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A Descriptive Exploratory Study of the Experience of Gay Partners of HIV-Positive Men

Jon Christensen PhD, MSN, RN
University of San Diego

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HAHN SCHOOL OF NURSING AND HEALTH SCIENCE

A Descriptive Exploratory Study of the Experiences of Gay Partners of HIV-positive Men

FINAL PRESENTATION

OF

Jon Christensen MSN, RN

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<u>DISSERTATION COMMITTEE</u>

Mary Rose Mueller PhD, RN, Chair

Patricia Roth EdD, RN

Susan Instone DNSc, CPNP

Abstract

HIV disease/AIDS has been the focus of much research since its introduction in 1981 and continues to have profound implications for those living with the disease and for those who are in close social relationships with them. One group that has received minimal attention in the HIV/AIDS literature is gay partners of HIV infected men. The aim of this study was to explore and describe the experiences of gay men living with a life partner who has HIV disease/AIDS who were not primary caregivers.

A qualitative study using an interpretive descriptive approach was employed to study the experiences of ten gay men whose partner had HIV disease/AIDS. The study was conducted in a large urban area in one of the western states within the USA, using a purposeful convenience sample. An unstructured interview process was utilized, the interviews transcribed verbatim, analyzed, and themes and patterns developed into a professional narrative conveying the most important findings focusing on clinical implications for nursing practice.

Significant findings that emerged from analysis of the study data included: (a) issues of disclosure of HIV serostatus both within and outside of the relationship; (b) influences on daily life including the impact on day-to-day routines and plans, effective coping, perceptions of the future of the relationship, and ways in which the relationship had been enhanced; and (c) perceptions of the healthcare system including care by physicians and care by nurses.

Implications for nursing practice included: (a) acknowledgement by the nurse of the role and importance of the participant in the lives of their HIV-positive partner is crucial in establishing rapport and developing a family-centered approach to care; (b) the need to combat the notions of homophobia and heterosexism by introducing the needs of this vulnerable population in early nursing curricula; (c) the ongoing need for education regarding HIV transmission; (d) assisting the study participants in identifying and implementing effective coping interventions by providing emotional support and by including them in their partner's care; (e) assisting the participant in identifying and developing skills and behaviors that will better allow them to "normalize" their lives; and (f) recognition that these participants may need increased community resources to assist in coping as well as integrating into the community as a whole.

The results of the study suggest that even though societal views on gay relationships are changing, issues regarding secondary stigma, disclosure, health, and support and education from the healthcare community continue to impact gay men and their partners.

Dedication

To Steve, for being there at the finish. And for my parents who would have been so proud.

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In appreciation to the men and women everywhere who fight tirelessly to improve the quality of life for LGBT individuals.

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Chapter 1: Introduction

Focus of Inquiry

The Centers for Disease Control and Prevention (CDC) estimate that approximately 1.2 million persons in the United States are infected with the human immunodeficiency virus (HIV). About 20 % of these individuals are unaware of their infection, and over 500,000 persons have been diagnosed with acquired immune deficiency syndrome (AIDS), an advanced form of HIV disease (CDC, 2011). Gay and bisexual men remain the population most heavily affected by HIV/AIDS in the United States. The CDC estimates that men who have sex with men (MSM) represented about 61% of all new HIV infections in 2009, and account for more new infections than all the other risk groups combined (CDC, 2011). Given that only 5% to 7% of American men have had sex with another man during adulthood, these figures represent a disproportionate infection rate when compared with other populations (Binson, Blair, Huebner, & Woods, 2006). The incidence of new HIV infections and AIDS diagnoses in this group has waxed and waned since the condition was first reported in 1981. Recent data, however, show an increase of HIV infection rates in MSM, particularly among young African American and Hispanic males, and gay couples (CDC, 2011).

HIV infection touches on all aspects of the lives of those infected. A vast body of literature has accumulated on this topic, including studies that link HIV infection with impaired, or a much higher risk for impaired, mental health (Demi, et al., 1997; Herek & Capitanio, 1999), physical health (Herek & Capitanio, 1999; Delahanty, Bogart, & Figler, 2004), social stigma (Herek & Capitanio, 1999; Parker & Aggleton, 2003), sexuality

(Deacon, et al., 2005), employment (Herek & Capitanio, 1999; Parker & Aggleton, 2003), and spirituality (Green, 1995).

HIV infection also touches on the lives of those in close social relationships with people living with HIV/AIDS (PLWHA) including: parents, spouses, children, healthcare professionals, professional caregivers, and other caregivers (Walker, 2006). Much of this research has focused on the social response to those in close relationships with PLWHAs, including the experience of secondary stigma and other forms of social discrimination (Wight, et al., 2007; Bogart, et al., 2008; Scambler, 1998). A comprehensive review of the literature, however, reveals that a group that has received far less attention is long-term, committed, gay life partners of HIV infected men, particularly those who fall outside of the caregiving role. Because of this gap in the literature, research is needed to uncover the unique perspectives and experiences of this group.

Background and Significance

The fact that this group has received minimal attention may be explained, at least in part, because of the lack of accurate data on the number of gay men in America, the number of gay men in a committed relationships/marriage, and the number of gay relationships/marriages where one or both partners has HIV disease/AIDS. Herek (1999) posits that one probable explanation is because continued prejudice and sometimes violence perpetrated against gay Americans, cause many gay men to be reluctant to disclose their sexual orientation, HIV status, and relationship/marriage status. Changes in the way information about households is collected in the United States Census, have allowed somewhat better estimates of the number of households headed by a person with a same-sex partner to be obtained. Revised data from the Census of 2010 from The

Williams Institute, UCLA, School of Law (Gates & Cooke, 2011) indicate that a total of 646,464 couples self-identified as gay in the 2010 census, with 131,729 classifying their partner as husband or wife, and 514,735 classifying the nature of their union as that of unmarried partners. Of these couples, 313,577, or 49% involved male partners.

Even with improved census data, the data-gathering methods from the Census Bureau still do not provide a complete picture of gay Americans and gay American couples. This fact, coupled with the reluctance of at least some gay individuals to disclose their sexuality, HIV status, and relationship/marriage status, demonstrates the fact that these estimates are a snapshot of a collaborative "best guess" and are likely underreported (Gates & Cooke, 2011). However, when comparing current data on the number of gay couples, compared with previously published data, it is clear that in the United States, more gay couples are choosing to establish and live in long-term partnerships and marriages (where allowed). What continues to be unavailable in the literature is an accurate representation of how many gay couples exist in which one or both of the partners are living with HIV/AIDS.

In spite of the inherent difficulties in estimating gay partnerships/marriages, gay couples – especially those in which one or both partners are living with HIV-disease/AIDS - have not escaped the attention of researchers. Of interest, however, is that the vast majority of studies have focused on the experience of the couple as a dyad, researching them together as the data source.

The literature on gay male dyads generally falls into one of two categories: one where disease - usually chronic - is part of the couple's experience and the other where disease is absent. In the latter case, the literature is vast but is not germane to the focus of

this study and therefore will not be analyzed as part of this study. In the case of the former, the focus is almost entirely on HIV disease and AIDS.

Disclosure and HIV Transmission Risk

A great percentage of the literature on gay male dyads where one or both partners are infected with the HIV virus, focuses on HIV transmission issues, risks, and concerns, and is mostly quantitative in nature. One of the foci from this literature that presents as particularly problematic for gay couples regarding HIV transmission is the issue of monogamy versus the decision to allow sexual encounters outside of the relationship (Gomez, et al., 2012; Neilands, et al., 2010). The issue of monogamy versus non-monogamy becomes an even greater concern in HIV serodiscordant couples who must acknowledge increased HIV transmission risks, and face the possibility that the HIV-seronegative partner may become HIV infected (Hoff, et al., 2010). The results of one recent study by Stephenson, et al. (2011) found that transmission among gay male couples is on the rise due to the fact that many gay couples find it difficult to negotiate issues of monogamy and sexual expectations within the boundaries of the relationship.

A large part of these negotiations include disclosure of HIV serostatus. The primary issue regarding disclosure of HIV serostatus is that many studies show that transmission risks are greater for those who do not know or do not inquire about a potential sex partner's HIV status, and much of the research done on this topic seeks to find effective interventions designed to encourage disclosure of one's HIV serostatus in order to reduce the spread of new HIV infections (CDC, 2011; Gomez, et al., 2012; Neilands, et al., 2010). In addition, Stephenson (2011) found that when gay male partners

sought HIV testing and counseling services as a couple, they were better able to open a dialogue about building a plan to address sexual health issues in their relationship.

Stigma

Another phenomenon that was prevalent in the literature on gay males and gay male couples was stigma. HIV-related, and HIV-related courtesy stigma remains one of the most researched topics on LGBT individuals and those in same-sex relationships (Herek & Capitanio, 2001; Fredriksen-Goldsen, 2007; Rutledge, et al., 2011; & Powell-Cope, 1998). So prevalent is the issue of both enacted and perceived stigma in this population that few articles reviewed as part of this literature review have little or no mention of stigma. Indeed, the opposite was found to be true as strong themes of, discrimination (Link & Phelan, 2001), loss of social status, political, cultural and economic consequences, and negative influences on health (Link & Phelan, 2006) were frequently encountered in this literature. Many of these studies found that there was a direct link between HIV-related stigma and HIV-related courtesy stigma and stress, disease, poor coping abilities, and decreased access to public services including healthcare services (Link & Phelan, 2006). Therefore, stigma emerged as a vital determinate of health as well as health outcomes due to an increase in disease and altered health outcomes based on limited healthcare access leading to a range of health disparities.

Relationship Dynamics

Stigma, fear of HIV transmission both within and outside of the relationship, and disclosure issues may have a major impact on relationship dynamics, and represents another finding within the literature on gay couples and HIV disease. One researcher

found that gay couples who had the added stress of HIV disease had higher rates of physical and emotional morbidities, decreased rates of positive coping behaviors, decreased ability to communicate effectively, disruption to normal routines, and were twice as likely to end the relationship than couples who did not have the added strain of HIV disease in the relationship (Gomez et al, 2011). This means that gay couples dealing with HIV disease within the relationship are at much higher risk for threats to the dynamics of the relationship and to the relationship itself and warrants further study to help identify support and other interventions designed to strengthen the quality of the relationship and impact its longevity.

The Partner as Caregiver

All of the previous themes identified from the literature on gay male couples used the couple dyad as the study participant. The one exception to this finding in which the gay partner of an HIV-positive individual was studied outside the couple dyad, was that of the partner as the primary caregiver, and focused primarily on their experiences in their role as a provider of care. Themes that emerged from this literature were: financial, psychological, and physiological effects of being a caregiver (Prachakul & Grant, 2003), issues encompassing end-of-life stressors (Miller, Chibnall, Videen, & Duckro, 2005; Aoun, Kristjanson, & Currow, 2005), bereavement issues surrounding the death of the individual who received the care (Aoun & Kristjansen, 2010; Land, Hudson, & Stiefel, 2003), and coping with issues such as stigma, death, grief, remembrance, and how to move on after the death (Prachakul & Grant, 2003; Folkman, Chesney, & Christopher-Richards, 1994).

The Partner as Study Participant

While the review of the literature on gay male couples and HIV disease, with subsequent theme identification, helps to identify the issues of salience to this population, it is important to reiterate the fact that the vast majority of the studies reviewed were completed by using the couple dyad as the study participant and focused on issues of importance to both members of the couple dyad. The one exception to this rule was that of the partner being studied exclusively in the role of caregiver for his HIV-positive partner. What is also highlighted through this review and analysis of the literature is that there remains a gap in the literature where research studies specifically focusing on the gay partner of an HIV-positive individual are conspicuously lacking. Currently, there are no published studies specifically addressing the perspectives on, and experiences of, being a gay partner of an HIV infected man outside of the caregiver role. Because of the key role played by the primary partner of an HIV-positive individual (Mitchell & Petroll, 2013), this omission represents a significant gap in the literature. While studies exploring the experience of living with HIV disease/AIDS among gay men are important from the couple's perspective, a better understanding of the individual partner's experience is integral to a full understanding of the social and individual dynamics involved in this phenomenon.

Problem Statement and Aim of Study

Men who have a primary partner living with HIV/AIDS (PLWHA) have a unique perspective on how living in this situation on a daily basis impacts their lives on numerous levels and in multiple dimensions. Much of the literature that has sought to address this perspective has been done by using the couple as the research participant, or

studied the partner only in a caregiver role. Because of this gap in the literature little is known about the perceptions and experiences of gay men in a long-term relationship with an HIV-positive partner outside of the caregiver role. Therefore, the aim of this study was to explore and describe the experience of gay men living with a male life partner who has HIV disease/AIDS. This investigation utilized a qualitative methodology and interpretive descriptive approach that included data collection obtained through individual one-on-one unstructured interviews with gay partners of individuals with HIV/AIDS. This approach was useful in finding, illuminating, describing, and disseminating knowledge, as well as potential theory building, which is of central importance to those involved in practice and research within the health professions (Thorne, 2008).

Significance to Nursing

The development of the science of nursing requires the establishment of a strong theoretical base upon which to develop knowledge, conduct research, and guide nursing practice (Chinn & Kramer, 1995; Kim & Killak, 1999). This ongoing development requires the identification of new and established concepts (Reynolds, 1971). The specific aim of this study was to explore the perceptions of gay men in a long-term relationship with an HIV-positive partner, and to develop new knowledge which could enhance understanding of the unique issues faced by this population that could contribute to a better understanding of the issues and barriers they face. The hope is that this knowledge can be utilized by nurses to inform and enhance current practice when interfacing with this population.

With this in mind, one concern to the discipline of nursing is the fact that there has been little research generated by nurse researchers, and the nursing literature lags

behind other disciplines in its inclusion of gay, lesbian, bisexual, and transgender health issues (Eliason, Dibble, and DeJoseph, 2010). Therefore, a better understanding of the dynamics, social-processes, and needs of this unique population – especially from a nursing perspective - is needed to more fully understand their needs and to better inform nursing practice, research, and education in the context of a family-centered care paradigm.

Family-centered care is a concept that nurses have valued and employed for decades. Studies show that families who were included in the care of their loved one reported fewer feelings of anxiety and improved coping strategies, both outcomes leading to higher patient satisfaction (Strickland, 1997). Patients reported feeling more supported, better health outcomes, and increased recovery time (Institute for Family Centered Care, 2008).

In the last 30 years, many disciplines have adopted a broader definition of family as the composition of families has dramatically changed, moving away from the more narrow definition of the nuclear family (Reigot & Spina, 1996). One definition of family by Friedman, Bowden, & Jones (2006, pg. 5), states that families are, "systems of interconnected and interdependent individuals, none of whom can be understood in isolation from the system". This broad interpretation includes the non-traditional definition of family which includes but is not limited to, single parents, gay and lesbian individuals, their partners and their children. In the practice setting, nurses encounter on a daily basis the many permutations of families and family structures, and must be prepared to provide, therapeutic family-centered care to each type of family encountered. In the most ethical and practical sense, nurses have a responsibility to not only treat the patient

in the context of the patient's family structure – traditional or nontraditional – but to treat each member of the family in a way that acknowledges each family member's individual roles and needs as a way to improve health for patient and family members alike (Friedman, et al. 2006).

Nurses must also be aware of the changing socio-political climate regarding the care and inclusion of nontraditional family structures. On April 15, 2010, President Obama released a memorandum written to Kathleen Sebelius, Secretary of the U.S. Department of Health and Human Services (HHS) instructing her to undertake a rulemaking process that would ultimately require all hospitals accepting Medicare and Medicaid funds to adopt non-discriminatory visitation policies to include same-sex partners and their children (The White House, 2010). President Obama's memo was written after he was inspired and moved by the case of Janice Langbehn who lost her partner of nearly 20 years, Lisa Pond, in Miami, Florida. Pond suffered a massive stroke shortly before leaving on vacation with their 4 adopted children and was taken to Jackson Memorial Hospital. The hospital denied Langbehn and the children access to see Pond for the next eight hours, in spite of the fact that the hospital had receipt of Pond's power of attorney which authorized Langbehn to act as her guardian and make medical decisions on her behalf.

With the nursing mandate to provide family-centered care, the need for nurses to advocate for social justice for disenfranchised populations, and the political and social movement to adopt a more comprehensive and tolerant view towards nontraditional individuals and families, nurses are in the unique position to be leaders in improving the health and health outcomes of a vulnerable group that continues to experience a multitude

of health disparities and limited access in the current healthcare system (Eliason, Dibble, & DeJoseph, 2010).

HIV Disease, Stigma, and Courtesy Stigma

One substantive theme that emerged from almost all literature addressing HIV and AIDS is that of HIV-related stigma and the parallel concept of HIV-related courtesy stigma. Because of the substantial impact of stigma on HIV affected individuals and those associated with them, these concepts were analyzed and addressed in chapter 2 of this dissertation. This analytic review includes: primary stigma, types of stigma (including HIV-related stigma), courtesy or secondary stigma, and HIV-related courtesy stigma. Although stigma is not the focus of this dissertation research, such a review is included to augment our understanding of the broader context within which this study of gay men in a committed partnership with an HIV positive partner was undertaken.

Chapter 2: Stigma, Courtesy Stigma and its Impact on Individuals Associated with People Living with HIV Disease/AIDS

Chapter 2 provides a review of the literature on primary stigma and courtesy stigma, including conceptualization of stigma, trends in empirical evidence, and stigma interventions. The literature on primary stigma is reviewed in order to set the stage for a discussion of courtesy stigma, which is in many respects a parallel concept. While courtesy stigma may differ from primary stigma in severity, it does not differ in terms of the basic social processes it is associated with. Another notable difference between primary stigma and courtesy stigma is that the latter derives its grounding from association, whereas the former originates from deviant behavior, physical condition, or group identity (Goffman, 1963). By considering the literature on stigma, the opportunities for conceptualizing courtesy stigma are better understood. Following this, a brief discussion of the stigmas surrounding HIV disease and those who are associated with individuals who are HIV positive or have AIDS are discussed. Courtesy HIV stigma emerges as a largely unexplored determinant of health and a complementary addition to the core of issues researchers have identified as affecting those who are closely associated with people living with HIV/AIDS (PLWHA).

Conceptualizing Stigma as a Social Determinant of Health

Stigma, which has etymological roots in the Ancient Greek practice of branding slaves, was defined by prominent stigma scholar Erving Goffman as the situation of the individual who is "disqualified from full social acceptance" and "reduced from a whole and usual person to a tainted, discounted one" (Webster's, 1913; Goffman, 1963). More

recently, Link and Phelan define stigma as the co-occurrence of five components: labeling, stereotyping, separating "us from them", status loss and discrimination (Link and Phelan, 2001). Each of these overlapping concepts clarifies how stigmas arise from the identification of a difference as socially relevant (Link and Phelan 2001).

The process of identifying differences is closely linked with the formation of a stereotype as an integral component of group differentiation (Link and Phelan 2001). The cognitive processes involved in stereotyping ensure that identification of negative attributes are transformed into enduring beliefs and behaviors; these processes become finely tuned and ingrained and may be enacted without conscious intent on the part of actors (Kulik et. al. 2008). Group differentiation is the third component of stigma and involves the social processes associated with separating identified groups into specific social categories. This is achieved, in part, by elevating identified differences to a master status. This means that stigmas become the primary lens through which individuals are viewed by others (Link and Phelan 2001). The fourth and fifth components, status loss and discrimination, focus on the types of stigma experienced by those labeled as different. The identified differences are moved into a range of social settings resulting in a variety of secondary outcomes, which may have little relevance to the original difference which formed the basis of group differentiation in the first place (i.e., the impact of gender and racial identity on social performance in tests).

Power is central to Link and Phelan's (2006) conception of stigma, as unequal power relations are a necessary precondition of stigma formation. For example, while labeling and norm- enforcement are common aspects of social life, only groups with some advantage over another have the power to make labels consequential at political,

cultural and economic levels (ibid.). Thus, stigmas can be traced back to broader social

inequities that enabled stigma formation (i.e., HIV+ serostatus and sexual identity are

preconditions associated with HIV-related stigma).

Types of Stigma

Stigmas are commonly organized into three main forms: tribal stigmas which are

based on race or other identity categories, behavioral stigmas which are rooted in deviant

conduct, and bodily stigmas which are often conceptualized as observable deformities

(Goffman, 1963). HIV-related and HIV-related courtesy stigmas, which are the focus of

this research study, can most readily be classified as behavioral stigmas, but often

intersect with other stigmas depending on HIV risk factors (i.e. how the disease was

contracted) and the identities of those involved (Benoit et. al. 2010).

Social Origins of Stigma

There are a variety of theories regarding the social origins of stigma, but they

generally fall into one or more of the following three categories: (a) perceived threats to

social order (norm enforcement), (b) survival (disease avoidance) or, (c) the outcome of

one group's desire to subordinate another for economic power or other gains (group

competition) (Kurzban and Leary, 2001; Phelan et. al. 2009; Strangor and Crandall,

2000). It is important to note that there is a dearth of literature examining the historical

evolution of stigmas, and researchers have identified this gap as problematic as such

information is crucial to understanding both the ongoing social construction and

disruption of stigmas (Phelan et. al, 2009).

The emergence of HIV-related stigmas is one notable exception to this gap. The

esteemed sociologist Dr. Rose Weitz (1991), published one of the first monographs on

the historical trajectory of HIV/AIDS as a disease entity, but more importantly provided a detailed, and in retrospect, accurate account of the sociopolitical construction of HIV-related stigma during a time when negative public attitudes and perceptions towards those who had contracted HIV/AIDS was at its most virulent zenith.

While specific stigmas (HIV-related stigmas included) are generally regarded as social constructs reflective of the concerns and fears in a particular time and place, the processes of disease avoidance, social norm enforcement, and competition for power are considered universal features of social life (Phelan et. al. 2009; Scambler 2009). Stigma processes are considered to be normal features of society in which everyone is engaged, rather than part of an abnormal process. As Goffman stated: "the stigmatized and the normal have the same mental make-up...he who can play one of these roles...has exactly the required equipment for playing out the other" (1963, pg.130-131).

Stigma has been similarly conceptualized by Scambler (2009) as the antithesis of what is considered honorable, desirable and upright (cf. Witgenstein, 1953). Thus, stigma and processes of stigmatization – defining the normal and the abnormal, or insiders and outsiders - can be considered alongside, and in relation to, other theories that seek to illuminate social hegemony.

The relationships between stigma and other aspects of social status, such as deviance, prejudice, discrimination, and social exclusion have not been widely explored. However, each tends to be used to draw attention to the way in which social status influences health, with many parallels in the applications of these concepts to current stigma research. Further consideration of these relationships, particularly in regards to the degree to which they are the same or complementary constructs, is needed in order to

develop theoretical and empirical knowledge of stigma as a social determinant of health, and to link stigma to the broader concept of socio-economic status. A discussion of the parallels between these concepts is addressed below.

Discrimination. Discrimination has been theorized as one aspect of stigma. Scambler and Hopkins (1986) describe felt (also called perceived) stigma as the perception of devaluation experienced by stigmatized persons, accompanied by a fear of encountering discrimination during social interactions (becoming a stigma target). Enacted stigma refers to observable acts of discrimination or discomfort on the part of the non-stigmatized (or stigma perpetrators). It is important to distinguish between these types of stigmas, especially in countries who have adopted equal rights legislation, as it allowed researchers to examine how stigmatized groups are most harmed by felt stigma, even in the absence of overt discrimination (Cree et al., 2004; Crocker and Quinn, 2000; Norvitilis et al. 2002; Scambler, 2009). While acts of discrimination (enacted stigma) can be profoundly damaging to health, felt stigma plays a powerful role in reducing self-confidence, inhibiting social interaction and reducing access to health resources as individuals engage in various forms of secrecy, covering, disclosure, and avoidance in order to limit their exposure to enacted stigma (Donkor et. al. 2007; Gray, 2002; Scambler and Hopkins, 1986; McRae, 2000). Scambler and Paoli (2008) later added the concept of project stigma to the distinction between felt and enacted stigma. Project stigma refers to felt (or perceived) stigma, but only entails a desire to avoid enacted stigma, without any accompanying sense of shame or guilt (ibid.). This third distinction helps account for individuals or groups who, for various reasons, exhibit resistance and defiance in the face of character attribution and associated prejudices, but who

nevertheless, make efforts to avoid exposure to discrimination by adopting similar practices of secrecy and instrumental disclosure (ibid.). Scambler (2009) suggests that this three part model of stigma can be similarly applied to behavioral deviance, with the language of stigma more often invoked when the topic of study is identity (race) and health (disability), and the language of deviance more likely to be initiated when the topic of study is a violation of moral-behavioral norms (IV drug use, homosexuality).

In summary, research applying the concept of discrimination to the study of health is synonymous with research on enacted stigma. Similarly, deviance and stigma are parallel concepts with the first more likely to be used with stigmas that contain an element of moral-behavioral achievement (homosexuality, presence of disease, substance use), and the second more likely to be used with stigmas that are based on characteristics for which the individual cannot be regarded as morally responsible (race, gender, disability). The implications of this distinction are significant because achieved statuses garner blame (Cao et. al., 2006), whereas ascribed statuses garner shame. It is important to bear in mind that some types of stigmas, such as contracting the HIV virus, will often encompass both shame and blame as the fuzzy boundaries of how one contracted the virus may stretch to incorporate both achieved (promiscuous, drug user) and ascribed victim (blood transfusion, neonate) statuses (Scambler and Paoli, 2008).

Prejudice. The distinction between felt/perceived and enacted stigma also contains parallels within definitions of prejudice. Prejudice is defined as felt or expressed antipathy based upon faulty and inflexible generalizations - a hostile attitude toward a person who belongs to a group and is therefore presumed to have the objectionable qualities of that group (Struber et. al., 2008). Following systematic comparison of a

variety of influential models of stigma and prejudice, Phelan et. al. (2008) argue that they are the same constructs, with the major difference between the two being that stigma is used when the focus is on disease, disability, and deviance, or the unusual, and prejudice is used when the focus is on issues of race, ethnicity, gender, age and sexual orientation (Struber et. al. 2008). A further difference is that the stigma literature tends to focus on the experience of victims, whereas studies of prejudice are more likely to focus on perpetrators (Struber et. al. 2008).

Thus, stigma, deviance, and prejudice are interrelated concepts, which are used to address various dimensions of difference depending on whether the difference is regarded as a combination of usual, unusual, ascribed or achieved.

Social exclusion. Social exclusion, an increasingly popular term within the health literature, also contains many parallels with conceptualizations of stigma. There is an increasing convergence between health research addressing issues such as marginalization, social exclusion and stigma and opportunity as fundamental determinants of health (Benoit et. al., 2010; Link and Phelan, 2002; Scambler, 2009). Galabuzi (2004:238) defines social exclusion as the inability of certain subgroups to participate fully in society due to structural inequalities in access to social, economic, political, and cultural resources arising out of the often intersecting experiences of oppression as it relates to race, class, gender, disability, sexual orientation, and immigrant status. Social exclusion takes place on a number of levels, including through structural exclusion from civil society (legal sanctions and relative or absolute exclusion from citizenship rights and protections), through denial of social goods (such as housing, education, and disability accommodations), through exclusion from social production

(denial of opportunity to contribute to social and cultural activities), and through

economic exclusion (unequal access to forms of livelihood and economy) (Galabuzi,

2004; Saraceno, 2005). The parallels between the concepts of social exclusion and stigma

suggest that these are also compatible constructs, with social exclusion differing in its

overall focus on the structural contexts and intersectional nature of stigma and

disadvantage, whereas stigma research has, until recently, maintained a focus on the

behavioral context and the impact of singular stigmas (Benoit et. al., 2010).

In summary, although additional systematic comparison of the literature

pertaining to stigma, prejudice, deviance, and social exclusion as social determinants of

health is required, it is likely each of these concepts focus on different dimensions of the

complicated relationship between social status and health. If this is the case, then models

for each of these concepts should be similar, allowing a variety of status constructs –

race, gender, disability, occupation, sexual behavior, substance use, mental health etc. –

to be considered interchangeably and, importantly, within their interactive context

(Scambler, 2009).

The implication is that these literatures may be brought together where it is

beneficial to do so in order to advance theoretical and methodological understandings of

stigma.

Stigma and Empirical Trends

Goffman

Much of the stigma literature, following Goffman's (1963) highly influential

research, focused on how stigmas are relational and most identifiable during social

interaction. Goffman differentiated between the discredited – whose stigmas were

observable – and the discreditable – whose stigmas could be concealed through effective information management (ibid.). Goffman's work focused on how stigmatized and non-stigmatized individuals arrive at working definitions of the rules of interaction, what happens when rules are broken, and how the rules shift in different contexts (ibid.). Goffman was interested in the structures of interaction that formed around stigmas as actors engaged in anticipating each others' thoughts via the *looking-glass self* (Camp et. al.. 2002).

Labeling theory

Following Goffman's work, a major category of empirical work was developed that focused on how the stigmatized react to, and manage, stigmas or labels in the context of social interaction and societal norms (Scambler, 2009). This body of work adopted a modified version of labeling theory, focusing on how expectations of labeling, rather than labeling itself, have a strong negative effect on social participation (Link & Phelen, 2001). One of the main premises of the modified labeling theory that heavily influenced stigma research during this period was that individuals have internalized negative representations of various conditions and behaviors before they become labeled with them; once labeled, these internalized messages are activated in personal identity formation and secondary deviances such as the "sick role", which may, in turn, result in withdrawal from, or modified participation in, various aspects of social life (Link et. al. 1997; Pilgrim and Rogers, 2005). The trend of applying modified labeling theory to stigma research spanned the period from the late 1970s to late 1990s (often referred to as the "personal tragedy era" of stigma research) and was heavily influenced by case studies of disability, mental health, and HIV/AIDS (Link et. al 1989; Scambler, 2004, 2009;

Scambler and Paoli, 2008). Much of the research from this era accepted that stigmas involved loss of self and biographical disruption followed by the adoption of coping strategies and adjustment (Scambler and Paoli, 2008).

Stigma Coping Strategies

Schneider and Conrad's (1983) typology of modes of adaption to stigma suggested that individuals fell into three categories of adjustment. The pragmatic type downplays their stigma by attempting to pass (discredited) or cover (discreditable), primarily by managing the manner in which, and to whom, their stigmatized attributes are revealed. The secret type may employ elaborate tactics to conceal their stigma reflecting an internalized poor self concept. The quasi-liberated type publicly proclaims their stigma in an attempt to sidestep any antagonism and to educate others (ibid.). These three basic responses of education, secrecy and withdrawal have been noted by others (Link et. al. 1989).

Also examining styles of adaption and coping, Miller and Kaiser (2001) similarly delineate two types: disengagement coping and engagement coping. Both can be further divided into voluntary and involuntary styles. Their findings suggest that persons at the greatest risk of stress are those who employ voluntary disengaged styles (denial, social withdrawal), or who are affected by involuntary responses (physiological arousal, rumination). Engagement styles – such as distraction (thought substitution, rather than thought suppression), evaluation/disidentification with domains where a stereotype is of importance, and cognitive restructuring (reframing experiences) are associated with less stress (Miller and Kaiser, 2001). Acceptance of "one's lot" was a cognitive engagement style not generally associated with positive outcomes, and the authors further note that

disidentification – or withdrawal from social structures where stereotypes and discrimination are likely - can be maladaptive if it is also associated with limited opportunities (Miller and Kaiser, 2001.). The most advantageous styles of coping included problem solving through collective action and emotional regulation - learned or instinctive strategies that reduce feelings of anger and anxiety - (Miller and Kaiser, 2001). These findings suggest that collective organizing can be an effective stigma management tool.

Documenting perceived and enacted stigma alongside the various coping strategies used by stigmatized persons has been of significant empirical interest because of the association with various levels of distress for the stigmatized. More recent investigations have expanded this model to focus on how coping and resistance practices, including passing, covering, withdrawal, and disavowal of others' perceptions, are preconditioned and limited by other contextual factors such as education, income, and group association. (Kusow, 2004; Miller and Kaiser, 2001; Scambler and Paoli, 2008).

Stigma and Health

Research regarding identity formation and coping with stigma laid the groundwork for scholars to begin to consider the individual and public health implications of stigma. At least five pathways from stigma to health have been developed in the empirical literature, with a focus on distress and opportunity exclusion as causal links (Krieger, 1990; Link and Phelan, 2006; Miller and Kaiser, 2001; Struber et. al., 2008).

Internalized stigma or self stigmas refers to individuals who adopt negative prejudices leading to diminished self concept and self esteem (Link 1987). Second, even

in the absence of internalized or self stigma, those who attempt to avoid the enactment of stigma by withdrawing socially from various contexts and structures experience reduced quality of social networks and support (Donkor and Sandall, 2007). Third, the stress and anxiety associated with perceived and enacted stigma has its own independent effect on mental health, often operationalized as depression symptoms (Stuber et. al., 2008). Fourth, enacted stigma results in underutilization of health services, and produces a number of secondary problems in the areas of employment/income, housing, and education as service providers and members of a community enact both conscious and unconscious forms of discrimination (Link, 1997; Link and Phelan, 2001). Fifth, in order to alleviate stress, stigmatized persons engage in behaviours (such as substance use) that pose further health risks, and are generally in a poorer position to engage in health promoting activities due to relative resource deprivation (Stuber et. al. 2008).

The health implications of stigmatization may be more damaging than the condition or attribute itself, especially if the stresses associated with multiple stigmas attached to one individual are experienced in a layered and/or cumulative manner (Benoit et. al, 2010; Stuber et. al. 2008).

Intervening in Stigma

Examining the historical contexts and evolution of stigmas provides a better understanding of how they are formed in interaction, but become embedded in structural and cultural systems; however, this type of inquiry forms a smaller part of the literature on stigma, which has instead primarily focused on how stigma influences the social interaction between stigma targets and stigma perpetrators, and more recently, on

how social exclusion and marginalization influence access to opportunities such as health and well-being.

Given these emphases in the literature, corollary efforts to reduce stigma have focused on: (a) educating the public by dispelling myths; (b) increasing contact with stigmatized populations by encouraging integration and identification of personal experiences of stigma; and (c) teaching improved coping strategies in order to strengthen stigmatized populations against the damaging effects of perceived and enacted stigma (Lee et. al., 2005; Pescosolido et. al. 2008).

Despite the increase of these strategies in the literature, research on the effectiveness of recent efforts to de-stigmatize individuals living with HIV/AIDS indicates that while knowledge of the disease is more widespread, and the ability to identify personal connections with individuals affected by HIV/AIDS has increased (using strategies a and b noted above), the negative prejudices associated with men who have sex with men, sex workers, and IV drug users have not been disrupted and potentially deepened (Pescosolido et. al, 2008). Similarly, Scambler (2009) reviews how the diversity and equal opportunity movements have resulted in more subtle forms of enacted stigma, and how efforts to empower disadvantaged groups are underpinned by top-down notions of education and self empowerment, which are pre-judged to be in the interests of devalued groups, but may be associated with more subtle forms of disempowerment.

While education strategies, if utilized thoughtfully and strategically, may form an important part of the continuum of stigma interventions, recent research focuses on two additional environments for stigma reduction (Lee et. al 2008; Pescosolido et. al. 2008;

Scambler, 2009; Link and Phelan, 2001). The first focuses on identifying contexts salient

to the lived experience of stigmatized groups and transforming the policies and practices

that govern these environments. Treatment and support contexts are especially important

within this strategy as caregivers may unwittingly deepen stigmas by enacting coercive,

regulatory interventions and by circulating messages that are not hopeful (Lee et. al.

2008; Link and Phelan, 2008).

The second focuses on structural determinants of marginalization, including

legislation and citizenship conceptions which set the stage for the acceptability of acting

on biases in a variety of downstream contexts (Pescosolido et. al., 2008). In order to

combat stigmas, welfare state policies must be embedded with notions of civility, rights

and concern (ibid.). Given this ambitious agenda, stigmatized groups and their advocates

can be brought together within larger coalitions aimed more generally at improving the

rights of marginalized populations; this latter strategy is also more befitting the models

described above, which highlight the intersectional nature of stigmatization processes

(Stuber et al., 2008).

Courtesy Stigma

In contrast to the relatively large body of literature on primary stigma discussed

above, existing research on courtesy stigma - the negative impact that results from

association with a person who is marked by a stigma - remains largely undeveloped.

In one of the first studies on courtesy stigma, Birenbaum (1970) observed that

social interaction between mothers of children with cognitive deficits and other parents

was inhibited (Corrigan and Miller, 2004). Echoing the coping strategies mentioned

above, Birenbaum noticed two main responses to courtesy stigma among parents with a

disabled child: some parents chose to conceal, manage, and downplay stigma-related information, whereas other parents openly demonstrated their acceptance of the stigma (ibid.). In general, he noted that parents of children with cognitive disabilities limited their involvement with stigmatized communities because isolating oneself within the stigmatized community tended to undermine the appearance of a normal life (ibid). As expected, parents also limited their information-sharing to those they perceived to be sympathetic, and sought out those who would participate in their fiction of normalcy by politely ignoring the stigma (ibid.). Finally, Birenbaum (1970) noticed that parents attempted to emulate conventional parental roles and actively involved their children in socially valid, normalized activities.

Although some of Birenbaum's interpretations have become dated as social responses to disability have shifted, his observations continue to hold explanatory salience, especially as they highlight how courtesy stigma, much like primary stigma, compels adjustments in social engagement and interaction among those who are associated with stigmatized persons. For example, more recent research indicates that parents of children with disabilities have been found to be at greater risk for depression and to attribute negative attitudes to other parents and service providers, even when there are no observable instances of discrimination (Norvilitis et. al, 2002).

Other research suggests that family members of stigmatized individuals curtail their own social interactions in order to avoid instances of enacted discrimination, or the strain and stress associated with having to confront other's misperceptions (Gray, 2002; Green, 2003).

Thus, one of the main points found within the courtesy stigma literature is that it leads, not unlike primary stigma, to social isolation and loss of social support, both of which are in turn linked to poor physical and psychological health outcomes (Corrigan and Miller, 2004;Thomas, 2006). In addition, courtesy stigma may impact the relationship between the stigmatized individuals and their family member. For example, considering the factors that influence parents' decisions regarding in or out of home housing for adult disabled children, Green (2003) discovered perceived courtesy stigma among parents was associated with both reports of care giving burden as well as the decision to transition a child to out-of-home professional care. This latter finding raises the issue of how the care giving relationship between the stigmatized and their associates may be negatively impacted as both experience reduced capacity and opportunity due to the strains associated with stigma.

The negative ramifications of courtesy stigma should not be considered an inevitable fact as close associates and family members of stigmatized persons undoubtedly have varying experiences (Green, 2003). In a study of the partners of persons with Alzheimer's disease, McRae (2000) found that courtesy stigma varied from fairly severe to almost non-existent. McRae's findings echo those noted earlier about primary stigma, which suggest that social status has a mediating effect on both stigma and courtesy stigma. The authors note that the availability of social support networks, and other contextual variables, such as the ability of partners to draw on more positive interpretations of the illness may lessen experiences of courtesy stigma (ibid.).

Corrigan and Miller (2004) similarly report that existing research on courtesy stigma among family members of persons with mental illness indicates that a good

portion of these associates do not report experiences of courtesy stigma. Reviewing the available literature, these authors suggest that courtesy stigma – in particular reports of avoidance by "normals" of family members of stigmatized persons – varied by nature of family relationship (i.e. child, spouse, parent), and the frequency of contact between the stigmatized person and their family member (i.e. whether or not the stigmatized person and family member cohabitated). Phelan et. al. (1998) found that higher educated family members were more likely to report perceived avoidance, which the authors interpreted to possibly be the result of greater perceptiveness of stigma processes, or diminished tolerance within social networks of higher socio-economic status. Corrigan and Miller (2004) report that a second dimension of courtesy stigma, one that is perhaps more prominent than reports of others' discrimination, concerns the notion that one's relationship with a family member with mental illness should be kept hidden as it is a source of shame to the family. The authors note two underlying narratives that give rise to courtesy stigma: blame and contagion. Parents, especially mothers, of persons with mental illness are most likely to experience blame as a common public perception; in the first half of the twentieth century mental health and disability were commonly regarded as the outcome of poor parenting (Corrigan and Miller, 2004). Spouses and siblings, in comparison to parents, are less likely to perceive blame for the onset of a mental illness, but experience blame with regards to their family member's compliance with interventions and the subsequent illness trajectory.

Corrigan and Miller's (2004) study raises a number of important issues about the origins of courtesy stigma that should be kept in mind in the context of the data presented below. First, with regards to family members they note two types of narratives that

uphold courtesy stigma and give rise to associated responsibilities: poor genetics and dysfunctional familial environment. These narratives theoretically do not apply to the professional associates of stigmatized persons, however, contamination, corruption and contagion narratives may. These narratives call into question the moral fabric as well as environmental and physical hygiene of persons who are professional associates of the stigmatized.

Following the stigma literature, it is likely that courtesy stigmas are upheld by a range of interactive narratives that span genetic, contagion, contamination, and corruption narratives resulting in a range of associated responsibilities for those that bear courtesy stigma.

Supporting the above noted assertion about corruption and contamination narratives, another tenuous dimension of courtesy stigma that has been identified in the literature concerns the ascription of characteristics of the stigmatized to their associates – "being known by the company we keep" (Kulik et. al, 2008). Sigelman et. al. (1991) found that students intolerant of homosexuality tended to assume that the voluntary associates of gay students were also likely homosexual, even when there was no direct evidence to support this assumption. Kulik et. al. (2008: 219) similarly found that in a work environment, employees who associated with stigmatized co-workers were regarded negatively due to automatic processing: "the stereotypes used during this automatic processing stage need not be the most appropriate; they need only be readily accessible in the perceiver's memory. Thus, physical proximity may be enough to link two individuals in a perceiver's mind and result in the perceiver's negative evaluations of one person spilling over onto the other." They later note that such initial impressions may

be modified depending on the perceiver's motivation (their values and tolerance), the norms and values of the work environment (the extent to which it encourages or discourages such bias), and the reasoning applied to the relationship. With regard to the latter, the extent to which the relationship is perceived as voluntary or involuntary, susceptible, as noted above, to contagion (which can also include contagion of ideas or behavior), and the degree of similarity of descriptive information between the stigmatized person and their associate can all have an effect on the degree of courtesy stigma ascribed.

The same phenomenon may apply to care workers of vulnerable populations; the supposition that one possesses similar characteristics to those being served, or the idea that one has personal, extensive knowledge of a stigmatized issue may form the basis of more subtle forms of discrimination on the part of "outsiders". While such assumptions of similarity may be unjustified at times, this issue is further complicated by the fact that it is also very likely that some persons working with stigmatized populations have first hand connections to the stigmatized identity as personal experiences and social networks may influence opportunities in career selection.

In one study it was observed that nursing students had negative perceptions of both mental health professionals and their patients (Sadow et. al., 2002). Interestingly, the authors of this study also found that while education helped improve nursing students' attitudes toward mental health professionals, it deepened stigmas associated with mental health clients. This finding echoes other research which suggests that one of the ways that courtesy stigma is managed is by using professionalization narratives to emphasize

differences between the those who receive, and those who provide, service (Baines et. al. 1992).

Finally, several scholars have noted that primary stigma goes hand in hand with the systemic provision of under-funded and inferior health and welfare services (Birenbaum, 1970; Link and Phelan, 2001; Link et. al., 2008). While many countries, including The United States, are struggling with escalating health care costs, there is a great deal of literature to suggest that services to vulnerable populations and the workforces who provide those services experience the most instability with regard to funding, and are the hardest hit by budget reductions (Chou, Tulolo, Raver, Hsu, & Young, 2013). In the United States, services to these populations are often provided in the non-profit sector, and government funding tends to focus on short-term services and meeting basic needs, with little opportunity to address upstream health determinants – racial discrimination, family life, education, early childhood, housing, violence, income security - in a more comprehensive fashion (Ibid).

The relevance of the latter point to the concept of courtesy stigma is that it suggests that one of the significant ways service providers experience courtesy stigma is in the very organization of their work environments, including having to carry out their work with stigmatized populations with inadequate resources and limited intervention modalities to draw on.

Thinking about the work performed by those whose paid and unpaid support to stigmatized populations, Corrigan and Miller (2004) importantly differentiate between direct courtesy stigma and vicarious stigma. This delineation highlights how the negative health effects associated with a relationship with a stigmatized person are only in part due

to being treated badly by others. The other source of strain – vicarious stigma – refers to the distress one experiences as a result of witnessing the negative effects of stigma on relatives, peers and service recipients (Corrigan and Miller, 2004). The burden associated with being privy to the effects of stigma raises the need to think about how to discern between the double edged sword of caregiving burden and courtesy stigma (Corrigan and Miller, 2004).

Wight et. al. (2007) similarly note that traumatic stress symptoms – operationalized as avoidant and intrusive thoughts - are common to persons diagnosed with HIV and their caregivers, further indicating that stress related to primary stigma is also experienced via association, even in the absence of courtesy stigma. The authors further note that this form of stress is experienced whether or not a caregiver has experienced personal trauma (in this case some caregivers also were diagnosed with HIV, whereas others were not).

These findings highlight how primary and courtesy stigmas intermingle in the strains experienced by those who are in close relationship to stigmatized persons.

As the available research on courtesy stigma is relatively small, there are several gaps in this literature, in addition to the lack of information regarding the presence of courtesy stigma among frontline health and social service professionals. One notable gap stems from the tendency to regard those who experience courtesy stigma as a uniform and distinct group – who would not otherwise experience stigma - except for their association with a stigmatized individual or group. It is more likely the persons working with stigmatized populations have varying levels of similarity to those they work with along a number of key demographic and socio-contextual variables such as gender,

race/ethnicity, sexual orientation, and family background. These relative similarities may have important implications for how the professional associates of stigmatized groups experience their work.

Also relatively absent, is any discussion of the prospect of co-occurring primary and courtesy stigmas. For example, consider persons who work professionally with a stigmatized group and who also have a child or partner who bears the same stigma (e.g. a same-sex partner of an HIV positive individual who may also be an HIV counselor).

Alternatively, consider persons who bear a stigma (or multiple stigmas), but also work professionally with others bearing the same stigma(s) (an HIV positive nurse who works with AIDS patients). In addition to potentially providing insights into why some workers are harder hit by workplace health risks (such as courtesy stigma) than others, locating care workers and those they serve according to broader socio-economic categories reveals important information about how vulnerability is systemically organized among those who experience primary stigma and those who form their support networks.

HIV-Related Courtesy Stigma

HIV-related courtesy sigma represents a sub-category of the courtesy stigma literature and occupies an even smaller part of the extant research in this area of inquiry. Kowalewski (1988) was one of the first AIDS scholars to identify that family members, partners of people living with HIV/AIDS, carers and health and social care professionals, as well as AIDS activists experience HIV-related courtesy stigma. He posited that stigma associated with HIV is contagious and groups such as gay men are guilty by association

and report courtesy stigma and suffer enormously as a result of loss of friends and harassment.

While the phenomenon of courtesy stigma is well established in the literature it was first identified by researchers who were conducting both qualitative and quantitative research in the area of primary stigma. For example, Cao, et. al., (2006) who were conducting a qualitative research study in China, found that not only did those with HIV disease experience discrimination which manifested as physical and social isolation, verbal stigma (i.e. gossip, insults), loss of role, and loss of resources, but other individuals associated with HIV infected individuals experienced similar types of discrimination. Family members and children were most likely to experience courtesy stigma, but even members of the same community were sometimes ostracized and excluded when interacting with friends and family members who lived in other villages or cities. Another study conducted by Bogart, et. al. (2007) examined HIV-related stigma from the perspective of multiple family members. Felt stigma, enacted stigma, and courtesy stigma were identified as three dimensions of stigma experienced by family members. It is important to remember that a precondition for courtesy stigma to exist is that the HIV status of the related family member must be known by one or more individuals outside the family unit. Many family members concerned about discrimination repercussions are hesitant to disclose the HIV serostatus of their family member and therefore, don't report courtesy stigma in as great a degree as they do felt stigma. Even so, many family members, especially children of HIV-infected parents, reported experiencing courtesy stigma in the form of social isolation, loss of friends, and being rejected.

Most research on HIV-related stigma has focused on specific family members and/or caregivers of HIV positive individuals and has been overwhelmingly conducted in the quantitative tradition. Examples include studies conducted that have focused on mothers (Antle, et. al., 2001; Brackis-Cott, et. al., 2003; Hackl, et. al., 1997; Ingram & Hutchinson, 1999, 2000; Sandelowski & Barroso, 2003a; Scrimshaw & Siegel, 2002; Vallerand, et. al., 2005). Some studies have collected data from children with HIV-infected parents (Antle et. al., 2001; Armistead et. al., 1999; Brackis-Cott et al., 2003; Reyland et. al., 2002; Vallerand et. al., 2005; Wiener et. al., 1998) or caregivers, including mothers, grandmothers, partners, other family members, and friends (DeMatteo et. al., 2002; Poindexter & Linsk, 1999; Powell-Cope & Brown, 1992). However, prior research has yet to explore HIV-related stigma issues from the perspective of same-sex-male partners of individuals living with HIV/AIDS.

In summary, prior qualitative research has described HIV-related courtesy stigma in various individuals including, siblings, caregivers, mothers, fathers, children, friends, and grandparents of PLWHA, though few of these studies were conducted by scholars and researchers from the discipline of nursing. However, no research studies to date have focused on the stigmatization of same-sex partners of PLWHA. This represents a gap in the literature and a qualitative analysis of the perceptions and needs of this population may assist researchers and clinicians in understanding the range of ways in which different types of stigma affect same-sex partners of a PLWHA, and for continuing the discourse related to social health determinants. Research of this type, done from the perspective of a nurse, could potentially add to the body of knowledge of nursing science and assist nurses to better address the needs of this vulnerable population.

Chapter 3: Scaffolding and Framing the Study Design

Gay men in America are disproportionately affected by HIV/AIDS than other at risk populations, and AIDS continues to be one of the leading health issues facing this group (Herek, Capitanio, & Widaman, 2002).

Recent data suggests that more gay men are choosing to cohabit in partnered relationships and marriages, but that there is also a rise in HIV infection rates among these partnered gay males (Stephenson et al., 2011).

There is a vast literature on HIV disease/AIDS. Much of this literature has focused on gay partnered couples as the data source. With the exception of a small body of literature that has looked at the experience of partners in the caregiver role, there is a dearth of research that has looked at the experience of being in a gay partnership/marriage with a HIV-positive partner.

The aim of this study was to explore and describe the experience of gay men living in a long-term committed relationship with a male partner who has HIV disease/AIDS. This Chapter describes the qualitative methodology utilized in this study, including the interpretive descriptive approach, a description of the sample and sampling process and information relevant to data collection and analysis, and procedures to safeguard the protection of research participants including informed consent.

The Qualitative Tradition

Qualitative research is most useful when little or nothing is known about a topic or phenomenon, and is effective when the researcher wishes to explicate meaning that groups or individuals affix to a social or "human" problem (Creswell, 2009). Paradigms

or worldviews are the beginning point for every qualitative researcher, and it is his or her worldview that in some measure determines the type of research conducted as well as guides the design of the specific study.

Nursing, as a discipline is unique when it comes to conducting research. This is partially true due to the fact that it takes its professional and scholarly history from a diverse number of disciplines including: sociology, medicine, anthropology, psychology, and education (Meleis, 2007). In fact most nurse scholars in the 1960s and 1970s were educated within the scope of those disciplines and brought those paradigms and research traditions and methods into the nursing domain. Nursing has been defined as a "human science" and as such, at times does not fit into any of the traditional disciplines (Thorne, 2008). Because of this history, some researchers in the discipline of nursing have had difficulty in adopting or accepting one paradigm for guiding the research process. This is especially true when the research question is of a clinical or health nature. Fortunately in the last decade nursing scholars are beginning to value the variety of methods available for research in a "human science", and are designing research approaches based on the research question rather than some arbitrary overarching paradigm for the discipline. Indeed, many nurse scientists are of the belief that nursing as a discipline is too complex to reflect the diversity within the nursing profession. Furthermore, to adopt a single paradigm would be what Fawcett (1989) describes as wearing blinders which might prohibit seeing things that are outside the field of vision.

There are many definitions of what a paradigm is. Lincoln & Guba (1985, pg. 15) define a paradigm, or an interpretive framework as, "…a systematic set of beliefs, together with their accompanying methods." Guba (1990, pg. 17) further refines this

definition by adding that a paradigm is, "...the net that contains the researcher's epistemological, ontological, and methodological premises". Taken together, these definitions suggest that a paradigm involves a basic set of beliefs that guide action. Within the discipline of nursing, Newman (1992) defines a paradigm as being pervasive in nature and that a paradigm's values are deeply imbedded in its followers. Kim (1997, pg. 168), states that a paradigm consists of "general scientific perspectives and traditions". I prefer Kim's definition because it infers methodologies that scientists apply to solve problems regardless of their philosophy and perspective or lens through which phenomena can be viewed.

The Interpretive Paradigm

Despite the fact that there were a number of paradigms in which I could have situated this study, the one most suited to meeting the goals of the study was the paradigm of interpretivism. The goal of the interpretive paradigm is to understand, describe, and derive meaning from the human experience. The interpretive paradigm is especially useful in the discipline of nursing because it recognizes a transactional epistemology (Lincoln & Guba, 1985). This is important to nurse scientists because it recognizes the esthetic, ethical, and personal knowledge inherent in nursing. Interpretive traditions acknowledge that reality has multiple meanings and that knowledge can be derived from sources other than the senses. The interpretive paradigm is also seen as more congruent with the language and beliefs of nursing including: holism, individualism, autonomy, and self determination. Finally, the interpretive paradigm helps to establish a theoretical base for the discipline which are representative of nursing views rather than borrowed from other professions, which ultimately offers new perspectives

and methodologies for answering the questions of the discipline (Newman, 1992). The interpretive paradigm is characterized by the ontological assumptions that reality is complex, holistic, and context dependent (Monti & Tingen, 1999). The focus of investigation is on human experience, focusing on subjectivity rather than objectivity. Because reality and human experience are variable, multiple ways of knowing are valued to uncover the knowledge that is an integral part of the human experience. Intuitive knowledge is recognized as being equally valuable to knowledge which is expressed in language or can be observed (Carper, 1978). Other important assumptions of the interpretive paradigm include: (a) reality is multidimensional and contextual; (b) meaning is constructed through social interactions; (c) interpretation is required to understand the world of meaning; and (d) meaning is influenced by historical and social perspectives (Creswell, 2009). For these reasons, and because I shared similar values, beliefs, and philosophical assumptions, it was both reasonable and logical that the interpretive paradigm was used to ground and guide the methods and design of this study.

Research Design

Strategies of inquiry within the qualitative tradition include designs or models that direct and guide specific approaches and procedures in a proposed research design. In the qualitative tradition, those approaches have typically included narrative research, Phenomenology, Ethnographies, Grounded Theory studies, and case studies (Creswell, 2009). Most of these approaches have developed over time, and were originally employed within the social and behavioral sciences, as well as the discipline of Anthropology. Early nurse researchers, who were educated in the social and behavioral

sciences, used these same strategies when doing research within the nursing discipline (Thorne, 2009).

As the discipline of nursing developed into a more mature science, nurse researchers started to question the benefit of methodologies that were developed within the context of other disciplines. In what Sandelowski (2000) defines as "the tyranny of method" in nursing research, she describes how many nurse scientists privilege certain methods over others, especially when some nurse scientists are using methods considered the "crudest form of inquiry", such as qualitative description over the more traditional methods of those mentioned above.

In 1997, nurse researchers, Thorne, Kirkham, and MacDonald-Eams proposed a new methodology designed to better meet the needs of scholars in the applied sciences who were struggling with ways to study and describe health and clinical problems. As with other nurse scientists they were unable to reconcile the methodological orthodoxy from other disciplinary traditions with clinical research problems and questions. Interpretive description evolved as a method to articulate a "qualitative approach to clinical description with an interpretive or explanatory flavor" (Thorne, et al. 2004). The authors state that interpretive description "is the smaller scale qualitative investigation of a clinical phenomenon of interest to the discipline for the purpose of capturing themes and patterns within subjective perceptions and generating an interpretive description capable of informing clinical understanding" (Thorne, et al. 2004). Furthermore, interpretive description differs from other types of qualitative description in that it demands that the findings of the research go beyond description alone since application implications necessarily need to explore the domains of explanation and meaning

(Thorne, et al. 2004). Thus, interpretive description is firmly grounded in the discipline of nursing.

Similar to other forms of qualitative methodology, interpretive description borrows strongly from aspects of grounded theory, ethnography, and naturalistic inquiry. It is therefore of little surprise that the philosophical underpinnings include: (a) a complex and multiple construction of reality that is situated in context, is socially constructed, and always subjective; (b) reflexivity of the researcher and reciprocity between the researcher and subject(s) always have an effect on the other: reality, meaning, and knowledge are co-created constructions between the knower and known; (c) theory is grounded in the data that emerges during the research process (Thorne, et al. 2004); (d) knowledge is derived from experience, art, and ethics; cognition, perception and experience affect what is seen or conceptualized; (e) human beings are holistic living organisms who are greater than the sum of their parts; and (f) inductive reasoning is used to identify patterns of meaning in the data.

Nurse scientists must address the complex health and clinical problems they face in everyday practice. Since nursing is a discipline that focuses on the human health experience with caring as a moral imperative (Newman, et al.,1991), the research purpose, questions, and aims inherent in this study provided a viable fit for using interpretive description as a research design approach. The subjects of this study interfaced with nurses and the health care system in numerous settings and ways as the primary support and dedicated gay partner of the individual living with HIV disease. Because of these interactions between subject and nurse, one readily sees health and clinical implications in the ways nurses can better support the partner of an HIV infected

individual. It is vital, especially for the population utilized in this study that nurses remember that when treating the patient they are also treating those with whom the patient interacts, and that due attention should be given to the primary partner when providing care for a gay patient living with HIV-disease/AIDS.

Methods of Collection and Analysis

Thorne (2009, pg. 35) states that, "Interpretive description does not prescribe an exact way to go about a study, but rather represents itself as a design logic model whereby the kinds of qualitative studies that are typically generated on behalf of the applied disciplines can be designed and enacted with meaningful results." However, design strategies in interpretive description closely follow many aspects of grounded theory, naturalistic inquiry, and ethnography including strategies such as concurrent data collection and analysis, inductive knowledge generation, and constant comparative analysis. The use of these techniques was employed in this study to produce a logical and coherent conceptual description that identified patterns, themes, variations, and commonalities that were most likely characteristic of the phenomenon being studied, and will be described in detail in the following sections on data collection, data analysis, rigor and credibility, sampling and recruitment, and ethical considerations.

Data Collection

Deciding on which data source(s) to use for this qualitative study was integral to the quality of this study. Thorne (2009) posits that gathering data from a variety of sources is preferable because it prevents what she describes as "refractive error" which she believes is likely to happen if only one data source is utilized. However, given the constraints of time and access the only method of data gathering utilized for this study

included one-on-one face-to-face audio taped unstructured interviews with the study participants. Study participants were interviewed in the absence of their partners to avoid biased or coerced responses. Because interpretive description is firmly located in the philosophical belief that the informant is the best possible source to report on his or her experiences regarding the phenomenon being studied (Denzin & Lincoln, 2005), it was logical that this technique was used in order to uncover meanings that the informants bring to their life experiences.

An unstructured interview approach was utilized for this study. According to Holloway and Wheeler (2006), the unstructured interview is useful because of its flexibility, allowing the study participant to talk about the issues of importance and interest to them rather than having the researcher guide the direction of the interview by employing questions that may be leading or coercive. The authors also add that the richest data may be obtained using the unstructured interview approach, but that this approach also leads to the largest amount of non-related data. In this study, the unstructured interview approach was useful as it allowed me, the researcher to avoid the use of a rigid interview guide that could have placed my agenda above that of the participant. Part of the unstructured interview technique that helped make it so successful, was the use of a broad open-ended question designed to allow the participant to answer the question without feeling constrained to follow a specific agenda. The opening question utilized for this study was: "Tell me what it is like to be the partner of someone who is living with HIV disease/AIDS?", and was indeed successful in allowing the study participant to talk about the topic(s) of his choosing.

Holloway & Wheeler (2006, pg. 81) further state that, "Even unstructured interviews are usually accompanied by an *aide memoire*, an agenda, or a list of topics that may be covered. There are, however, no predetermined questions except at the very beginning of the interview". Although questions of a specific nature were avoided to minimize leading the study participant in a particular direction, I did employ the use of an "*aide memoire*" which allowed me to explore issues of interest, especially those issues that current literature suggested could be found in related populations (Ibid), and issues that were brought up by participants in previous interviews. Thorne (2008, pg 116) corroborates using the literature in this way and further states that, "Because you are concurrently collecting and analyzing data, it is entirely appropriate to draw generally on the larger data set as a point of reference when constructing follow-up questions." Finally, Holloway and Wheeler (Ibid, pg. 82) differentiate the *aide* memoire from an interview guide used in semi-structured interviews by stating, "The questions in a semi-structured interview are contained in an interview guide with a focus on the issues or topic areas to be covered and the lines of inquiry to be followed. The interview guide, however, ensures that the researcher collects similar types of data from all informants." The *aid memoire* for this study was not used as an interview guide; rather it was used in instances where the participant either struggled with moving to a new topic or had completely exhausted the topic that the participant chose. In addition, each *aid memoire* topic was broached using only broad open-ended questions so as not to lead the participant. The *aide memoire* for this study included the following topics: (a) feelings or perceptions of being partners with someone with a chronic disease; (b) perceptions of social interactions with family, friends, co-workers, etc.; (c) types of social support

received; (d) coping strategies employed; (e) interactions with the health care system and care providers; and (f) challenges and rewards of being in a relationship with an HIV-positive partner. While the use of the unstructured interview approach limited the number and types of interview questions, in no way did it constrain me as a researcher in my ability to use follow up questions or probes, in order to allow the informant to elaborate on what they had said or to explore new lines of inquiry.

Interviews were conducted face-to-face and scheduled at a time that was convenient for the participant, and were held primarily in their homes, although a few were conducted in a neutral, quiet, and secure location outside of their homes. In this way privacy and anonymity were valued and protected. Telephone interviews were not utilized for this study. The interview included only the partner of the HIV positive individual, to avoid interfering with interview dynamics that might present or become problematic to the research process were the partner present. Also, it was believed that responses to questions during the interview may not have been as candid were another person present. The exclusion of the partner during the interviews was not found to be a barrier to the active participation of any of the interviewees. Interviews lasted on average about 60 minutes, with the shortest interview lasting 38 minutes and the longest one lasting 70 minutes. It is important to note that the length of the interview neither constrained the participants from full participation, nor affected the quality of the interview data. For example, even though the shortest interview only lasted 38 minutes, that particular participant spoke extraordinarily fast during the interview process and had very few pauses or breaks between topics or thoughts. Indeed, when the interviews were transcribed, both I and my dissertation chair agreed that "thick description" prevailed in

all of the interviews conducted. When initially contacted, and before the consent form was signed, potential interviewees were told that the interview might last between 1 and 2 hours in order to give them adequate time to answer the interview questions without feeling rushed or compelled to complete the interview within a proscribed amount of time.

The audio taped interviews were transcribed verbatim within two days of the completion of the interview. In addition to the interview recordings and subsequent transcripts, field notes and a journal were written or audio recorded (and later transcribed) within 24 hours after the time of the interview. These documents included: methodological notes, personal notes, reflexive notes, observational notes, and process notes, which helped to explicate "speculation, feelings, problems, ideas, hunches, impressions, and prejudices" (Bogdan & Biklen, 1992, pg. 117).

Data Analysis

Data analysis in the qualitative tradition usually involves suspension of preconceived theoretical notions by the researcher (Thorne, Reimer Kirkham, & O'Flynn-Magee, 2004). However, interpretive description presumes that the researcher brings some level of theoretical and/or clinical knowledge to the table (Thorne, 2008). Because of this it was important for me as the researcher of this study to be aware that the theoretical framework and/or personal experience or beliefs might influence the data analysis process. To avoid this, I constantly considered if my own personal and clinical experiences were being used to inform the study and relied on frequent feedback from my dissertation chairperson during the data analysis process (Kearney, 2001).

As with data collection, interpretive description is not informed by one privileged

way of analyzing data, rather there are a multitude of "recipes" to draw on from the qualitative methodological literature (Thorne, 2000). Morse (1994, pg. 23) describes the analytic process as being comprised of "comprehending data, synthesizing meanings, theorizing relationships, and recontextualizing data into findings." In interpretive description the researcher must be constantly reminded that it is the researcher and not the process that drives the analytic process (Thorne, Reimer Kirkham, & MacDonald-Emes, 1997).

It is important to reiterate that within interpretive description, as in all interpretive models, the process of data collection and analysis happened in tandem to produce iterative interpretations of the data as well as guided and shaped the direction of future inquiries (Thorne, 2008). Thorne et. al. (1997, pg. 172) posits that what is even more important than the coding process is that the researcher constantly explores questions such as: "Why is this here? Why not something else? And what does it mean?" In following this process, these authors and nurse researchers believe that interpretive conclusions will be more legitimate. "Qualitative data analysis is best understood in the doing; it is inherently experiential rather than technical."

In order to provide structure to this study the following steps for coding and data analysis were used: (a) as data was collected and transcribed (I transcribed all of his own interviews) it was read through in its entirety to obtain a general sense of the data and to reflect on its overall meaning; (b) through the process of transcribing the interviews, the data was coded and field notes and journal entries written after each interview to assist in organizing and preparing the data for analysis; (c) the data was coded using chunks, paragraphs, or segments that helped bring meaning to the data; (d) from the coded data I

began the process of identifying themes, commonalities, and patterns; (e) the themes, patterns, and commonalities were then developed into a "professional narrative" or story that conveyed the most important ideas and findings of the analysis; and (f) an interpretation of the "meaning" of the data was presented in Chapter 5 in a way that best described the phenomenon and implications for clinical practice (Creswell, 2009).

Rigor, Validity, and Credibility

According to Emden and Sandelowski (1999, pg. 3), "credibility occurs when complexities are made visible through the analytic process and are articulated with an openness or 'criterion of uncertainty' that acknowledges a certain tentativeness about the final research outcomes." In this qualitative research study both rigor and credibility were established in several ways. First, it was important to obtain a broad sample within the population of interest to obtain a rich collection of data where thick description prevailed. Unlike quantitative research where the sample size is established *a priori*, in qualitative research the sampling continues until the amount of data collected is sufficient to reach saturation (Denzin & Lincoln, 2005). Data saturation was achieved in this study after interviewing the 10th participant and was corroborated by the dissertation chairperson of this study.

The technique of constant comparison or coding data for a category and comparing it with other data to look at similarities and differences was another method used as a check on validity (Glaser & Strauss, 1967). These authors advocate the technique of concurrent coding and analysis. Utilizing this technique was one more way in which this study was checked for methodological validity.

Denzin and Lincoln (2005) raise the issue of the difficulty of assessing validity of

interpretation. Since the researcher approaches the research with various assumptions and a view of the way in which the world works, it is conceivable that the interpretation of a study will differ with the research. Unfortunately, there is no simple answer to this problem. While the authors offer some criteria with which to evaluate interpretation in a study depending on the type of approach that has been taken, interpretation merits care even if solely from an ethical standpoint (Denzin & Lincoln, 2005).

When using quantitative methods of research, reliability refers to consistency with repeated measurements (Powers & Knapp, 1995). However, it is difficult to assess reliability in qualitative research due to the contextual nature of this approach (Gillis & Jackson, 2002). In fact, some sources use more general terms as "methodological rigor" or "credibility" to describe issues related to ensuring a high standard of qualitative research (Glaser & Strauss, 1967).

Finally, creating a clear, concise audit trail was an additional way of ensuring a rigorous study. Rodgers and Cowles (1993) provided a useful guide that assisted me as a novice researcher in making every step of the process explicit. The guidelines covered by the authors was vitally important in helping me keep every step in the study explicit, with an audit trail that included interviews and field notes; the concurrent methodological and analytical documentation (constant comparison) including decisions that I made , strategies used in the approach to the data, any changes in interview questions that were made as data were obtained; notes relevant to analysis of the data as categories became apparent; and a diary of the personal thoughts and feelings of mine during the process of analysis. It was essential to be able to visualize and retrace every step in the construction of the findings. In a qualitative approach the responsibility for minimizing the potential

for bias and ensuring rigor in research falls on the investigator. Unlike quantitative research where particular areas are prone to problems with validity, reliability and bias, qualitative research demands constant vigilance for problems from beginning to end.

Sample

A purposeful convenience sample of 10 gay male participants whose life partners have HIV/AIDS were recruited and interviewed for this study. A purposive sample was utilized because this approach generated valuable information about partners of HIV-positive men and provided some understanding of the issues they face through their association with a person living with HIV disease. Inclusion criteria included: (a) living as a primary partner in a committed relationship with an individual with HIV or AIDS; (b) participants were at least 18 years of age or older; (c) that they identify as gay, and that they had been with their HIV-positive partner for at least 6 months. One study by Gomez et al. (2012) found that gay couples that had been together for at least 6 months to a year had a more realistic view of what it means to be in a committed relationship and articulated a higher level of commitment to the relationship.

Recruitment

Initial recruitment was accomplished by using personal, social, and professional networks. Individuals from these networks generally had personal, professional, or volunteer experience that provided access to this study population. Potential participants were given a research flier that included my contact information and about half of the study participants called or emailed me to express their desire to participate in the study. The other half indicated interest in learning about the study by providing their personal contact information to the person who approached them about the research study. I

subsequently contacted them by phone or email. On initial contact the purpose of the study was discussed and if the participant was willing to participate a date and location were agreed upon to begin the data gathering process. Electronic recruitment efforts included posting the research flier (see addendum B) on social media pages of HIV/AIDS organizations and community-based organizations that catered to gay and lesbian individuals. Permission to post fliers on these social media sites was obtained by contacting the appropriate resource for each organization. It is interesting to note that no participants were found by using electronic recruitment. All of the participants were from large urban cities in a state in the western United States of America (USA). All participants were recruited and interviewed from November, 2012 through April, 2013.

Ethical Issues and Protection of Human Subjects

Human Subjects

Internal Review Board (IRB) approval for this study was obtained through the University of San Diego before data collection began. All participants in this study were adults 18 years of age or older and signed consent was obtained and informed consent including the purpose of the study and any benefits or risks was explained. Risks to the participants included: time spent in scheduling and participating in the interview, and negative emotions that may occur while participating in the study, especially when talking about emotional issues. Potential benefits included: an increased understanding of the challenges and issues faced by gay men whose life partners are living with HIV/AIDS. Participants were given adequate time to review the consent form and to ask questions regarding the nature of the research, the research process, or the researcher

himself. All participants were provided a copy of the signed consent form that included the contact information of the researcher's dissertation chairperson.

Ethical Issues

Ethical issues emphasized protecting the anonymity and dignity of all participants. This was done by conducting the interviews in a safe and secure location, by avoiding the use of any identifiers that might allow someone to identify the participant, by keeping field notes, transcripts, audio tapes, and any other parts of the research process secure. Data will be stored in a locked and secure place for at least three years according to University of San Diego IRB policy and recommendations from the Department of Health and Human Services, and will be destroyed after that time. Informed consent with a signed consent form was obtained before beginning each interview.

Chapter 4: Presentation of Study Findings

June 5, 2011 marked the 30th anniversary of the acquired immunodeficiency syndrome (AIDS) epidemic. Even after years of intensive, highly-focused, preventative education and awareness at the grassroots and governmental levels, human immunodeficiency virus (HIV) disease and AIDS continue to affect gay men more than all other risk groups combined (CDC, 2011). Although there is a vast body of research regarding gay men and HIV risk, one group that has received minimal attention in this literature is gay partners of HIV infected men, particularly those who fall outside of the caregiving role. For this reason, the aim of this study was to explore and describe the experiences of gay men living with a male life partner who has HIV disease/AIDS independent of the full-time caregiving role.

Demographics of Participants

Demographic data was gathered and compiled on 10 participants who have been in a committed relationship with their HIV-positive partner for at least one year. All participants were male and identified their sexual orientation as "gay". None of the participants identified as "transgender". Demographic data included:

- Age, which ranged from 26 to 53 years old with a mean age of 45.7 years.
- Education level: two had completed high school, five had completed 4 years of university and held bachelor degrees, and three were prepared at the master's degree level.
- Household income ranged from 32 thousand to 2 million dollars per year.

- Time in the relationship ranged from 1 year to 27 years, with the mean being 9.65 years. A table, (see appendix A) is included as a summary for the demographic data described above. Actual names of all participants and their partners were changed to a pseudonym to protect their anonymity.

Major Themes

Three major themes on the experiences of living with a male partner with HIV/AIDS from the perspective of the research participants were identified during coding and analysis of the data from the interview transcripts. The first theme dealt with the issue of disclosure of HIV serostatus, and encompassed two distinct sub-themes: (a) how and when the participant learned about his partner's HIV serostatus, or in other words, how his partner's HIV-positive serostatus was disclosed to the participant; and (b) the participant's decision with whom, and with whom not to share his partner's HIV-positive serostatus. The second theme identified the influences on the quality of the relationship, as well as the influences on the participant himself, in response to living with a partner with HIV/AIDS. Sub-themes within this theme included: (a) the participants' fear of contracting HIV from their HIV-positive partner, which influenced decisions about sex, sexual behaviors, and intimacy; (b) the impact that living with a life partner with HIV disease/AIDS had on day-to-day life including, routines, emotional health of the participant, and coping abilities; and (c) the participant's perceptions of the future of the relationship and his evolving role within the relationship. The final theme explored the perceptions of the participants when interacting with the healthcare system and healthcare providers and included the following sub-themes: (a) perceptions of the

healthcare system; (b) perceptions of care by physicians; and (c) perceptions of care by nurses.

Disclosure

Disclosure of one's HIV serostatus, especially in serodiscordant couples, has been a highly emotional topic since HIV testing was initiated and made available to the public, and in the eyes of many, is viewed as both an ethical issue as well as a public health concern. Disclosure of HIV serostatus in this study population focused on two distinct issues: (a) how and when the participant learned about his partner's HIV-positive serostatus (partner-to-partner disclosure); and (b) the decision-making process to whom the participant disclosed his partner's HIV-positive serostatus.

Partner-to partner HIV serostatus disclosure. The issue of HIV serostatus disclosure within the context of the relationship emerged as an important finding in this study, as all but one participant, (Jim) shared their experience of how their partners' HIV-positive serostatus was disclosed to them. Six of the 10 participants stated that their partner was upfront about their HIV serostatus from the beginning of the relationship, and disclosed his HIV status either before having sex for the first time, or shortly after the first sexual encounter. How and when the participants' partners shared their HIV status with them had practical meaning for most of the participants, and symbolic meaning for some of the participants.

For the participants Bryce and Glenn, both stated that they learned of their partner's HIV status before their first sexual encounter. Bryce met his partner at a gym, and after exchanging phone numbers and making plans for their first date, his (future) partner said, "before we go out you need to know..." and disclosed to Bryce that he was

HIV positive. For Bryce the practical meaning of this early disclosure was that his (future) partner wanted Bryce to be comfortable, understand and prepare for the ramifications of being with an HIV-positive individual, and be fully informed about safe-sex practices. Because of Bryce's partner's early HIV-positive status disclosure, Bryce's perception was that his partner acted in a caring and responsible way as evidenced by this statement: "...he was very open about it [his HIV-positive serostatus] and wanted my input, and wanted me to be comfortable, and was very knowledgeable about transmission issues and wanted me to be safe. ...which I thought was really thoughtful and responsible".

Glenn's experience was somewhat different, in that his future partner came to him as a friend who needed to talk to someone for emotional support due to the fact that he had recently been diagnosed with HIV infection. The friendship later evolved into a romantic, and then a committed, relationship. As with Bryce, Glenn perceived having the knowledge of his future partner's HIV serostatus as a benefit that reflected positively on his perception of his partner when he stated at the end of the interview, "...we have had a wonderful life together". Both Bryce and Glenn entered into their respective relationships with full knowledge of their partner's HIV serostatus which had a direct influence on their early perceptions of their partners.

For the participants whose partners did not disclose their HIV serostatus immediately, there were two issues that emerged that helped maintain the integrity of the relationship and the participant's positive perception of their partner. The first issue was one that was not directly related to partner disclosure, but involved an *a priori* decision by the participants to practice safe-sex behaviors. This decision was universal and not

only included practicing safe-sex behaviors with their future partners, but indeed extended to all potential sex partners. The second issue was that even though HIV serostatus disclosure did not occur before the first sexual encounter, disclosure did in fact occur very soon after (usually within 24 hours) the first sexual encounter.

Robert, John, Bruce, Scott, Derrick, and Tom all stated that not knowing their partner's status before the first sexual encounter was not problematic as they all approached potential sexual partners with the same assumption, that "everyone is HIV positive". Robert met his partner early on in the HIV epidemic before testing was widely available, so Robert stated that for his own protection he adhered to the paradigm that he would always practice safe sex, and did so with his future partner before, during, and after the time that the HIV test was widely available and his partner's HIV status was finally known. Robert recounts his early sexual encounters with his partner:

> Before he [Robert's partner] was tested we just assumed that he was positive, and this was at the point where they had figured out this safe-sex thing, and so I just went about the business of our relationship thinking that we needed to be careful sexually and that he would probably die soon. It [disclosing his HIV status] didn't really affect how I felt about him as a person. He has been and is a wonderful partner, and I have the belief that in some way or some form we will always be together, and will always be part of each other's lives in some way.

Scott and Derrick both found out about their partner's HIV serostatus within 24 hours of their first sexual encounter. Both stated that they practiced safe sex and did not express concern over not knowing their partner's HIV serostatus before having sex for the first time. Derrick's comments summarize the feelings expressed by both Derrick and

Scott when he said: "I wasn't too concerned about getting HIV from him since I always had safe-sex with all my partners, but it meant a lot to me that he told me about his being HIV positive so soon after we met. It made me feel like he cared enough about my health and well being and about having a potential relationship with me, that he told me about this early on". Tom did not learn of his partner's HIV status for about a month after they started having sex. Tom, who was also the youngest participant, stated that he was always strict about practicing safe-sex behaviors even before meeting his partner, so finding out 3 to 4 weeks later did not seem to bother him, and stated that the reason that his partner took so long to disclose his HIV status was, "he was very nervous when he finally did tell me…and when he did tell me he said that he waited not only because he did not want to jeopardize our relationship, but also because he felt like we had been safe, and he had not exposed me to anything. I was touched by the fact that he didn't want to lose me and that was the reason he took so long to tell me [about his HIV-positive status]".

The outlier for partner disclosure was Ryan, who not only discovered his partner's HIV serostatus two and a half years into their 5-year relationship, but did not find out directly from his partner. Ryan recounts his experience:

It's interesting I think, because…we just happened to be in the hospital for some other infection, and the doctor came in and said, 'so, people who are HIV positive tend to have more of this', and that was the first I had heard of it [his partner's HIV serostatus. And when I tell that to people their reaction is more like, 'I would have been mad'…so I guess it probably affects me perhaps less than other people because it didn't feel like it changed a lot for me in terms of the viability of the relationship being long-term.

Even though Ryan made this initial statement about the viability of his relationship, he later makes a number of statements that point to the fact that the late disclosure and the fact that it did not come from his partner, had some damaging effects on the relationship as well as Ryan's perception of his partner.

So it's possible at some level...that my lack of empathy when he is ill, is just based on how much of this is going to be my future. So I think at some level it's probably been detrimental to the relationship...and that probably comes back a little bit around to not disclosing his HIV status to me earlier, like, wow, not very caretaking of you in terms of our early experiences. And again, I'm pretty careful, or pretty good about thinking it's my responsibility if I don't know somebody's status, that that's my risk that I'm taking and not the other person's responsibility. But I think to some extent two and a half years is a long time to withhold information.

Disclosure of partner's HIV serostatus. Disclosure of their partners' HIV-positive serostatus to others outside of the relationship was also a concern expressed by most of the study participants, and involved a conscious decision-making process or use of a hierarchy of priorities (prioritization process) when making the decision of whether or not to share this personal information outside of the relationship. This process was slightly different for each participant, but generally encompassed 3 distinct levels of prioritization: (a) the partner's desire or preference to whom the information should be disclosed; (b) the participants' desire for privacy, or belief that this information was only his concern or that of his partner's; and (c) the participants' and their respective partners' fear of actual or perceived consequences.

Partner preference. All of the participants were sensitive to their partner's preferences and desires when considering with whom to share their partner's HIV-positive serostatus. In fact, when broaching the topic of outside HIV serostatus disclosure, the first consideration made by most of the participants was deference to how their partners wanted to address this issue which highlighted an ethical and moral grounding by the participants. It was as if the participants recognized that this was not their story to tell. Ryan was the only participant whose partner directly instructed him not to share his HIV status with anyone outside the relationship: "Well, that is definitely an issue because he has asked me not to disclose that [his HIV-positive serostatus]". Both Derrick and Glenn had partners who expressed discomfort with having someone else, even though it was their partner, sharing this information without their knowledge or consent. Glenn's partner came from an ultra-religious upbringing and associated his HIV status with a perceived "moral lapse in judgment and life-style choices", making it difficult for him to be open about sharing his serostatus due to feelings of shame and self-directed blame. Glenn states:

> ...both Lance and I came from very religious families, and I think the fact that he
> has a disease that was sexually transmitted, has brought a lot of shame and
> embarrassment to him personally. There are times when he even has a
> difficult time talking to me about his disease, and will say things like, 'well, I got
> myself into this mess, I knew how the virus was transmitted and I couldn't
> control my sexual urges, and...I still struggle with the morality of same-sex
> attraction', so I feel like he is very much a victim of his upbringing.

Similarly, Derrick's partner expressed the same notion of "shame" associated with the disease, although he did not have the same religious roots as Lance.

So important was their partners' wishes regarding outside disclosure of their HIV serostatus, that just about every participant made it clear that it was their number one consideration when making their decisions about HIV disclosure outside of the relationship. For example, Tom was sensitive to his partner's wishes concerning outside disclosure of his partner's HIV-positive serostatus, but stated, "...but he [Tom's partner] feels like he wants to be honest and upfront about everything in his life...so I follow his lead for the most part". Not only did the majority of participants express similar beliefs, but it was also the first thing that every participant talked about when asked about outside disclosure.

Privacy. Bryce's statement, echoed by Jim, about his decision-making process is illuminated in the following statement: Bryce: "I think I only share it [my partner's HIV-positive status] with people who are friends. They are the only ones that would need to know, and actually they don't even really need to know, it's just something that I would like to share so I can talk about things with friends and be able to be honest about it. Otherwise, it's just nobody else's business"; Jim: "Mostly I don't think it's anybody's business".

Glenn's thoughts corroborate those of Bryce and Jim with a slightly different interpretation: concern for his partner's privacy as well: "...I always try and turn it around, and ask myself how comfortable would I be with someone else sharing this information about me without my permission? And when I ask myself that question, it's clear to me that it's nobody's business but Lance's". And finally Bruce adds his

comment: "So to try and keep some sense of normalcy in our lives, we tend to keep this information [his partner's HIV-positive serostatus] private".

Not all of the participants actually used the word "privacy", when discussing the issue of outside disclosure of their partner's HIV serostatus, but some did, and for those who did not, it seemed clear that the decision to share this information wasn't necessarily based on partner preference or fear of consequences, but often fell firmly in the domain of maintaining some level of privacy within the relationship and thoughtful analysis of who they wanted to share this information with and who had no legitimate claim to it.

Consequences. After assessing their partner's wishes regarding outside HIV serostatus disclosure, followed by protecting their own privacy, the privacy of their partners, and maintaining the integrity of the relationship, most of the participants considered consequences – both real and perceived - as a third-level priority when deciding whom to tell about their partner's HIV-positive serostatus. Statements that support this supposition are as follows: Scott: "I told my friend and she freaked out...so in that particular instance we are no longer close, we no longer talk"; Bryce: "I have not shared this with any family members. I think if I did, that there would be negative repercussions"; Jim: "...I also think that sharing one's sexuality, and sharing one's HIV status is risky. Risky in terms of, now people have information about you that they can use against you"; Bruce: "Telling people that you have AIDS, that is hard to deal with, that's something that you don't want to share with people unless you feel it is absolutely necessary to their interaction with you. ...I don't want people at work to know...I don't necessarily want to lose my job, or have any complications with people that I work with"; and John (who is an actor):

And you can't help but have professional concerns that you are no longer going to

be cast in straight roles, that you're going to be stereotyped now as a gay actor...

but nonetheless at the end of the day, producers still care about the bottom line. If

you turn around and   say that you are either yourself at risk for HIV or if you

don't have it yourself and your partner suddenly, and I think some of this is

conscious and some of this is unconscious, there is an oh, oh concern, 'can I

cast this person in a show, can I ensure him for a film, will I be in a position

where this investment that I've made of years of my life and potentially millions

of dollars of my money might go down the tubes because this man's partner gets

sick and he has to leave my shoot or he has to leave my play on tour'.

Tom and Robert were the only two participants who expressed few reservations

about sharing their partner's HIV-positive status based on fear of consequences. Tom

stated, "Sam is so out to everyone about being gay and being HIV positive, I mean, all of

our friends know, we live in the gay Mecca of _____, and he even posts stuff about it on

his [social media] page so I don't have a problem sharing that stuff with other people

either". His main consideration seemed to be to keep his family and friends informed

about all aspects of his life, including his partner's HIV serostatus. Robert's feelings

mirrored those of Tom's as evidenced by the following statement: "Jamie and I are both

very, try as desperately as possible to be open, and we pretty much are. I'll tell anybody

pretty much anything if I know they're interested and are not going to hurt me".

The first level of the decision-making approach consisted of the participants

assessing the wishes of their partners in sharing the partners' HIV serostatus. This

assessment process was slightly different for each participant, but there were

commonalities among all the participants that emerged as major consideration, and included asking their partners how they felt about outside disclosure, respecting their partners' wishes regarding disclosure, and negotiating with whom, and with not whom the disclosure would occur. Every participant who broached the issue of partner-to-partner HIV serostatus disclosure began their discussion of the issue by deferring to their partner's wishes regarding outside disclosure and emphasized the fact that their partner's permission was a crucial first step in making their decision, and that consultation with their partner was equally important.

The first level of decision-making took into account the desires of the partner regarding outside disclosure whereas the second level of decision-making was strictly an internal process that each participant employed in helping them make the decision about their partner's HIV serostatus disclosure, and represented the next step of the decision-making process. For the majority of the participants this decision was made at a conscious and rational level and it was clear that they had given the issue due diligence before proceeding with their decision. Because this was a conscious decision, the rationale for why and how they came to these conclusions was quite clear from the interview data and included: (a) the fact that their partner's serostatus was already known by others outside of the relationship dyad, thus making the decision-making process more of a black and white one for the participants who said that most people already knew, or assumed they knew, so it wasn't difficult for them to make that leap of faith in sharing this information with other people; (b) the participant's need for privacy, or the belief that it was no one else's concern; (c) the participant's need for validation or social support; (d) trust; and (e) risk assessment, which included assessing the potential for

consequences, both perceived and enacted, that may be directed towards the participant or towards his partner.

The final level of the decision-making process entailed the fear of the consequences that either had occurred, or might occur in relation to disclosing their partner's HIV serostatus. Consequences that were identified by the participants included: strained family relationships, loss of friendships, loss of privacy, issues regarding personal safety, loss of employment, other professional concerns, and potential financial consequences. At the heart of all of these concerns was the issue of discrimination grounded in stigma, spanning the dual fears of courtesy HIV-related stigma, and stigma directed towards the LGBT community. For the participants these two fears were closely interwoven and were seen as two parts of the whole as they did not talk about one issue without also mentioning the other.

Influences of HIV/AIDS on the Relationship

During his interview in response to, "What are your perceptions about living with an HIV-positive partner?" Glenn stated what many of the other participants identified as a central issue in gay relationships in which one partner has HIV disease: "Sometimes I think it's hard to separate issues in a relationship that are related to HIV disease, and issues that are simply related to being in a relationship period". But as normal as many participants wanted to view their relationships, one of the strongest themes to emerge from the study data was that of how living with a partner with HIV/AIDS changed, influenced, or affected specific aspects of the relationship, and all of the participants identified areas in their respective relationships that were directly influenced by the fact

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that their partner had HIV/AIDS. Perhaps Jim said it best by his opening interview statement:

> Well, I imagine it's pretty much like any other kind of relationship. I think it probably has challenges, and I think that there are some things that are probably enhanced in the relationship because of Brian's HIV status. I will say that any time you're dealing with a chronic illness, it adds a level of complexity that you might not get in any other kind of relationship...and I'm not sure that HIV disease is that much different in terms of carving out a relationship, than diabetes or any other type of chronic illness. I think one thing that might make HIV disease a little bit different than other illnesses, is in terms of how it affects day-to-day functioning in a relationship, in that HIV disease is probably a bit more unpredictable.

Glenn's statement, shared at the end of the interview, mirrored Jim's beliefs: "The challenges of our relationship are mostly based on the people that we are rather than the HIV disease itself, although the HIV disease certainly does seem to add to the burden of the other issues that we face as a couple".

Three sub-themes emerged as priority concerns for the participants when identifying aspects of their relationships that had been affected by their partner's HIV disease, and included: (a) the participant's fear of HIV transmission and its influences on sex and intimacy; (b) the impact on the participant of living with an HIV-positive partner on day-to-day life events and activities, emotional health and coping concerns, and on the relationship itself; and (c) the participant's perceived future of the relationship (morbidity & mortality) including his perceived evolving role within the relationship.

Fear of contracting HIV and its influences on the relationship. All but one of the participants was HIV-negative, and expressed concerns about contracting HIV disease themselves. Fear of contracting the virus also led to changes in the relationship regarding how the participants negotiated and viewed sex and intimacy as well as its influence on sexual behaviors expressed both within and outside the context of the relationship. Tom's words, regarding transmission fears were echoed by every other participant except Bruce, who was already HIV-positive:

Like I said we have a lot of sex, and even though I feel like I am being safe, it's just the frequency that makes me feel like I might be at a little bit higher risk than the average person. Like, we don't do anything that involves penetration, but then we don't really use condoms for other things like [oral sex], and I don't think a lot of people get HIV from that, but sometimes you hear stories that there are people out there where that's all they did, and they still got it. So I would say that is on my mind a lot and I go in for testing religiously about every three months".

Likewise, though Bryce spent numerous hours doing his own research, and speaking with various physicians about transmission concerns, his thoughts corroborate Tom's when he stated: "I guess I wonder sometimes, you know, about my own safety. I don't obviously want to become HIV-positive. I can't not think about it, and it is on my mind every single time we are intimate".

Despite the amount and the accessibility of information regarding safe-sex behaviors, the boundaries of what behaviors are considered "safe" versus the behaviors that are considered "unsafe" were unclear in the minds of many participants, and while most of the participants altered their sexual behaviors, all but Bruce expressed concern

that even behaviors considered low-risk for HIV transmission remained concerns for them. Scott's statement was exemplary of others' concerns: "My partner has a lot of pre-cum, I mean a lot, and I didn't know anything about pre-cum, so my reservations were more, how do I protect myself, and where are those boundaries"? For many of the participants it was these types of doubts and insecurities that made decision about intimacy and sexual practices with their partners most challenging.

A major challenge in every relationship that occurred due to HIV transmission fears was that of negotiating sex and intimacy. This was a challenge not only within the context of the relationship itself, but also, since all but two of the participants stated that they were in an "open relationship", (meaning that one or both members of the couple, was having sex outside the relationship), it was also a challenge outside the context of the relationship. For some participants the open relationship was an agreed upon mutual decision made by both partners. For example, Tom stated: "...because we live in _____ and there are beautiful men everywhere, it makes it hard to be monogamous. Not that we really are, we never set that up as one of the rules of our relationship, and it doesn't bother either one of us when we have sex with other people. Sometimes, we will meet other men, or other couples, and we will end up having sex with them as a couple". This agreed upon arrangement was the norm for other participants as well, including Robert, Ryan, and Bruce. Other participants, however, expressed discomfort or unhappiness at being in an open relationship as it was against their wishes, and expressed a desire to be in a monogamous relationship. Bryce, John, and Derrick shared this sentiment, best summarized by Bryce's following comment: "...as it turns out, he continues to see other people from time to time, which is not okay with me, but I guess we're working on that".

Intimacy, viewed mostly in terms of sexual desire and frequency was noted as a concern by a few of the participants. Robert and his partner were not currently having sex with one another which he postulates was due to getting older and "something that naturally happens anyway is that your sexual interest for each other wanes", and Bruce stated that, "After the diagnosis, we didn't have sex for awhile. We had lots of physical intimacy but I met my sexual needs outside of the relationship. I didn't really want to have sex with him after he got so sick".

In addition to the open relationship issue, another challenge regarding sex and intimacy was how the participants negotiated and navigated sexual behaviors with their partners. All of the participants identified changes in either their desire for frequency, or actual changes in their sexual behaviors and practices. The following statements supported this finding: Bryce stated:

> So we went to see his doctor and he told us, 'you cannot transmit the disease in this way', and 'this is never going to happen so don't worry about this'. So he [the doctor] was very specific about that. And Ken…kind of went down a laundry list of the types of intercourse, or sexual things that one does, and just asked the doctor, what's the risk factor with any of these things, and the doctor went over each one, so I made some changes to the things we were doing in the bedroom.

Scott stated: "We talked about it, and I talked to my doctor and I did my own research, and I thought that I was going to be safe. We participated in low-level risk things and I am okay with that. We just don't engage in high-risk activities such as [unprotected anal intercourse] and swallowing". Robert also noted: "At times there is a little bit of a challenge in being safe when we have sex. We have mostly been safe, but maybe four or

five times during our relationship I [had anal intercourse with] him without using

condom. It was just so frustrating to not be able to just have spontaneous sex". Derrick's

concerns summarized this difficult issue:

> Everything we do with each other has a risk attached to it, some things have high
>
> risk, and some things have low risk. We really don't do any of the high risk things
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> anymore, but even with the low risk things, you just never know. So my challenge
>
> is to try and stay engaged sexually without worrying about getting the virus but
>
> still have a satisfying sex life.

It was interesting to note that as old as the HIV epidemic is, as advanced as the

scientific knowledge regarding pathophysiology and transmission is, as much information

about transmission that's available from electronic and expert resources exists, and as

accessible as these resources are, the men in this study continued to express HIV

transmission fears regardless of how much information they had personally, or how

accessible expert resources were to them. This suggests that when gay men who are well

educated in HIV transmission issues continue to express concern about transmission, that

perhaps their fear is not only grounded in a lack of knowledge, but perhaps more

accurately belongs in another domain such as emotional concerns, need for ongoing

support in expressing their fears and doubts, or a deficit in their ability to cope with their

fears. It was interesting that very few of the participants expressed a need for more

knowledge about transmission – with the exception of a few specific sexual behaviors –

but almost all of them expressed a need for validation of knowledge, validation of sexual

behaviors, validation of their transmission concerns, and the need for resources and

interventions designed to assist them in better coping with their fears and concerns. This finding for clinical practice will be discussed in more depth in Chapter 5.

Impact on Day-to-Day Life. Another major sub-theme that manifested itself during data analysis was that all of the participants had to face the fact that in living with a partner with a chronic illness, daily life would forever be altered. Most of the things in their lives that were impacted were unexpected, and therefore, many of the participants had trouble dealing with the changes emotionally and many expressed difficulty in coping with the unexpected changes. The one exception to this was that except for one participant, all other participants expressed some level of appreciation for what they perceived as positive outcomes of living with an HIV-positive partner. Aspects of life that were identified by the participants as being most affected were: daily activities and routines, emotional stability, enhanced appreciation for certain aspects of the life that the participants had built with their partner, and a decrease in their ability to cope.

Impact on routines. One of the most difficult adjustments for the participants to make was that they had to adjust daily activities and routines on a regular basis. This was based on numerous factors but mostly centered on the reality that HIV disease can be unpredictable, and due to illness or inability to carry out daily activities and functions, was a challenge that had to be factored in as a major variable in the "dealing with an HIV-positive partner" equation. Participants identified many areas in day-to-day life that were affected by their partner's HIV status, but centered mostly on social activities, work/professional activities, the maintenance of house and domestic activities, and intimacy issues.

Both Scott and Jim talked about making adjustments during periods of their partner's acute illness. For Scott the issue was the imbalance of workload that occurred when his partner was unable to help with mundane household tasks such as housework, grocery shopping, and home maintenance, but also expressed frustration at having to cancel social events and having to forego sex and intimacy during his partner's sometimes protracted recovery. In one particular case Scott and his partner stayed up late talking while sharing what Scott describes as "an extremely intimate moment", but states that the next day, not only did Scott have to do all of the work around the house, but that his partner was unavailable emotionally and sexually for several days thereafter. He summarized his feelings regarding the experience: "So that was like a high, but then the crash comes in where I'm resentful that I have to do everything, angry that, you know, if I had known the next day this would happen would I have stayed up so late, would we have had this moment?" Jim expressed similar concerns and stated: "So, even the best-laid plans sometimes have to be altered because of the unpredictability of the disease. Most of our close friends are pretty understanding when we have to cancel plans at the last minute…other people who are unaware of Brian's HIV status aren't quite as understanding, and I think we have earned the label of 'flaky'". Tom expressed concerns about his partner's absence from work, as well as the added pressure on him to keep his partner's mental and physical health in check.

What I know is that there are days when he just has a hard time getting out of bed. Those days seem to come in clumps. I mean by that, that he'll have days when he doesn't feel well, and instead of just taking one day off of work, or just spending a few hours in bed trying to recover, he ends up spending the whole week staying in

bed. So the challenge I think is to try and help him maintain his mental health...but I also have to go to work, I also have to take care of the house, and cook so he doesn't lose weight...the daily activities of maintaining a household, falls to me.

Disruption of daily routine for most of the participants was more than just a minor irritation, and many participants expressed the belief that it affected their functioning at work. It also affected their ability to maintain positive coping behaviors, caused resentment towards their partners, increased their work load including physical tasks as well as emotional tasks, and generally made life more of a "juggling act".

Emotional effects. "It's a bit of a tightrope act, interesting in that it brings out every emotion, there is anger and upset and an irrational fear I think sometimes, and there is a lot of emotionalism that sometimes feels good, I feel as if I'm more empathetic, and more caring than I might have been when we got into our relationship." This statement of John's summarized the range of findings that were identified by other participants regarding emotional responses to having an HIV-positive partner and surfaced as a strong sub-theme. Participants used words like, "betrayal, anger, fear, envious, nervous, and resentment" when describing their feelings towards their HIV-positive partners. Because there is an affective component to every relationship, Scott's statement summarized the views of other participants' feelings when he said: "...and we thought that every Christmas was going to be his last...and well, he's been dying now for his entire life, and it's so, there is an emotional scale that I have, and I think there is an emotional component on me, it's hard to refill the emotional well in myself".

Many of the participants struggled with their feelings, especially if they were negative, towards their partners. Jim stated that he felt resentful at times, and that that feeling made him feel ashamed, even though he acknowledged that he just couldn't help feeling that way at times. He stated that when he felt like he had to take on an unequal share of the responsibilities in the relationship and in their home, that those feelings became intensified.

What these findings mean for many of the participants is that their emotional health was easily and frequently compromised when attempting to take on an unequal burden of the shared responsibilities inherent in a relationship. For all of the participants this caused emotional lability, but most had difficulty accepting this. It also made it more difficult to initiate self-care measures due to the perception that they had to be "the rock, or the responsible one" during their partners' illnesses.

Coping. Because of the emotional toll that affected every participant on some level, coping was an issue identified as being problematic. Coping behaviors covered a broad spectrum and included behaviors such as, drinking alcohol, talking with others, writing about and sending their concerns to their partners, outside support, sharing their partner's HIV serostatus with others, and withholding sympathy or other support from their partners. Some participants believed that their ability to cope was further compromised, because in some cases they were not allowed, or did not feel comfortable sharing their partner's HIV- positive serostatus with other friends or family members in an attempt to honor either their partner's wishes to keep their HIV status confidential. In many cases they simply did not trust other people with this information. One participant stated: "I mean it's already bad enough that they know we are living together as a same-

sex couple, and it's caused enough family problems, that I would never trust them with this level of information". Ultimately, the ability to cope with the anonymity surrounding their partner's HIV serostatus and the many challenges encountered in living with an HIV-positive partner was an individual process for each of the participants, and they met this challenge with varying levels of success. Most, however, found ways to cope effectively, but emphasized the fact that there were times when they felt very alone and often without adequate resources to cope well. Scott summarized the feelings of many with this statement:

> Actually I don't want sympathy, or somebody's expounding of their thoughts or feelings about the situation. I want somebody who can be supportive and help me live through, Oh my God, Michael's been down for several days, I have to go to work, I have to maintain the house, I have to clean, I have to get groceries, I now have to do both of our work, and when he gets better, it's not like I get a break, it just goes back to sharing the work 50-50. So there's never a balance, it never comes back to where he takes over everything, or he takes more of a load when he gets better. It's that level of support that helps me get through those hard times.

Compromised coping emerged as a major issue related to having a partner with HIV disease and highlighted the fact that resources were needed to assist with workload in the relationship, to allow the participants to share their concerns and frustrations regarding their partners' illnesses, and to help them explore, identify, and implement enhanced coping behaviors. The participants were clear that assistance with coping wasn't an everyday occurrence, but when their partners became ill and could no longer assist with the many daily tasks involved in maintaining a household, that their ability to

cope became compromised, and it was at this point that assistance was needed. It is important to highlight the fact that when many of the participants arrived at the point of compromised coping, signaling the need for assistance, that this was also the time they had the most difficulty asking for assistance.

"The silver lining". As difficult as it was to cope and come to terms with the negative emotions, many of the participants also identified positive emotions that were experienced because of their partner's HIV-positive status. Scott, Derrick, Jim, Robert, John, and Glenn all expressed appreciation for having an HIV-positive partner, and recounted experiences and emotions that they otherwise would not have experienced. Some of their statements included: John stated: "I would never say I'm glad this happened, but I do think that it's brought certain things into our relationship that did not exist before...I can appreciate that there are some changes in the way we are with each other and in the way we are in the world that we perhaps wouldn't have achieved otherwise". Derrick supported John's statement by stating: "Having a partner with HIV makes you appreciate every day that you have together". Jim stated:

> And as the relationship continued, and in a lot of ways became stronger...my
> mindset was very much, live for today...and so I think that it forced us in many
> ways to confront issues so that they did not fester, and it allowed us to bond in
> ways that perhaps many gay couples do not have the benefit of. Really, I tried to
> see every day together with him as a gift, and I continue to feel that way to this
> day.

Glenn stated: "But what I think the HIV disease does do, is make us mindful of the time, and even more than the amount of time, the quality of the time, that we have together".

While the majority of the data suggested that there were many "difficulties and challenges" in living with an HIV-positive partner, it became apparent that many of the participants also felt that their relationship was enhanced in some ways by this situation. This means that many of the participants also perceived their lives to be better in some ways than it would have been had they not met and made a commitment to their HIV-positive life partner. These positive sentiments were often expressed at the end of the interview, and were touching and emotional affirmations that even in the midst of adversity, participants expressed that there is often much to be thankful for as well.

Perception of the relationship's future and role challenges. The future of the relationship, in both qualitative and quantitative arenas, was a concern expressed by the study participants and was usually expressed in the context of mortality and morbidity issues, although other concerns regarding the future of the relationship were also shared. In spite of the fact that HIV disease has become much more manageable and mortality rates have sharply declined over the last 15 years, most participants expressed concern that their partner could die prematurely, or that acute or chronic illnesses could affect the quality of their time together. Tom stated what many other participants expressed also: "Yeah, I think a lot about not only about Sam getting sick, but some people with HIV disease can still get things that can kill them. I guess I don't think about that a lot, I mean it crosses my mind probably on a daily basis, but not in a way that I can't handle..." Glenn's thoughts supported Tom's concerns regarding his concerns about future health and mortality issues:

> ...I might say that fear is one of my constant companions: fear that Lance will get
>
> sick, fear that his HIV status might affect our relationship in unknown ways and I

might lose him, and fear that the worst thing possible could happen, which is that Lance could die...and it is something that is on my mind every day of my life...

While concerns regarding mortality and morbidity issues were almost constant companions, there was an overriding feeling of hope that almost every participant expressed, and their collective belief in a long a healthy future with their partners was best expressed by Jim when he stated: "There are certainly different challenges when dealing with a complicated chronic illness, but I think the positives greatly outweigh the negatives".

The research participants also reflected on their current and future role within the partnership. While there was a wide range of responses on how they viewed their current role in the relationship, most of the participants also talked about how they saw their role in the future. A predominant theme in their perceptions of their future roles was that of being a caregiver. Morbidity issues were most certainly on their minds as each participant anticipated being a caregiver at some point in the future. No participant talked about the hope or possibility of a cure for the HIV virus, and many alluded to the belief that their partner, at least at some point in the future, would be dealing with either major morbidity issues, or would not live a normal life span. In the minds of the participants, it seemed that they simply accepted the belief that long-term and severe morbidity, and/or early mortality, were foregone conclusions regarding the HIV-disease trajectory.

With these thoughts and beliefs, which occupied a dominant place in the minds of most of the participants, perceptions of what the future held in terms of caregiving, was expressed by each of the participants. Ryan was the most vocal in his opposition to becoming a long-term caregiver:

I work in a caretaking profession and I really don't want to be an at-home

caretaker. And I've noticed with his illnesses and stuff like that, how little

responsibility I want to be in a nurturing role, so you know as awful as that

sounds, if he were to become really sick, such that he needed care, it would have

to be from an outside source.

Other participants shared similar views but not quite as strongly as Ryan. Bryce stated:

"...nor do I have a real desire to try and take over the role of his caregiver, especially

since he has such a great doctor and other support from friends and family". Jim:

I like taking care of people to an extent and then I want them to take

responsibility for themselves....when I know that it's more of a mood or

emotional thing, I lose patience, and don't want to be in that nurturing role

anymore. I would not make a good nurse, because I do not have the patience and

understanding it takes to take care of someone over the long haul.

Derrick adds his concerns to those of Ryan and Jim.

I hope it doesn't come to that [long-term illness] because I don't relish spending

the rest of my life trying to take care of a sick partner, for which I have no

aptitude or desire, or trying to maintain a caring and close relationship with a

person who can't really hold up his end of the bargain. I think I would have to re-

evaluate the relationship if it did come to that.

Early in the AIDS epidemic mortality rates were extremely high, and the partners

of those who succumbed early to the disease, were thrust, sometimes unwillingly, into the

role of caregiver as there were often no other options available. As HIV disease and

AIDS have progressed to that of being more chronic in nature, fewer gay men who have

partners with HIV disease are being forced into that role. Many of the participants in this study expressed an aversion to being conscripted to a permanent and long-term role as a caregiver and expressed concerns, not only about their ability to be successful at being caregiver, but also about the perceived consequences to their own lives, but to the quality and viability of the relationship itself. This data seems to represent a point-of-view that has been rarely expressed until now.

Interactions With the Healthcare System and With Healthcare Providers

Every participant experienced at least one interaction where they, when accompanying their HIV-positive partner, interfaced with the healthcare system, healthcare providers, or both. The majority of the participants broached this topic during the course of the interview without a prompt or direction from me. It is also important to note that this was not a question that was asked specifically of the participants. For the remaining participants, all but one asked about some of the topics that had been brought up by other participants. As the researcher I used this opportunity to talk about several of the themes that other participants had talked about and invited the current participant to elaborate on any of those topics of their choosing, but was done in a manner that did not direct them to any specific topic or question. The majority of the participants chose to share their stories of one or more instances where they had interacted with the healthcare system, health care providers, or both. The participant's perceptions of those experiences constitute the third major theme and their experiences fell into three main sub-theme groupings: (a) interactions with the healthcare system; (b) interactions with physicians (MDs); and (c) interactions with nurses. Interfaces with the healthcare system included a broad range of settings, but most services were sought in the following areas: physician's

offices, outpatient clinics, community resources, and, hospital or inpatient admissions, whereas those with healthcare providers focused exclusively on MDs and nurses.

Interactions with the healthcare system. Most of the participants who shared their perceptions of an interaction with the healthcare system described their experiences using neutral terms and emotions. During an inpatient admission for his partner's diagnosis of an acute antibiotic-resistant infection, John described his perception of the hospital setting: "I would say the bureaucracy of the system was a frustration to both of us at a number of points. How unique that is to gay men or how unique that is to HIV/AIDS, I couldn't say". Derrick shared similar feelings when his partner was admitted as an inpatient: "The hospital itself felt like a big impersonal machine that ran efficiently enough, but didn't really create an atmosphere where one felt comfortable navigating the system. Most of the workers seemed efficient enough, but not really warm or caring. I suppose that's because healthcare is probably run as a business now-a-days". Tom, whose experience was at an Sexually Transmitted Infection (STI) Clinic made this comment about his experience in a community setting: "And what I remember about that experience was it was all just so impersonal and like sterile, where people talked to you from behind a glass window, and the person that checked us wore a gown, gloves, and a mask, and hardly said three words to us". The most positive assessment of a healthcare interaction was told by Glenn when sharing an interaction he had in the emergency department (ED). This encounter was necessitated by the fact that his partner had cut himself quite badly while making dinner, and because there was a significant amount of blood involved, Glenn felt a moral and ethical responsibility to the staff caring for Lance to share his HIV-positive serostatus. The response by the staff in the department was:

"They seemed to take the news as a matter of course, did not react poorly,....and not seem to be doing anything differently than what they were already doing, which seemed to put us both at ease. I told them upfront the minute we were in the exam area, that we were partners, and I would be staying with him throughout the ER stay. No one batted an eye at that, and they ended up addressing us both when speaking to us or when giving us instructions about wound care and medications, so for the most part it was a positive experience".

Interactions with physicians. As impersonal as the healthcare setting was perceived, the most positive perceptions of the participants were experienced when interfacing with physicians. This was a universal finding among all of the participants who spoke about their interactions with their partner's physician. Bryce was probably the most complimentary as his partner's physician took time to assess Bryce's knowledge regarding transmission risk factors and general knowledge of HIV disease, treatment, and medications. At one point he mentioned that the interaction with the physician was more like "I was being invited into somebody's living room for a drink and a little chat about this sort of stuff rather than some hard and fast trip to an unsympathetic doctor". Bryce was so pleased and impressed with this interaction with this physician that he talks about it, not once, but on three separate occasions during the course of the interview. Jim had a similar experience with his partner's physician and described him as, "very good by the way, was very attentive. He stopped by Brian's room at least twice a day, and sometimes more often". Glenn is equally pleased with his partner's care at the hands of his physician and made this comment regarding his most recent visit: "I like his doctor very much, he is very patient with Lance, he explains things very well, his bedside manner is superb,

and he spends as much time as he needs to, to satisfy both of us. He of course knows our situation, and treats me very well, greets me by name, educates us as a couple, and allows me to ask questions and be part of the process related to lance's care and treatment options".

Perceptions regarding physicians and physician care were seen as positive by every participant who addressed this issue. A unifying theme that was present in most of the participant's accounts of physician interaction was that the physician had intimate knowledge of not just the participant's partner, but also of the participant himself. The participants equated this knowledge with being accepted as a gay couple, being treated as the patient's legitimate partner, and being acknowledged as having education and emotional needs that differed from those of their partners.

Interactions with nurses. The perception of how the participants evaluated the interactions they had with nurses was vastly different than their perceptions of MD care. The consensus by most of the participants was that the care delivered by nurses was competent, efficient, and that they performed their duties adequately. However, what many of the participants felt was lacking in the interaction was "caring", "warmth", and a more personal approach. The participants stated that due to the fact that they were at their partner's bedside for long periods of time, they hoped for not only acknowledgement of this status, but that they would be treated as any significant other or family member would be who was in a similar situation. Most felt this did not happen, and not only did most of the nurses encountered not acknowledge the participants partner status, neither did they include the participants in the care planning or teaching processes. One participant felt like the partner status was known to most of the staff, including the

nurses, based on the fact that they were holding hands most of the time and through other "obvious" but nonverbal cues, but none of the nurses took the opportunity to verify or clarify the nature of the relationship. This was experienced in a similar way by other participants. Ryan was the most vocal about his interactions with the nursing staff and how he was treated by them during his partner's two-week inpatient hospital stay. Ryan felt he was imminently qualified to evaluate the quality of nursing care for two main reasons which were based on the length of the hospital stay (2 weeks), and on the fact that he works closely with nurses in a hospital setting as part of his profession. He stated:

> I think I felt a little, not in a bad way because I work in a hospital too, so I'm familiar with nurses and their role and their sort of interactions and what is normal and typical, so nothing struck me as atypical. I just felt very peripheral to the experience because when they would come in to help with medications or to look at wounds and stuff like that I was asked respectfully to step out of the room. But generally there was not a lot of acknowledgement from the nursing staff like, 'oh it's nice of you to come in so often and It's nice you are here', but it didn't really happen with the nursing staff.

Bruce shared a similar experience but focused more on the lack of education, especially regarding end-of-life issues, that he felt both he and his partner were denied: "I will say I don't think there was a lot of counseling from the nurses who took care of John. For instance no one came by to just ask us how we were doing, or to say let's talk about such and such, or to ask John or me if we were feeling scared that he may be coming to the end of his days. I was able to talk to friends and family about that, but none of the nurses took the time to talk to us about those kinds of things". Glenn and Derrick shared

similar accounts, and Glenn's words summarized their collective experience: "What was not positive was the fact that most of the nurses in the ER were very cool and business-like, almost like automatons, and while they were not hostile, you got the feeling that you were making a mess out of their day, and that didn't seem to fit the model of a caring nurse. I'm not sure what would have made them seem more caring; it's just that they didn't seem to make the effort to try and get to know us on a personal level". John's experience during one of his partner's inpatient stays was similar to the other participants and he shared the following story:

> I remember one incident where a nurse on the day shift came into the room to do
> something, I think like give Brad some IV medication or change an IV bag or
> something like that, and while she was very professional with Brad, she didn't
> give me the time of day, and I found it unusual that after I had been there, day
> after day with him, that I was treated like an outsider, or visitor, and not like a
> member of the family, or as his partner. She wasn't unkind, but I would think if I
> were a nurse I might be thinking, 'this person will be going home with my patient,
> and I need to make sure that he gets enough information about his disease that
> they can help him regain, and maintain his health.' That just seems to make sense
> to me".

Finally, Jim's account of his interaction with nurses during his partner's inpatient stay seemed to corroborate the experience of other participants:

> ...the nurses seemed to just be kind of in the background. They did their jobs,
> they were competent, they treated us fine, but with one or two exceptions, they
> just didn't really stand out in terms of how they interacted with me or us. Like I

said, Brian got really good care, but I don't really remember the nurses talking to us, or me , about what was going on with Brian, what the plans for his care were, or how he was responding to treatment. It seems like they just left that up to the doctor to handle. Looking back, it does kind of surprise me that they never asked who I was, or took the opportunity to get to know me....I guess the best word that comes to mind to describe the nurses as a group, is neutral.

Perhaps the most important reason given for being dissatisfied with nursing care was that none of the nurses who interacted with the study participants asked about the nature of the participant's relationship with the patient. As stated earlier, this emerged as being so important to the participants that even when they said, "The nurses were angels", or "The nursing care was very good", they invariably followed up with a statement like Jim's, "Brian [his partner] got really good care [from the nurses] but I don't really remember the nurses talking to us, or me, about what was going on with Brian, what the plans for his care were, or how he was responding to treatment", or Glenn's, "...and that didn't seem to fit the model of a caring nurse. I'm not sure what would have made them seem more caring, it's just that they didn't seem to make the effort to try and get to know us on a personal level". For these and perhaps other reasons, the study participants were not as generous with their praise for the nurses as they were for physicians.

The one exception to these not so positive perceptions of nursing care came from Jim, who mentioned that the care from one particular nurse stood out as particularly good. He based this on the fact that this nurse: "engaged with me and us quite a lot. I think maybe he was gay himself, and perhaps that made him a little bit more comfortable

with us, and it seemed like he ended up talking to us more, not just about medical issues, but also about other things".

Perhaps the most important reason given for being dissatisfied with nursing care was that none of the nurses who interacted with the study participants asked about the nature of the participant's relationship with the patient. As stated earlier, this emerged as being so important to the participants that even when they said, "The nurses were angels", or "The nursing care was very good", they invariably followed up with the perception that they were disappointed because the nurses didn't engage them in conversation, nor did they involve the participants in the patient's medical or nursing plan or how the patient was responding to treatment. For these and perhaps other reasons, the study participants were not as generous with their praise for nurses as they were for physicians.

In conclusion nursing care was viewed mostly in a pejorative way, in which the care did not involve the partner in planning or teaching, nor did it engage the partner as a significant influence in the patient's (the participant's partner) recovery or health maintenance processes. The one exception to this was the nurse that stood out because he reached out to the patient's partner and treated him in a way that made him feel he belonged and was part of his partner's medical care and recovery process.

What must be made clear is that none of the participants made explicit statements identifying the nurse as a registered nurse (RN). This leads to some speculation as to the credentials of the nurses that were referred to in this study. In their accounts, most of the participants talked about specific duties that were performed by the nurses which indicated that they were most likely either registered nurses (RNs) or Licensed

Vocational Nurses (LVNs), but it is in fact unclear, whether the nurses referred to by the

participants were RNs or LVNs.

Chapter 5: Discussion

The Literature Review in Context

As a prelude to writing the proposal for this study, a comprehensive review of the literature was completed. The lines of inquiry that were initially focused on included: gay men in committed partnerships; gay couples; HIV disease and AIDS; and living with a partner with HIV-disease/AIDS. Much of the literature on these topics revealed strong and recurring themes regarding discrimination, social stigma, internalized stigma, homophobia, and secondary stigma. Some of these themes were firmly grounded in the healthcare context and focused on health disparities for lesbian, gay, bisexual, and transgender (LGBT) communities (Krehely, 2009; & Neville & Henrickson, 2006). Because these themes were so prevalent in the gay and HIV/AIDS literature, the initial literature review completed in preparation for this study focused on secondary (sometimes called courtesy) HIV stigma and was explored as a parallel concept and phenomenon to primary HIV stigma. In developing this line of inquiry a discussion of the larger concepts of primary and secondary stigma was necessary in order to understand and situate the literature for both primary and secondary HIV stigmas. A review of the literature on primary stigma established a large contribution by the social, behavioral, and healthcare sciences, but illuminated the need for a larger focus on secondary stigma by these disciplines. Likewise, the literature for primary HIV stigma was comprehensive and well researched, whereas secondary HIV stigma literature remained largely underdeveloped. Though still in its infancy, the secondary HIV stigma literature has

shown that stigma, both perceived and enacted, is experienced by individuals and groups who are in close social relationships with those living with HIV/AIDS.

It was somewhat surprising that gay male partners of HIV/AIDS affected gay men were not included in the literatures on secondary stigma outside of the caregiving role. While addressing this gap in the literature is important, this research was designed with a broader focus in mind: that of the experience of living with a partner with HIV/ADIS in the context of a long-term committed gay relationship. Nevertheless, I have included this comprehensive review of the literature on the phenomena of stigma, in all its complexities, in this dissertation. It is my hope that it will inspire explorations on this topic within the context of gay men living in committed partnerships with an HIV/AIDS affected partner.

Contextual Considerations

It is also worth noting that the 10 interviews for data collection were completed no later than April 2013. Since that time, recent polling data emphasizing the public's acceptance of homosexuality and legal marriage rights for same-sex couples, the June 2013 decision handed down by the United States Supreme Court (SCOMA) finding portions of the Defense of Marriage Act (DOMA) unconstitutional, the overturning of proposition 8 in California which prohibited legal recognition of same-sex marriage in that state, and the fact that some states have passed laws that allow marriages, domestic partnerships, and enhanced rights and protections for same-sex couples, emerge as examples of rapidly evolving social paradigms and values regarding legal and human rights for gay individuals and couples in the United States of America (USA). As public opinion regarding same-sex rights and protections as well as the social landscape

changes, it may be that future studies of gay men in general, and HIV/AIDS affected men and their life partners may yield different findings.

I turn now to the interpretation of findings from this dissertation research, followed by a discussion of the implications and limitations of this study, and ending with the implications of these findings for nursing practice.

Interpretations of Findings

Disclosure of HIV-Positive Serostatus

As identified in chapter four on findings, disclosure of HIV serostatus was identified as a major issue for all of the study participants and encompassed two areas: (a) how and when the participant's partner disclosed their HIV-positive serostatus to them; and (b) the decision-making process utilized by the participant in deciding with whom and with whom not to share their partner's HIV-positive serostatus.

Dilemmas and issues surrounding disclosure of one's HIV serostatus have been well documented in the literature. The majority of the studies reviewed in the past 5 years focused on the risk of HIV transmission in non-disclosure, which becomes an even greater concern in HIV-discordant (e.g., when one partner is HIV-positive and the other is HIV-negative) couples (Gomez, et al., 2010). Almost all of the studies focused on transmission concerns in the context of anonymous or casual sexual encounters, and none of the studies reviewed focused on partner-to-partner disclosure within a partnered gay couple. In one study by the CDC (2006), findings suggested that only about 54% of PLWHAs who have sex, fully disclosed their HIV-positive serostatus before having sex with that partner, 22% disclosed sometime after having sex with their partner(s), and 24% never disclosed the fact that they were HIV positive. What was also important about this

study was that the authors found that having an HIV-positive partner and/or being in a primary relationship were characteristics predictive of disclosure.

Based on these data, the CDC recommended frequent HIV testing for gay men so that not only is HIV serostatus known by the individual, but that disclosure with potential sex partners would also be encouraged. These finding were corroborated by other HIV researchers (Gomez, et al., 2012; Neilands, et al., 2010; & Hoff, et al., 2010), and emphasized the fact that sexual transmission of the human immunodeficiency virus – especially among gay men – continues to be an issue of primacy by individuals at risk, research communities, and healthcare groups (Crepaz, N., & Marks, G. (2001). What is not well address in the literature, however, is partner-to-partner HIV serostatus disclosure within a gay relationship dyad and represents a significant gap in the literature.

Some of the results from the research presented here paralleled those in the extant literature regarding disclosure of HIV serostatus and HIV-transmission concerns. For example, while all of the participants in this study had some concerns about contracting HIV from their partners, it was not the overriding one, and may be attributed to the fact that all of study participants had made *a priori* decisions to adhere to safe-sex guidelines during any sexual encounter. Data analysis from chapter four suggested that participants in this study were much more concerned about maintaining and nurturing the relationship, negotiating an open relationship, figuring out how to navigate banal daily tasks and activities, and assisting their partners in maintaining optimal physical and mental health. Moreover, all of the participants from this study, except one, had prior knowledge, or was informed by their partners shortly after the first sexual encounter about their partners' HIV-positive serostatus.

What represents a gap in the literature, however, is that very few of the studies reviewed, focused on disclosure issues and concerns within a committed gay partnership/marriage, and those that did, used the partner dyad as the study participant. To the best of my knowledge, this is the only study that utilized an individual of an HIV-positive partner in a committed gay relationship as the study participant, and represents a new and unique perspective heretofore unexplored that will hopefully assist future researchers in finding ways to reduce HIV transmission among gay couples in a committed relationship/marriage, better understand HIV transmission issues and fears from the perspective of the gay partner of an HIV-positive individual, and assist practitioners in designing effective interventions (especially teaching interventions), for supporting the gay partner of an HIV-positive man in remaining HIV-negative and in coping with the ramifications of their situation.

One salient example that illustrates the challenges faced by this study population that is not well addressed in the literature, is that the majority of the participants in this study were concerned enough about HIV transmission that most made *a priori* decisions to practice safe sex even when the HIV serostatus of their partner was unknown. This decision included all sexual encounters, and not just those with their partner/future partner. What this means is that even though the participants expressed appreciation that they were informed by their respective partners about their HIV-positive serostatus before or shortly after their first sexual encounter (with the exception of one outlier, see chapter 4), few, if any, were overly concerned about contracting HIV since they had already committed to safe-sex behaviors before engaging in any sexual activity.

Analysis revealed that what did emerge as concerns for the participants, however, were issues surrounding having an HIV-positive partner, which impacted and increased fears of transmission due to frequency of sex, unclear boundaries regarding which sexual behaviors were safe and which were not, and since most were in open relationships, the concern that their partner might be exposed to STIs or other infections which might impact the health of both partner and participant. What this means for this specific population is that they may need more focused education regarding the risks of varying sexual behaviors (especially those considered lower risk for transmission of HIV) and how to negotiate those behaviors with their partners. While all of the participants had knowledge of what was considered "safe" sexually, and all were committed to practicing safe sex, most expressed concern over sexual practices where less is known or perhaps written about HIV transmission risk, and expressed the desire for enhanced education from health care providers and community-based HIV/AIDS organizations.

Another need expressed by the study participants included emotional support. Most of the participants felt that they could not always burden their HIV-positive partner – who they believed was already overburdened due to the effects of having to live and cope with HIV disease and/or AIDS – with their own emotional needs, and also expressed a desire to protect their partners from "undue emotional upset or strain". However, the majority of the participants emphasized that they "felt alone and isolated" because they did not always feel free to share their partner's HIV serostatus with "outsiders" and therefore had no realistic option on which they could rely to express their own issues and concerns. In one study by Darbes, Chakravarty, Beougher, Neilands, & Hoff (2011) that utilized partnered gay male couples as the study participant found that

HIV-specific social support was consistently predictive of decreased unprotected anal intercourse (UAI) regarding sexual behaviors with sex partners outside of the relationship, and that identifying couples who needed this level of social support and providing the appropriate resources were important factors in reducing HIV transmission as well as enhancing relationship satisfaction and commitment. The findings of Darbes, et al., (Ibid), dovetail nicely with the findings that were expressed by the participants of this study regarding the need for emotional and social support.

This desire for support was reiterated in the final theme when participants shared their perceptions and experiences with the healthcare system and healthcare providers regarding education and support, and will be addressed in more detail when that theme is analyzed in this chapter.

The second issue regarding HIV disclosure involved the participant's decision to share their partner's HIV-positive serostatus, which included a decision-making hierarchy, not only regarding whether or not to share their partner's HIV serostatus, but also, if they did decide to share that information, with whom, and with whom not would they choose to share it. As stated earlier, current studies do not address this issue from the perspective of the gay partner of an HIV-positive individual, and represents a unique perspective on this issue not addressed by other researchers.

What was learned from the results of this study regarding the issue of disclosing their partners' HIV serostatus was that every participant was acutely aware of the complexity of this issue, and understood that it had implications, not just for the study participant himself, but for his HIV-positive partner as well. Due to this partner-dynamic, all of the participants were thoughtful when addressing this subject and the following 3-

level decision-making hierarchy was identified, which I believe could be the early foundation for developing a practice-level theory regarding the decision-making process for gay men in a committed partnership whose partner is HIV-positive. This assumption was made because current literature has not addressed the issue of how gay men with an HIV-positive partner go about constructing a decision-making process for sharing their partners' HIV status outside of the relationship.

All participants eventually learned of their partner's HIV-positive serostatus, and with the exception of Ryan, learned directly from their partners, learned immediately before, or very shortly after their first sexual encounter, and all had knowledge of safe-sex behaviors and non-safe-sex behaviors and were committed to employing safe-sex behaviors before and after knowledge of their partner's HIV serostatus. But what seems to be quite important about partner disclosure in this study, is that those participants who learned about their partner's HIV-positive serostatus either before having sex, or shortly after having sex, had more positive perceptions of their partners in terms of being caring and responsible as opposed to Ryan's experience. The participants, who perceived that their partners were caring, expressed a more positive outlook on the quality and longevity of their respective relationships.

Analysis of these findings indicate that early disclosure of HIV serostatus may have an influence on how the participants perceive their partner in terms of caring and supportive behaviors, as well as how committed the participant is to the relationship and in how they might view the long-term viability of the relationship. This finding is probably not much different for gay couples as it is for straight couples, and early perceptions of caring, veracity, concern for the welfare of the participant's health and

well being, and fidelity, may be indicative of both the quality and the longevity of the relationship.

On the issue of stigma, both courtesy HIV-related, and gay-related, the literature is clear that individuals from one or both of these populations is at risk for both enacted and perceived stigma (Link & Phelan, 2006; Herek & Capitanio, 1999), and can experience immense suffering in the areas of social exclusion (Green, 1995), compromised mental health (Demi, et al., 1997; Herek & Capitanio, 1999), compromised physical health (Herek & Capitanio, 1999; Delahanty, Bogart, & Figler, 2004), sexuality (Deacon, et al., 2005), employment (Herek & Capitanio, 1999; Parker & Aggleton, 2003), and spirituality (Green, 1995).

The findings on courtesy stigma in this study parallel the findings in extant literature, and mirror similar concerns and themes of "loss of job", compromised coping, lack of social support, and compromised family and personal relationships. The findings from this study not only add to the existing literature but help to build a case for continuing scholarly and theoretical dialogue and analysis on the effects of real and perceived stigma on the health and well being of vulnerable populations including gay men, gay couples, those living with HIV disease/AIDS, and those who are closely associated with them.

In summary, while HIV transmission concerns affect all gay men who participate in anonymous, casual, or frequent sex with other men who may or may not be HIV-positive, the concerns of the participants of this study were more focused on the need for focused education regarding sexual behaviors where less is known or published about transmission risk, and the need for a higher level of emotional support that the

participants felt they didn't always get from outside sources, from their own partners, or from the healthcare community. These findings have health promotion implications as well as the opportunity to provide focused educational interventions and higher levels of emotional support by the healthcare community and healthcare practitioners. Lastly, when approaching this population of study participants, both researchers and practitioners must be aware that issues of sexuality and health are inextricably linked in the minds gay men who are struggling with those dual concerns, and that both assessment and development of interventions should be approached in a comprehensive manner.

Influences of HIV Disease/AIDS on the Relationship

This theme explicated the perceptions of the study participants on how the relationship was altered or challenged, often on a daily basis, by the fact that they were living with a partner who had HIV disease. This theme was further divided into sub-themes that identified three areas that the participants felt were most impacted by living with an HIV-positive partner, and included: (a) fear of HIV transmission and its effect on sex, intimacy, and sexual behaviors; (b) impact on day-to-day life and functioning, emotions, and coping; and (c) perceptions of the future nature of the relationship and their evolving role within the relationship.

Fear of contracting HIV. Fear of HIV transmission from their partners was a concern expressed by the study participants which effected other aspects of the relationship including frequency of sex, sexual behaviors, and other forms of intimacy. For most of the participants this represented two areas of concern: transmission risk based on current sexual practices and uncertainty regarding transmission risk of those

practices, and emotional support needed to address the added stress of having an HIV-positive partner.

On the issue of partner-to-partner transmission fears, the literature is moot on transmission fears within a partnership dyad, and it appears as if these findings add a new dimension and level of insight into this issue, shedding light on the fact that intimacy is affected by frequent thoughts of adherence to safe sexual behaviors, concerns regarding sexual frequency, and uncertainty regarding lesser known modes of HIV transmission. There is certainly a body of literature that focuses on transmission concerns, and (Marks & Crepaz, 2001) is an example of one study that looked at transmission fears. This study can hardly be used as a comparison as it focused on casual and anonymous sexual encounters where the HIV serostatus of the partner was unknown. Furthermore, the study participants were not in a committed relationship, nor did the study focus on the interaction between partners in a dyad situation.

However, on the issue of the need for support, the literature is clear that addressing the emotional concerns of gay men regarding HIV transmission issues is one of primacy, and in some cases equally as, or more important than specific education regarding modes of transmission and their associated risks. Darbes, et al. (2011) found that implementing specific types of social support to the gay partners of HIV-positive men resulted in a decrease of UAI both within and outside of the relationship dyad. Additional findings suggested that not only were these focused support interventions crucial to reducing the spread of HIV through unsafe sexual behaviors, but contributed additional benefits in the form of relationship satisfaction and commitment. Hoff & Beougher (2010) added support to these findings with the additional contribution, that

increased communication regarding HIV transmission, especially in HIV serodiscordant couples, was another strategy whose employment lead to better outcomes regarding HIV transmission, reduction of transmission fears, and increased relationship satisfaction. While inter-dyad communication did not emerge as a strong theme for reducing HIV transmission fears in this study, there is no doubt that the need for social, emotional, or other types of support was certainly something that was articulated as being valued by these study participants, and is complimentary to the findings in the existing literature on this topic.

Influences on daily routine and coping. The findings in this sub-theme focused on how living with an HIV-positive partner impacted daily activities, planning for the future, emotional stability, and the ability to cope during times of increased stress, taking on more responsibilities in the home and in the relationship.

In related studies on this topic that used other study populations such as families (Bogart, et al. 2007), mothers, wives, children, siblings (Thomas, 2006; & Murphy, 2007), and caregivers (Walker, 2006), emerging themes influencing the impact on daily life and routines, impact to the primary caregiver, and planning for the future included: felt stigma, social isolation, loneliness, and fear that others would find out about their HIV-positive loved one. I feel there is some overlap of themes between the finding of this study and the findings of studies using a different study population. However, I believe that there are more discrepancies than commonalities. For one reason, the participants in this study identified as the primary partner of the individual with HIV/AIDS, which changes the lens through which disruption of daily routine and emotional health and coping are viewed. While many other studies postulated that poor coping and emotional

health was compromised due to interrupted routines and daily stress, most participants from other studies did not start out as a stigmatized group and therefore typically had better access to resources and other family member on which to rely for support. This was not necessarily true of the participants of this study. In addition, the participants seen in related studies were already in the role of the caregiver and were used to a fully functioning support group that had built up around them over a long period of time. This was not true for this study, and the participants often found that they had to rely on themselves when their partner suddenly became ill and was unable to fulfill their part in terms of household and relationship duties and tasks.

One recent study by Wight, Beals, Miller-Martizez, Murphy, and Aneshensel (2007) developed a conceptual model of traumatic stress symptoms in AIDS caregiving family dyads, which focused on identifying those at risk for traumatic stress, measuring the severity of the stress, and implementing measures designed to ameliorate the stress. The focus of this study was not on gay partners, however, the principles of the model could be extrapolated to assist the population from this study. Issues that contributed to stress from the model such as, daily activities, overload, social constriction, stigma, emotional distress and financial worry certainly have direct application to the needs expressed by the participants in this study and provide a practical way in which theory can be used to support the emotional health and coping of these men.

While there is some literature that addresses the impact of living with an HIV-positive partner on daily activities, emotional stability, and coping, the findings from related studies don't appear to be as congruent in describing the day-to-day impact on being with a primary partner with HIV disease as was found by the participants in this

study. These study findings, then, illuminate a perspective that has been poorly represented in the past and contribute new knowledge to the extant literature on this topic.

Future of relationship and evolving roles. The focus of sub-theme 3 was on the participants perceptions of the future and of their evolving role, specifically that of caregiver, within the relationship dyad. Findings that were important in this sub-theme were: fear of early partner mortality, partner morbidity, financial concerns, and the possibility that the participant would be unwillingly conscribed to a permanent caregiving role.

HIV disease/AIDS has definitively progressed from a death sentence to a manageable chronic disease (Fredriksen-Goldsen, 2007). While this represents hopeful news for the HIV/AIDS community, one cannot escape the fact that people with HIV disease/AIDS still succumb to the effects of living with this disease. Findings from this study support this assertion and one of the concerns expressed by the study participants was that of early mortality. There was some ambivalence about this finding by most of the participants. On one hand, there were concerns about their partner dying before they reached late adulthood, and most expressed the desire to keep their partner with them as long as possible. On the other hand, the perceptions by many participants is that the knowledge that their partner may die "before their time", enhanced the relationship by providing a means for enhanced communication, appreciation for living in the moment, and participating in life in a way that they might not have done had the mortality issue not been in the back of their minds.

A number of studies corroborate the findings in response to fear of early partner mortality, and parallel the findings of this study. Wright & Coyle (1996), were among the early researches whose findings support the fact that most gay men in a relationship with an HIV-positive partner expresses concerns about the premature death of a partner and the toll that those thoughts have in terms of development of depressive symptoms, daily coping, and relationship quality.

Perceptions of the Healthcare System and Providers

Few, if any, previous studies have examined perceptions of the healthcare system and healthcare providers from the perspective of the gay partner of an HIV-positive individual. This represents both a gap in the literature and provides a new perspective into the perceptions and needs of this unique study population. Related studies using other study populations have spent little energy in exploring the study participant's perceptions of the healthcare system, choosing instead to focus on other research issues and questions.

Two prominent foci emerged as important for the study participants: (a) perceptions of interactions with physicians; and (b) perceptions of interactions with nurses.

Perceptions of care by physicians. Participants' perceptions of their interactions with physicians were overwhelmingly and universally positive. It should be noted that all physician encounters referred to by the study participants referenced their HIV-positive partner's physician and not their own personal physician.

There are three study conditions that lend explanatory salience for these findings. The first is that interactions with physicians were almost always experienced in the office

setting, and were described by most participants as "relaxed, unhurried, and caring". The second explanation is that with the exception of one encounter, all of the physicians referred to in this study were HIV specialists. To most of the study participants this represented someone who had the most updated, accurate, and reliable knowledge and information regarding HIV/AIDS, medications, and transmission issues. As stated earlier, this is what many of the participants wanted (although not all had access to these specialists), and when they had access to this expert source of information, they had a more positive perception of the interaction. The third condition was the fact that the physician had prior knowledge of the nature of the participant's relationship, and was therefore able to build appropriate rapport without having to do an assessment of the situation first.

In reviewing the literature on perceptions of interactions with physicians by the partner of an HIV-positive patient, there were no results found. What is present in the literature are studies that frame perceptions of the healthcare experience by HIV-positive gay men (Eliason, Dibble, DeJoseph, & Chinn, 2009), health disparities of HIV-positive men (Krehely, 2009), and the prevalence of heterosexism in healthcare and among healthcare providers (Morrison & Dinkle, 2012). Because of this omission, the findings from this study regarding perceptions of physician care add a new dimension and perspective to the conversation on perceptions of physicians, but by the partners of HIV-positive patients, and not the patient themselves. This opens the door for other researchers to complete follow up research on this population and continue the contribution to the literature regarding this unique group.

Perceptions of Care by Nurses. As stated in Chapter four, the perceptions of the participants and how they evaluated the interactions they had with nurses was vastly different than their perceptions of those with physicians. Related studies using different study populations do not address perceptions of nursing care. This study represents a unique perspective into how the nurse, and their performance, is viewed through the eyes of the gay life partner of an HIV-positive patient.

Perceptions of nursing care in this study revealed that the participants did not feel valued as the partner of the patient, nor did the nurse take the time to assess the nature of the relationship between the participant and the patient, and lastly that the nurse interacted primarily with patient with acknowledgement of the partner and that the interaction was competent but perceived as "uncaring".

It is important to note that, as opposed to the setting where physician interactions occurred, interactions with nurses occurred almost exclusively in an inpatient setting during a time when the study participant's partner had been hospitalized. Instead of feeling like they were in a relaxed "living-room like" environment, the participants reported the hospital environment as "sterile, neutral, and non-caring". In addition to the negative feelings about the physical environment, they also reported feeling highly stressed due to their partner's illness (reason for admission). It is also worth noting that interactions with physicians were more consistent, meaning that many participants' partners had had the same physician for many years, meaning that those physicians had ample opportunity to build rapport and were able to obtain privileged and private information regarding the participants, including the nature of their relationship (i.e. same-sex partners). Lastly, as a nurse who understands the dynamics and barriers that

nurses face, it is important to remind the reader that nurses, due to work schedule, scheduling of patient assignments, a multiple patient workload, and/or the requirement to float to other areas in the hospital, often do not have the same opportunity to get to know patients on as intimate a level as their physician colleagues. Therefore, physicians' interactions with study participants were more frequent, personal, intimate, and were developed and sustained over a much longer period of time.

Nurses who encounter two men in a hospital room may not always be clear about the nature of that relationship, and because some may feel uncomfortable asking about the nature of the relationship, or feel like it might be an invasion of a patient's privacy, might not avail themselves of the opportunity to assess the nature of the relationship. In addition, the literature suggests that some nurses may be homophobic, or adhered to a heterosexist paradigm regarding patients and patient care (Dinkle, et al., 2007; Morrision & Dinkle, 2012), leading to unequal treatment, and in some cases outright discrimination.

The participants in this study did not suggest that homophobia or heterosexism were at play regarding their treatment by nurses, nor did they refer to any overt forms of discrimination, leading one to believe that the experiences reported by other LGBT individuals (Ibid) does not mirror the experiences of these study participants. What must not be overlooked, however, is that the way nurses are expected to interact with patients and their significant others is firmly grounded in Peplau's (1997) mid-range theory of interpersonal relations. This theory began as a way for psychiatric nurses to begin to build rapport with their patients, but was later expanded to include nurses in all specialties and all settings. The stated purpose of this theory is to improve nurses' relations with patients and is achieved through the nurse's understanding of his or her

own behavior, helping others identify personally experienced difficulties, and applying

principles of human relations to the problems that arise in the context of relationships.

One of the primary assumptions of this theory is that it is the nurses' responsibility to

assess and intervene based on the needs of the client (Ibid). Based on the interview data,

the participants in this study suggested that this did not happen with them.

Implications

Disclosure

The dual issues of HIV serostatus disclosure both from a partner-to-partner

perspective as well as use of a decision-making process regarding HIV-positive

serostatus disclosure outside of the relationship is of value to both the research

community, and to those who practice in the applied fields. For researchers, it has some

explanatory value into the decision-making process for outside HIV serostatus disclosure

issues and may be used to help both researchers and participants understand the issues

involved in the HIV disclosure debate. There is also opportunity for theory building in

this area as this data has helped lay the foundation for the identification of a formal

decision-making process that gay men may use in deciding with whom to share their

partner's HIV serostatus, and could be taken to the next step through further study of this

study population to determine if individuals in similar situations would validate the

findings from this study. For practitioners it means emphasizing and making an effort to

build appropriate rapport with same-sex partners of HIV-positive men in order to better

assess and meet their emotional needs surrounding support and disclosure issues It also

means finding innovative ways to assess how participants make disclosure decisions, why

they make the decisions that they do regarding disclosure, and in assisting those

individuals in coming to terms with their emotions and rationale when grappling with the questions of how, why, with whom, and when to share private and potentially damaging information regarding their partner's HIV serostatus. This is especially true when the individual whose partner has HIV disease is in a setting where he is not the primary patient.

Influences on Daily Routine and Coping

The usefulness of these data to society, the research community, and practitioners of the social, behavioral, and healthcare sciences has many implications. The first implication is that life for the individual whose partner has HIV disease will never be "normal" despite the repeated wishes of the participants for a normal life. When faced with issues of acute illness, loss of income or employment, fear of discrimination, isolation, fear of contracting HIV, and a rather uncertain future (HIV still has no cure, although mortality rates are much lower that they once were), the need for support outside of the relationship to assist with coping with current stressors, development of new and perhaps more effective coping mechanisms (one participant relied heavily on alcohol as a coping behavior), feelings of isolation, and the need for enhanced education regarding how to better navigate a relationship that must deal with a myriad of daily challenges and stressors, the partner of an HIV-positive individual can himself become "paralyzed" with feelings of not being able to cope and is at higher risk for a decay of both physical and mental health. Scott summarized the feelings of many of the participants when he stated: "…it's hard to refill the emotional well in myself".

This means that the data from this study could possibly be used to (a) increase awareness of the needs and challenges faced by this population; (b) be used to help the

partners of HIV/AIDS affected men develop more effective coping mechanisms; (c) ameliorate the negative effects of stress and isolation; (d) provide needed education that the study participants identified as lacking; and (e) assist the participant in identifying and developing skills and behaviors that will better allow them to "normalize" their lives.

Another implication is the opportunity for advanced and detailed HIV education that encompasses HIV pathophysiology, HIV medications and side effects, and HIV transmission. Most of the participants expressed knowledge of the major HIV transmission routes but had many doubts about the modes of transmission that were less well known or published. Study participants also stated that their HIV-positive partners who had access to HIV medical specialists were generally well informed about HIV issues (transmission, pathophysiology, meds, etc.). Unfortunately, this did not always translate to the study participant being well informed, and some participants even stated that they were asked to leave during educational sessions, or were not present when HIV education opportunities presented themselves. While the need for focused education in these areas was somewhat met by the medical community for a few of the study participants, the rest, most of whom did not have direct access to physicians who specialized in HIV disease, sought information elsewhere, such as the internet, but either did not always trust the information they found there or there was insufficient detail to fully answer the questions that they had. This necessitated the need for confirmation from a healthcare provider or community-based HIV/AIDS organization that could corroborate the information on HIV transmission that they were finding on the internet. Healthcare practitioners have an invaluable opportunity to recognize the same-sex partner of an HIV-positive patient as a legitimate and invaluable asset in supporting both the

patient and the partner in focused HIV information and care. This opportunity not only meets the needs of the patient but the partner as well in providing comprehensive family-centered care.

A third implication based on the findings from the study sub-themes is that of educating the public regarding the needs of gay partners of HIV-positive men and helping to change societal views in this area. While tolerance for the gay HIV-positive individual has changed for the better in the last 10 years, some people still have the belief that their HIV infection is a moral issue, that this happened because the gay HIV-positive person was sexually active with many (most same-sex) people, and that those who are in a primary partnership with an HIV-positive individual are equally culpable.

Findings from studies such as this one can be used by nursing leaders, healthcare practitioners, nursing educators, and community agencies to help communities understand that helping these vulnerable members of their community maintain mental and physical health, allows them to more fully engage, participate, and contribute to the communities in which they live, and ultimately strengthens the community as a whole.

Perceptions of Physician and Nursing Care

Implications for Physician Care. The implications regarding the participants' perceptions of physician care are threefold and include: (a) that physicians should continue to recognize the patient's partner as a valuable resource and as someone deserving of time and education during the interaction with the HIV-positive patient; (b) other healthcare providers should strive to emulate the behaviors modeled by these physicians; and (c) physicians should regularly reassess the knowledge deficits and education needs of the study population as many of them still voiced concerns regarding

HIV transmission, HIV medications, HIV treatments, HIV testing recommendations especially regarding frequency, and risk evaluation of current sexual behaviors, and recommendations for ways in which the study participants can continue to prevent HIV transmission and safeguard their health.

Study participants emphasized their desire to be actively involved in their partners' care, and felt "validated and useful" when this occurred. They also expressed the need to be identified as the patient's partner and wanted to be treated as someone with the social standing inherent with that designation, including being actively involved in the plan of care and being privy to information and education that might affect (both positively and negatively) the health of their partner. Most of the participants also expressed a desire for being recognized and treated as someone with legal rights when it came to their partner, although most acknowledged that they were aware that they did not have the same legal rights as a heterosexual married couple. Still, their desire to be treated as if they did have those rights was apparent in their comments regarding this issue. In short, the study participants' desire to be *recognized* as the "spouse" of their gay partners, emerged as being so important to them that those who recognized this status as privileged were perceived in a positive light, and those who did not take the time to either inquire about their status with their partner, or who did not recognize their status as privileged, were perceived in a negative light. This was true even when the participants stated that other aspects of the care were good.

Implications for Nursing Practice. Given the inequities of setting and structure in comparing positive perceptions of MD interactions with not so positive nursing interactions by the study participants, the implications for nursing practice are quite clear.

Nursing practice is based on the belief that patients are best treated in a therapeutic milieu that includes patient preference, patient autonomy, setting, and inclusion of the patient's significant other(s) (Potter & Perry, 2011). This is not a new concept and nurses have embraced the notion of "family-centered care" for decades. What is new, however, is the changing social climate regarding same-sex relationships, social acceptance, and legal rights. Nurses would benefit from being informed about both the social and legal changes regarding the desires, needs, and rights of same-sex couples. The need to simply be acknowledged as one half of a same-sex couple was so clearly articulated by the participants of this study that a practice that all RNs could adopt would be to assess the nature of the relationship when coming in contact with a male couple in the inpatient setting before doing almost anything else. Most of the study participants stated that they gave subtle, as well as not so subtle clues as to the nature of their relationship which included, holding hands, sitting in bed with the patient, and other verbal and non-verbal cues. If a nurse is astute in learning to read these cues, he/she can easily broach the subject regarding the nature of the relationship by referring to one or more of these behaviors. It cannot be overstated, based on the response of the study participants, how important it is for the nurse to take this first step in what would most likely lead to the halo effect, meaning that all other aspects of the nurse and their care would be viewed through this positive lens, and would go far in establishing early and lasting rapport.

One study found that gay persons often face the assumption that they are heterosexual unless and until they state otherwise (Sinding, Barnhoff, & Grassu, 2004). Nurses are in a crucial position to combat the notion of heterosexism commonly

encountered in the healthcare system and by healthcare providers, meaning that the assumption is that all patients are heterosexual unless otherwise revealed (Morrison & Dinkle, 2012). Once the nature of the relationship is established another important implication would be for the RN to actively include the partner in care planning, medication, treatment, discharge, preventative, and follow-up care and educational issues. The benefits of including the patient's significant other(s) in care decisions and education are clearly articulated by nursing experts, and it is clear that same-sex couples have the same needs as those of their straight counterparts (Eliason, DeJoseph, Dibble, Deevey, & Chinn, 2011). A number of studies regarding nurses' attitudes and perceptions regarding gay patients have been published in recent years (Neville & Hendrickson, 2008), and it should come as no surprise that homophobia exists in nursing as it does in other parts of society. Nurses who struggle with this belief can seek guidance from a trusted mentor in learning ways to focus on the health of the patient and his partner rather than the moral implications (Arnold & Boggs, 2010).

Researcher Reflections

As the researcher for this study I have had a lifelong passion for HIV issues and have dedicated a large portion of my life to combating ignorance about HIV issues, especially in the areas of HIV transmission, homophobia, and helping raise public awareness of the many issues, barriers, and challenges faced by those individuals living with HIV disease. I have volunteered in HIV/AIDS organizations since 1985 and have performed many hours as a volunteer, acting as: HIV counselor (pre- and post-HIV testing), food bank volunteer, board of trustee's member, HIV housing assistance, an HIV buddy, and respite care volunteer. During my PhD program I was introduced to the

concept of secondary HIV stigma, and because I have had personal experience in this area as an HIV volunteer, developed an interest in studying this phenomenon. Finally, because of my personal interest and experience with both HIV-related and secondary HIV-related stigma, I went to great lengths to make sure that analysis and interpretation of the study findings were not influenced by my interest in this phenomenon. My research chairperson and dissertation committee members were instrumental in assisting me with this endeavor. The research question that was chosen opened up new opportunities for learning about a population with whom I had little previous exposure: gay partners of HIV-positive men in a committed relationship. The interviews with these men provided new insight into the challenges faced by them, and I felt privileged to have had the opportunity to interact with them and to learn about their experiences during their journey with their HIV-positive partner.

Suggestions for Future Research

This qualitative study was conducted using an interpretive descriptive approach. Because little was known about the research question prior to this study, I was able to use an unstructured interview process, allowing the participants the freedom and leeway to talk about any topic of their choosing regarding the question of what it was like living with an HIV-positive partner. Many of the findings from this study represent new data regarding this population that is found nowhere else in extant literature. However, because there are few other studies similar in nature to this one, there is ample opportunity for further research related to this research question and for this research population. Few researchers have utilized this population when studying gay couples or HIV disease and further research using this population would be helpful in generating

new findings and knowledge about their insights into the current state of the gay male relationship where one partner is HIV-positive. This study was conducted in a large urban area in the western USA, and the findings reflect the current socio-political environment in that area. Similar studies conducted in rural areas or in other regions of the USA could potentially uncover new insights into this population and could act as a comparison and companion to this study. Three themes were identified in this qualitative study, and based on those themes, the opportunity exists to conduct quantitative research studies to help quantify and understand those phenomenon using different methodologies and approaches. Finally, little research has been conducted by nurse researchers in the area of gay, lesbian, bisexual, and transgender (GLBT) issues. Based on the recommendations of this study, there is ample opportunity for other nurse researchers to conduct further research in settings where services and care are actually provided to this population.

Strengths and Weaknesses

Strengths of Study

The strengths of this qualitative study were based on the adherence to and rigor in the use of the interpretive descriptive approach. This approach allowed me, the researcher to explore the perceptions of a population that had not been well represented in the HIV/AIDS literature. The particular strengths of this study included: (a) useful for describing a phenomenon not well studied in current literature; (b) useful for studying a limited number of cases in depth; (c) useful for describing a complex phenomenon; (d) provided individual case information; (e) provided understanding and description of study participants' personal experiences of the phenomenon (the emic or insider's viewpoint); (f) data was collected in a naturalistic setting; (g) data was generated in a

grounded way which could be used in a tentative but explanatory theory about the phenomenon; (h) data was based on the participants' own categories of meaning; (i) thick description was achieved that allowed for detail and specificity in the analysis of the data; (j) the data from this study was collected in a specific geographic area that could be utilized in a way that might be responsive to local situations, conditions, or needs; (k) the interpretive descriptive approach used was useful in generating implications for the discipline of nursing as well as other disciplines; and (l) the sample size, though smaller than desired, achieved both depth and breadth (Holloway & Wheeler, 2006; Creswell, 2009; Denzin & Lincoln, 2005; Thorne, 2009).

Weaknesses of Study

The weaknesses of the study included: (a) the knowledge and insights produced might not generalize to other people or other settings; (b) the data collection and analysis process was time consuming; (c) recruitment for the study population proved to be more difficult than anticipated resulting in a smaller than desired sample size; (d) the analysis process and subsequent results might be more easily influenced by the researcher's personal biases; (e) when referring to nurses, it was unclear whether the participants were referring to registered nurses or licensed vocational nurses; and (f) participants over the age of 60 could have been included in the study to increase breath even more (Holloway & Wheeler, 2006; Creswell, 2009; Denzin & Lincoln, 2005; Thorne, 2009).

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Appendices

Appendix A

Demographic Data of Participants

Participant	Participant's Partner	Age	Number of Years in Relationship	Level of Education
Ryan	Allan	52	5	4 years College (Bachelor's Degree)
Robert	Jamie	53	27	High School Diploma
Scott	Michael	43	8	7 years College (MBA)
Bruce	John	35	10	4 years College (Bachelor's Degree)
John	Brad	45	8	4 years College (Bachelor's Degree)
Bryce	Ken	51	1.5	7 years College (MFA)
Tom	Sam	26	1	High School Diploma
Glenn	Lance	52	10	7 years College (Master's Degree)
Jim	Brian	51	15	4 years College (Bachelor's Degree)
Derek	Gregory	49	11	4 years College (Bachelor's Degree)

Demographic Data Form

Demographic Data Form

1. How old are you? _____

2. What is your city of residence? _____

3. How would you describe your ethnicity? _____

4. What is your current level of education? _____

5. What is your yearly household income? _____

6. What is your religion? _____

7. What is your occupation? _____

8. For approximately how long have you been in this relationship? _____

9. Are you legally married? Yes_____ No_____

10. In which State were you married? _____

11. If you are not married, have you been through a commitment ceremony? Yes___ No___

12. How would you describe your current health status? _____

_____

Research flier

You are invited to participate in a research study involving gay men in a committed relationship!

Jon Christensen PhD(c) is a doctoral student at the University of San Diego involved in research that focuses on issues that affect gay men.

The purpose of this study is to learn more about issues faced by gay men in committed partnerships or marriages: specifically, partners or spouses of men who are HIV positive or who have AIDS.

You are eligible if:

❖ You have been in a committed gay relationship or marriage for at least six months.

❖ You are at least 18 years of age.

❖ Your partner or spouse is HIV positive or has been diagnosed with AIDS.

❖ Your primary residence is in the state of California.

The research involves one hour of your time to conduct a one-on-one audio taped interview at your home or a location of your choosing.

If you are interested in sharing your story about living with an HIV positive partner please call, text, or email Mr. Christensen at 323-363-7645; jchrist4@sbcglobal.net

Appendix D

IRB Consent Form

University of San Diego

Consent to Participate in Research

I invite you to participate in a research study conducted by Jon Christensen, a PhD student in the Hahn School of Nursing at the University of San Diego (USD). Dr. Mary Rose Mueller is the USD faculty advisor for this study and can be reached at (619) 260-4572. Your participation in this study is voluntary. Please read the information below, and ask questions about anything you do not understand before deciding whether or not to participate.

- **PURPOSE OF THE STUDY**
Past research has shown that individuals living with HIV disease and/or AIDS face discrimination due to stigma. More recent research has shown that those closely associated with individuals living with HIV disease and/or AIDS also face discrimination. This type of stigma is called stigma by association or courtesy stigma. Some research has been done in the area of courtesy stigma, but to date, there is little known about gay men in a committed partnership whose partner has HIV disease and/or AIDS.

You are being asked to participate in this study because your partner has HIV disease and/or AIDS, and your experiences as a partner of someone living with HIV/AIDS will help nurses like me, and other caregivers, learn more about the issues faced by you and others in your situation. Results of this study may help illuminate discrimination faced by people like you with the hope that these results will help eliminate or decrease the incidence of courtesy stigma and discrimination.

- **DURATION AND LOCATION**
Your participation in this study will consist of an interview with me that will last for approximately one hour to one and a half hours during one day. This study will be conducted at your home or at a location of your choosing where confidentiality can be maintained. You will not be asked

to share things during the interview that you are uncomfortable talking about.

- **PROCEDURE**

  If you volunteer to participate in this study, the following things will be important for you to understand and consider:

  1. Read this consent form and ask any questions. Sign the consent form if you desire to participate.

  2. The interview will be recorded using a digital recording device. If at any time during the interview you feel uncomfortable or anxious please let me know and the interview will be stopped or postponed.

  3. The taped recording will be heard only by myself and will be kept in a locked file cabinet at all times when I am not using it. No one else will have access to the recording at any time. The recording will be destroyed at the end of this research study.

  4. You will be identified using a pseudonym (fake name) only. At no time will your real name be used or connected with your recording. Your anonymity will be ensured at all times.

  5. If you become fatigued during the interview, the digital recorder can be turned off until you feel rested enough to resume the interview.

  6. You will be given a copy of the full informed consent form.

  7. You participation in this research is entirely voluntary.

- **POTENTIAL RISKS AND DISCOMFORTS**

  There is a risk that you may share some personal or confidential information by chance, or that you may feel uncomfortable or become anxious while talking about some of the topics. Remember that you do not have to talk about anything that you do not wish to share.

- **ANTICIPATED BENEFITS TO SUBJECTS**

  There will be no direct benefit to you, but your participation is likely to help me find out more about courtesy stigma experienced by you and others who are in a similar situation.

- **CARE FOR RESEARCH RELATED DISTRESS**
  If at any time during the interview process you experience anxiety that becomes uncomfortable or uncontrollable, please contact your personal health care provider, or call the National Alliance on Mental Illness (NAMI) hotline number

where a mental health professional can assist you. The NAMI hotline number in California is: (916) 567-0163.

- **CONFIDENTIALITY**

    When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. Your identity will be protected at all times.

    Your information will be kept confidential and secure by keeping forms in a locked file cabinet. All subjects will be identified by a code number. The list of code numbers with the subject names will be kept in a separate lock box in a different location. All data entered into computers will be password protected. This information will be stored only for the duration of the study and then destroyed.

I have read the foregoing information, or it has been read to me. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction. I consent voluntarily to be a participant in this study

Print Name of Participant_____

Signature of Participant _____

Date _____

        Day/month/year

I confirm that the participant was given an opportunity to ask questions about the study, and all the questions asked by the participant have been answered correctly and to the best of my ability. I confirm that the individual has not been coerced into giving consent, and the consent has been given freely and voluntarily.

 A copy of this consent form has been provided to the participant.

Print Name of Researcher_____Jon Christensen_____

Signature of Researcher _____

Date _____

            Day/month/year