research in this area point to the need for social work practitioners to develop strategies for encouraging older adults to disclose their diagnosis to supportive people in their lives. Social workers also need to counsel clients 50 years and older on how they can judiciously disclose their diagnosis in order to minimize possible stigma that may result from injudicious disclosure.

Discussion of Additional Findings on Older Women Living with HIV/AIDS

Special emphasis was given to the findings that emerged from interviews with women who were 50 years and older and living with HIV/AIDS. Several findings that were related to the experiences of older women and that were not directly linked to their stigma experiences emerged from the study. These findings were included in the study as they pointed to the need for greater prevention and education efforts among women 50 years and older who were living with HIV/AIDS. In general, women in the United States have been under-represented in prevention efforts when compared to men because of inherent patriarchal values that exist in society, which seeks to promote the cause of men’s health over that of women (Peterson, 1997). Among older adults who are living with HIV/AIDS or are at risk of being exposed to the virus, older women are perhaps the most underrepresented in prevention efforts (Binson et al., 1997).

According to Binson and Pollack (1997), older women (50 years and older) and women in their midlife (40 years to 49 years) represent 25% of all women who are living with HIV/AIDS and are 4% of the cases reported in the United States. Some women have been infected at a younger age and are living longer due to advances in medicine (Mack & Ory, 2003). Even within the population of older adults, being an older woman and of any sexual orientation other than heterosexual was more likely to increase stigma associated with the disease (Emlet, 2005). Older women in the study stated that they became less careful about protection as their chances of getting pregnant went down. Some women spoke about how birth control had been the major issue for their generation and they did not expect to be infected with HIV/AIDS. This finding confirms existing research that while this group continues to be sexually active, they are not adequately informed of the risk that unprotected sex may expose them to such as sexually transmitted diseases in general and HIV/AIDS in particular (Lindau et al., 2006). In a study conducted with older women in a general medicine clinic, Henderson et al. (2004) found that older women did not have adequate knowledge of the sexual transmission of the virus. Most information that they had on sexual transmission of the virus was derived from sources like the television and other media sources (Henderson et al., 2004).

Being both older and a woman are associated with lower levels of knowledge about how HIV/AIDS is contracted and the use of protective measures such as condoms (LeBlanc, 1993; Schable et al., 1996). A study conducted by Neundorfer et al. (2005) found that most women 50 years and older who had been diagnosed with HIV were less likely than younger women to have used a condom or to have been tested for HIV. Older women may find it more difficult to negotiate condom use as they may not have used them before and post menopause may find it awkward to discuss the use of protection with partners when this protection is against disease and not pregnancy (Zablotsky, 1998).

Older women in this study had not developed sexual negotiation skills and did not speak to their partners about STDs and using condoms. Participants expressed a need for greater awareness of older women's vulnerability to the disease. The literature on women 50 years and older living with HIV/AIDS has shown that older women who are in long term relationships or who are married find it difficult to negotiate condom use with their partners as the use of condoms may give the impression that the woman believes their partner is unfaithful (Zablotsky & Kennedy, 2003). Older women may also be unaware that a healthy looking sexual partner may have HIV/AIDS and that protective measures should be used in all sexual interactions (Zablotsky, 1998). Older women often do not know the sexual histories of their partners and are embarrassed to ask them these questions (Neundorfer et al., 2005). HIV positive participants in the study conducted by Neundorfer et al. (2005) also stated that the men who had infected them had known about their own HIV status and had not disclosed it to the women. The women who had never been tested found no reason to suspect they had been infected and failed to associate symptoms of HIV such as diarrhea and losing weight with having the disease. During their marriages, especially long-term marriages, women may have had only one partner and HIV/AIDS and STDs were not a concern. Prior to their marriage, they may not have been sexually active or, if they were, they were more likely to be concerned about the stigma of premarital sex or pregnancy.

The primary mode of HIV/AIDS transmission for women who participated in this study was heterosexual transmission. Women had been diagnosed at a later age than most men in the study. In addition, findings confirmed existing research that women 50 years and older were not adequately educated about the risks of contracting HIV/AIDS and about the need to protect themselves. Female participants spoke about the lack of education and awareness campaigns for older women living with the disease. These findings point to the need for further research in this area. Practitioners need to assess the unique needs of older women living with disease and plan support programs for them.

Discussion of findings of this study have pointed to need for innovation in theory, suggestions for social work practitioners to plan interventions with older adults living with HIV/AIDS, and changes in existing policy to reduce stigma experienced by them. In the next section, I discuss theoretical implications of the findings.

Theoretical Implications

The underlying theories used to inform this study were: 1) Goffman's (1963) theory of stigma and 2) the strengths perspective in social work practice (Saleebey, 2006). Goffman's understanding of stigma has been considered a seminal work that has provided the framework for numerous studies that have examined the stigma experiences of various groups with chronic conditions. The study also presents definitions of stigma, namely enacted stigma or the actual experience of stigma, and felt stigma or the fear of possible stigma (Green & Platt, 1997). The strengths perspective in social work practice was used because it provided an alternative to the medical model and expanded on previous models to support the full range of experiences of adults 50 years and older living with HIV/AIDS.

This study did not aim to verify any existing model related to stigma. A phenomenological exploration of respondents' experiences of stigma, their responses to the stigma, and possible personal growth that they may have experienced was conducted. Goffman's theory of stigma was not used as an explanatory model of stigma. Rather, it was presented in order to provide the reader with an understanding of existing stigma theory. Similarly, the strengths perspective was presented as a possible theoretical framework within which the strengths responses to stigma could initially be understood.

This study's findings confirmed some of Goffman's ideas on the stigma trajectory. As Goffman (1963) suggested, stigma experiences discredit respondents who are living with HIV/AIDS. HIV/AIDS is an undesirable trait that often overshadows all that is positive about persons living with the disease. For example, respondents in the study shared how friends and family members with whom they had close personal relationships stopped speaking to them once they found that the respondents were HIV positive. In the next section, I discuss three theoretical innovations that emerged from this study. First, additions have been made to Green and Platt's (1997) definitions of enacted stigma and felt stigma. Second, concepts from both Goffman's stigma theory and the strengths perspective have been merged in this study in order to provide a clearer explanation of how participants respond to stigma. Third, this study presents an examination of the critical decisions of disclosure and non-disclosure and the impact these decisions on older adults' experiences of stigma, their responses to stigma, and personal growth experiences.

Enacted Stigma and Felt Stigma Experiences

Current findings in this study have been largely organized under the headings of enacted stigma and felt stigma. These definitions of stigma were derived from Green and Platt's (1997) definitions of stigma. The authors' stated that the experience of stigma from having HIV/AIDS could be divided into two categories, the first being enacted stigma or a direct experience of discrimination and the second being felt stigma or a fear of possible stigma. Stigma is a dynamic concept. Respondents experience stigma in multiple and interactive ways. They may have an enacted stigma experience, or they may fear possible stigma and have a felt stigma experience. Even more, they may have both enacted and felt stigma experiences. Findings show that stigma experiences and the responses that participants have to stigma are shaped by their previous experiences of stigma as well as the social context in which they reside. This study's findings add to Green and Platts (1997) definitions of enacted and felt stigma by providing an understanding of how different types of stigma interact with each other.

Merging the Strengths Perspective and Goffman's Theory on Stigma

Goffman's (1963) theory on stigma is limited in that it assumes all responses to stigma would be negative responses like passing and covering behaviors. His theory of stigma has also been criticized for assuming that people who experience stigma are unhappy because they are stigmatized and are unable to get over their feelings of distress. Findings show that not all respondents who experience stigma have negative responses to it.

Findings of this study merge the principles of the strengths perspective with Goffmans' (1963) conceptual understanding of the "own and the wise" and provide a more complete understanding of the respondents' stigma experience. Four strengths responses to stigma were identified. These are resilience in the face of stigma, seeking membership in support groups, respondents empowering themselves with the help of supportive people, and education and volunteering.

Goffman (1963) introduced the concepts of the "own and the wise" (pp. 19) in his model of stigma. Individuals in the "own" category share the stigma condition (HIV/AIDS) of respondents and are sympathetic to respondents living with the disease. Individuals in the "wise" category do not have HIV/AIDS but treat respondents who have HIV/AIDS with dignity and respect.

Respondents in this study received support and guidance from members of support groups who shared their diagnosis. They also received support from family, friends, and people in their workplace who helped them empower themselves and manage their stigma. One can see an overlap here between Goffman’s (1963) concepts of the own and the wise, and Saleebeys’ (2002) strengths perspective principles of empowerment and membership. The two theories merge and frame respondents’ strengths responses to stigma. While Goffman’s “own and wise” are merely sympathetic, “the own” (other respondents with HIV/AIDS) and the “wise” (family, friends and other supportive members of society), in this study act as support mechanisms and intermediaries who encourage respondents to empower themselves and combat stigma. Findings provide a more complete understanding of respondents’ strengths responses to stigma. The principles of the strengths perspective and Goffman’s conception of the “wise and the own” have been merged in this study to provide a framework within which older adults’ strengths responses to stigma may be understood.

Disclosure and Non-Disclosure

Once respondents received their diagnosis, two critical decisions shaped their experiences of stigma, their responses to stigma, and the personal growth they underwent. As stated earlier, respondents in this study who consistently disclosed their diagnosis seemed to demonstrate greater personal strengths responses and experienced more personal growth. This finding adds to existing understanding of the stigma experienced by people living with HIV/AIDS. While previous studies have indicated that it is important for people to disclose their diagnosis so that the spread of the disease may be contained, findings from this study show that an understanding of respondents' disclosure and non-disclosure decisions may provide insights into transforming negative stigma experiences into positive strengths and growth experiences. The decision to disclose not only impacts the spread of the disease, it also provides the context for participants to respond to stigma in positive ways and further develop personal growth by being of service to others who are trying to combat stigma.

Implications for Social Work Practice

My findings indicate that older adults face challenges in places where social work interventions could help to produce more positive health and quality of care outcomes. Funding for HIV prevention is largely given to groups perceived to be at the greatest risk, like gay men or injection drug users. Older adults living with HIV/AIDS are not specifically targeted as they are considered to be a small group. However, this study has shown that this group has unique needs that are not being met. As more drugs become available, larger groups of adults living with HIV/AIDS are going to age and it is extremely important for social work practitioners to address the needs of this population. Four key implications for social work practitioners are discussed below: 1) Using respondents as resources in the planning and implementation of stigma prevention programs 2) Using family and friends as resources in combating stigma; 3) Forming support groups for older people living with HIV/AIDS; and 4) Counseling respondents about disclosure of their diagnosis.

Using Respondents as Resources in Educating Family Members and Friends and Other Members of Society

Findings in this study indicated that respondents experienced the largest amount of stigma from their family members and friends. They were also stigmatized in the workplace by employers and experienced stigma from a variety of other sources at varying intensities. A large portion of stigma experiences occurred due to a lack of knowledge about how the disease is spread. Family members and friends were fearful of contracting the virus through touch, through the use of common toilets, and silverware. Over the years, HIV/AIDS education and prevention programs have emphasized that the disease is only spread through sexual contact, the use of contaminated syringes or through a blood transfusion in which the patient may receive contaminated blood. Despite these public campaigns, respondents in the study indicated that the message had not reached their families, friends, and society at large. As a result, they experienced stigma and discrimination at the hands of family members and friends. There is clearly a need for greater outreach and education among the families of older adults and among older adults themselves on how HIV/AIDS is contracted and spread.

Findings have shown that respondents were able to combat stigma if they were given an opportunity to educate family and other members of society about the disease. They also wished to give something back to other individuals living with HIV/AIDS, which is an indicator of personal growth. Social work practitioners can help adults 50 years and older who are living with HIV/AIDS empower themselves by encouraging strengths responses to stigma and personal growth.

A key strategy would be to use older adults as resources in the planning and implementation of stigma management programs. The use of peer counselors and outreach coordinators from the subgroup that a program may be targeting is a strategy that has been successfully used by many HIV/AIDS organizations for other sub-populations who are at risk of HIV/AIDS (Brown et al., 2001; Boudin et al., 1999). Findings have shown that some respondents helped other respondents with HIV/AIDS to manage stigma and educated family members and friends about the disease. Social workers could recruit older adults to take on the role of peer counselors and outreach coordinators within stigma management programs. Further, their insights on how stigma occurs would be extremely beneficial in implementing an effective stigma prevention program.

An important finding in the study was that respondents often isolated themselves because of fear of possible stigma and this may prevent them from accessing support systems. This may make it difficult for organizations to reach older adults who are not utilizing their services. Using older adults as outreach coordinators may be a successful strategy as they would be able to access venues which other adults 50 years and older frequently access. They would also be received as insiders in these venues and could then speak about HIV/AIDS prevention and resources that are available for adults 50 years and older who are living with HIV/AIDS.

Using Family and Friends as Resources in Combating Stigma

Other key resources that social work practitioners could use in stigma management efforts are family and friends of older adults who are supportive of them despite their diagnosis. Findings show that some family members and friends acted as support systems for adults 50 years and older and helped them empower themselves to combat and manage stigma. Family members and friends also acted as intermediaries who stopped people from further stigmatizing respondents living with HIV/AIDS. Family and friends who were supportive of respondents living with HIV/AIDS were reported as central in efforts to prevent and manage stigma. Social work practitioners can plan stigma management programs so that supportive family members can help older adults living with HIV/AIDS disclose their diagnosis and strategize how to minimize the stigma experience from other family and friends.

Forming Support Groups for Older People Living with HIV/AIDS

Findings in this study have also shown that some respondents benefited from the guidance and friendships they developed in support groups. Some respondents in the study attended support groups that had been organized for all adults living with HIV/AIDS. Research that has examined older adults support networks has found that many people in these support networks are HIV positive (Poindexter & Shippy, 2008). Older adults use venues like support groups to form new friendships. Relationships with people within their support networks often replace other relationships that older adults lost through stigma and discrimination (Poindexter & Shippy, 2008). Social work practitioners should encourage their older clients to attend support groups in order to help them end the isolation they have experienced living with HIV/AIDS. Few female participants in the study had attended support groups that focused on women. Clearly, persons at risk for HIV/AIDS may have similar issues and experiences to discuss, but within this “at-risk” group there may also be individual differences that would warrant the division of support groups by age for instance. Research has indicated that AIDS Service Organizations (ASOs) and Community Based Organizations (CBOs) do not have services tailored to the needs of adults 50 years and older that are living with HIV/AIDS (Linsk, Fowler, & Susan, 2003). Support programs do not provide enough information about issues that are related to aging with HIV/AIDS such as menopause and increased isolation. Younger adults may find it difficult to empathize with issues raised by adults 50 years and older in support groups. Older adults may also find it difficult to share their problems with staff in AIDS Service Organizations who have not been trained to deal with issues arising from aging with HIV/AIDS (Linsk et al., 2003). Organizations should experiment with the formation of special groups, which would have only older participants such as older women and focus on their issues and stigma experiences.

Counseling Respondents about the Disclosure of their Diagnosis

An important finding of the study was that decisions to disclose or to not disclose were central to respondents’ experiences. Respondents were often scared of disclosing their diagnosis to sexual partners either because they expected to be stigmatized or because they had experienced stigma in the past and anticipated it in the future. Older adults are often considered by practitioners to be asexual or have a limited amount of sexual activity. A number of respondents who participated in the study wanted to be sexually active and some respondents reported being sexually active. The sexually active participants of this study described that they had experienced stigma from society related to being sexually active. They also explained they were uneasy about disclosing their diagnosis to potential sexual partners because they were fearful that potential partners would not only reject them but could then reveal their diagnosis to other people.

According to Thorogood (2002), health organizations find it difficult to raise awareness about HIV/AIDS among older populations because they are embarrassed to discuss the implications of unsafe sex on public health. This is particularly true for older populations who are not perceived to be at risk for sexually transmitted diseases in the first place. Because one of the primary means of HIV transmission is through unprotected sex, it is extremely important for social work practitioners to recognize that respondents living with the disease are sexually active, or at least consider being sexually active, and to provide non-judgmental counseling services which would help respondents negotiate disclosure to potential sexual partners. Counseling should also be provided to older adults to help develop strategies to cope with the possible rejection they may experience when they disclose their HIV/AIDS diagnosis to potential sexual partners.

While findings have revealed that there are many positive consequences of disclosure, the decision to disclose is a difficult one because it exposes older adults to possible stigma. Social workers need to work with older clients on issues such as the appropriate time to disclose their diagnosis, to whom they should disclose their diagnosis, and how they can minimize the risk of stigma. One example could be utilizing the help of supportive family members to disclose their diagnosis to parents or friends.

Social workers also need to assess the historical experiences of clients who have aged with the disease. These clients are more likely to have felt experiences of stigma which are a result of their previous enacted stigma experiences. Clients may not share their felt stigma experiences easily and social work practitioners will have to probe further in their assessments to understand the relationship between clients' previous enacted stigma experiences, their felt stigma experiences, and their responses to stigma.

The decision to disclose or not disclose occurs in many venues; one of these is the workplace. Respondents described having to negotiate their decision to disclose in the workplace very carefully as they ran the risk of either losing their job or experiencing stigma from colleagues in the workplace. In the next section, I discuss additions to existing policy that could protect respondents from stigma in the workplace

Policy Implications

Findings from this study point to the need for identification of policy changes that could help ensure that older adults living with HIV/AIDS do not face stigma and discrimination in the workplace. Social policy has often been geared towards the needs of groups that are considered to be at highest risk and moved away from focusing on the needs of those who are perceived to be at low risk (Orel, Wright & Wagner 2004). Policy makers also need to focus on the needs of adults 50 years and older living with HIV/AIDS. In this section, I will examine two policy measures: 1)

The *Americans with Disabilities Act* which protects people living with HIV/AIDS from stigma in the workplace and 2) The *Ryan White Care Act*

Americans with Disabilities Act

Some respondents who participated in the study shared their experiences of stigma and discrimination at the workplace that they underwent when they disclosed their HIV/AIDS diagnosis at work. In the United States, employers can legally dismiss any employee if they think that they are unfit or not fulfilling their job responsibilities adequately, however, any employee who has HIV/AIDS and feels that they have been unfairly dismissed because of their diagnosis can seek legal recourse under the *Americans with Disabilities Act* (Studdert, 2002). Drafters of the *Americans with Disabilities Act* included provisions in the act that protected people living with HIV/AIDS against discrimination at the workplace. The interpretive guidelines of the ADA further reinforced the protections that were established in the original draft for adults living with HIV/AIDS. Though there were a few legal cases in the early 1990s which challenged whether adults who were asymptomatic fit the definition of having a disability, the courts ruled that even asymptomatic adults were considered disabled and were to be protected by ADA legislation (Studdert, 2002).

Title I of the ADA addresses possible discrimination in the workplace. It expressly states than an employer cannot discriminate against any employee in hiring, firing, advancement, and compensation of that employee on the basis of a disability that he or she may have. Employers are also supposed to provide reasonable accommodation for a disabled employee as long as the accommodation does not cause undue hardship for the employer. Some of the accommodations that employers should provide under the guidelines of the ADA are time off to see the physician, time given for medication adherence, and possible flexible work hours to reduce fatigue.

A few respondents in this study faced discrimination from their employers. One older adult was fired after he disclosed his diagnosis to the employer. The *Americans with Disabilities Act* has provisions not only to protect adults from discrimination but also to facilitate a comfortable workplace environment for any adult living with HIV/AIDS.

Some of the barriers that prevent older Americans living with HIV/AIDS from accessing the legal protections of the *Americans with Disabilities Act* are fear of disclosure to employers and other employees in the workplace. One older adult in this study also expressed a sense of helplessness stating that it was very likely that he or she would not have the money for the long legal battle required to prove he or she had been discriminated against in the workplace.

The problems that older Americans living with HIV/AIDS have with the act occur in the areas of 1) not having enough trust that their employer will protect their confidentiality and 2) in the enforcement of the act. Social policy makers need to address these barriers by amending the ADA by 1) Incorporating guidelines in the Act for training employers about illegal discriminatory practices related to HIV/AIDS. Advocates should then make sure training includes content about older populations who have HIV/AIDS and possible discriminatory practices; 2)

Strengthening provisions that hold employers accountable if they disclose the older adults’ HIV/AIDS status to anyone without the older adults’ expressed permission; and 3) Including provisions to expand education of all groups, including older adults about their right to legal recourse under the ADA. A portion of this expansion should be targeted toward holding workshops for adults 50 years and older living with HIV/AIDS which would provide them with information on where to access affordable legal counsel if they wanted to sue the company they worked for on the basis of discrimination.

Social workers should advocate for the rights of older adults who have been fired from companies because of their HIV status. Due to advances in medication, more and more older adults living with HIV/AIDS are entering or returning to the job market. It is extremely important that they are protected against possible stigma in the workplace because of their diagnosis.

Ryan White Care Act

The *Ryan White Care Act* was passed in 1990 to provide funding for direct services for people living with HIV/AIDS. The act was passed in memory of Ryan White, a teenager who died of AIDS after being infected through a tainted hemophilia treatment. Ryan White faced extensive stigma and was dismissed from school because he had contracted HIV/AIDS. Ryan White became an advocate for the cause of people living with HIV/AIDS and the act was a significant policy measure in both reducing the stigma associated the disease and making treatment available for people living with HIV/AIDS (Marx, Hirozawa, Soskolne, Liu, & Katz, 1996).

This study examined the *Ryan White Care Act* because it has roots in the stigma experiences of people diagnosed with HIV/AIDS in the early days of the epidemic. It is important to understand if and how this policy measure, which addresses the needs of stigmatized adults living with HIV/AIDS, has evolved in order to explore if it has addressed the needs of the growing group of adults 50 years and older who are either aging with the disease or have been newly diagnosed with HIV/AIDS.

Each state receives Ryan White funds through a block grant and distributes these funds to AIDS Service Organizations in order to provide money to people living with HIV/AIDS. Most adults living with HIV/AIDS that have accessed services have received their services at AIDS Service Organizations (ASOs). AIDS Service Organizations operate independently with the exception of following certain rules laid out by the federal government for states that receive *Ryan White Care Act* funds.

Each state that accesses Ryan White funds is required to form a state consortium which makes decisions on which groups should be targeted by *Ryan White Care Act* funds. A study conducted by Hickey (2008) of four Midwestern states examined whether prevention education was made available for older populations with HIV/AIDS. The author interviewed directors of AIDS Service Organizations and attended State Consortium Meetings where decisions were made on which groups should be targeted to receive *Ryan White Care Act* funds. Findings from her study revealed that most ASO directors in the study felt there was not enough money to provide targeted prevention education for older adults living with HIV/AIDS

(Hickey, 2008). Additional findings showed state consortia meetings followed guidelines set by the federal government and the CDC. *Ryan White Care Act* funds are allocated to groups that have traditionally been perceived as at risk groups, like men having sex with men (MSM) and certain minority groups in which the rates of HIV/AIDS are rapidly rising. Hickey (2008) posits that certain groups such as MSMs are expected to indulge in risk behavior like unprotected sex, but it is difficult for policy makers to imagine older adults indulging in sexual activity that could increase their risk of contracting HIV/AIDS. There is clearly a need to understand sexuality in older adults and their risk of HIV/AIDS. Greater advocacy is required to ensure that policy makers are informed of the growing population of adults 50 years and older with HIV/AIDS so that funds may be allocated for prevention education for this subgroup.

Findings from the study point to the need for innovations in theory, social work practice, and policy to address the needs of adults 50 years and older living with HIV/AIDS. While this study explored multiple facets of respondents' experiences, it also had some limitations. The next section of this paper focuses on this study's limitations.

Limitations

This study conducted a phenomenological exploration of respondents' experiences of stigma, their responses to stigma, and their experiences of personal growth. While the methodology was chosen to provide the maximum space for respondents to voice their experiences and to allow me to conduct an in-depth analysis, a weakness could be related to my personal characteristics. As an Asian younger woman, I did could not have shared the lived experiences of participants in the study. The sample size of this study was intentionally small in order to gain a deeper look at respondents' experiences. Future research could explore these issues with larger, more diverse populations. This study was conducted in a Midwestern state and had a sample of only Caucasian and African American respondents. A more diverse set of respondents in a variety of areas of the country would undoubtedly yield additional important findings. This study examined the overall experiences of populations 50 years and older living with HIV/AIDS, but greater attention needs to be paid to the unique experiences of older women living with HIV/AIDS and to the experiences other minority elders living with HIV/AIDS.

Future Research

Analysis of the interviews conducted for this study revealed areas of future research. Research is needed to see if the current model of stigma, presented in this study, can be used as an explanatory model in other studies on the stigma experiences of older adults living with HIV/AIDS. The current study used an open ended questionnaire and a phenomenological approach to provide participants with the maximum opportunity to voice their experiences. In the future, I would like to use a structured questionnaire to further examine specific stigma experiences that emerged from this study.

Health care researchers also need to study HIV/AIDS as a disease that occurs across the lifespan. Interventions should be planned to meet the needs of infected adults as they age with the disease because stigma experiences transcend age. Further research is required to examine which stigma experiences are specific to older adult populations as opposed to stigma as it is experienced by all adults living with HIV/AIDS.

Future research also needs to focus on stigma experiences of specific groups of respondents like women and minorities in order to examine if their experiences of stigma are different from white male respondents. Female participants in this study reported that they were more focused on pregnancy and were not acculturated to the risks of unprotected sex which was not associated with pregnancy. Women in the study also reported that doctors were reluctant to discuss issues of sex and sexual transmission of diseases with older women. This finding is consistent with literature which points out that these older women are seen as asexual and that service providers are reluctant to counsel them about sex and sexually transmitted diseases (Dunn & Cutler, 2000).

Additionally, special attention needs to be focused on the aging MSM (men having sex with men) population who are often ignored both by health professionals and the gay community in prevention efforts. Evidence based research should be conducted on which practice interventions are effective in helping gay older adults manage stigma.

This study has also examined the impact of disclosure and non-disclosure decisions on older adults’ experiences. Further research with other populations should be done to see if these decisions impact them in the same way. Lastly, more in-depth research examining the impact of the age at diagnosis on the stigma experiences and disclosure decisions of adults 50 years and older living with HIV/AIDS is needed.

Conclusion

The purpose of this study was to increase understanding of how older adults who live with HIV/AIDS experience stigma, how they respond to stigma, and their experiences of personal growth that resulted from their responses to stigma experiences. While this study did not compare the stigma experiences of older and younger adults living with HIV/AIDS, the study supports existing studies which state the older adults living with the disease find it difficult to disclose their diagnosis and seek social support (Emlet, 2006c). Findings from this study also highlight the experiences of older adults who have aged with the disease. These adults were more likely to have experienced severe enacted stigma in the 1980s and 1990s and to have seen others living with HIV/AIDS experience stigma. Even though the intensity of stigma has reduced over the years, findings indicate that adults who have aged with HIV/AIDS were more likely to anticipate and have felt stigma experiences and not disclose their diagnosis than those who were diagnosed more recently.

A key contribution of this study is the merging of different theories like Goffman’s theory on stigma and the strengths perspective in order to provide a fresh look at the relationship between stigma, strengths, and personal growth experiences of older adults living with HIV/AIDS. This study also presented a model that explores the impact of the decision to disclose on older adults’ experiences. Areas where social work practitioners could help adults 50 years and older reduce stigma were identified.

These included counseling older people living with HIV/AIDS negotiate sexual encounters and forming support groups.

Further, this study identified adults 50 years and older, their families, and friends as key resources who could help practitioners plan and implement stigma management programs. It also proposes additions to the *Americans with Disabilities Act*, which would help respondents living with HIV/AIDS combat stigma in the workplace. This work adds to the already existing body of knowledge of stigma and HIV/AIDS by examining the experiences of adults 50 years and older living with the disease whose experiences have not been extensively researched in the literature. Recent advances in the medical field have resulted in an increasingly larger number of people who are diagnosed with HIV/AIDS and reach an older age. It is important that we continue to develop a research agenda on stigma and other issues affecting this population.

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APPENDIX A: Demographic Information Survey

I would like to ask you some questions to gather some general information about you

1. Could you tell me your age and birth date?

2. What would you consider to be your gender?

Male ☐ Female ☐ Other ☐

3. How would you describe your sexual orientation?

4. How would you describe your relationship status?

Single ☐ Married ☐ Partnership ☐

Same Sex Relationship ☐ Divorced ☐ Widowed ☐

5. With what ethnicity do you most identify?

African American ☐ Caucasian ☐ American Indian ☐

Hispanic ☐ Asian American ☐ Other (please specify) ☐

6. Please describe your educational status?

8th grade or less ☐ Some high school ☐ High school graduate ☐

Some college ☐ College graduate ☐

7. How would you describe your income status?

$ 0- 10,000 ☐ $10,001- $20,000 ☐ $20,001-$30,000 ☐

$ 30,001-40,000 ☐ $40,001-50,000 ☐ $ Greater than 50, 000 ☐

8. Could you tell me your age at diagnosis?

20-30 yrs. ☐ 31-40 yrs. ☐

41-50yrs. ☐ Over 50 ☐

Adapted from the survey by:

Albice, T. J. (2000). Older adults' knowledge levels, attitudes towards, and risk behaviors regarding HIV/AIDS. M.S.W. dissertation, California State University, Long Beach, United States -- California. Retrieved October 12, 2007, from ProQuest Digital Dissertations database. (Publication No. AAT 1401597).

APPENDIX B: Interview Guide

Introduction and Interview Questions

Thank you for participating in this interview. I really appreciate the time that you have taken to share your experiences and the trust that you have placed in me by sharing these experiences. This interview will examine your experiences as an individual living with HIV/AIDS. In the process of conducting the interview, I will ask you about your personal experience of living with HIV/AIDS and the difficulties and discrimination that you may have faced as a result of this diagnosis. Together, we will also explore how you have dealt with this diagnosis, the skills you may have employed in managing HIV/AIDS and the supports that you may have received from different sources such as members of the medical community, social service organizations, family, and friends. Before I begin this interview, are there any questions that you would like to ask of me?

1. Could you describe to me the moment when you were diagnosed with HIV/AIDS.
Probes (feelings, reasons for diagnosis, time of diagnosis, circumstances under which HIV/AIDS status was revealed, their current physical status, disclosure)

2. Tell me about your response to the diagnosis.
(Probes: Some fears could be with regard to revelation to family and friends, revelation to members of the community

3. Did you share the news of your diagnosis with anyone?

4. How did the people you told about your diagnosis respond?
(Probes: experiences faced at the hands of medical professionals and service professionals, any form of discrimination and stigma from employers, friends, family members, and general society/community).

5. What other kind of reactions have you experienced?

6. Have you ever faced these kinds of responses and reactions to any other situation prior to your diagnosis?

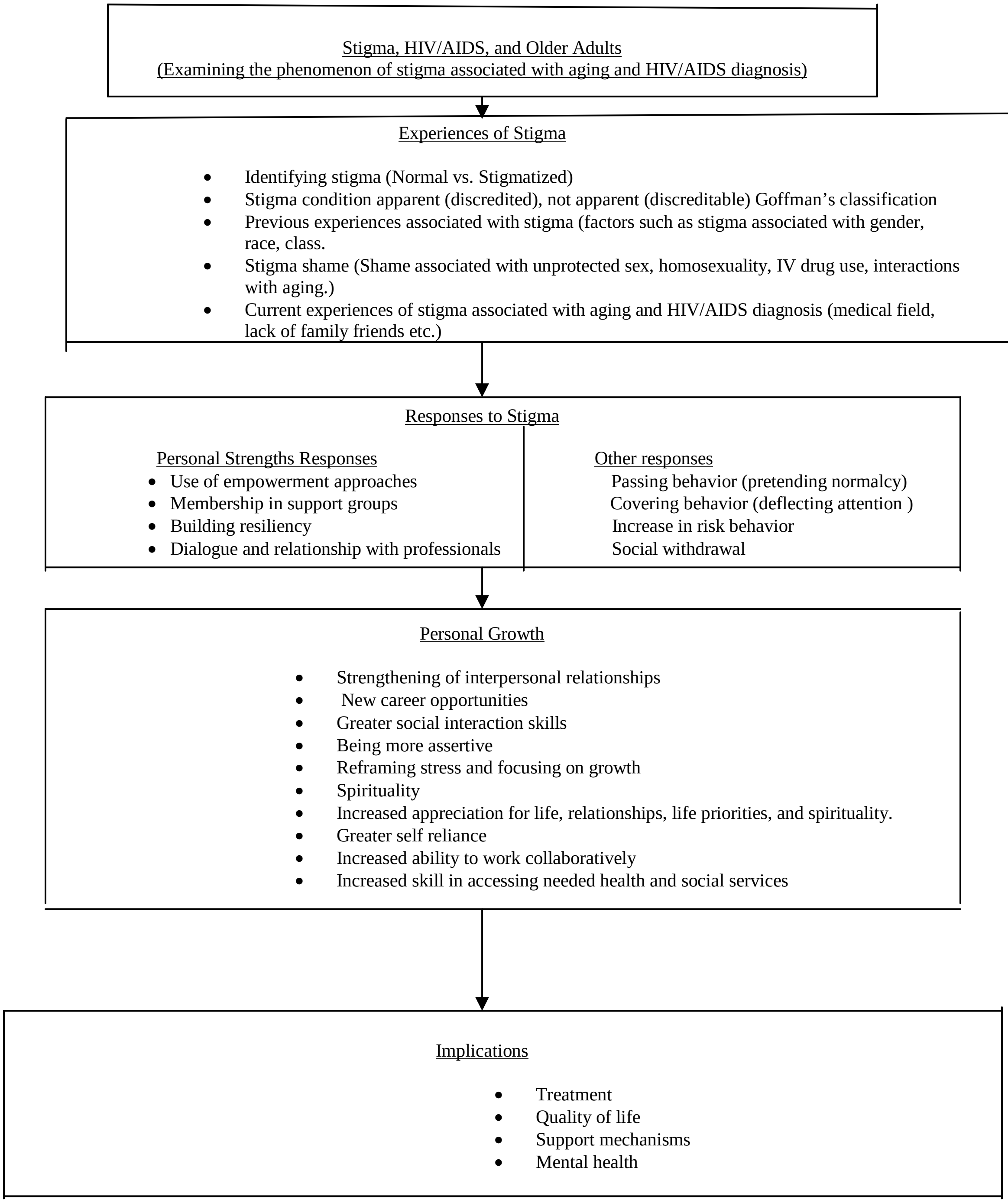
7. Tell me about some things you have done to manage your diagnosis and the responses that you may receive to your diagnosis.

8. How has this experience changed you?

Thank you for participating in the interview. I am really grateful for all the personal details that you have shared with me. I will send you a summary of my findings to ensure that I got them right.

APPENDIX C: Old Conceptual Model

Figure 2: Old Conceptual Model (presented in the proposal defense)



Conceptual Model

The conceptual model for the proposed study is based on the theoretical framework and review of literature. This model only attempts to demonstrate possible areas and concepts that may be explored as a part of the proposed study and possible implications for social work practitioners. It is not meant to be an explanatory model of stigma nor is it meant to be tested.

Experiences of stigma. Goffman (1963) has stated that individuals whose stigma condition is apparent (for example, individuals who are very ill with full blown AIDS) and individuals whose condition is not apparent (an individual who has HIV but is otherwise healthy) may have very different experiences of stigma .Further previous stigma experiences associated with race, gender, and class may have influence how older adults respond to current stigma associated with HIV/AIDS. Older adults may also experience prejudices from others commonly associated with this diagnosis (individuals with HIV/AIDS must be injecting drug users).Older adults may be stigmatized in social settings, within their families and by other groups.

Responses to Stigma

Different individuals may respond differently to the experience of being older and having an HIV/AIDS diagnosis For the purpose of this study, I have suggested two kinds of responses. These are personal strengths responses associated with personal growth and other responses.

Personal Strengths Responses. Personal strengths responses are responses that correspond with the various strengths concepts that have been laid by Dennis

Saleebey (2006) in his explanation of the strengths perspective. Goffman's (1963) conception of stigma gives us an understanding of how people experience stigma and what may be some of their responses to stigma. While Goffman's premise that stigma may discredit an individual and how an individuals' initial response to stigma may be negative, examples of these being a lack of disclosure or loss of support may be sound, he misses an important link in not including how many stigmatized people overcome this stigma and go on to live positive, enriched lives. It is important to move beyond the negative image of a stigmatized person. To do this, I would like to discuss some of the principles that form the foundation of the strengths perspective and how they may be applied to understand the personal strengths responses, positive growth, and the experiences that older adults with HIV/AIDS may have when they deal with their stigma.

The strengths perspective is based on the two philosophical principles of "liberation and empowerment" (Saleebey, 2006, p. 7) and "alienation and oppression" (p.9). These principles are based on the supposition that though people face stressful and difficult circumstances everyday, there is a capacity for change. In the case of older adults with HIV/AIDS, there is stigma that is associated both with aging and having HIV/AIDS. However, despite facing difficult circumstances, human beings are resilient and emerge stronger from these experiences. This belief is the crux of main points of the strengths perspective.

The "lexicon of strengths" (p. 10) suggested by Saleebey (2006) includes the development of "competence, capacities, and courage; promise possibility, and positive expectations; and resilience reserves and resources” (pp. 10). The core concepts of the strengths perspective such as empowerment, membership, and dialogue are ways in which individuals develop their lexicon of strengths.

Some examples of personal strengths responses are those individuals who: A) make use of empowerment approaches; B) seek membership in support groups of individuals who may have HIV/AIDS or who are older; C) use spiritual resources or; D) those who engage in collaborative dialogue with medical and service professionals to access effective care despite their stigmatizing condition.

Other Responses. Other responses would include responses such as hiding ones diagnosis, deflecting attention from diagnosis, delaying or denying treatment, increasing risk behavior, and social withdrawal.

Personal Growth

I examined existing literature for any studies that had explored the positive consequences of stigma. Not many studies have examined whether there are any positive consequences to having a stigmatizing condition. I was unable to find a single study which had explored the positive consequences of the stigma experienced by older adults with HIV/AIDS. However, a few studies have been carried out on how people with other stigmatizing conditions may have benefited from their stigmatizing experiences and may have experienced personal growth as a result of their stigmatizing conditions (Hermann & Miall, 1990; Shih, 2000).

Hermann and Miall (1990) conducted a qualitative study with people with chronic and non-chronic psychiatric problems and childless women and found that the stigma associated with these conditions led to positive responses and changes such as new career opportunities, strengthening of interpersonal relationships, and personal growth experiences. According to Shih (2000), current literature on stigma has examined the negative responses and consequences to stigma that people have experienced. She stresses that research needs to focus on factors that have helped individuals overcome the negative influences that stigma has on their lives. Shih (2000) also suggests that individuals who handle their stigma well work from an empowerment model rather than a coping model in response to their stigma. The empowerment model views stigmatized individuals as active participants who can make a change in their world and be empowered in the process. Some of the skills identified by Shih (2000) that helps stigmatized individuals overcome stigma are compensation strategies such as being more assertive and having more developed social interaction skills.

Other studies have explored how people living with HIV/AIDS demonstrate personal growth and empowerment after their diagnosis and through the course of their lives. Leserman, Perkins, and Evans (1992) conducted a qualitative study with 52 asymptomatic gay men and found that men were able to reframe their stress to maximize their personal growth and were able to look at the disease as an opportunity for personal growth.

Dunbar, Medina, Mueller, and Wolf (1998), examined how women who have HIV/AIDS deal with the stress of their diagnosis and “transform their lives in positive and productive ways (pp. 144)”. They state that by failing to recognize the personal growth and strengths that women with HIV/AIDS develop, social workers may be minimizing the power and self determination of their clients.

Some of the ways that the women in this study demonstrated personal growth were: going through a process of introspection about their past and using past experiences with stressful situations to deal with their current stress; understanding the value of time and developing a greater respect of life; making decisions to live a full life each day; and developing a renewed sense of union and empathy with the people in their lives. The women in the study described how they had channelized the pain of their diagnosis into living more positive lives and had experienced tremendous personal growth. Women who disclosed their status to their loved ones, sought spiritual solace, and developed new relationships were able to demonstrate greater personal growth.

Another study that explores personal growth demonstrated by people who have HIV/AIDS has been carried out by Milam (2004). His study showed how people with HIV/AIDS demonstrated personal growth by showing an increased appreciation for life, relationships, life priorities, and spirituality. They also show greater self reliance. Most people with HIV/AIDS demonstrated some personal growth but many were not aware of the growth over a period of time. People living with HIV/AIDS who demonstrated greater personal growth and who derived positive meaning from their HIV/AIDS diagnosis were more likely to show less symptoms of depression and greater psychological well being (Farber, Mirsalimi, Williams, & McDaniels, 2003).

These studies demonstrate that stigmatized populations and people with HIV/AIDS were likely to demonstrate personal strengths and eventually personal strengths responses lead to personal growth in their lives. However, there are no studies that have examined how older adults with HIV/AIDS who experience stigma demonstrate personal strengths and personal growth. Older adults with HIV/AIDS may demonstrate both personal strengths responses as well as other responses that are not strengths related when they experience stigma. They may also demonstrate both these kinds of responses. Personal growth may be demonstrated by an increased manifestation of personal strength responses. Some of the signs of personal growth that have been identified by the both the literature on positive responses to stigma and by the literature on how people live with HIV/AIDS demonstrate growth are: strengthening of interpersonal relationships and seeking new opportunities (Hermann& Miall,2000); developing greater social interaction skills (Shih, 2000); being more assertive (Shih, 2000); reframing stress and focusing on growth (Leserman et al., 1992); going through a process of introspection about the past and using past experiences with stressful situations to deal with their current stress(Dunbar et al., 1998); understanding the value of time and developing a greater respect of life; making decisions to live a full life each day(Dunbar et al., 1998); and developing a renewed sense of union and empathy with the people in their lives (Dunbar et al., 1998). Other signs of personal growth are increasing spirituality; increased appreciation for life, relationships, life priorities, and spirituality. People who demonstrate personal growth also show greater self reliance (Milam, 2004).Personal growth may have a positive impact on mental health, perceived quality of life, and willingness to receive treatment for older adults with HIV/AIDS.

Implications for Treatment and Life Goals

The final piece of this conceptual model will explore how the experience of personal growth or the lack of it influences different facets of older adults’ lives in areas such as treatment, preventive behaviors, building support mechanisms, and mental health.

APPENDIX D: Specialized Plot Analysis

Table 2: Specialized Plot Analysis (Disclosure and Non-Disclosure Experiences)

Participant	Disclosure	Stigma Experience	Strengths Responses	Non-Disclosure	Other Experiences (which were not strengths related and were not non-disclosure)	Personal Growth	Age at Diagnosis	Diagnosed Before the Passage of Protective Legislation (Pre-Legislation
014 Shana	Disclosure to intimate partner	Stigma from intimate partner. Partner blamed her for giving him the disease when he had actually given it to her (Enacted stigma from intimate partner)	Refusing to be stigmatized by partner (Resilience)	----------------------	-------------------	----------------------	60 +	------------------
	Disclosure to strangers	Stigma faced at the hands of strangers	Refusal to be labeled and stigmatized (Resilience)	---------------------	-----------------	--------------------		
	Disclosure to family members	----------------------	Support from family members on disclosure of diagnosis. (Empowering themselves with the help of supportive people)	-----------------	-------------------	Giving something back to the community		
004 Jacque	Disclosed her HIV/AIDS diagnosis to family members	------------------------	Received support from family members (Empowering themselves with the help of supportive people in their lives) Public speaking for the cause of women and HIV, Advocacy for women over 50 living with HIV (Education and Volunteering)	--------------------	------------------	Giving something back to society because of support received from family (Giving something back to the community)	50+	Pre legislation
005 Patrick	Disclosure to intimate partner	---------------	Received support from partner (empowering of self through support of significant people in older adults lives)	------------------	-----------------	-----------------	50+	----------------------
	----------------	Expected to be stigmatized by family members because they had previously stigmatized him for being gay (Anticipated Stigma)	-----------------	Did not reveal diagnosis to family members (Non-disclosure)	------------------	-------------------		
	Disclosure to case manager	------------------	Received support from the case manager and became a peer counselor so he could help others the way he had been helped (Empowering themselves with the help of supportive people)	------------------------	--------------------	Giving something back to the community	50+	

012 Andrew	Disclosure to family	Family withdrew from him for sometime (Stigma from family and friends)	Forgiveness for family members who stigmatized him (Resilience)	------------------	--------------------	-------------------	50+	Pre Legislation
	Disclosure to medical professionals		Received support from medical professionals (Empowering themselves with the help of supportive people)					
	Disclosure to person who delivered news of diagnosis	News delivered in unsympathetic manner (Enacted stigma)	Decided to become a counselor and help deliver news of diagnosis to others with HIV/AIDS (Education and volunteering)	---------------	------------------	Giving back something		
016 Wallis	Disclosure to sexual partner	Partner disappeared from his life (Enacted stigma from sexual partner)	----------------------	-------------------	---------------------	------------------	50+	-------------
	Disclosure in the workplace	------------------	Support from members in the workplace (Empowering themselves with the help of supportive people)	---------------	----------------------	-------------------		
018 Lincoln	Disclosure to medical professionals	Stigmatized for being gay and HIV positive	-------------	-----------------	-------------	-----------------	50+	------------
	Disclosure to members of support groups	---------------	Membership in support groups	--------------	--------------------	----------------		
	Disclosure of family members	-------------------	Support from family members (Empowering themselves with the help of supportive people)	------------------	--------------------------	----------------		
003 Martha	-------------------	Felt that she would be judged negatively by her neighbors (Anticipated Stigma)	Moved to another place where she could start afresh and where her confidentiality was protected (Resilience)	--------------------	-------------------	------------------------	41-50	--------------
	Disclosure to former pastor	Stigma from pastor of church she attended earlier Expected stigma in the church she was currently attending (Felt Stigma: Anticipation of stigma)	-------------------	Did not disclose her HIV/AIDS diagnosis to the pastor of her current church.	------------------------	------------------------		
	Disclosure to family members	Family members labeled her because of her diagnosis (Stigma from family and friends)	Refusing to be labeled (Resilience) Became a peer counselor (Education and volunteering)	-------------------	-------------------	Spiritual growth Giving back to the community		
006 Jonathan	Disclosure to family members	-----------------	Received support from family members (Empowering themselves with the help of supportive people)	-----------------	---------------------	-------------------	41-50	--------------
	Disclosure in the workplace		Received support from colleagues (Empowering themselves with the help of supportive people)					

007 Sarah	Disclosure to family members and friends	Was stigmatized by some family and friends	Received support from some family members. (Empowering…) Laughed at hurtful words used by family members (Resilience) Sought help from members of support groups (Membership in support groups)	-------------------	Isolated herself from family and friends sometimes rather than reveal her diagnosis (Isolation)	----------------------	41-50	------------
008 Richard	----------------	Expected to be stigmatized in the workplace (Anticipation of stigma)	------------------------	Non -disclosure in the workplace	--------------------	-------------------	41-50	-------------
	Disclosure to family members and friends	Faced stigma from family members, discomfort sharing silverware, toilets (Stigma from family and friends)	Refusing to be labeled by family members and friends (Resilience)	------------------	-------------------	-------------------		
	Disclosure in church	------------------	Received support from members in church (Empowering themselves with the help of supportive people)	---------------	--------------------	Greater spiritual connection (spiritual growth)		
013 Keegan	Disclosure in the workplace	Stigmatized by colleague for being gay and HIV positive (Actual Stigma in the workplace)	(Empowering themselves with the help of supportive people)	----------------	------------------	---------------	41-50	------------
	Disclosure in support groups	-------------------	Support from members of support groups (Empowering themselves with the help of supportive people)	----------------------	--------------------	------------------		
017 Caitlin	Disclosure to family and friends	Some Family and friends stopped talking to them because they feared they would contract the disease	Other family members supported her (Empowering herself with help of supportive people) Educating friends about how the disease is spread (Education and volunteering)	--------------------	------------------------	---------------------	41-50	-------------
	Disclosure in the church	-------------------	They supported the older adult and attended programs with them (Empowering themselves with the help of supportive people)	--------------------	-------------------	----------------------		
	Disclosure in support groups	----------------------	Support from members of support groups (Empowering themselves with the help of supportive people)	------------------------	----------------------	------------------		
019 Toby	Disclosure in the workplace		Supported by members in the workplace (Empowering themselves with the help of supportive people)				41-50	------------

	Disclosure to family members	-------------	Support from family members (Empowering themselves with the help of supportive people)	---------------	--------------	--------------		
	----------------	Expected stigma from potential sexual partners	--------------	Did not disclose his diagnosis to potential partners	-----------------	---------------------		
001 Arnold	-----------	Saw Brother being badly treated by family for being gay and HIV positive (Anticipation of stigma)	-------------------	Non- disclosure of HIV/AIDS diagnosis	Isolation from family members (Isolation)	------------------	31-40	Pre Legislation
	He disclosed his HIV/AIDS diagnosis in the support group)	Stigma in support groups (Enacted experience of stigma)	------------------------	--------------------	Withdrawal from the support group (Isolation)	-----------------------		
	He disclosed his diagnosis in the workplace	Was fired from his job (Stigma in the workplace)	Was glad that he had stood up for himself (Resilience)	---------------------	Felt helpless and as if he couldn't do anything (helplessness)	-------------------		
002 Hank		Thought he would be stigmatized for being bisexual and having HIV/AIDS by family members (Anticipated stigma)	--------------	Did not reveal her diagnosis to the family.			31-40	Pre legislation
	---------------	Fear of disclosure by members in support groups (Anticipated stigma)	Still continued to attend support groups (Membership in support groups)	Did not reveal his diagnosis in support groups but still attended the groups (Membership in support groups)	-------------------	Wanted to volunteer with people who had HIV/AIDS (Giving something back to the community)		
009 Matthew	---------------	Had previous experience of stigma because of being gay (Anticipation of stigma)	--------------------	Non- disclosure to family members	--------------------	Giving something back to the community	31-40	Pre Legislation
	Disclosure to medical professionals	Faced stigma from medical professional (Enacted stigma)	Advocacy for people living with people with HIV/AIDS (Overall response to stigma)	---------------------	------------------------			
010 Chris	Disclosed diagnosis to friends	--------------	Received support from friends Empowering themselves with the help of supportive people	-------------------	------------------------	-------------------	31-40	Pre Legislation
	Disclosed diagnosis church	---------------	Received support from members of church Empowering themselves with the help of supportive people	-------------------	-------------------	----------------		
	Disclosure at the workplace	-------------------	Support in the workplace Empowering themselves with the help of supportive people	----------------	------------------------	--------------------		
011 Cory	Disclosure to family	-----------------	Support from family members Empowering themselves with the help of supportive people	----------------------	--------------------	-------------------	31-40	--------------------
	------------------	Expectation of stigma from church members (Anticipation of stigma)	--------------------	Did not reveal diagnosis in church	--------------------	--------------------		

015 Bailey	Disclosure to medical professionals	----------------	Support from medical professionals (Empowering themselves with the help of supportive people)	------------------	------------------	-------------------	31-403	Pre Legislation
	Disclosure in the workplace	--------------------	Support from members in the workplace (Empowering themselves with the help of supportive people)	--------------------	-----------------	-------------------		
	Disclosure to family members	Stigma from family members						
020 Phillip	Disclosure to potential sexual partners	Rejection and stigma from potential partners	Continues to disclose their status to potential partners				31-40	Pre Legislation
		Anticipation of stigma from potential partners	Continues to disclose their status to potential partners					
021 Sabrina	Disclosure to friends	Best friend stopped talking to them (enacted stigma), hence expected to be stigmatized again (anticipated stigma)		Did not disclose diagnosis to friends for sometime because of this experience			31-40	Pre Legislation
	Disclosure to family	Some family members discriminated against her	Sister acted as an intermediary and helped Sabrina disclose diagnosis to family members, lessened impact of familial stigma. Became an advocate for people living with AIDS, also experienced spiritual growth) (Empowering themselves with the help of supportive people)	-----------------	--------------------	Giving something back Giving something back to the community Spiritual growth		
			Advocacy for the cause of older adults living with HIV/AIDS					
	Disclosure in support group		Membership in support groups					