

“I’m Part of this Family”: How Five Care-Giving Partners of Gay Men

Story their Experiences

by

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Abstract

This study, whose purpose was to develop insight into the experiences of gay care-givers, examined how five Canadian care-giving partners of gay men storied their experiences, or how they constructed their subjective realities in the form of narratives. The five participants, all of whom were recruited either directly or indirectly with the help of community agencies, took part in two in-depth semi-structured interviews designed to invoke narratives relating to their identification as care-givers, their experiences mitigating challenges and encountering rewards, and their overall stories as gay carers. Though each of the participants' stories was analyzed individually, a cross-case analysis revealed a number of common themes spanning the respondents' stories. These realities included perceiving “choice” in committing to care, experiencing anticipated, felt, and overt expressions of homophobia and heterosexism, valuing gay-friendly sources of support, and constructing unique definitions of “family” and “partnership” in the context of care. A close analysis of the study's findings suggested that though many of the participants appeared to story complex issues found in the context of same-sex caring partnerships by attributing subjective meaning or significance to these realms of experience, an intricate array of structural factors also appeared to influence how these carers storied their lives as gay care-givers. Implications of the study's findings on social work practice at various levels of intervention, as well as recommendations for the pursuit of future research in related fields of inquiry, were outlined.

Preface

All procedures of this research were carried out with adherence to the guidelines and ethical grounds for research involving human subjects presented by the University of British Columbia Behavioural Research Ethics Board. Approval was granted under the certificate number H10-03042 by the Behavioural Research Ethics Board.

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Chapter 1 - Introduction

The study of informal care-giving, particularly in the context of illness, has expanded substantially in recent years as a recognized area of academic inquiry. This trend may be attributed to a number of factors. Most apparently, increases in populations of older adults across the developed world (World Health Organization [WHO], 2010; WHO, 2011) have prompted the emergence of a growing body of literature that specifically addresses the needs of this demographic (Cahill, 2007), as well as the perspectives of those informally involved in the care of frail or ailing seniors (Globerman, White & McDonald, 2002; WHO, 2010). WHO, for instance, has indicated that adults over the age of 80 comprise the fastest growing population in developed nations (WHO, 2011), and that such demographic patterns reveal the need for movements in research and policy that specifically recognize the informal support networks of elderly adults with physical and other caring needs (WHO, 2010).

Although some research has indeed attributed heightened interest in the realm of care-giving to demographic trends, some evidence also suggests that informal care-giving is becoming a particularly salient phenomenon as Western welfare states reduce services in an era of economic globalization, and accordingly, replace formal community services with kin-based care (Brann-Barrett, 2010; Caldwell, 2007; Globerman, White & McDonald, 2002; Greaves et al., 2002; Hankivsky, 2004; Kadushin & Egan, 2005). For instance, in their study of social workers serving American home and community care patients, Kadushin and Egan discovered that not only were patients with complex psychosocial needs often neglected by virtue of increasingly limited system resources, but also that the presence of “family care” among these service users constituted a significant predictor in the “claw back” of needed services. Although Kadushin and Egan's work represents the realities of service provision in the United States, some evidence suggests that Canada's health and social service infrastructure is marked by similar issues. For instance, Greaves et al. have documented the increased strain on (primarily female) Canadian kin-based care-givers supporting palliative patients as publicly-funded

health care services become progressively over-wrought with system-wide resource shortages.

In light of the many factors that may be prompting a heightened interest in care-giving research, a review of literature on informal care reveals that indeed this phenomenon is now considered a relevant and worthwhile area of inquiry. Despite this emerging interest, however, few attempts have been made to explore the experiences of lesbian, gay, and bisexual (LGB) care-givers (Fredriksen, 1999; Hash, 2001; Hash & Cramer, 2003). Although the pursuit of such research may at first appear unnecessarily specific, and therefore not a relevant dimension of the care-giving experience, the limited research that currently exists on LGB care implies the contrary. Specifically, this growing body of literature has revealed that non-heterosexual care-givers are often exposed to realities that are particular to sexual minorities, including expressions of homophobia and heterosexism, and that therefore their experiences are likely to yield perspectives not yet addressed in mainstream care-giving research (Fredriksen-Goldsen & Hoy-Ellis, 2005; Hash & Cramer, 2003).

Based not only on the relevance of exploring informal care for service providers (including social workers), but also more specifically on the potential need for further inquiry into the experiences of non-heterosexual care-givers, I examine the experiences of five Canadian same-sex care-giving partners of gay men, and specifically explore how they “story” their experiences, or how they construct their subjective realities in the form of narratives. In sections that follow, I will attempt to provide further justification and rationale for my decision to examine this particular realm of experience, and then delineate issues of importance that have surfaced during the course of this study. Prior to engaging in this discussion, however, I outline definitions of terms and constructs that I will use throughout this paper. I also clarify the social and historical contexts that underpin the study, as well as the epistemological assumptions that govern the primary research objective being pursued. Such a foundational analysis will serve as a basis for positioning and framing components of the study that I intend to develop in greater depth as I engage with the stories of five gay care-givers.

It is important to note, at this point, that the study is particularly concerned with the “storied” experiences of illness-related care-giving among gay men. Justification for focusing exclusively on narrative realms of experience, as well as this specific demographic, will be provided more substantively as the study's primary research objectives are explored at greater length in later sections of this paper.

Definitions

Caring and Care-Giving. Since, first and foremost, this study is concerned with the experiences of giving care, I begin this section by substantively defining the construct of informal “care-giving” as it is used in the scope of this study. Prior to fully discussing my theoretical conceptualization of care-giving, however, I wish to more fundamentally clarify that although I understand care-giving to refer to several exemplars of “care,” including for instance child-rearing (Noddings, 2002; Tronto, 1993), this study explicitly refers to expressions of care-giving, among adult care-recipients and care-providers, that are located in the context of illness.

Pearlin, Mullan, Semple and Skaff (1990), whose work has often been considered seminal in care-giving literature (Chappell & Reid, 2002; Knight, Lutzky & Macofsky-Urban, 1993), distinguish “caring” from “care-giving” in conceptualizing this field of study. Caring, they suggest, refers to the affective component of an individual's commitment to the well-being of another, whereas care-*giving* relates more specifically to the behavioural expression of this relational bond. Further, they argue that although both of these constructs are likely to be found in a wide array of primary relationships, including kin-based ties and informal friendships, the practice of care-giving may become particularly pronounced in circumstances (including illness) that distribute the “burden of care” disproportionately on one person in a relational field. According to Pearlin et al., it is within these situational contexts that care-giving, as an extension of one's natural caring role, may become a significant dimension of one's identity and experience, and therefore also become relevant as a focus of inquiry.

Though Pearlin et al.'s (1990) conceptualizations of “caring” and “care-giving” have predominated in mainstream care-giving research (Chappell & Dujela, 2009; Chappell & Reid, 2002), theorists associated with an emerging body of literature have criticized definitions posited by these early writers (Molyneaux, Butchard, Simpson & Murray, 2011; O'Connor, 2007). O'Connor, for instance, who has explored the processes through which care-givers might come to position themselves as carers, has determined that informal care providers are likely to label or ascribe meaning to their caring roles when they interact with others in similar circumstances, and in fact may not reference perceived issues of “burden” when they assign significance to their caring activities. Indeed, as O'Connor discovered in her study, carers may, in the absence of such interaction, consider their provisions of support and assistance to simply constitute extensions of their relational roles (e.g., “spouse” or “child”). Molyneaux et al. have expanded on this critique by suggesting that carers may altogether sense discomfort in identifying with care-giving identities that are associated with stress and burden, and may instead choose to preserve care-recipients' relational identities by “giving care” in contexts that do not construct “receivers” of support as sources of strain. They have also deconstructed the dichotomy implicit in earlier distinctions between “care-givers” and “care-receivers” by arguing that caring relational contexts may not in fact reflect this binary, and that instead, “caring roles” might be considered reciprocal by many who provide and receive care. The position implied by both O'Connor and Molyneaux et al. is that the definition of “caring” and “care-giving” may depend on the relational contexts that carers find themselves in, and consequently, that such definitions may vary substantively based on the construction of care-givers' subjective experiences.

In this study, I choose to adopt conceptualizations of “caring” and “care-giving” developed by O'Connor (2007) and Molyneaux et al. (2011), and therefore attend to how individual self-identified “care-givers” might subjectively understand and define these terms. In other words, other than specifying my focus on caring activities found in the context of illness, I consciously avoid defining the

parameters of what might constitute “caring” and “care-giving,” and instead emphasize participants' subjective definitions of these terms. This decision is based on the reality that limited research has been conducted on the experiences of non-heterosexual carers (Hash, 2001; Fredriksen-Goldsen & Hoy-Ellis, 2005), the notion that these realms of care may be uniquely shaped by homophobia and heterosexism (Hash & Cramer, 2003), and therefore the potential need to afford greater attention to the subjective interpretations of “care-giving” that may be held by lesbian, gay, and bisexual care-givers. Importantly, throughout this study, the terms “care-giver” and “care-giving” are hyphenated, particularly in order to acknowledge that many carers do not explicitly associate with the potentially static label of “caregiver,” but instead “give care” in a complex and ever-changing relational context in which identities are constantly negotiated and (re)constructed (O'Connor, 2007). Further, although distinctions have often been made between “caring” and “care-giving,” particularly by Pearlin et al. (1990), I choose to use these terms interchangeably throughout the study for the purpose of convenience.

“LGB” and “Gay”. So far, I have referred to the acronym “LGB” to discuss the umbrella of non-heterosexuality commonly understood as gay, lesbian, and bisexual, and I have additionally employed the word “gay” to more specifically describe same-sex attraction or orientation among men. In this section, I wish to thoroughly clarify my use of these terms, particularly since the construct of “LGB” will be invoked regularly in my review of relevant literature, and more importantly, since the word “gay” will be used to discuss a key concept embedded in the design of this study.

“Homosexuality,” as a term, was originally coined in 1869 by Karoli Maria Kertbeny, a Hungarian journalist, in response to the passing of a Prussian law intended to criminalize sexual behaviour between men (Drescher, 2010; Katz, 1995). Kertbeny had originally developed the word to normalize varying expressions of sexual identity and thus to argue against the legitimacy of sodomy laws, despite subsequent appropriation of this label by state institutions engaged in regulating

“homosexual deviancy” across Europe and North America (Drescher, 2010). Though the terms “gay,” “lesbian,” and “bisexual” emerged several years following the “creation” of homosexuality as an identifier, the development of these terms was similarly prompted by a perceived need to challenge discriminatory practices targeting non-heterosexuals. Indeed, as Wong (2011) has explained, the construction and use of “LGB” labeling emerged as a means for challenging state-sponsored persecution of sexual minorities in large American urban centres during the 1960s. In using the terms “lesbian,” “gay,” and “bisexual,” according to Wong, non-heterosexuals were not only more capable of organizing politically, but were also effective in fostering a shared consciousness of “homosexuality” that sought to counter dominant discourses of “sexual deviancy.” At present, the identifiers associated with “LGB” lexicon are widely used, and though they are thought to represent certain contemporary expressions of homosexuality, they are also said to reflect the historical realities of twentieth century “queer” movements that took place across the Western world (Altman, 1996; Wong, 2011).

In light of the issues I have invoked, I recognize that the terms “LGB,” “gay,” “same-sex attracted,” and “non-heterosexual” may each carry distinct cultural, political and historical connotations (Altman, 1996; Turner, 2000; Wong, 2011). Though I use these constructs interchangeably in the context of this study to refer to same-sex attraction or orientation for the purpose of convenience (with “gay” referring specifically to the expression of such phenomena among men), I do so with sensitivity to the possibility that participants and readers may ascribe unique interpretations to each of these identifiers. I recognize, in other words, that these labels may not necessarily represent realities that are fixed and easily-defined, and that instead, loosely imply shared experiences associated with non-heteronormative delineations of sexuality. Further, though I acknowledge that “queer” lexicon often includes “transgender” under the umbrella of non-heterosexuality (“LGBT”) (Cahill, 2007), I explicitly choose not to incorporate gender identity issues in the scope of this study. I consciously adopt this position since appropriately acknowledging the experiences of trans-identified persons would require

distinct frames of analysis that adequately address issues of gender expression and identity, and not necessarily matters of sexual orientation, among transgender individuals (Williams & Freeman, 2005).

Homophobia and Heterosexism. The final set of terms that may require some definition include the constructs of “homophobia” and “heterosexism,” particularly since the apparent presence of these factors in the lives of gay carers constitutes part of the rationale for conducting the study. Originally, the word “homophobia” was developed to refer to an irrational fear of sexual minorities, and more specifically, a dread of being in close quarters with lesbian women, gay men or bisexual persons (Weinberg, 1972). Although the construct of “homophobia” has historically been criticized for its potential alignment with diagnostic conceptualizations of “phobia” (Herek, 2000; Shields & Harriman, 1984), the meaning of the word has grown over the years to broadly represent discrimination or prejudice against sexual minority groups (Dermer, Smith & Barto, 2010). Indeed, in this paper, the term “homophobia” is used to represent expressions of discrimination that relate in some way to issues of sexual identity.

Whereas the term “homophobia” has evolved to signify overt hostility against sexual minority groups, the construct of heterosexism has been developed to refer to the systemic privileging of heterosexuality, or to the notion that “straightness” is ideal and preferred (Herek, 2004; Pharr, 1998). In other words, “heterosexism” has come to describe the ideological influences that maintain systems of hierarchy associated with heterosexual privilege, and that therefore render heterosexuality more acceptable than same-sex sexual orientation. Though the distinction between homophobia and heterosexism may, on the surface, appear insignificant, employing the construct of heterosexism is often helpful in locating systemic sexuality-related issues that would likely otherwise remain invisible and covert (Herek, 2004; Pharr, 1998), particularly within relatively unexplored realms of reality, of which gay care-giving is one (Hash, 2001; Hash & Cramer, 2003).

Issues of Sexual Orientation in Canada

So far, I have introduced this paper by defining key constructs associated with the study at hand, and in so doing, have devoted significant time to explaining frames of references related to sexual orientation and identity. Despite my attempt to substantively explain issues of non-heterosexuality more broadly, however, I have yet to discuss how these realities may specifically be contextualized in the social and historical fabric of Canadian society. I recognize the importance of outlining how non-heteronormative sexuality might be understood and experienced more locally in Canada, particularly as expressions of sexual orientation and identity, as well as manifestations of homophobia and heterosexism, often vary significantly depending on the cultural, legal, and historical contexts in which they are located (Altman, 1996; Foucault, 1990; Wong, 2011).

Similar to several other Western nations, “homosexuality” or same-sex sexuality may have first formally surfaced in Canadian public life upon the introduction of “buggery laws” that were intended to prohibit sexual activity between men (Warner, 2002). According to Warner, these laws, which had originally been created in Britain to support and enforce the protestant church's position on same-sex sexual behaviour, were formally adopted by the Canadian colonial government in 1859 via the Consolidated Statutes of Canada, and recognized same-sex sexual activity among men as an offense punishable by death. Interestingly, sexual behaviour between women was not acknowledged in any realm of public discourse at this time (Warner, 2002). After being reclassified as an “offense against morality” in 1892, particular acts associated with male homosexuality were eventually decriminalized by the Canadian federal government in 1969 (Kinsman, 2010; Warner, 2002).

Kinsman (2010) has noted that although specific sexual acts were decriminalized in 1969, legal protections for sexual minority groups, particularly in relation to sexuality-based discrimination, continued to remain absent for several years following this event. This lack of protection from homophobia enabled state institutions to engage in practices that continued to suppress same-sex sexual

orientation, including, for instance, state-sanctioned police raids on gay and lesbian establishments across Canada's metropolitan centres that were intended to restore “decency” (Kinsman, 2010; Warner, 2002).

Despite the challenges experienced by Canadian non-heterosexuals through much of the twentieth century, the eventual legislative recognition of sexuality-based discrimination in various Canadian provincial jurisdictions, as well as the passing of the Canadian Charter of Rights and Freedoms in 1982, prompted lobbying efforts by lesbian and gay activists to seek sexuality-related protection in Canada's federal human rights framework (O'Neill, 2006; Warner, 2002). Due particularly to the influence of the Charter of Rights and Freedoms, as well as the grassroots movements that took place following the passing of this piece of legislation, Canada's legal human rights framework now explicitly includes issues of sexual identity in its scope of recognized protections (EGALE, 2005; Warner, 2002). This point is particularly relevant to the study being conducted, as Canadian same-sex partners presently have access to a variety of social and legal resources, including marriage, that other non-heterosexuals have yet to access in other regions of the world (GLAD, 2010). For instance, as Hash (2001) has explained, a significant portion of the difficulties now affecting American gay and lesbian care-givers relate to the lack of legal recognition surrounding same-sex partnerships in the United States, and this absence of legal protection may not necessarily be as applicable to the lives of LGB care-givers residing in Canada.

Having described the extent to which same-sex care-giving partners may now be legally protected in contemporary Canada, however, it is important to note that the homophobic and heterosexist realities permeating Canada's past are still very much present in varying manifestations. For instance, as Brotman et al. (2007) have explained in their study of Canadian LGB care-givers, though explicit legal recognition of same-sex care-giving partners may no longer be an issue of concern in Canada, non-heterosexual carers are still likely to encounter discriminatory attitudes by health

professionals and other service providers. Further, heterosexist belief systems are still likely to affect Canadian LGB care-givers who, in the process of navigating support services for their partners, might be required to explain and justify their relational roles to formal systems of care. In other words, the study is being conducted on the basis that homophobia and heterosexism are likely to affect the lives of LGB carers in Canada, though these factors may be somewhat mitigated by social and legal contexts that afford some protection from manifestations of discrimination found in other regions of the world.

Adopting a Constructivist Position

In attempting to thoroughly introduce issues related to the experiences of LGB care-giving, I acknowledge that although I have discussed critical factors that might justify the pursuit of this piece of inquiry, I have not yet explained my own relationship with the study of non-heterosexual care. In this section, I hope to provide a brief overview of my personal experience with the issue under study, and then to discuss the theoretical grounds for engaging in this reflective exercise.

On discussing my subjectivity in relation to this piece of inquiry, I am first inclined to delineate my own social location as a frame of reference that is likely to have shaped the parameters of this study. Being myself a gay social worker employed in health care, I have often been sensitized to scenarios in which care-giving partners of gay patients have explicitly discussed the challenges of providing care in social contexts that they describe as being dismissive of non-heterosexual experience. I have also been witness to countless interactions, specifically between health professionals and informal LGB care-givers, in which service providers appeared to lack an awareness or a recognition of how care-giving and care-receiving may be experienced uniquely in relational contexts that are often systemically undervalued.

One particular incident remains salient with me as a catalyst for first contemplating this study. Once, following my involvement in daily medical rounds, I began discussing a patient's discharge plan with a member of the interdisciplinary team I was working with at the time. After revealing that this

male patient would be returning home to reside with his “husband” (a term used by the patient himself), this team member began laughing dismissively. “You mean his wife,” she replied. I corrected her, and watched surprisingly as she continued finding humour in this brief exchange: “very well then, to each their own.” At this moment in time, I was still new to the hospital environment, and so a number of staff members may have been unaware of my sexual identity as a gay man, including this particular interdisciplinary team member. However, I was awestruck that this attitude had apparently prevailed despite the presence of sexuality-related human rights legislation in Canada (EGALE, 2005), as well as the seemingly increased openness of married gay and lesbian couples within the hospital system I had found myself in.

I began considering that perhaps, homophobia and heterosexism had continued exerting influence on service delivery in health care, despite the human rights legislation and policy, as well as the greater overall tolerance toward sexual minorities, that had permeated Canadian society following the passing of the Charter of Rights and Freedoms (Warner, 2002). However, I was also cognizant of my own sensitivity toward these possibilities, given not only my identity as a gay man, but also my position as a social worker with greater access to dominant discourses located on the “inside” of the medical system. Indeed, since institutional realities can be said to often implicitly reflect the interests of dominant groups, while simultaneously rendering invisible the lives of marginalized “others” (Smith, 1987), I may have on the one hand been privy to language that explicitly demarcated otherwise implicit relations of power, and on the other, “seen” experiences not “seen” by heterosexual health professionals.

Accordingly, I understand that the basis for this study may not only be located in external experiences associated with gay care-giving, but also in my own subjectivity as a gay social worker and researcher. Similarly, I acknowledge that the results of this research may be products of co-construction that are likely to have arisen in my interaction with research participants, since elements of

shared reality have potentially framed how respondents' experiences have been understood and conceptualized. This position is consistent with a constructivist orientation in qualitative research, particularly when one considers the acknowledgment of reality as “co-constructed,” and the abandonment of objectivity, as comprising elemental components of this epistemological lens (Clandinin & Rosiek, 2007; Creswell, 2006; Freedman & Combs, 1996).

Adopting a constructivist position may be particularly appropriate when engaged in research that is concerned with issues of sexuality. Indeed, qualitative research in the field of LGB studies often requires that a researcher adopt a reflexive position in relation to her or his own sexual identity, specifically as the product of such inquiry is likely to be framed and conceptualized entirely differently depending on the extent to which the researcher acknowledges her or his “queerness” throughout the research process (Rooke, 2009; Walby, 2010). For instance, Rooke has insisted that, in her research with lesbian women, her own self-identification as a member of this group, and consequently her recognition of knowledge as “co-constructed,” facilitated a process of inquiry that enriched her rapport with participants and that therefore strengthened the authenticity of her findings.

Rooke (2009) has also suggested, however, that categories of “queerness” are often unfixed, highly contextual, and substantively varied depending on the array of factors that construct a subject's social location. Therefore, although I acknowledge elements of shared experience that might have framed the basis and results of this study as products of “co-construction,” I qualify this understanding with a recognition that the reality I have shared with participants is likely to have been partial. I am cognizant, after all, that I am a health professional, and that my notion of “queerness” may have been differently located on the basis of class and other sources of privilege, specifically in comparison to the realms of experience that may have constituted participants' sexual identities. In adopting a constructivist position, I have relinquished claims to objectivity in recognizing the intersubjective basis and nature of my study, while at the same time, constantly “checking” and re-constructing my

interpretations of these experiences with differently-located participants whose feedback has likely strengthened the authenticity and genuineness of my findings. These processes of acknowledging and practicing “co-construction” will be elaborated on further as I discuss issues of credibility in chapter three.

Chapter 2 - Literature Review

In this chapter, I present the conceptual basis for developing insight into the experiences of five Canadian care-giving partners of gay men, and specifically into how they “story” their experiences, primarily by offering a review of literature relating to this research objective. I begin this discussion by first analyzing three dominant lenses or analytical frameworks that have traditionally governed the study of care-giving, including stress and burden perspectives on care, feminist lenses used to conceptualize caring phenomena, and finally, more contemporary constructivist approaches to inquiring into the experiences of care-giving. In critically examining these three frames of analysis, I explicitly argue that non-heterosexual experience has remained largely absent from the theoretical debates associated with each of these positions, but that constructivist approaches to the study of care may afford greater flexibility in incorporating LGB perspectives on care. Following this reflexive overview of the three dominant orientations to care-giving research, I then outline bodies of inquiry that have, in some capacity, been related to the narratives of same-sex care-giving partners of gay men. Here, I specifically address literature on care-giving among men, on caring phenomena in the context of HIV/AIDS, and finally, on nascent research relating to LGB care-giving. The chapter, through references to the entirety of the literature review, culminates in an explicit justification for studying caring experiences among care-giving partners of gay men. I end the section with a framework for pursuing the research question being considered.

Stress and Burden Perspectives on Care

Though in the preceding chapter, I made brief references to stress-related perspectives on care-giving, primarily by describing traditional definitions of “care” that have been grounded in presumptions of “burden,” I wish to more substantively analyze this theoretical framework in the section that follows. In tracing the origins of this conceptual lens, perhaps it is important to first note the work of Zarit (beginning with the collaborative landmark study by Zarit, Reever and Bach-Peterson

[1980])). Indeed, Zarit's research may constitute a legitimate starting point for discussion on the stress and burden model, particularly as many have ascribed great significance to his work in contributing to the development of stress-related perspectives on care, and more broadly, to the study of care-giving (Braun, Scholz, Hornung & Martin, 2010; Higginson, Gao, Jackson, Murray & Harding, 2010; Knight et al., 1993; Sorensen, Pinquart & Duberstein, 2002).

Zarit's Care-Giver Burden Interview and Its Influence. Zarit's work on care-giver burden comprises perhaps some of the earliest attempts at formally conceptualizing the realm of care-giving, though a few studies had either directly or indirectly addressed care-related issues and experiences prior to the emergence of this research (e.g., Lowenthal et al., 1967; Sanford, 1975). One study led by Zarit et al. (1980) has particularly been deemed seminal in the literature on care-giving (Knight et al., 1993; Sorensen et al., 2002). In this study, Zarit et al. developed (and also tested) an interview protocol intended to assess care-giver “burden,” that was then used to determine relationships between care-giving realities (e.g., the duration of the care-recipient's illness, her/his functional independence, and other factors), and the presence of “burden” or “strain” among care-givers. Though a number of findings associated with this study were considered notable by Zarit et al. at the time of its publication, including the apparent significance of social support as a sole predictor of strain in caring contexts, this study subsequently became highly influential in conceptualizing care-giving as a reality marked by stress and burden (Knight et al., 1993; Sorensen et al., 2002).

Indeed, in the years that followed the release of this study, research on caring and care-giving appeared increasingly concerned with assessing and mitigating the presence of “burden” among carers. In one often-cited study, for instance, Cantor (1983) attempted to measure the prevalence of strain or burden among various types of informal care-givers, including friends, children and spouses, and then determined a need for support services targeting the latter two kin-based groups as carers who appeared to report the greatest burden. Importantly, such considerations of “stress” and “burden” may have had

significant influence on how care-giving was acknowledged and addressed in health care policy at this time. For instance, in a policy position paper by Doty (1986), that was later recognized by Stone, Cafferata and Sangl (1987) as a notable review and appraisal of care-giver policy in the United States, the writer recommended that the primary objective of support services targeting carers include the alleviation of emotional burden or strain. Though all of the above research, inquiry and discussion may have been primarily applicable to American contexts during this time period, several examples exist to suggest parallel trends in Canada. Indeed, whereas a Canadian body of research relating to the experiences of care-giving was slow to emerge, a number of the early Canadian pieces associated with care-giving literature included explicit references to notions of stress and burden (CSHA, 1994; CSHAWG, 1994; Yaffe, 1988).

Interestingly, because Zarit et al.'s (1980) seminal study was aimed at examining issues of distress among carers of older adults with cognitive impairment, this research prompted others to specifically focus on the prevalence and nature of stress-related experiences among care-givers of people with dementia (George & Gwyther, 1986; Haley et al., 1987; Kiecoltglaser, Glaser, Shuttleworth, Dyer, Ogrocki & Speicher, 1987; Rabins, Mace & Lucas, 1982). For instance, George and Gwyther (1986), with reference to the work of Zarit et al., attempted to ascertain the “actual” impacts of caring for persons living with dementia, specifically by measuring elements of “well-being” among dementia care-givers and non-carers, and then by comparing these two sets of measurements to isolate care-giving “burdens” among dementia carers. Aside from prompting dementia-specific research in the field of care-giving, however, the emergence of stress and burden perspectives on care also triggered research that was aimed at assessing gendered differences in “care-giver burden” for the first time (Fitting, Rabins, Lucas & Eastham, 1986; Pruchno & Resch, 1989), as well as inquiry intended to assess the effectiveness of stress-alleviating interventions for care-givers (Gallagher, 1985; Toseland & Rossiter, 1989).

Despite the influence of Zarit et al.'s (1980) work on the study of care-giving, and the overall expansion of “care” as a recognized field of inquiry following the publication of their research, some began recognizing the need to develop a stronger theoretical basis for inquiry into care-giver burden by the late 1980s (Knight et al., 1993). Indeed, during this time period, Zarit (1989) himself argued that the continued conduct of primarily descriptive quantitative research on care-related “stress” and “burden” would likely not significantly advance knowledge in this area of inquiry, and that consequently, studies aimed at deepening the theoretical basis of care-giving would likely be necessary in their stead. Some, including Callahan (1989), even rejected some of the overall premises of the stress and burden model, by arguing that many interventions aimed at alleviating “care-giver burden” often did not prove effective, and that constructs associated with this model were therefore unlikely to effectively inform practice or policy. It is under these circumstances that literature on “coping,” as opposed to primarily descriptive quantitative research on the prevalence “stress,” began emerging to complement existing studies on care-related burden (Knight et al., 1993).

Care-Giving, the Stress Process, and Coping. Following the recognition of the need to develop the theoretical basis of research on care-giver stress, an attempt was made by Pearlin et al. (1990) to advance this area of inquiry beyond the supposed redundancies earlier identified by Zarit (1989). In their seminal work, Pearlin et al. developed a framework for conceptualizing the stress process among carers, and then identified factors that could potentially mitigate care-giver distress. In “mapping” the stress process, these writers referred to: (1) contextual factors (e.g., care-giving history and financial status), (2) primary stressors (e.g., “objective” and “subjective” indicators of the care-recipient's condition), (3) secondary role strains (e.g., family conflict), (4) secondary intrapsychic strains (e.g., “global” and “situational” self-appraisals), and (5) mediators (e.g., “coping” and “social support”), all of which were said to interact with one another in complex patterns to produce “outcomes,” or different expressions of care-giver distress. The researchers cautioned that the conceptual framework be simply

read as a “heuristic device” (Pearlin et al., 1990, p. 591) and not as a reflection of reality, particularly as individual relationships between each of the framework's components had not yet been tested or studied closely, and since the lens therefore represented a theoretical possibility.

In spite of limitations identified by Pearlin et al. (1990), however, their work became subsequently recognized by some as constituting an important contribution to the body of care-giving research (Knight et al., 1993). Indeed, a large number of studies that followed the work of Pearlin et al. were arguably influenced by notions of a “stress process” in the realm of care-giving, and the possibility of “mediators” (including coping strategies) that could serve to mitigate care-related distress. Perhaps most importantly, given the incorporation of “coping” constructs within this new framework of care-giver distress, a significant proportion of studies associated with Pearlin et al.'s model centered on assessing the effectiveness of interventions aimed at enhancing “mediating” factors, including coping strategies, located in care-givers' experiences of the stress process. This body of literature specifically included research on the potential usefulness of psycho-educational programs (Hepburn, Tornatore, Center & Ostwald, 2001; Hudson, Aranda & Hayman-White, 2005), respite services (Gitlin, Reeve, Dennis, Mathieu & Hauck, 2006), and individual and group counselling (Mahoney, Tarlow & Jones, 2003) for care-givers, among other interventions. Aside from literature on the effectiveness of stress or coping-related interventions, however, research stemming from the work of Pearlin et al. also included attempts at strengthening the theoretical base of this model (Chappell & Reid, 2002; Skaff & Pearlin, 1992). For instance, in their study examining the relationship between various “mediators” of stress, Chappell and Reid found that social support was related to well-being (but not burden), and thus recommended that well-being be incorporated into the conceptual framework of the stress process.

Despite the significant influence of Pearlin et al.'s (1990) work in framing research on care-giving and the stress process, it is equally important to acknowledge the notable role that mainstream

literature on stress and coping, including the work of Lazarus and Folkman (1984), may have played in shaping some stress-related research on care-giving (Chappell & Dujela, 2009; Patrick & Hayden, 1999). Lazarus and Folkman, who posited that individuals afflicted with stressful circumstances respond to stress by either employing emotion-focused coping (a strategy aimed at changing one's emotional response to a stressor) or problem-focused coping (a process involving the alteration of an external stressor), have in fact shaped some care-giving literature, despite the competing popularity of the model developed by Pearlin et al. on care-specific stress and coping. An example of such literature is a recent study conducted by Chappell and Dujela, in which the researchers sought to study the prevalence of problem-focused and emotion-focused coping in a sample of caregivers. These writers also attempted to measure the prevalence of a third “category” of coping: seeking social support. In this study, the writers found that although the majority of respondents reported using mechanisms associated with problem-focused coping, most caregivers used all types simultaneously. Chappell and Dujela also discovered that those scoring high in “neuroticism” were less likely to use problem-focused coping and more likely to use negative emotion-focused coping strategies.

Regardless of the particular conceptual framework being used in discussions on burden, stress, and coping in care-giving research, it is possible to suggest that these analytical lenses have been highly influential in framing how care-giving has been understood, defined, and studied over the last number of decades. Whereas on the one hand, these frames of analysis have been supported by many engaged in care-giving research (Knight et al., 1993; Sorensen et al., 2002), models of burden, stress, and coping have also, however, been the subject of some criticism in the field of care-giving (Perry, Lynam & Anderson, 2006; Ward-Griffin, Brown, Vandervoort & McNair, 2005). For instance, Perry et al. have noted that the “burden” perspective may often times neglect an analysis of complex reciprocities that may be found in relationships between care-givers and care-recipients, and that the lens may also therefore fail to acknowledge the rewards that many may encounter in caring for others.

Perhaps more importantly, Ward-Griffin et al. have noted that although some stress-related care-giving research has indeed uncovered gendered realities in the realm of care (e.g., Blood, Simpson, Dineen, Kauffman & Raimnon, 1994), this literature has often failed to acknowledge structural issues that subordinate women (and other groups, including LGB carers [Fredriksen, 1999]) in the context of care, since it has focused on individual coping styles and responses to stress. In light of these criticisms, I wish to begin exploring feminist lenses on care and care-giving, which, aside from stress and coping frames of analysis, have also constituted an important force in the conceptualizing of care-giving phenomena (Hankivsky, 2004; Ward-Griffin et al., 2005).

Feminist Lenses Used to Conceptualize Care

In exploring governing feminist frameworks related to the study of care, Hankivsky (2004) has conceptually drawn distinctions between two theoretical orientations – first and second generation theories of care – that have historically influenced conceptualizations of care-giving in feminist literature. Both of these lenses appear to find their origins in literature that is located entirely beyond the realm of stress and burden research, and therefore seem to deviate significantly from these stress-related perspectives in their approaches to theorizing the experiences of care-giving. In the section that follows, I provide a brief overview of these feminist frames of reference as comprising key theoretical discussions on care. Though I acknowledge that these two analytical orientations conceptualize “care” as a broad construct that includes (among other issues) parenting practices, care for persons with disabilities and elder care (Hankivsky, 2004), I discuss these theoretical frameworks' conceptions of “care” specifically as they relate to informal care-giving in the context of illness.

First Generation Care Theorists. Several writers (Hankivsky, 2004; Noddings, 2002; Turner, 2005) have identified the work of Carol Gilligan (1982) as being highly influential in the development of care frameworks associated with first generation feminist theorists. Gilligan suggested differences in the development of ethical thinking between boys and girls. In particular, she argued that existing

research on the development of ethical reasoning in children, which in her time was premised on the human ability to apply abstract principles of justice over the lifespan, was male-centred and therefore failed to acknowledge that many women appeared to develop moral orientations based on principles of care. Both implicitly and explicitly, in asserting this position, Gilligan suggested the existence of a feminine worldview that could be qualitatively distinguished from dominant (and arguably masculine/patriarchal) interpretations of reality. According to Gilligan, women's understandings of the world were more likely to be aligned with an emphasis on care, due primarily to the predominantly feminine experiences of mothering and nurturing.

Gilligan's (1982) understanding of a feminine orientation based on ethics of care, in turn, prompted a number of feminist writers to analyze the mechanisms by which the neglect of this worldview reinforced the tendency to undervalue women's caring roles in the private sphere on the one hand, and the marginalization of “care ethics” in discussions of social policy on the other. Noddings (1984), for instance, drew attention to the under-recognized construct of “natural caring,” or the care-taking relationship that is situated between mother and child, and discussed its absence as a conceptual framework in debates surrounding social policy. Other first generation writers explicitly drew relationships between the devaluing of “maternal care” in a male-dominated public sphere and the patriarchal neglect of countless other social issues that may be aligned with a care perspective. For instance, Ruddick (1989) suggested that a recognition of maternal care in the domain of public discourse would facilitate a collective valuing of all issues pertaining to “care” (including diverse forms of care-giving), as well as an overall commitment to notions of community.

Hankivsky (2004) has conceptualized the analytical framework discussed above as the foundation of first generation care theory. First generation care theorists, accordingly, can be said to have conceptualized “care-giving” as experiences that could be central to notions of womanhood, and more broadly, to feminine worldviews based on ethics of care. This framework, in turn, may have

provided these writers with a lens that first exposed the devaluing of “care” (maternal and other) in a primarily male-dominated public sphere, and that consequently helped to deconstruct the invisibility of such a perspective in public debates related to social policy.

Second Generation Care Theorists. A large number of feminist writers, whose positions were premised on criticisms of first generation conceptualizations of “care,” developed literature that Hankivsky (2004) would subsequently identify as “second generation.” Before discussing frameworks pertaining to this body of literature, it may be necessary to first outline the theoretical and ideological problems that some feminist writers found with conceptions of “care” posited by first generation theorists. First, some researchers maintained that no inherent sex differences were found to exist between men and women in their orientations of “justice” versus “care,” respectively (Walker, 1984). In other words, women were deemed no more likely to adopt care-based orientations to moral reasoning than did men. This discovery, in turn, challenged first generation theorists' tendency to align notions of “care” with conceptions of womanhood and femininity. Perhaps more importantly, other writers (notably O'Neill, 1989) argued that, in the process of linking women's identities deterministically with maternal predispositions, first generation conceptualizations of “care” could further marginalize women by naturalizing and depoliticizing sexist processes of subordination in the domain of care-giving.

Based on the aforementioned criticisms, second generation care theorists primarily argued that although care-related practices and responsibilities were often feminized and therefore disproportionately imposed on women through socially constructed mechanisms of marginalization, conceptualizations of “care” should neither inherently nor naturally be aligned with the female sex. Indeed, Tronto (1993, p. 103), a prominent second generation theorist (Hankivsky, 2004), described care-giving as a “species activity” that, although traditionally defined as “feminized labour,” encompassed all facets of the human experience and therefore merited material and social recognition

in the public sphere.

According to Turner (2005), second generation feminist writers such as Finch and Groves (1983) have been among the care theorists who have most strongly influenced contemporary conceptions of care-giving in mainstream social work literature. In their study, they deconstructed the under-recognition of care-giving responsibilities assigned to adult daughters of chronically-ill parents, primarily by suggesting a relationship between feminized constructions of their care-giving roles and the systemic devaluing of their labour in the public sphere (Finch & Groves, 1983). Turner has described this work as being elemental to contemporary (or “second generation”) understandings of “care-giving,” particularly since its nascent documentation of the social and economic costs of care-giving has been foundational in the consideration of “caring” as a public issue.

Second generation care literature, with its emphasis on the deconstruction of feminized and under-recognized caring labour, has arguably become a primary vehicle for analyzing current trends in the erosion of formal health services and, more specifically, publicly funded home care. Indeed, in the field of social work, Turner (2005) has discussed present day care-giving literature as being concerned with expansions in elderly and chronically-ill populations, increasing resource shortages in formal home care (with less than five per cent of Canadian provincial budgets often being allocated to these services), and the combined effect of these factors on an unpaid source of “informal” caring labour composed primarily of female kin.

A number of examples exist to suggest the key role that second generation care literature has played in feminist analyses of care-giving (Aronson & Neysmith, 2006; Baines, Evans & Neysmith, 1991; Greaves et al., 2002; Hooyman & Gonyea, 1995; Morris, 2001; Rutman, 1996; Ward-Griffin et al., 2005). A Canadian study by Greaves et al., for instance, uncovered the strains that under-resourced home care services placed on (primarily female) care-givers of palliative patients, and consequently outlined the need for federal and provincial standards surrounding the funding of formal community-

based care. In another study, Rutman considered the effects of invisible caring labour on the perceived powerlessness of female carers, and recommended that care-giving be afforded formal recognition in the realm of health care policy as a means of addressing this reality.

Although feminist conceptualizations of care-giving have arguably been necessary in light of the disproportionate burden of informal care often borne by women (Hankivsky, 2004), the assumptions embedded in this lens have prompted writers to construct the private sphere of care in heterosexual terms. Indeed, Hash and Cramer (2003) have noted that LGB issues remain unexplored in caregiving research, since traditional caregiving literature has predominantly attended to the experiences of caregiving adult daughters, or caring female spouses often presumed to be heterosexual. In the section that follows, I wish to discuss emerging approaches to understanding caring and care-giving, including those rooted in constructivist assumptions of reality; though bodies of literature associated with these lenses have yet to adequately acknowledge LGB care-giving, constructivist conceptualizations of care arguably afford greater flexibility in recognizing and addressing the experiences of non-heterosexual carers.

Constructivist Orientations in the Study of Care

In recent years, relatively nascent conceptualizations of caring and care-giving phenomena have emerged, many of which have been located within the broader theoretical framework of constructivism. The use of constructivism, as a lens, entails the study of reality as an intersubjective (or relational) product of social construction, as well as the recognition of the role of language in shaping notions of truth (Freedman & Combs, 1996). Applied to care-giving, this frame of analysis facilitates an examination of how caring experiences might be constructed within a variety of relational contexts, and also enables a consideration of how language and discourse might factor into such processes of social construction (Adams, 2000).

The work of Adams (1998, 2000) and O'Connor (1999, 2007), which have arguably comprised

some of the first to deliberately place issues of informal care within discursive frameworks, may serve as legitimate starting points for discussing relatively recent conceptualizations of care-giving grounded in constructivist frames of reference. In his research, for instance, Adams (2000) examined the processes through which care-giving may be co-constructed and defined in interactions between formal and informal care-givers. He concluded that although past care-giving research may have often positioned caring experiences as comprising relatively objective processes located within individual carers (eg. “stress” and “coping”), caring phenomena and identities may actually be better understood as experiences that are “negotiated and constructed through talk” between persons in varying relational fields (Adams, 2000, p. 797). Similarly, in her work on carers' positioning processes, O'Connor (2007) has concluded that “care-givers” often do not self-affiliate with this label unless they interact with others in similar positions, and that in constructing their identities as “care-givers,” carers draw upon story-lines or narratives that might sometimes compete with discourses related to their familial or relational roles as spouses, children, or other kin. Both Adams and O'Connor, in other words, exposed the possibility that care-giving might indeed comprise phenomena that are discursively produced, and that these processes of social construction may be located in complex relational realities that are likely to vary according to context.

One important theme that has emerged in constructivist care-giving literature includes the notion that a false dichotomy may have been developed, in traditional conceptualizations of care-giving, between “care-giver” and “care-receiver” (Graham & Bassett, 2006; Molyneaux et al., 2011). Graham and Bassett, for instance, conducted a study on the narratives of nearly one hundred dyads of “co-carers,” and examined elements of reciprocity that may be reflected in interactions between persons with Alzheimer's disease and their “co-carers.” Importantly, they discovered that shared meanings can continue to exist among parties involved in caring relationships, despite cognitive declines experienced by the individual diagnosed with Alzheimer's disease. They also concluded that

these shared meanings may transpire as elements of interaction, environment and disease progression come together to influence complex processes of co-construction, and that persons being “cared for” express insight through their active involvement in these processes.

Though constructivist literature in the field of care-giving has yet to adequately address how LGB carers (or care-recipients) might necessarily construct their experiences in their unique (and under-studied [Hash & Cramer, 2003]) relational contexts (perhaps with the exception of Aronson [1998]), some evidence exists to suggest that this framework might be appropriate for examining non-heterosexual realms of caring experience. First, constructivist lenses have been applied to the study of carers situated in non-Western cultural contexts, and in this area of inquiry, have been successful in helping to identify unique conceptualizations of care-giving that may have not been well-attended to in prior research (La Fontaine, Ahuja, Bradbury, Phillips & Oyeboode, 2007). This analytical framework might have indeed been useful in assisting researchers to recognize varying and context-dependent constructions of “care,” particularly since use of the theoretical orientation requires an inductive attention to how meanings transpire intersubjectively in the realm of care-giving (Adams, 2000). Second, some writers in the field of LGB aging, for instance including Cronin (2004) and Cronin and King (2010), have explicitly argued that inquiry into the experiences of non-heterosexual elders, including older LGB care-givers, may best be guided by frames of reference that inductively recognize complex subjectivities at the interface of elders' narratives and their larger structural contexts, and have thereby loosely implied the relevance of constructivist epistemology. Indeed, given the potential applicability of constructivism as a framework for studying the lives of LGB carers, this lens will partially be drawn upon and referred to in discussing findings associated with this study.

Male Care-Giving

So far, in reviewing literature relating to the research question being pursued, I have attempted to discuss dominant analytical frameworks that have governed the study of care-giving in the last

number of decades. In the remaining sections of this chapter, I wish to begin addressing literature that has, in some way, been related to the lives of gay care-givers, and choose to start providing this overview by reviewing research that has been broadly conducted on the experiences of male care-givers.

Several writers have described the field of care-giving as being heavily concerned with the experiences of female carers (Houde, 2002; Russell, 2007; Yee & Schulz, 2000). As mentioned earlier, however, this strong emphasis on women's caring experiences is arguably justifiable since women have often disproportionately been found to engage in caring (and under-recognized) caring labour in the private realm of the nuclear family (Ward-Griffin et al., 2005). Nonetheless, beginning with the emergence of stress and burden perspectives on care-giving, many researchers began to address the experiences of male care-givers, initially focusing on how men in conventional kinship roles (e.g., “husbands,” “sons,” etc.) might experience stress and burden differently compared with women located in similar relational contexts (Fitting et al., 1986; Horowitz, 1985; Zarit, Todd & Zarit, 1986). Zarit et al., for instance, conducted a longitudinal study tracking the prevalence of burden among “husband” and “wife” carers over a period of two years, and found that although women reported higher levels of burden in initial stages of the study, gender-specific differences in measurements of distress appeared to narrow at the two-year mark. A study by Chang and White-Means (1991) is also notable, primarily because it revealed a tendency for men to report a lower likelihood of engaging in personal care, and since this specific finding was replicated in later studies of male care-givers (Yee & Schulz, 2000).

Despite the influence of stress and burden perspectives on research involving male care-givers, feminist and constructivist lenses have also been used in guiding contemporary inquiry on the experiences of men who give care (Kaye & Applegate, 1990; Russell, 2007). Kaye and Applegate, for instance, drew attention to the significant number of men who had been found to give care in national care-giving surveys conducted in the United States, and loosely relied on both feminist and

constructivist lenses to critique gendered assumptions in the field of care-giving that had rendered male carers' experiences primarily invisible and unrecognized. Russell, in a more recent study, similarly drew on literature associated with these theoretical orientations, and argued that male carers in his research actually reported engaging a variety of activities typically deemed “women's work.” In their struggle with care work, he argued, these men appeared to negotiate “masculine scripting” and the presence of entrenched gender norms, and in the process, seemed to undertake and make sense of activities not considered congruent with essentialist expressions of masculinity.

The work of Russell (2007), compared to other research on male care-giving (Zarit et al., 1986; Yee & Schulz, 2000), may be of particular relevance to the study of gay care-givers, particularly because this writer revealed the possibility that the construction of male caring may vary significantly depending on relational context. For instance, in referencing the experiences of the men he interviewed, Russell found that each man appeared to convey, interpret, and negotiate unique interpretations of masculinity according to subjective understandings of his relational context, and therefore indirectly suggested the possibility that a male carer's position within a non-heterosexual relational context might invoke distinct constructions of gender and caring. The applicability of Russell's analysis to the study of gay care-giving may not be surprising, particularly since, as mentioned previously, constructivist lenses relating to care may be most appropriate for examining under-studied and distinctly-situated caring contexts (Adams, 2000).

HIV/AIDS Care-Giving

One may at first dismiss the relevance of HIV/AIDS to addressing the experiences of non-heterosexual care-giving, particularly since LGB groups have been found to provide informal care in a variety of contexts that may not necessarily relate to the epidemic (Fredriksen, 1999). However, LGB community responses to HIV/AIDS have often been identified as instigators in establishing complex networks of “queer” interdependence, support and mutual aid, and the legacy of HIV/AIDS in LGB

communities has therefore been implicitly understood as an historical origin of publicly-visible care-giving among sexual minorities (Kayal, 1993; King, 1995).

For instance, Kayal (1993) has discussed the extent to which homophobia and heterosexism were at the root of governmental and institutional indifference toward HIV/AIDS during the initial stages of the epidemic, and how LGB community organizations politically responded to such neglect by creating informal community-based systems of care for the first time. Kayal has explicitly noted that although the illness was primarily inflicted on gay men at this time, non-heterosexual communities comprising gay/bisexual men, lesbian/bisexual women, and trans-identified persons would collaborate during the start of the epidemic to attend to the caring needs of the many adults infected with HIV. Indeed, without necessarily invoking the term “care-giving,” due likely to the heterosexist assumptions underlying this construct (Hash, 2001), Kayal and others (King, 1995; Omoto & Crain, 1995) have implied that, during an epidemic that was highly stigmatized on the basis of its associations with “queerness,” informal HIV/AIDS care among sexual minorities became collectively constructed by diverse non-heterosexual groups as a unified political statement against homophobia and heterosexism.

As with other realms of care-giving, stress and burden perspectives on care-giving have been highly influential in shaping seminal studies on HIV/AIDS care. Interestingly, even within this beginning body of formal inquiry, writers focused almost exclusively on the experiences of stress, burden, and coping among gay carers (Folkman, Chesney & Christopher-Richards, 1994; Folkman, Chesney, Cooke, Boccillari & Collette, 1994; McCann & Wadsworth, 1992). For instance, in their research on burden among HIV-positive and HIV-negative care-giving partners of gay men with AIDS, Folkman et al. found that seropositive care-givers appeared to report greater levels of burden, and after controlling for extraneous variables, the writers tentatively asserted that these differences in burden could indeed be attributed to seropositivity. Such research, although seemingly clinical in scope, may have had a profound impact on the recognition of HIV/AIDS care-giving as a unique area of inquiry,

since it uncovered sources of stress and burden that could likely not be found in other caring contexts, and thereafter prompted other writers to study these phenomena qualitatively (Bunting, 1996; Haas, 2002).

Qualitative studies in the field of HIV/AIDS care-giving have, once more, been predominantly focused on examining and uncovering the experiences of gay men located in this context. For instance, in one study, Haas (2002) specifically drew upon the principles of grounded theory to examine the experiences of both sero-concordant and sero-discordant gay male couples coping with HIV/AIDS infection, and found that social support functioned as both a source of coping among individual respondents, and also as a factor in helping couples maintain their intimate relationships. Despite the continued emphasis on the experiences of gay carers, however, qualitative research on the experiences of HIV/AIDS carers as a broad group (regardless of sexual orientation) has also emerged. For instance, in one study, Bunting (1996) examined the experiences of a large group of heterosexual and non-heterosexual HIV/AIDS care-givers and care-recipients, and found that, regardless of sexual identity, respondents often described their experiences as “journeys” that were constantly negotiated and re-negotiated at different points during the progression of the illness. Interestingly, some feminist writers have notably drawn attention to the lack of attention and recognition that has been afforded to the role of female carers in the legacy of the HIV/AIDS epidemic, and have specifically outlined the need for more inquiry into the realities of women who have given care to HIV/AIDS patients during this time (Ciambrone, 2002; Schiller, 1993).

Though a large number of studies in the realm of HIV/AIDS care-giving have indeed heavily emphasized the role of non-heterosexual male carers, even sometimes at the expense of recognizing the experiences of other care-givers (Ciambrone, 2002; Schiller, 1993), some HIV/AIDS research may particularly be credited for exposing the prevalence of care-giving activities among non-heterosexual adults. In particular, a landmark quantitative study by Turner, Catania and Gagnon (1994), which

included questions relating to sexual orientation in its scope of inquiry, highlighted the disproportionate number of gay males involved in the informal care of persons living with AIDS. In this study, although under 6% of all heterosexual men and women in urban centres reported caring for a person affected by AIDS, 33% of lesbian/bisexual women and 54% of gay/bisexual men indicated involvement in this area of care. These findings prompted not only the researchers (Turner et al., 1994) to assert the need for inquiry into the broader (non-HIV-related) experiences of LGB carers, but more importantly, also explicitly provided others (notably Fredriksen [1999]) with rationale for pursuing the study of non-heterosexual care as a general field of research.

LGB Care-Giving

Research on the overall experiences of LGB carers arguably may have started when Fredriksen (1999), with specific reference to the earlier HIV/AIDS study conducted by Turner, Catania and Gagnon (1994), attempted to expose the prevalence of caring responsibilities among lesbian women and gay men in her research. Although Fredriksen's (p. 142) definition of care-giving included the "full range of caring responsibilities," from elder care to parenting activities, her study was significant in documenting the particular presence of illness-related caring activities among LGB adults. In this study, 27% of gay and lesbian respondents reported providing some form of informal care to an adult with an illness or disability. Interestingly, 82% of these research participants reported experiencing varying types of discrimination and/or harassment relating to sexual orientation, and those providing informal care were significantly more likely to report these experiences. In identifying early attempts made at studying LGB care, it is important to also mention a study conducted by Aronson (1998), in which the writer explored the experiences of lesbian care-givers and care-receivers; although this study primarily positioned its findings within a broader feminist framework, it was notable in uncovering interlocking expressions of heterosexism, as well as other factors, underpinning the lives of the women under study.

Recent literature in the area of LGB care-giving research has been specifically aimed at expanding insight into issues unique to non-heterosexual carers. Favoured methods of inquiry have been quantitative, and studies have been primarily influenced by stress and burden perspectives on care (Fredriksen-Goldsen, 2005; Shippy, 2005), though there have been some attempts made to study LGB care-giving phenomena qualitatively (Hash, 2001; Brotman et al., 2007). In the subsections that follow, I first provide an overview of quantitative studies geared at studying the experiences of LGB care-givers in the context of chronic illness, and then outline the limited qualitative research currently available in this field of study. The studies I describe have all employed broad definitions of “care-giving” that encompass activities ranging from largely instrumental support (e.g., arranging transportation) to assistance with personal care. However, all of the studies have addressed care-giving in relation to illness.

Quantitative Research on LGB Care. Quantitative studies relating to the care-giving experiences of LGB adults have been predominantly concerned with measuring the prevalence of distress-related variables among LGB carers. For instance, in his study, Shippy (2005) attempted to determine potential predictors of care-giver burden, as well as well-being, among LGB adults providing informal care to persons with chronic illness. Interestingly, Shippy drew categorical distinctions between care-givers of “family of origin,” versus those providing support to “families of choice,” and in so doing, discovered that the former group reported higher levels of care-giver burden. Related to this finding, Shippy observed that “family of origin” care-givers (particularly women) were sometimes expected to provide care by their families simply based on heterosexist assumptions of LGB “singleness,” and that the presence of these expectations was positively correlated with measurements of care-giver burden. Further, among care-givers of “families of choice,” relatively few carers reported seeking formal support, and among those who did pursue professional services, a significant minority (26%) reported difficulties related to stigma and discrimination in their relationships with care

providers.

A study by Fredriksen-Goldsen (2005), which was aimed at studying predictors of well-being and distress among care-givers of gay men affected by HIV/AIDS, is worth mentioning. Although Fredriksen-Goldsen, in this instance, did not specifically study LGB care-givers (but rather carers of gay men), a significant portion of the study's participants (82%) self-identified as gay or lesbian. In examining the study's findings, Fredriksen-Goldsen discussed the presence of discrimination (surrounding both issues of sexuality and HIV/AIDS status), in combination with other variables such as low income and high physical strain, as strong predictors of distress in care-givers of gay HIV/AIDS patients. This writer, however, also took care in discussing the significant relationship existing between low levels of discrimination and overall well-being among these care-givers.

One final quantitative study is worth mentioning, particularly since it deviates thematically from other quantitative studies related to LGB care-giving. In this study, Grossman, D'Augelli and Dragowski (2005) sought to study the relationship between care-giving, care receiving, and the willingness to provide care, all in the context of chronic illness, among LGB adults. Two thirds of respondents reported providing informal care to an adult and one third reported being care-recipients. Interestingly, respondents with previous experience as care-recipients were more likely to express a willingness to provide similar care in the future.

These quantitative studies highlight a number of important realities, all of which are arguably framed in terms that pertain to stress and burden models of care. Notably, though some predictors of distress found among LGB care-givers have not directly been linked with issues of sexual orientation (for instance, lacking an adequate income, being female, and experiencing high physical strain [Shippy, 2005]), other distress-related variables identified have been arguably unique among this population. As discussed by both Fredriksen-Goldsen (2005) and Shippy, these LGB-specific factors include varying manifestations of discrimination surrounding sexual orientation. Grossman, D'Augelli and Dragowski's

(2005) study, although different in its focus of inquiry, emphasized the prevalence of LGB care-giving and care-receiving in the context of illness, and in the process, arguably revealed the necessity for considering the pertinence of LGB-specific distress predictors in mainstream care-giving literature.

Qualitative Research on LGB Care. Qualitative researchers concerned with LGB care-giving issues have primarily attended to the unique nuances associated with care in LGB communities, particularly emphasizing the roles that sexuality-related stigma and discrimination might play in distinguishing these realities from conceptualizations of care normally considered in mainstream care-giving literature. In Hash's (2001) exploration of gay and lesbian care-giving partners' experiences, for instance, she found that although her respondents identified issues that were similar to those regularly reported by heterosexual care-givers, including general expressions of stress and loss, these participants also described unique experiences that may have been indicative of homophobia and heterosexism. For instance, in this study, care-givers regularly reported (1) lacking support from “family of origin” relatives who would not acknowledge their same-sex relationships, (2) being met with homophobic hostility by health professionals, (3) refusing to seek support due to fears of being discriminated against, and (4) keeping the nature of their relationships secret to avoid conflict with potentially hostile health professionals (Hash, 2001). Since the study was undertaken in an American context, care-givers also commented on the lack of legal spousal recognition often needed to guarantee care planning arrangements existing between care-recipients and themselves (Hash, 2001). An expansion of this study (Hash and Cramer [2003]) uncovered similar factors pertaining to the unique experiences of LGB care-givers, all of which related to manifestations of homophobia and heterosexism in formal and informal systems of care.

A Canadian qualitative study by Brotman et al. (2007), which drew attention to the experiences of *caring for* LGB adults (whether or not their care-givers self-identified as LGB themselves), is also worth discussing. Interestingly, although many respondents in this study defined themselves as

heterosexual, these care-givers reported experiencing homophobia and heterosexism simply by virtue of associating with LGB care-recipients. For instance, in this study, care-giving heterosexual children reported that they were often reluctant to seek formal support (from health professionals), as well as informal assistance (from friends, for example), since they were cognizant of discriminatory attitudes embedded in these systems of support. In addition to observing these unique realities, Brotman et al. also uncovered subtleties associated with care-giving partners' experiences of discrimination. For instance, one respondent in this study disclosed that he had carried his ailing partner to the bathroom to embrace him away from potentially disapproving health professionals, which in turn revealed the often overlooked manifestations – and effects – of internalized homophobia in the absence of overt discrimination.

Whereas the study by Hash (2001) qualitatively exposed primary themes relating to the care-giving experiences of LGB adults, Brotman et al. (2007) elaborated on these issues by exploring the nuances of caring for ailing LGB adults. Writers in both of these studies implicitly highlighted the need for qualitative inquiry that would uncover invisibilities not readily recognized using quantitative approaches to research, primarily by making use of inductive, loosely constructivist methods of inquiry to expose how LGB care might be constructed in unique relational contexts. Indeed, though quantitative studies may have provided evidence of the presence of distress-related variables (including discrimination) unique to the care-giving experiences of LGB adults, these qualitative studies may have then revealed the processes through which homophobia and heterosexism might intersubjectively construct and shape the lived experiences of LGB adults in the context of care.

Methodological Debates in LGB Care-Giving Research. Within the limited body of literature on LGB care-giving, proponents of quantitative and qualitative inquiry recognize the lack of research on care-giving phenomena among LGB adults, and argue the need for considering their respective methodological preferences in guiding future research. Notably, Fredriksen-Goldsen and Hooyman

(2005) argue that rigorous quantitative methods are necessary in the pursuit of further inquiry, particularly as a means of uncovering the overarching realities of stress and burden that pertain to marginalized LGB adults in the context of care-giving. Hash and Cramer (2003), on the other hand, discuss the need for further qualitative inquiry in this area of research, particularly since LGB care-giving issues remain relatively unexplored. These writers particularly emphasize that traditional care-giving literature has neglected to conceptualize “care” as an activity that encompasses the experiences of LGB adults, and argue that the use of qualitative methods is necessary in the co-construction or uncovering of complex, potentially misconstrued realities pertaining to these experiences. Hash and Cramer further posit that employing qualitative methods in the study of LGB care-giving phenomena could provide opportunities for the empowerment of research participants, particularly as they would become capable of claiming their own voices and constructing their subjective realities in the process of participating in research.

In light of the historical origins of care-giving research that I have outlined earlier in this paper, I am tempted to align myself with the position outlined by Hash and Cramer (2003). There appears to be a lack of qualitative research that is aimed at inductively producing knowledge based directly on the caring experiences of LGB adults. Despite my alignment with this perspective, however, I do also acknowledge the importance of past quantitative studies that have cumulatively highlighted the presence of care-giving issues among LGB adults. Without this research, perhaps the notion of “care” in LGB populations would have been considered a theoretical anomaly, and the assumptions embedded in traditional care literature would have remained primarily unchallenged.

Relevance of Presented Literature to the Research Question

So far, I have discussed three dominant analytical frameworks that have governed the contemporary study of care-giving, and I have subsequently provided an overview of literature that might pertain to the experiences of gay men, namely research on male carers, on care-givers of

HIV/AIDS patients, and on LGB care. Throughout this literature review, I have notably highlighted the possibility that non-heterosexual care may not adequately be addressed in the literature associated with the three analytical lenses underpinning the study of care, but that constructivist frames of reference might afford greater flexibility in recognizing the nuanced distinctions of these experiences. Indeed, I demonstrated that this analytical framework might have, in the past, assisted researchers to recognize unique constructions of “care,” particularly through its focus on the inductive production of knowledge in relational contexts (Adams, 2000), and that therefore it might be applicable to the study of the largely neglected and under-studied experiences of non-heterosexual care-givers.

In the latter sections of this literature review, I began specifically outlining nascent explorations in the realm of LGB care. In this section, not only did I draw attention to homophobia and heterosexism as comprising unique realities located in the everyday experiences of non-heterosexual carers, but I also highlighted the “newness” of this field of research, and consequently the need for pursuing inquiry that would aim to broaden knowledge on these distinct experiences. Though I did not specifically address the need for addressing the experiences of gay care-givers in this particular section, I discussed the history of the HIV/AIDS epidemic substantively in a preceding segment of the paper, and in so doing, clarified the central role of gay care-givers in the context of the epidemic as grounds for focusing my research on this sub-demographic of non-heterosexual carers.

Given the applicability of constructivism as a theoretical lens for studying the experiences of gay care-givers, and more importantly, the overarching need to examine the unique (and arguably under-recognized) experiences of gay carers, the need for a study aimed at developing insight into the lives of non-heterosexual male care-givers is clear. Further, since an attendance to the narratives of these men may facilitate a process of inviting an inductive “sharing” of these uniquely-positioned realities (Cronin & King, 2010), the use of an approach to research that attends to “storying” or narrative processes used among these carers, as vehicles to inductively understanding their experiences,

may be particularly appropriate. Accordingly, the research question I pursue in this study is as follows: how do five Canadian care-giving partners of gay men story their experiences? Though I acknowledge that in this chapter, I have not addressed the specific relevance of narrative inquiry in great detail, I will develop my rationale for studying “storying” or narrative processes among gay carers more substantively in this study's chapter on methods.

Chapter 3 - Methods

As discussed in preceding sections of this paper, the purpose of this study is to develop insight into the experiences of gay carers, specifically by examining how five Canadian care-giving partners of gay men “story” their experiences, or how they construct their realities in the form of narratives. Thus far, I have developed a rationale for pursuing this research objective by outlining related literature, by pointing to the lack of research on LGB care-giving, and by particularly emphasizing the relevance of studying gay carers' experiences. In this chapter, I first discuss the overall design of this study, as well as the conceptual basis for using a narrative approach in exploring the experiences of gay care-givers, and then outline the methods that are used in the pursuit of this study. Specifically, following an overview of the study's design, as well as an outline of narrative inquiry in relation to care-giving, I explore issues related to participant recruitment, data generation, data analysis, ethics, and credibility arising from this piece of inquiry. I conclude with research limitations specific to this study.

Research Design

As implied in preceding sections of this paper, the current study is qualitative in nature, and relies primarily on constructivist-oriented narrative methods for exploring how five Canadian care-giving partners of gay men story their experiences. Qualitative methods, in general, are often best suited to studying areas of reality that may have not yet been adequately explored (Flick, 2002), particularly as they are often inductive and centered on respondents' subjective experiences of social phenomena. Five participants, each of whom took part in two in-depth interviews, responded to three broad areas of inquiry intended to elicit their stories as care-giving partners of gay men. In the subsequent sections, following an overview of the applicability of narrative inquiry to the current study, I provide a more substantive review of each of methodological issues pertaining to the study's research design.

Care-Giving as “Storied” Experience: The Applicability of Narrative Inquiry

Care-giving has often been considered to be a sequential experience involving transitions (Burton, Zdaniuk, Schulz, Jackson & Hirsch, 2003) that might at times centre on carers' complex processes of self-identifying as care-givers (O'Connor, 2007). Indeed, some literature suggests that care-givers often come to understand their caring positions as extensions of their relational/familial positions, and in turn, recount care-giving narratives that revolve around negotiating their caring identities vis-a-vis their kin-based relationships with care-recipients (O'Connor, 2007). Since the realities of non-heterosexual care-givers are possibly located in familial contexts that deviate to some extent from the relational realms of heterosexual carers, due in part to the presence of homophobia and heterosexism (Hash, 2001), the “storied” processes through which gay care-givers negotiate their positions as “partners” or “family members” vis-a-vis their identities as “carers” may be unique (Brotman et al., 2007; Brown, 2009). The study of these narrative processes, however, cannot be conducted without attention to the discursive mechanisms that facilitate the construction of “stories” in the first place. Indeed, though “narrative” may be specified as one particularly noteworthy dimension of gay carers' experience, studying this realm of reality may not be possible methodologically without attention to conversations between “researcher” and “participant” that arguably give rise to the co-construction of stories (Hollingsworth & Dybdahl, 2007). It is primarily for this reason that constructivist-oriented narrative inquiry is being used as a tool for studying “storied” realities as highly relevant facets of gay care-giving experience.

Importantly, however, narrative inquiry may also constitute a relevant method for the overall study of care-giving processes. Indeed, since the nuanced complexities of care-giving experience are often revealed in narratives that are said to surface in the context of discursive interaction (Nolan, Grant & Keady, 1996), a researcher's attendance to these co-constructed narratives could enable her/him to recognize subtleties of care-giving experience otherwise left unacknowledged (Adams,

1998). In other words, narrative inquiry may not only assist in exploring potentially rich elements of gay carers' experiences in particular, but it could also enable an analysis of how these realities might be understood in the context of care-giving as a constructed experience.

According to Lieblich, Tuval-Mashiach and Zilber (1998), the qualitative study of narratives may include attention to the form (e.g., the structure of stories), and/or content (e.g., what is contained in stories) of participants' narratives. In conducting this study, I focused first on “how” participants actually constructed narratives relating to their care-giving experiences (e.g., “form”), and then examined the content found within these narrative structures more specifically. Importantly, though some models of narrative analysis stipulate the importance of attending to temporal sequence in identifying the form of stories (e.g., Mischler, 1986), I employed a method of narrative inquiry, originally developed by Clandinin and Connelly (2004), that recognizes how stories may be structured temporally, spatially, and/or interactionally. Accordingly, I first identified temporal (time-based), spatial (space-based), and interactional (relational) dimensions of care-givers' stories, and then analyzed the content found within these organizational structures. I elaborate further on my use of this model of narrative inquiry in my section on data analysis.

Participants

I recruited four participants with assistance from local social service agencies serving lesbian, gay, bisexual and transgender (LGBT) clients. These organizations provided me with avenues for disseminating my recruitment poster both physically and electronically, and additionally assisted with identifying informal LGBT-related e-mail list-serves that would enable me to reach care-givers not directly accessing services. I anticipated challenges associated with recruitment from the start, particularly given sampling difficulties often associated with this population (Fredriksen-Goldsen & Hoy-Ellis, 2005), and although I considered the prospect of using snowball sampling to address this reality, participating care-givers were unable to identify other potential respondents. One participant,

who was located in a different Canadian urban centre, replied to a recruitment poster after it was sent by a personal contact.

In inviting respondents who self-identified as same-sex care-giving partners of gay men with chronic illness, I recognize that I specified particular selection criteria, and therefore loosely relied on purposive sampling strategies to help me draw respondents with subjective experience in my area of research. Interestingly, though participants each appeared to hold varying definitions of “partnership,” “chronic illness,” the term “gay,” and even the construct of “care-giving,” I accommodated these differences during the process of recruitment, particularly as I believed the accomplishment of my research objective would require my openness to distinctions in how each gay carer would experience his reality. Indeed, this flexibility in the recruitment process was likely necessary in the conduct of this study, particularly as I had identified a lack of research focused on the specific subjectivities of gay carers, and as my primary aim had therefore originally included an understanding of unique meanings and complexities revealed in the narratives of gay care-givers.

Though a sample size of five is considered inadequate for producing findings that are statistically generalizable, the goal of this study was to illustrate possibilities relating to the “storying” processes of gay care-givers. Morse (2000) has explicitly suggested that sample size, in the context of qualitative research, is only significant in relation to the desired objectives of a study, and has argued that smaller sample sizes may be appropriate for research intended to invoke in-depth analyses of participant narratives. Perhaps more importantly, Clandinin and Connelly (2004), whose model of narrative inquiry is specifically being used in conceptualizing this study's findings, have suggested that smaller sample sizes may enable researchers to generate rich narrative data that might serve to illustrate “storied” experiences and realities particular to individual participants.

Table 3.1 – Participant Characteristics

Pseudonym	Age	Current or Past Care-Giver (Length of Time Since Experience)	Legal Nature of Partnership with Care-Recipient	Nature of Care-Recipient's Illness	Length of Partnership	Length of Care-giving
Pedro	39	Current	Married	HIV	7 years	7 years
Rob	22	Current	Common-law	Arthritis and nystagmus/astigmatism	8 years	5 years
Nick	44	Past (10 years)	Legally undefined	HIV/AIDS	7 months	7 months
Joseph	55	Past (1 year)	Married	Gastric cancer	27 years	11 months
Mylo	44	Current	Common-law	CVA/stroke/aphasia	15 years	2 years

Data Generation

Respondents participated in two in-depth (1 to 1.5 hour) semi-structured interviews. During initial interviews, I encouraged the care-givers to share their stories by specifically asking them: (1) how they had come to self-identify as care-givers (assuming their existing identification with this label, based on selection criteria used for the study), (2) the challenges and rewards they had experienced in their stories as gay care-givers, (3) their overall stories as care-giving partners of gay men. I incorporated the first question into the structure of the interview to address the reality that self-identifying as a care-giver often occurs in a complex relational context (O'Connor, 2007), the contents of which have been relatively unexplored in LGB care-giving research. Similarly, I used the second prompt to invoke the potentially unique elements of gay care-giving narratives, particularly in light of literature that has addressed homophobia and heterosexism as sources of challenge (and possible reward) that are specific to LGB carers (Hash, 2001; Hash & Cramer, 2003). I intentionally added the

third area of inquiry into the design of the study, primarily because the study was intended to facilitate an understanding of “how” gay care-givers structure their narratives, and since a relatively open-ended prompt would likely elicit stories that are subjectively structured by participants.

It is important to note that although the three aforementioned areas of inquiry guided initial interviews with participants, I relied primarily on informal conversational prompts to elicit stories from participants. Indeed, after asking carers to provide me with accounts relating to the three realms of experience, I invariably invited in-depth descriptions of their narratives, and often only interjected when I required clarification or further detail on particular elements of participants' stories.

Hollingsworth and Dybdahl (2007) have suggested that in order to explore how participants might “story,” or structure their experiences in narrative form, questions may necessarily be limited and left open-ended to facilitate the sharing of such subjective realities. These writers posit that conversation, rather than questioning, may far more easily elicit “story-telling” processes in qualitative research.

Prior to conducting follow-up interviews with each participant, I transcribed the contents of the first encounter, and identified narrative themes pertaining to respondents' experiences as care-givers. Second interviews were intended for the care-givers to review these themes, and to allow them to elaborate on dimensions of their “storied” experience that I had identified as being salient in the context of their initial interviews. My decision to incorporate second interviews was based on a perceived need to render interpretations of “storied” experience that would be, to some extent, consistently aligned with respondents' realities. Indeed, Hollingsworth and Dybdahl (2007) understand narrative inquiry to be often located amid interactions between researcher and participant, the realm of which requires review and collaborative co-construction, particularly if one is to adopt a constructivist position in relinquishing claims to objectivity.

Data Analysis

I relied heavily on Clandinin and Connelly's (2004) three-dimensional model of narrative

analysis to guide the process of data analysis. This model, which (as mentioned previously) is premised on the notion that the content of stories is not only structured temporally, but also organized according to elements of interaction (both personal and social) and physical/situational space, enabled a thematic analysis of “storied” experience that attended specifically to how participants would refer to each of these dimensions literally or figuratively in organizing the content of their narratives. For instance, in hearing the particular significance a participant would ascribe to movements or transitions between different locations, this model would assist me in recognizing physical space as a key structural component relating to the participant's “storied” experience, and would then me to attend to the thematic content located within the narrative structure of physical space. Clandinin and Connelly's model of narrative analysis may have been particularly appropriate to incorporate into the design of this study, particularly since past LGB care-giving research has highlighted the possibility that non-heterosexual carers experience discrimination differently depending on situational and physical context (e.g., home versus an institutional setting) (Brotman et al., 2007; Hash, 2001).

Following first interviews, I specifically transcribed interviews, examined transcriptions in great detail several times, and then took notes that were intended to summarize participants' stories. Following this process of note-taking, I analyzed dimensions of time, space or interaction that appeared to form the structure of carers' stories, and after delineating these apparent narrative structures, I then attended to the actual content found within these categories. In other words, I first identified the structural components of participants' narratives, which together comprised primary themes relating to their experiences, and then focused on the array of experiences contained within these organizational structures.

I conducted second interviews with participants to review my initial interpretations of their stories. The follow-up encounters constituted opportunities for me to convey my understanding of participants' stories to each of the carers, and to identify analyses of form and content that would most

genuinely resonate with the care-givers' own realities. Indeed, following the transcription of these second interviews, I consulted Hollingsworth and Dybdahl's (2007) work on the role of conversation in the construction of narratives, and used this recognition in broadening, narrowing or revising my analyzed scope of “storied” experience within the context of loosely structured follow-up “conversations” with participants. It is important to note that Clandinin and Connelly (2004) have specified the need to consult multiple sources of data in applying their model of narrative inquiry, and although I did not necessarily rely on a variety of media (e.g., journal entries or visual representations) to examine findings, my initial analyses of first interviews were actually written as “field texts” that were then shared with participants, and were left subject to re-analysis and co-construction during informal follow-up encounters.

At the final stage of analysis, I extrapolated themes that appeared to arise across participants' stories, specifically by consulting my earlier field notes, and by identifying similarities in narrative structure and content among participants. However, I engaged in this activity with great caution. As Clandinin and Connelly (2004) note, cross-analysis in narrative inquiry can at times result in superficial and reductionistic renditions of participants' accounts, and the richness of narrative data may therefore be lost in the process of comparative case analysis. Accordingly, in analyzing and conceptualizing data across participants' stories, I committed myself to identifying each of the generated themes with the individual respondents who may have discussed these realities, and also to specifying nuanced differences in how each of these participants may have described apparently similar phenomena. Indeed, in my discussion of the study's findings, I identify, by pseudonym, each participant who may have discussed a similar theme as another respondent, and make attempts to outline subtle differences in how these thematic experiences are discussed and “storied.”

Ethics

Several ethical issues are particularly important to note. Perhaps most apparently, given the

reality that homophobia and heterosexism have been found to exist in non-heterosexual realms of care (Hash & Cramer, 2003), I had anticipated some respondents might ask me about my own sexual identity before deciding to divulge potentially sensitive areas of their lived experience as gay men, and in fact, I was asked to disclose my sexual orientation on a number of occasions. In addressing this issue of self-disclosure, often identified as an ethical concern relating to the maintenance of boundaries between researcher and participant (Walby, 2010), I chose to identify myself as another gay man, particularly in order to establish trust and rapport with other participants, and also to acknowledge the role of my own subjective experience in shaping the design of the study. Some writers, including Rooke (2009), have recognized the suitability of self-disclosure in the context of LGB-related research, specifically since key experiences are likely to be withheld from researchers who are unable to establish trust with LGB participants.

Other ethical issues associated with this study pertain to the realities of studying members of a marginalized group. As sexual minorities are often the target of discrimination and negative stereotyping, they arguably comprise a vulnerable population in the context of research, and may therefore be considered particularly susceptible to experiencing feelings of distress in discussing their lives with researchers (Rooke, 2009). Indeed, as James and Platzer (1999) have specified, non-heterosexual participants may encounter painful emotions in divulging details of their experiences with homophobia and heterosexism, and may require access to LGB-specific support to mitigate these expressions of distress. In order to address any negative feelings that would potentially arise during the course of interviews with participants, I brought information on free local LGB counselling services to all my meetings with respondents.

Though I recognized and attempted to mitigate possible experiences of distress among participants, I also acknowledged that other ethical issues relating to the marginalization of the study's participants would likely not be addressed as easily. Perhaps most notably, since sexual minorities

have been historically pathologized in research, or have alternately been represented inauthentically in the name of “objectivity” (James & Platzer, 1999), I was cognizant of my need to honour participants' subjective understandings of their stories as best as possible. Accordingly, I adopted measures to ensure renditions of respondents' stories that felt authentic to them, for instance by incorporating follow-up interviews to receive feedback on initial analyses, and also by taking full responsibility for any digressions I may have made from the accounts of participants. In writing this study, I similarly accept complete responsibility for any perceived issues of misrepresentation that may be brought to my attention, and understand my need to reconsider the credibility of this study's findings in the event that respondents question renditions of their narratives. Clandinin and Connelly (2004) have indeed specified that although researchers inevitably retain “ownership” over the design, conduct, and findings of studies, they may mediate any issues of representation that consequently transpire by accepting “relational responsibility” for narratives that might not be portrayed authentically.

One final ethical issue that is important to recognize in the context of this study relates to the limits of confidentiality. Specifically, since I interviewed five care-giving partners of gay men, all of whom (except for one) were based in one particular Canadian urban centre, I acknowledged that the identities of these men could be easily exposed in a localized community that is relatively small and close-knit. I attempted to address this risk by ascribing pseudonyms to each of the participants, and by specifically asking them about their comfort in having details of their care-giving experience made available to a large audience, occasionally consisting of others they would likely know. All participants expressed willingness to share their experiences for the purpose of this study, though a number requested – and received – explicit confirmation that only pseudonyms would be used to refer to them in the context of the study.

It is important to note that the study was subject to full ethical review by the Behavioural Research Ethics Board of the University of British Columbia, and was granted approval under the

number H10-0304. In addition, the provisions in the informed consent form were thoroughly explained to all participants before they were asked to sign it, and they were explicitly told of their right to withdraw from the study at any point.

Credibility

In considering issues of credibility, qualitative researchers are often first required to reflect on the epistemological bases of any given study before deciding how the process and product of inquiry might most appropriately be evaluated (Mason, 2002). Such consideration is particularly relevant since fundamental assumptions of “truth” often shape the nature of a study's design, and therefore largely determine standards for conducting inquiry and for reaching desired research objectives. For instance, for post-positivist research that is particularly concerned with “objectively” uncovering a particular realm of experience, the process of enhancing rigour might include triangulation, or the collection of data from various sources, and criteria used to assess the study's overall effectiveness might consequently include an evaluation of whether the triangulated data indeed reflect an objective generality, and support the transferability of the study's findings (Creswell, 2007; Maxwell, 2005).

Since constructivist-oriented narrative research is often premised on the notion that reality is constructed intersubjectively (Clandinin & Rosiek, 2007), conventional post-positivist methods intended to enhance and to assess the relative “objectivity” of findings often do not apply (Creswell, 2007; Mason, 2002). Indeed, in specifying issues of credibility pertaining to narrative research, Creswell suggests that the strength of such inquiry may be evaluated, among other points, by its adherence to the following set of non-traditional criteria: an in-depth focus on single cases, the development of a chronology that connects different aspects of a story, the telling of persuasive stories, and the researcher's own positioning or reflexivity within the scope of the study. Mason (p. 176), in addition to the above criteria, suggests that “arguing narratively” includes illustrating that a particular rendition of a narrative “is meaningful or reasonable.”

I drew significantly on the points invoked by Creswell (2007) and Mason (2002) for enhancing, and then evaluating, this study's credibility, respectively. First, in attempting to strengthen the design of the study, I employed Creswell's work by reflexively acknowledging my own experience and location as a gay man in the context of this study, and then by focusing on the in-depth study of single cases, on the chronological or "storied" construction of narratives associated with these cases, and finally on the "telling" of these stories in the write-up of the study. In evaluating the study's credibility, I aligned myself with Mason's emphasis on "meaningfulness" in narrative research by attempting to establish authenticity with participants whose lives I was attempting to recount in the study. Specifically, I ensured that all my initial analyses of data be subject to in-depth review by respondents during follow-up interviews, I made modifications to my interpretations accordingly, and finally, I attempted to write the study's findings using both these modified analyses, as well as direct quotes originating from respondents' accounts. Indeed, "member checking" and "giving voice" may legitimately be considered two ways of assessing rigour in qualitative research, particularly for studies that are constructivist in nature, and that therefore rely on conversation as a unit for constructing reality (Hollingsworth & Dybdahl, 2007).

Limitations of the Study

As already mentioned, since the intent of this study was not to produce findings that would be statistically generalizable, perhaps the most apparent limitation of the research includes the specificity of its findings. However, given my attempts at generating and analyzing data that might be rich and that might authentically reflect the experiences of those it seeks to represent, I hope to have supplanted limitations in generalizability with the depth and subjective "meaningfulness" of narratives invoked in the study. Indeed, as discussed by Clandinin and Connelly (2004), although narrative researchers rarely seek to illustrate realities that are said to exist identically across cases, those engaged in such inquiry aim instead to highlight in-depth renditions of individual lives that offer enriched insight into

the possibilities of subjective experience.

Another important limitation associated with this study is perhaps far more subtle. Namely, since I have engaged in some cross-case analysis, I am cognizant that the overall richness of results may have been compromised to some extent in this process of cross-comparison, particularly as qualitative narrative research often relies on in-depth analyses of single cases (Clandinin & Connelly, 2004; Creswell, 2007). As I have mentioned previously, however, I have attempted to preserve the richness of single-case analysis by consistently attributing examples of shared experience to the stories of specific respondents, and by elaborating on nuanced differences that might exist among these examples. It is my hope to have produced a narrative study that is not only replete with the methodological strengths of narrative inquiry, but also one that has sought to identify some commonality in the lives of five gay carers whose experiences may have been more or less marked by the challenging realities of homophobia and heterosexism.

Chapter 4 - The Stories

Pedro's Story

Pedro was the first person to reply to my recruitment poster via e-mail, after specifically being forwarded this information by a personal contact of his at a social service agency. He expressed relief at the prospect of sharing his story, particularly as he had had few opportunities to discuss his experiences as a care-giver. On our first meeting, he shared with me that he had been caring for his partner Andrew, a Caucasian HIV-positive man in his fifties, for a number of years. Pedro specified that he had been with Andrew for a total of seven years and had been married to him for five. He shared with me that he was 37 years of age himself and was of Mexican descent, having only transitioned to Canada upon meeting his partner online while still in Mexico. His role as a care-giver included providing his partner with support on daily instrumental and personal care tasks, and also occasionally encompassed providing him with assistance on medical decision-making during acute health crises related to the progression of HIV. Interestingly, Pedro did not disclose his own HIV status, and in fact did not appear to ascribe great significance to his own relationship with the illness. Clandinin and Connelly's (2004) work proved applicable in analyzing Pedro's story, particularly since he appeared to organize his story into a number of narrative structures that were grounded in his interactions with either his partner or with his larger social context, all of which were contextualized both temporally and spatially.

“Day by Day”: Consciously Committing to a Caring Role. In discussing how he had come to identify as a care-giver, Pedro traced the origins of this story to his previous role as a care-giving partner of a gay man with leukemia, approximately ten years prior to meeting Andrew. He disclosed to me that, at this time, he had made a conscious choice in committing to a caring role:

I met a guy that was very honest in the beginning, he told me that he was suffering of cancer of the blood, leukemia. And well, I didn't care, and we started dating; he was an

amazing person, free-spirited person. But after four months, he started with the issue that I'm a healthy person with a sick person. We were laying in bed, and I said I'm willing to be with you, to share, and to help you. But it was my decision. That was my approach.

Pedro described to me that, in meeting Andrew during the couple's first in-person encounter in Mexico, his future partner had explicitly informed him of his HIV-status, and had communicated the potential for Pedro to find himself in a caring role were he to commit to a relationship with him. The participant had once again perceived this event to signify choice in positioning himself as a care-giver, and had invoked memories of his ex-partner in the decision-making process:

I asked him for 24 hours to make up my mind. I was like, “obviously I can say no,” and he can move on with his life, and I stay in my country, and I can meet someone healthy and have a normal life. What came to mind was my ex-boyfriend, the one with leukemia. And I was like, “maybe he was the introducing person, maybe he was like the first approach, and now I have an opportunity.”

Interestingly, Pedro implicitly referenced this element of choice as a relational component of care that would likely not define caring narratives located in “family of origin” contexts. Indeed, he perceived the care-giving positioning process within heteronormative family structures as being marked more by obligation or conventional “morale” than necessarily by choice:

You see a man and a woman, and they have been married for 20 years, and now he has Alzheimer's or cancer or something, even though there's no love there, [morality] makes one person take care of the other, no? ... But when you have a situation in your hands, like you can say “yes,” or “no,” complete freedom, I feel like it's a good challenge ... I [even asked] him, if I cannot get used to this new life, can I come back [to Mexico]? Can I quit living with you? And he gave me that “yes,” he said we will do it day by day.

And that line relieved me of a lot of pressure: “well, okay, let's do it day by day.”

The theme of “choice,” despite being located at a point in time identified as the past, permeated Pedro's story as he recounted events leading to the present, and even as he described foreseeable events in his future partnership with Andrew. Pedro insisted, for instance, that regardless of any trajectory his marriage with Andrew might take in the future, death may still be an inevitable end result, and this prospect encouraged him to live in a present context that is marked by conscious decisions to “do good things” in his intimate life as both partner and care-giver.

“Kisses, kisses”: Issues of (In)Visibility. Pedro insisted that, overall, he had been satisfied with interactions among health professionals in formal systems of care. However, he was quick to add that he and his partner had often sensed covert expressions of homophobic discomfort by health professionals surrounding their sexual identities, particularly as their marriage had started interfacing with formal systems of care. Pedro appeared to understand the consequence of such homophobia to include compromises in their safety, most significantly when the couple's partnership had become visible to service providers. Moreover, he was concerned that Andrew, by virtue of being a care-recipient, had become more vulnerable to potential maltreatment by health professionals each time the couple's non-heterosexuality would be “outed” to service providers:

Speaking of the [home support] people who are supposed to help Andrew, they're very bad with him; they don't respect him ... When they're arriving, I'm leaving. So it's like, “have a good day,” kisses, kisses. But we don't do it front of them, because ... we don't know how they will react. I worry that he will be alone with these people, you know?

Despite Pedro's tendency to reference implicit issues of visibility related to sexual identity, however, he also described what could be understood as a heterosexist invisibility that was reinforced by health care professionals located in formal systems of care. More specifically, Pedro discussed that aside from sensing covert expressions of discomfort by service providers, he and Andrew had often

been mistakenly assumed to be related to one another in the context of a nuclear family structure (e.g., as “father and son” or “uncle and nephew”), rather than being recognized as a same-sex couple. Though the participant appeared to attribute the presence of such assumptions to be based on expressions of heterosexism (“They don't even hear it when we say we are partners...”), he also suggested an apparent age difference between he and Andrew as being influential in the surfacing of such presumptions. Regardless of the potential origin of these apparent errors in judgment, Pedro added that he would negotiate such presumptions by not affording them significant weight in the construction of his relational narrative with Andrew:

In my case, [service providers] always think that he's my uncle, or even my father at this point. They don't even hear it when we say we are partners, you know? Obviously he looks older because of the illness. Personally, I don't care. I don't care what other people think.

In constructing Pedro's narrative during the course of both interviews, the theme of “(in)visibility,” as well as its perceived consequences, appeared to become significantly more pronounced when Pedro would recount events associated with Andrew's heightened vulnerability as a care-recipient. One example of this thematic foregrounding was found in Pedro's perception of being hyper-visible as a same-sex care-giving partner when he was asked by members of Andrew's family of origin to make decisions related to life support during his partner's stay in intensive care. Pedro specified that this expression of visibility, rather than being perceived as inherently positive or negative, bestowed a level of responsibility on him that prompted the participant to negotiate this sudden and frightening “spotlighting” by attempting to identify and advocate for Andrew's best interests:

Two of his brothers were with me at that time, and I looked at them, and they said:

“you're the partner, and we will respect your decision.” So it was a big responsibility

that I don't even wish on my enemies, because you don't know what to do. You must respect his will, but at the same time, you think: “what happens if he needs a little more time?”

Several other examples were found to suggest Pedro's salient role as an advocate when Andrew's health status combined with his visibility as a gay care-recipient to produce a heightened vulnerability. Pedro put it succinctly, in describing how he understood his role during these events, by telling me: “He as a survivor; for me, it's someone that I respect a lot, someone that I want to protect.”

Interplays of Race, Culture, Age, Sexuality and HIV/AIDS Stigma Across Care-Giving Contexts.

Interestingly, during the course of telling his story, Pedro appeared to equally discuss his sexuality and his care-giving role as primary dimensions of his experience, each of which would in turn fluctuate in salience depending on situational factors. For instance, Pedro would repeatedly contrast his relationship with other partnerships he deemed “normal,” and when asked specifically about his reference point for “normalcy,” he referred both to the non-heterosexuality of his partnership and his care-related dimensions of his relationship as markers of distinction, of which one would often surface more strongly according to context. Indeed, he believed that his engagement in a same-sex partnership reflected a deviation from heteronormative perceptions of “normalcy,” that his involvement in a caring arrangement differentiated his relationship from those of other gay men, and that these two markers of difference would become more pronounced depending on situational factors:

Obviously for straight people we are not “normal” ... But talking in the gay world, a “normal” thing is ... you know, healthy, so we can do things together, like going to the movie theatres, coming for dinner, going to the disco and dancing for hours, going out, you know? ... That kind of thing. When you are with a person that is not one hundred percent healthy, you need to miss those things.

Despite the salience of Pedro's sexual orientation and care-giving position in the construction of

his story, however, the respondent frequently described how these two realms of experience would shape his story in varying ways depending on their interplay with other factors. For instance, though Pedro appeared to place particular centrality on his gay identity as a primary force underpinning his care-giving narrative, he drew attention to how his reality as a gay carer for an HIV-positive partner had been experienced differently, compared to his life in Canada, while he and Andrew had been in Mexico to visit his family:

I guess I [have] a bigger challenge when I go back to Mexico ... The last time that we were there, we were a couple, we were not married yet, so we had many awkward, uncomfortable situations. It wasn't because of him, it wasn't because of me, it was because of the people around. And they can't understand when you say "HIV" or "AIDS." People jump, like they are scared that, even we look at you, they will get sick. I know there have been changes in the last few years, but you still see those attitudes. So it's something that we keep very, very private. The "official" version in Mexico is he has cancer.

Indeed, in noting that he experienced a "bigger challenge" traveling to Mexico as a gay care-giving partner of his HIV-positive spouse, Pedro appeared to suggest that the homophobia and heterosexism often accompanying the expression of his sexual identity were perceived to be less pronounced in a Canadian context, and that his non-heterosexuality would therefore interact with his cultural ties to Mexico and with HIV stigma to produce a different reality during visits to his home country. In spite of this seemingly greater level of tolerance the respondent appeared to experience in his Canadian life with Andrew, however, Pedro was clear that other difficulties, some of which would likely not be encountered in Mexico, appeared conversely more pronounced in Canada. Most notably, Pedro made implicit references to how Canadian service providers would sometimes make assumptions about the nature of his relationship with Andrew, based on interlocking factors of age and race, and would in the

process exhibit indirect manifestations of racism:

In [Canadian] health things, you are with more open-minded people. At the same time, it doesn't mean everybody's gay, but yes, you need to be open. I think the thing that moves [service providers] more, or shocks them more, because I see it, is when they see the difference of age ... They really jump a little bit ... In my mind it's like, they think "oh, this is the hot Latino who is taking advantage of this sick Canadian guy," sometimes. I cannot say that I'm 100 percent sure, but sometimes you have that feeling. With time, they realize that we are a common couple, that we are equals, that, you know?

Accordingly, I recognize that discussing Pedro's experiences simply as a function of his position as a "gay" care-giver may be incomplete. It is apparent to me, specifically given the many examples that Pedro invoked to demonstrate the interaction of multiple identities in the course of his story, that the respondent perceived sexual identity and care-giving to comprise only fractions of a greater, more complex reality. Indeed, although Pedro would consistently highlight the particular relevance of his sexual identity and his care-giving position in marking significant components of his narrative with Andrew, he would repeatedly allude to the complex uniqueness and fluidity of these experiences: "I believe that each person is a river – we have certain things shared, but inside of us there is energy that is running, running all the time, and we are changing."

Creativity in Constructing Gay-Friendly Sources of Support. Throughout the recounting of his narrative, Pedro would make references to issues that he felt would potentially be universal among most informal care-givers, including the physical challenges of providing care, as well as the emotional difficulties of navigating relational boundaries. However, Pedro would repeatedly suggest feeling isolated, particularly as a gay care-giver, in managing these experiences. He indicated that whereas heterosexual care-givers would likely locate sources of support within their families of origin to mitigate these stressors, his caring relationship with a gay man required him to access support systems

outside of this conventional family structure, of which few existed to alleviate his isolation:

For straight people, there's always more understanding from the family [when one person is a care-giver]. For gays, the families are a little bit apart, or a lot apart ... In my point of view, in my role, I feel alone. Sometimes, it's like where do I turn? Who will [be there] to tell me I'm doing okay, or how I feel is normal?

When I asked Pedro specifically if he would ever consider accessing generic care-giver support groups to help with the potential difficulties of giving care in his relational context, he responded by questioning whether these primarily heterosexual networks of support would be receptive to him, particularly in light of HIV/AIDS stigma:

I guess the question should be for them. How comfortable would they be if a gay guy comes and talks about his AIDS partner? ... We're talking about an older generation, where even being gay was bad enough. And getting AIDS was like, the double price of being the bad sheep of the family. You can't imagine that. So for straight people, yes it's a stigma, and it's a double stigma. So how comfortable or how supportive would they be?

Pedro disclosed to me that, in attempting to mitigate his isolation, he had sought and received support from Andrew's gay nephew in the span of his journey with his partner. He added that this family member had likely offered support due to “connections” he had identified with the couple, based on a shared sexual identity. Due in part to this interaction with Andrew's nephew, Pedro felt gay care-givers lived experiences that could sometimes only comfortably be shared with other non-heterosexuals, and in addition, encountered challenges (e.g., including expressions of homophobia and heterosexism) that only other gay men or lesbians would be willing and able to appropriately support and assist with. Pedro's overall story, particularly in light of this final point in his narrative, appeared to revolve around not only confronting the complex realities of providing care as a Latino same-sex

partner of a gay man with HIV, but also focused on the importance of locating appropriate sources of support in mitigating difficulties associated with these experiences.

“An Opportunity”: *Storying Meaning in the Context of HIV/AIDS Care*. A conclusive theme in Pedro's story included his apparent tendency to locate meaning in his experience as a partnered caregiver of a gay man with HIV. Pedro appeared to draw meaning, first, from his understanding that he would fulfill a familial function by committing to the well-being of his partner, and that his devotion to Andrew's health would therefore serve as an opportunity to construct family in a non-heterosexual context:

I remember when he told me [he was HIV-positive]. I was like, maybe now I have an opportunity. As a gay man, I won't have children, and I won't have a traditional family ... [so] this is my commitment.

In addition to locating meaning in unique constructions of “family” that appeared specific to his life with Andrew, Pedro also attributed significance to his caring role by believing himself to be a witness in the larger story of the HIV/AIDS epidemic. Indeed, he used “survivor” discourse in describing exactly the meaning he ascribed to his role as a care-giving partner of a gay man with HIV:

Picture this – we are in Titanic, all the pieces out at sea and everything. I think he's a survivor, and I'm a lifesaver, a board. I'm only that part that he's holding. And I'm not doing too much to be honest, like that thing ... But at the same time, because he is holding the piece that I am, it makes me feel different than the rest of the pieces ...

Later, because I like to read, I don't want his life to get lost, so maybe I'll write something, it's not perfect, but just for me, you know?

In light of Pedro's tendency to construct meaning in the context of his caring relationship with Andrew, it is apparent to me that although he had shared difficult realities with me during the course of two interviews, many of which appeared to pertain to his sexual identity, he seemed to draw on many

of these sources of challenge to invoke significance and purpose. I recognize, in analyzing these particular fragments of Pedro's story, that the participant would likely not explain his story by simply discussing challenges associated with his realities as a gay carer, but would more importantly suggest these sources of meaning as mitigators in the processing of these experiences, and as markers of a story he is likely to value far into his future.

Rob's Story

Rob also responded to my recruitment poster via e-mail only a few hours following Pedro. He first explained to me that his partner Allan had been diagnosed with chronic arthritis, as well as a combination of neurological conditions that had caused a severe deterioration in his eyesight over the years. He shared with me that he and his partner were both in their early twenties, but had been together for eight years and had plans of getting married. Rob explained that his role as a care-giver primarily entailed coordinating and organizing Allan's medical appointments, and occasionally assisting him with instrumental physical tasks involving manual force. Rob also disclosed to me that he and Allan had originally lived in a more rural setting, and had transitioned to their current urban location some years ago. The use of Clandinin and Connelly's (2004) model generated an interesting analysis of Rob's story, as his account appeared to be organized into four distinctly located narrative structures – one grounded in his interaction with Allan vis a vis his positioning as a care-giver, the other founded spatially in the context of his experiences physically accessing health care settings with Allan, a third based primarily on his interaction with a social context replete with interrelating ableism and homophobia, and a fourth comprising his temporally evolving relationship with Allan.

Beyond the Illness: Mutual Care at the Interface of Homophobia. As in my interview with Pedro, I began my encounter with Rob by first asking him about his process of identifying as a care-giver. Rob disclosed to me that both he and Allan had consistently taken care of each other prior to declines in Allan's health, primarily by “looking after” each other in a homophobic rural setting that

would often pose immediate threats to their safety as a couple. Following their transition to a large urban centre, Allan's fluctuating health had started requiring greater attention, and only at this point had Rob begun positioning himself as “more” of a care-giver:

From our peer groups, at school and everything else [in our home community], we definitely needed each other to be there in terms of protection. And then as his physical disabilities got worse, it kind of more so fell on me.

Rob explained to me that Allan, upon noticing this shift in the couple's previously reciprocal caring roles, felt inclined to offer his partner the option of leaving the relationship. Although Rob was even given a span of time to reconsider his commitment to the relationship during this period, similar to Pedro, he considered this gesture to be a reflection of his partner's concern for him, and so he felt this “break” merely reinforced his commitment to Allan:

He did call things off for a couple of weeks, to give me time to really consider what that meant, and even the fact that he did that is kind of a testament to how much he cares about me, and how much he loves me. I'm not going to walk away from that.

In attending to the specific structure of Rob's relational narrative with Allan, it became apparent to me that Rob would refer to elements of a caring reciprocity, which had initially defined their relationship in the context of a homophobic environment, as being maintained in spite of Allan's reliance on informal care. Indeed, to make his point succinctly, he indicated: “it's not just a one-sided thing; Allan isn't constantly taking from me,” and then added: “it's a much more full dynamic than anything I've ever had,” referring specifically to the context of mutual care that had been founded in the past, and that continued to remain in the present.

“Not Allowed to Come in”: Battlegrounds for Contesting Legitimacy. Unlike Pedro, Rob described having experienced overt hostility in interactions with Allan's service providers. When I asked him how he explained the presence of such hostility, he readily understood this behaviour to be

rooted in discriminatory attitudes held by health professionals: “it's homophobia, plain and simple, is what it is; they're being homophobic.”

Interestingly, Rob appeared to “story” the challenges of experiencing discrimination by describing how his relationship with Allan had been consistently delegitimized in medical settings. Indeed, in telling me his story of encountering homophobia as a care-giver, Rob began invoking a narrative structure that revolved primarily around the couple's forays into primary care offices and other health care institutions, and the consequent sense of “illegitimacy” he felt was regularly ascribed, within these spaces, to his relational roles as care-giver and partner.

The participant began weaving this “storied” structure by explaining to me that he had initially been surprised, having transitioned with Allan from a rural setting to an urban centre, to have noticed expressions of discomfort by professionals while making medical appointments on Allan's behalf:

Staff [at medical offices] tended to get a little terse with me over the phone when I told them I was making appointments for my partner, but I figured this is Vancouver, this isn't Alberta, so this isn't gonna be a problem, why would it be a problem? And then going to the places where I made appointments, always tended to be really interesting.

Upon going into these settings, Rob told me he would often be prevented from accompanying Allan when his partner would be called to see the attending physician. He discussed one event in particular detail to make his point:

I heard Allan crying. And I wanted to come in, so I knocked on the door and that's when they were [testing for arthritis], right? And the doctor, when he opened the door, he was standing there with his hands on either side of the door, like that, and he seemed casual and calm enough, so I just said “can I come inside if you guys are done talking?” And Allan called me, and it was like this pitiful plea, right? And I went around the doctor, and he just leaned really casually to one side [blocking me], and I was like,

“really, are you gonna do this to me? ... Just let me come in, I'm not gonna do anything”

... Back and forth back and forth. Big argument ... then they finally let me inside with him.

Rob explained to me that experiences of “not being let in” have been repeated on numerous occasions, and have forced the couple to become more vocal in negotiating accompaniment. In sharing this experience, he contrasted it with the potential effortlessness that would be required of a heterosexual partner requesting accompaniment:

If Allan wants me to come in [to see the doctor] with him, we have to expressly say so and be really firm about it and push the issue, which is ridiculous. When I need to follow my female friends, I literally just follow them in and nobody says a word about it. And then I see this happen to me, and that's sad.

Although Rob and Allan had both planned their marriage long before the onset of these difficulties, the participant was convinced that he and his partner required legal recognition as a couple before they would be taken seriously in seeking retribution for these perceived injustices:

Not being allowed to go in the room when Allan was getting tested for his arthritis, that pissed me off more than absolutely anything. And I know for a fact, if we had been married, me getting as mad as I did to be let in, would have had way more weight, when talking to the director and everything, instead of just, “oh, I'm his boyfriend slash caregiver,” you know?

However, he also believed that such a “standard” for legitimacy was arbitrary and unjustified, particularly since he perceived unconventional definitions of partnership to merit acknowledgment and respect in formal systems of care:

If you're talking about legitimizing your relationship, the more health care professionals that you associate with, the more referrals that you get, you dig deeper into these

bureaucratic standards. And it's legitimacy that I don't think should be necessary at all ... if we're both more comfortable, then why does it matter?

Accordingly, Rob believed such standards to only be of relevance in interfacing with formal institutions, including medical systems. He appeared, in contrast, to place significant value on the meaning he and Allan had placed on their relationship internally as a factor in sustaining their bond through these experiences: "I can't imagine going through anything without him, and getting through it okay."

Interrelations of Homophobia and Ableism. It is important to note that although Rob identified as a care-giving partner of a gay man with an illness upon first contacting me, and had particularly emphasized his experiences with homophobia and heterosexism in this context, he appeared to conceptualize Allan's condition more as a disability than an illness, and thus seemed to believe that issues of disability were as pertinent as those of sexuality in defining the couple's collective narrative. First, in elaborating on his positioning as a care-giver, Rob described to me that although the couple's non-heterosexuality had indeed prompted both himself and Allan to adopt reciprocal caring roles in a largely homophobic rural environment, Rob's understanding of his partner's disabling conditions triggered the respondent to become active in mitigating a perceived source of additional vulnerability:

I've had friends that were like [partner] before, in the sense that they either had physical disabilities, or they identified outside of the gender binary, or had alternative sexualities. I never felt the need to take care of them, because it was either one or the other, it wasn't both. There was always one leg where they could strongly stand by themselves. But with Allan ... I did feel a degree of responsibility that stemmed mostly from his physical disability.

Despite Rob's perception of Allan's particular level of vulnerability, however, the participant disclosed to me that he had been critical of attitudes, namely held by his friends and acquaintances, that

had unfairly positioned Allan as globally “less able” than the respondent during the initial onset of his health conditions:

I didn't really think too much of [caring for Allan] at the time, until my friends started commenting on it, like asking me, “doesn't it feel weird having to take care of him all the time?” One friend basically said, “don't you feel you're just holding on to a retard?,” which was not okay ... but it didn't bother me until Allan started overhearing these things, and it hurt him. And that's when him and I have a long discussion about it, and I told him that if he needed me to do these things, I don't care. Like, that's kind of part of what living together is. He definitely does his share of things around the house, so this is one of my shares.

Interestingly, Rob appeared to suggest that such attitudes had also been expressed by health care professionals he had interacted with in the course of his journey with Allan, and that the presence of these belief systems had often combined with the systemic manifestations of homophobia and heterosexism discussed earlier. When he began describing these experiences of encountering what he explicitly labeled “ableism,” he was adamant in suggesting that Allan possessed a variety of talents and capabilities that rendered such realities unjustifiable, and he even expressed a reluctance in identifying as a “care-giver” for fear of having such discrimination reinforced:

I remember that we touched on ... not being permitted in the room while Allan is getting treatment. [Other issues are] a little more subtle ... even just to touch back on infantilizing, like we just discussed, is like the way certain doctors, certain care providers, will speak to me, and not Allan about his issues, when I'm honestly just there to basically be his escort ... like, escort to the office and home ... because it has nothing to do with me. And I don't know if I'd even tie that to homophobia, just as much as, you know, ableism ... Like, Allan is far smarter than I will ever be, he speaks far better than I ever

will, but everyone treats him like an infant ... And that's why I hate to say, "I'm his care-giver," because people will automatically leap to this assumption, or they assume that I'm using him or something.

"Without Failing": The Evolution of Rob's Relationship with Allan. Given the extent to which Rob's care-giving narrative appeared based on his perception of Allan's heightened fragility as a gay man with a disability, it may not be considered surprising that the participant drew attention to an imbalance in power that he believed had marked the start of his active care-giving role with his partner. Indeed, Rob described to me that he was cognizant of his initial tendency, during the early onset of Allan's health conditions, to attempt to protect his partner from disability- and sexuality-related vulnerabilities, and to therefore unknowingly support a dynamic of co-dependence he would otherwise not be content with:

[Homophobic and ableist attitudes] made me angry. Between the two of us, I'm definitely much more aggressive. And so it got to the point where I became really protective of him for a long time, which did have a detrimental effect on our relationship for about a year, because I became overly protective ... I wouldn't let him do anything on his own, and ... at the same time, I had made him feel like he couldn't function without me.

Rob, however, was clear in suggesting that his relationship had evolved significantly since this time, specifically in light of two factors that he felt were elemental in reducing co-dependencies between himself and Allan. First, as Rob disclosed to me, he had eventually been diagnosed with epilepsy himself, which he believed had produced an "equality" between him and his partner in navigating experiences of living with disabilities. Perhaps more importantly, Rob also described that he and his partner, in attempting to mitigate systemic ableism and homophobia/heterosexism within the context of their caring partnership, had been encouraged by their persistent commitment to one another

through these difficulties, and had therefore re-discovered elements of a reciprocity that had defined their relationship prior to the onset of Allan's symptoms:

These are big things to deal with, so if anything comes up less than, I know that I can depend on him, without failing. He knows that he can depend on me. So we always have each other in our lives no matter what ... Like, I have my friends, I have my family, everything else, but in Allan, I have my boyfriend, he's my best friend, he's my family, and more than that, I know he's always going to be behind me. It's not even a matter of, that he owes, or I owe him, it's just become a natural dynamic for us to be each other's constant support system through anything at all. And we've already been through the worst, so everything else is just going to be a cake walk.

Indeed, Rob even suggested that, in light of the many experiences he has survived with his partner, he has storied Allan into his life as “family.” He suggested to me that this reality has presented itself with a number of challenges, but also with the promise of an identity that has been more conducive to the construction of his current family:

I'm not part of [my family of origin] here. I'm part of this family here, which is me and Allan, and that has brought with it a whole new structure of identity that I've had to come to terms with.

Accordingly, in describing and analyzing Rob's story, I acknowledge that although this participant's care-giving narrative drew heavily on themes of discrimination, as well as examples of mediating ongoing difficulties, I am also conscious that the respondent had constructed a story that was largely premised on the collective survival and triumph of the couple's togetherness. Indeed, in tracing the temporal trajectory of Rob's narrative, this theme appeared most pronounced, and seemed to particularly indicate that the couple's persistence assisted Rob to make meaning of the systemic injustices he appeared to encounter as a non-heterosexual care-giver of a gay man with an illness or

disability.

Nick's Story

Following Rob's involvement in the study, some time passed before any more potential respondents contacted me to participate in the research. Nick, who was the first to reply to an outreach e-mail sent through an LGBT organization some months after Rob had contacted me, disclosed to me that he had in the past identified as a care-giver to an HIV-positive gay man named William. He shared with me that although he had an interest in participating in the study, he was uncertain whether he would meet eligibility criteria for this study, as he believed his relationship to this man did not meet conventional definitions of “partnership.” Specifically, since Nick had dated William for some months prior to his active involvement as a care-giver, had made arrangements to support William if he were ever to fall significantly ill, and had not defined this relationship explicitly in intimate terms when William had eventually sought Nick's support, he was unsure whether this caring role would fall within the scope of “partnership.” I explained to Nick that the outlined criteria were subjective, and that if he himself believed his care-giving position to have been located in the context of partnership, I would welcome him to participate in the study.

It was on these terms that Nick told me his story; one that involved caring for a dying HIV-positive man ten years prior to the interview, for a length of approximately seven months. He described to me that he had provided the full range of caring support to this man, including transportation, instrumental assistance, cleaning, occasional personal care, medical decision-making, and emotional support, and had maintained this level of involvement until William's death. Nick explained to me that his engagement as a care-giver had been a profoundly spiritual experience for him, and that he continued to ascribe great importance to this period of his life throughout the years. Importantly, prior to participating in formal interviews, Nick disclosed to me that (unlike other participants in the study) he had been a carer for William in a relatively rural setting with few LGBT-

related services and resources. Similar to Pedro, Nick did not disclose his HIV status, nor did he appear to attribute significance to his own relationship with the virus. In applying Clandinin and Connelly's (2004) approach to data analysis, Nick's story appeared to be organized into several themes that were primarily temporal – but also interactional – in the context of an ever-changing caring relationship.

“Can I Count on You?”: Arranging for Care Amid Uncertainty. Nick began recounting his story by first explaining the circumstances under which he had met William. He described to me that he had relocated to a non-urban setting with limited avenues for meeting other gay men approximately 14 years ago, and had at this point encountered William while rollerblading at a park. He and William had established a meaningful connection immediately, but it was not until nearly three years following their first encounter that they began dating regularly.

Nick disclosed to me that he had been aware of William's HIV status long before dating him, but that this issue “didn't really bother [him].” He also explained to me, however, that William started expressing a desire to stop taking his HIV medication early during the course of dating, specifically in order to enjoy the clubbing scene in a nearby urban centre, and to experiment with “party drugs” in this context. Nick, having recently started a difficult process of recovering from alcoholism at this time, decided that he would not be capable of continuing this relationship under the circumstances specified by his dating partner, but when asked by William if he would be there for support in the event that assistance would be necessary, Nick made a commitment to provide such support. Nick described to me that he remembered this particular exchange as a particularly important moment in his life:

So he wanted to start going to some dances, do some clubs in the city, and try some party drugs, and all that kind of stuff. So I said to him, “I really care about you, and I really love you, but I can't do this, cause I'm just a year sober.” I had just taken my first year cake in AA, and so, “I can't go out with you...” And when he left my apartment that

night, he asked me specifically, and I remember it, “if things get rough, can I count on you?” and I said, “of course.” I never even really thought at the time what that would mean ... there's just moments in life that really define you, you know? ... And it sticks out in my mind, like that moment, and when the door closed with him in the hallway. It's like a childhood memory that you just remember, you don't know why, but you just remember, right? And I remember that moment.

Nick explained to me that approximately five or six months following this momentous event, William called the respondent and asked him if he would visit him at his home. The participant recounted that upon agreeing to this visit and arriving at his friend's residence, he had sensed that William was in the process of dying, and that he was implicitly expected to fulfill his initial agreement to help him with this transition. Indeed, he vividly remembered the very moment in which he stepped into William's home, and discussed how he acknowledged the position he would likely begin taking on in the scope of this man's life:

I mean, he was dying, you know? And he didn't want to go into the hospital, he didn't want to see anyone, so I just kind of, you know, I started cleaning up. I was doing the dishes, and I was standing at the sink doing the dishes. My back was to him, and he couldn't see me, and I just started crying, cause I knew that he was dying. And so I was doing the dishes and I was crying, and I kind of pulled myself together, and then that's how it all started ... geez, I don't really even know that I identified myself as a care-giver ... you just do what you do, right? ... I asked him what he needed, I went to the grocery store, and I just went to his house every day after that. It was just one of those things that you just do.

Interestingly, Nick disclosed to me that he had never explicitly labeled his relationship with William prior to engaging in his role as a care-giver, and even following the initiation of his caring

support, he continued to maintain relative ambiguity in defining the nature of this relationship. Indeed, the participant suggested that, likely due to differences in the social backgrounds of the two men, Nick began first dating William out of “convenience,” and then gradually recognized a connection or bond with this man that would remain primarily unidentified during the entirety of their time together:

I mean, mostly, William would not have been the type of person that I would have dated or seen, right? ... But then because it was a small town, and he kind of got further than what he would've if we would've been in a larger centre, I actually got to know him. I allowed myself to get to know him, and then that kind of shifted. So I was able to look at him differently from ... But then too, I mean, we still, this relationship stayed pretty much non-descriptive really.

Despite the ambiguous nature of the relationship, however, Nick recognized his bond with William as meaningful, particularly when he started taking care of this man. Indeed, not only did he recount ascribing great significance to his caring experience with William, but he also discussed feeling particularly connected or bonded with this man during the progression of his illness, and finding evidence of this reality as he read through a journal he had maintained during this time:

And I was reading the notes that I had written down, in a weird way, I fell in love with him as he was dying, but in a completely different context ... there was always that connection, like when I walked into the room, and saw him ... there was always this sense of energy, something between you and I. I've never, well, I mean, I've experienced it with other people; you know, you meet someone, and you just sort of know you like them right away and you trust them ... but there was always this energy that I had never experienced before.

Nick's experience self-identifying as a care-giver is particularly notable, since the participant obviously considered himself an important part of William's life without labeling or institutionalizing this

relationship in any way, and since the results of related qualitative studies have indicated that partnered same-sex care-givers often do not receive recognition as care-providers by health care professionals in the absence of formal documentation (Brotman et al., 2007; Hash, 2001). Nick's experience suggests that it is possible for a gay carer to actively choose not to formally label a same-sex relationship, but still identify as a significant person committing to the care of an ailing adult.

Balancing a Spiritual Connection with a Need for “Getting the Job Done.” In hearing Nick recount the events that followed the start of his engagement as a care-giver, it quickly became apparent to me that the participant ascribed great spiritual significance to his caring relationship with William. Indeed, Nick described to me that, for him, the spiritual dimension of this experience could perhaps be said to constitute the most important element of his story with William: “the biggest [part of this story] is the understanding of spirituality [that came with the experience]; it just helped define it for me, and show me how to use it to help me through life, so that was the biggest gift.”

Nick specified that as William's illness began progressing following his initial visit to the care-recipient's home, and as the participant's involvement in William's care consequently grew, he began noticing apparent peculiarities in his everyday life as a care-giver, to which he would eventually begin ascribing spiritual significance. It is important to highlight, prior to describing examples of these occurrences, that many such incidents were shared with me during my two interviews with Nick, and that I may only be capable of sharing, within the limited scope of this study, a small portion of what the participant came to understand as his spiritual journey with William. Having provided this caveat, one notable example of the idiosyncrasies described by Nick, which he would subsequently assign spiritual significance to, included his sense that William would accompany him in spirit each time he would sleep elsewhere during the night:

I would be at [my friend's] house where I was [often spending the night], and I could still feel his presence with me. It was just weird. It was so bizarre. It was like he was

coming to visit somehow in the evenings, like I could just feel him. Yeah. And it was almost like he was holding me.

Indeed, Nick recounted experiences such as the one described above, and suggested that such incidents would provide him with evidence of a spiritual significance underpinning his role as a care-giver: “so [these events] kind of validated that [my role] for me; and also, there's an emotional attachment to those experiences that I, I mean that's huge, and so deep really.” Accordingly, although he described to me that his caring activities at this time included practical support such as cooking, cleaning and occasionally providing personal care, Nick appeared to place particular emphasis on the spiritual and emotional support that he believed he was able to offer William while the care-recipient was dying in his home:

And I mean, really, I didn't do much. I just kind of helped him, you know? You know, like, sort of be his emotional support, with the transition of life to death, or crossing over, or whatever you want to call it, right? And then, even after he was gone, I sort of put a little bit of closure for other people around him and stuff. So I mean, I was just really a vehicle for a means to an end, kind of.

Despite Nick repeatedly referring to the state of spiritual connectedness that he felt he had experienced in his caring relationship with William, the participant eventually described an incident that marked a shift in how this spiritual reality would continue being lived as the care-recipient approached death in the late stages of his illness. Nick recounted to me that, upon visiting William one evening to initially find the care-recipient particularly difficult to rouse from a heavy sleep, he followed William's decision to finally seek formal medical care, after originally honouring his reluctance to receive hospital treatment for HIV-related conditions in a rural setting:

I think actually, had I not been there, I think he would have died. Yeah. So, William and his instructions; he got very specific. He's like, “okay, go into the kitchen and turn on the

kettle, there's this tea, you're gonna make me a cup of tea,” so I made him a cup of tea and he's drinking his tea in his room. Then it's like, “get these pants, get these clothes, get all your stuff,” and I didn't know. I'm like, “okay, what's all this instruction about?,” “Go to the phone, dial the hospital, and tell them I'm coming and that I have HIV.” And I'm like, “okay, it's about time.” That's what I thought.

Having transitioned with William from the care-recipient's home to a formal hospital setting, Nick disclosed that at this time, he felt the need to balance his continued spiritual connection with William together with his more practical commitment to honouring this man's wishes in an institutional setting. In recounting this part of the story, Nick particularly appeared to attribute at least some of his heightened “alertness” in a hospital setting to William's anxiety of encountering HIV-related stigma in a rural hospital with no past HIV/AIDS experience, and therefore his potential need to be a strong advocate for the care-recipient's interests:

[William] knew the hospital had no awareness or no understanding of it. Cause when he had pneumonia, before, when he was outed by HIV, that happened I believe in [the city].

So he was aware that HIV hadn't really hit the [rural] hospital... And William was the first in that hospital.

Although Nick repeatedly described to me that he did not experience overt homophobia or heterosexism while being with William at the hospital, he nonetheless appeared to imply that some of his increased groundedness was based on perceived threats of experiencing such discrimination. For instance, Nick revealed to me that, prior to meeting with health care professionals upon William's hospital admission, an advocate from a local AIDS advocacy organization had attempted to warn the participant about the possibility of experiencing homophobia, and had specifically attempted to help Nick be taken seriously as William's care-giver by a potentially dismissive medical team. Indeed, this worker had alerted Nick to the potential experience of institutionalized homophobia, and had therefore

somehow defined this setting for the participant as one in which he would have to tread with caution as a gay care-giver:

I remember [the worker] saying to me, before going to meet the hospital staff, like the doctors, to talk about life support ... she said, you know, "I'm worried about you going in there, and being like this flamboyant, curly haired gay man." And I just remember looking at her going, cause she was concerned that they weren't going to take me seriously. I just thought, "well that is kind of weird." Like, in a way, I thought [I might not be taken seriously], but I didn't really, you know?

Interestingly, Nick suggested that although medical staff were primarily appropriate and respectful of his important role in William's life, he also explicitly described to me that this reality may have partially arisen out of the advocacy work done by the AIDS organization he had been in contact with, the fact that the care-recipient's sister supported Nick's important position, as well as the participant's own sense of confidence as a gay man:

[The AIDS organization worker] kind of backed me up, and I think having [the AIDS organization] doing that when I was meeting with these people, was really helpful ... And also, William's sister supported the fact. So between myself and [sister] it wasn't just me ... And I haven't experienced tons of homophobia in my adult life ... I think largely in part it's because I am very comfortable with who I am in my own skin. And I think that reads really clear to other people, and so, it doesn't give them any ammunition, and I think the same thing with this whole thing. Like, that those people didn't have any ammunition.

Regardless of the extent to which medical staff at the hospital appeared to acknowledge the important position that Nick believed himself to occupy in William's life, it is important to note that the granting of such recognition had been particularly important to Nick during the care-recipient's hospitalization.

In reading through the participant's narrative, it is apparent that such acknowledgment was particularly significant for Nick when William had stopped being responsive closer to the end of his life, and when Nick consequently had to help make treatment decisions in the interests of this man. Although Nick himself described that his relationship with William continued to remain somewhat undefined and unlabeled through to the very end stages of William's life, he felt it just for such considerations to be superseded by the intimate connection he had formed with the care-recipient prior to making such decisions:

I did identify myself as being the person that he gave the instructions to take him off life support. Like, I was the one. And there also was that unspoken connection that he and I had between each other, like I knew that I was to be this for him; to be this person who took him to his grave really.

What it all Means: Making Sense of the Story. In attending closely to how Nick “storied” his account of caring for William, he appeared to complete his narrative by discussing the spiritual significance he associated with the care-recipient's eventual death at the hospital he had been taken to, and by describing subsequent attempts he had made at making spiritual sense of his experiences as a gay carer. Indeed, he started this section of this story, similar to the preceding segment, by discussing peculiar coincidences he encountered as William entered the final stages of his life, as well as the events that followed his death, and by ascribing particular meaning to these experiences. For instance, Nick described to me that whereas he and William shared a birthday, the care-recipient ironically died on his ex-wife's birthday, and given the strained relationship the care-recipient had had with this woman prior to his life as a gay man, Nick believed that this apparent coincidence signified an intended “ending” for a man whose presence he had once shared a deep connection with:

William and I having the same birthday, he dies on his ex-wife's birthday. I don't know how people can dismiss any of that kind of stuff as coincidence, but, so I mean,

everything worked out the way it was supposed to, right?

Though, indeed, Nick described to me that he felt successful in finding spiritual meaning throughout – and after – his experience with William, he noted having a significant need to discuss his spiritual experiences with other gay men during this period of time. He suggested to me, in fact, that he felt particularly alone during the span of his care-giving relationship with William, and did not feel his heterosexual friends could provide him with the same type of spiritual support that a group of non-heterosexuals could offer him at this time:

I really needed other gay men that had experienced the same thing, just to kind of tell me. Cause many, many times, I thought I was losing my mind, like I really thought that I wasn't going to be okay ... My straight friends, as supportive and as loving as they were, they didn't get it, I don't think ... I felt really, really, really alone. I felt kind of isolated from it all, and I don't know if that's just the grieving process in general, or if it was just the fact that, cause really, the gay community locally, where I was, was non-existent really.

Having heard Nick discuss his lack of experience of sexuality-related discrimination, I was curious to hear how he believed a supportive group of gay men could have made a difference in helping him with the caring experiences he had encountered earlier. At this point, Nick suggested that only other gay men would have likely understood the spiritual significance he had assigned to his caring position at this point in time, particularly since many had helped peers die amid the HIV/AIDS epidemic during the era, and had therefore likely had similar experiences in attaching spiritual meaning to informal care:

I do think that gay men have the ability to be more in-tuned spiritually, and I think that's why when so many of these gay men died of AIDS, [other] gay men helped them through that process. Like we really have contributed something to society.

In fact, Nick even contrasted the experiences of his life as a care-giver to caring activities he had observed his grandmother undertake as the participant's grandfather had been dying:

I watched my grandmother help my grandfather die, but there was no spirituality happening there for that woman whatsoever. And she goes to church every Sunday, but there was nothing like that. I think that's the difference between the gay and the straight; [heterosexuals are] not as in-tune with all of that. And how can they when they don't have the same experiences, you know what I mean?

Interestingly, when I asked Nick why he believed gay men appeared to be more “in-tuned” with spiritual experiences than their heterosexual counterparts, the participant described to me that sexual minorities often break taboos, encounter difficult experiences, and may therefore be more inclined to construct spiritual meaning in their experiences. Indeed, he suggested that idiosyncrasies (such as those experienced by Nick) are quite often everyday occurrences, but that experiencing life as a sexual minority may prompt non-heterosexuals to ascribe spiritual significance to these apparently meaningless events:

I think [gay men experience spirituality] partly through the difficulties of what we go through in life, right? And then these coincidences happen all the time, like the coincidences that I experienced with William and all that kind of stuff ... And so, I think you just kind of gain that sensitivity to it, and maybe openness. Because as gay men, we've already broken so many taboos, right? So I think we're more open to different ideas and ideals, you know?

Accordingly, I acknowledge that although Nick described realities that may have deviated significantly from those uncovered in some other qualitative studies of LGB carers (Hash, 2001; Hash & Cramer, 2003; Brotman et al., 2007), his story highlights at least some issues unique to living life as a gay carer. Namely, Nick's significant emphasis on spirituality, specifically in the context of his

caring relationship with William, appears to have been rooted in his perceived need to construct meaning within a conventionally undefined/unlabeled relational field that may have largely been placed in the sociohistorical backdrop of the HIV/AIDS epidemic. Indeed, not only did William explicitly compare his experience to what he perceived would be “typical” of a highly defined heterosexual care-giving relationship (his grandmother's) in explaining his understanding of spirituality, but he also suggested that his need to construct spiritual meaning may have been tied to the collective reality of gay men's experiences with HIV/AIDS. Nick story is significant in illustrating that, even when issues specific to homophobia and heterosexism are not necessarily overt, the realities of gay carers may still contain dimensions that are uniquely situated in a social context underpinned implicitly by these ideological value systems.

Joseph's Story

Unlike other participants, Joseph was informed of the study after a personal contact of mine sent him a recruitment poster for the study. Upon first contacting me, Joseph explained that he identified as a care-giver to his same-sex spouse, but did not fully elaborate on details of his caring relationship until the date of our interview. Importantly, since Joseph was located in a geographically distant urban centre, I interviewed him via telephone. This means of generating data, though not necessarily conventional, proved to be sufficiently effective in allowing me to establish rapport with the participant, and in helping me to facilitate a means for hearing his story.

Joseph explained to me that he had been with his partner Edwin for over 25 years when the latter began experiencing symptoms that would eventually be diagnosed as gastric cancer. At the time of the interview, it had been over one year since the death of his spouse. The participant clarified that although he had provided informal care to Edwin for approximately thirteen months in total, his partner received a formal diagnosis eleven months prior to his death, and so he felt he had formally supported him through the illness for just under a year. Joseph was understandably still in the process

of grieving the loss of his partner, but was nonetheless receptive to discussing his experiences at length. He explained to me that he had provided Edwin with both instrumental assistance and personal care throughout the span of the illness, and additionally believed himself to have been elemental in ensuring that his partner's end of life wishes be respected and honoured. As with Nick's story, when I applied Clandinin and Connelly's (2004) model of narrative analysis to Joseph's retrospective story, his narrative appeared to be organized primarily temporally, though it also contained elements that could be considered interactional and physical.

From Pre- to Post-Diagnosis: "The Way It Is." Joseph began narrating his experiences as a care-giver by first describing the onset of Edwin's symptoms. He explained to me that at this time, he had simply started assisting Edwin with an apparent manifestation of fatigue, and that the couple only gradually became concerned with the worsening of the still undiagnosed medical condition when symptoms appeared to become more pronounced:

He could still do things; he could still go out, and you know, go to the library, and visit friends and that kind of thing. But it was increasingly clear that whatever he did wore him out, and so I became the active one in sorting all of the day to day activities. He could feed himself and dress and bathe and do all that kind of stuff yet, in that period. It was just that he was getting more tired every week.

Joseph emphasized that both he and Edwin had maintained some level of optimism in the absence of a formal diagnosis, and more importantly, that the participant himself had not identified as a care-giver during this period in the relationship:

From January 1st till the end of April was, you know, thinking it was sort of temporary, and not really realizing any care-giver role. And then when he was diagnosed ... then it became clear that this is the way it is.

The participant clarified for me that, upon hearing about Edwin's diagnosis, he began formally

identifying as a care-giver. During this positioning process, which indeed took place following the labeling of Edwin's medical condition, Joseph suggested that Edwin's first post-diagnosis medical appointment comprised a particularly pivotal moment in his identification as a carer, primarily since the respondent had never before accompanied his partner into the office of the couple's family doctor. Joseph explained to me that not only did this specific incident help him realize the severity of his spouse's health condition, but it also assisted him in knowing that his role as a care-giver would be formally recognized and valued in the time to come:

He had to follow up first after the phone call to go in to the doctor and meet. And I went with him, and went in with him, and that's the first time I'd ever done that with him ...

That was an example, I guess, of the care-giver role, or being a part of a discussion between him and his doctor ... It struck me, you know, the seriousness of his situation, and the role, and I guess the positive role that I could play to bring him some comfort and to help him with the burden of listening and asking questions, and listening to the answers, and you know, that kind of thing.

The importance that Joseph appeared to place on this specific event may particularly be of interest, since in Rob's story, it was evident that a lack of access into medical offices had been deemed especially harmful to this carers' well-being. Hearing Joseph discuss the value of easily entering a medical office and being granted full acknowledgment as a care-giver within this environment, I began considering the particular significance that public recognition may have for a gay care-giver affected by his partner or spouse's declining health.

Interestingly, in describing his positioning process as a care-giver, Joseph was clear in suggesting that he would never consciously deliberate on his role as a care-giver during this stage, or even after this junction in time. Instead, he would often consider it to merely comprise an extension of his relational role as Edwin's spouse:

There was never any, clearly, any question ... you just sort of, when you've been together twenty six years at that point, and you've had a very good life, and you've had a good relationship, you just do what has to be done for each other.

It is important to note that this particular understanding of positioning may have represented a marked difference between this participant's reality and the experiences of other respondents, particularly as others, until this point, had discussed positioning more as a function of deliberate choice rather than explaining it as an extension of familial responsibility. It is possible that the length of Joseph's partnership with Edwin, combined with the fact that the couple had been married, factored into this dimension of the participant's narrative, which in turn appeared to closely align itself with O'Connor's (2007) research on the interaction between care-giver positioning and the negotiation of familial roles.

Living in the Moment. In hearing Joseph discuss the events that followed Edwin's diagnosis, the participant appeared to story these experiences as a series of incidents that occurred relatively quickly, and that therefore prompted him to live the remainder of his life with Edwin on a moment-to-moment basis. He described to me, for instance, that although he began assuming greater responsibility for different facets of the couple's day-to-day errands, he felt this progression to merely constitute an implicit extension of his natural role in the relationship, and he consequently did not feel the need to reflect consciously on the rapidly occurring changes:

It's just, in terms of the chores, like if I put it that way, around the house and having a tradesperson in to do something or whatever, I tended to do that anyway, because it was okay, Edwin disliked doing it. So those things, you know, I took one hundred per cent control over. I started, you know, like he would do most of the cooking and all that kind of thing, and I assumed that role, which was sort of different for me. It just developed. It wasn't really talked about. Like it was acknowledged by Edwin just how much he valued what I was doing, but you know, in terms of taking on those jobs, you don't talk

about them. You just start doing them ... And then, you knew, like from day one, that he would die from it, but when you live in the day, and you get so involved, I didn't think a lot about it. We talked a little bit, but we didn't. I guess we felt we didn't have to talk a lot about the end.

Importantly, when Joseph described these changes to me, he also emphasized that he believed the relationship had remained truly reciprocal during this time, since he felt Edwin continued to contribute to Joseph's care in his own way: “well, he was in a caring role obviously; I mean, in any relationship, you both care for each other, and so I'm not implying that he didn't look after me.”

Joseph disclosed to me that during the progression of Edwin's illness, he began experiencing a significant level of physical and emotional strain, though he also suggested that he did not recognize these realities at the time, and that informal networks of support helped him mitigate these sources of stress. In particular, he discussed the important role that his friends played in assisting him to negotiate these challenging changes:

I got tired, and I put on weight, and that kind of thing ... not eating properly, and that kind of stuff. But at the time, you didn't really think too much. You get friends, and they visit, they'd stop in and offer to help and that kind of thing ... But the toll was there physically and emotionally.

Joseph indicated that as Edwin approached the end of his life, and then eventually returned home to die in a familiar setting after several hospitalizations, he experienced significantly painful emotions, and he felt as though Edwin's visiting sons were helpful in helping him live through this difficult moment in time:

I guess you're so living in the day that you don't, I didn't let sort of my emotional state take over until after he died. And it was extremely hard ... [Yet] I was very fortunate. I couldn't have done it without, Edwin has two sons, grown sons, and they live far away,

one in Whitehorse and one in South Korea. I was very fortunate that they were able to come when he was in the hospital yet. And then [when] we brought him home, they stayed here with us. Edwin was home for about ten days, and so the three of us looked after him for those ten days.

It is important to note that, in narrating his care-giving experiences, Joseph repeatedly discussed feeling appropriately interacted with, specifically as a gay carer, by health professionals. Indeed, he suggested on several occasions that professionals would consistently ask both himself and Edwin open-ended questions about the nature of their relationship, which in turn provided them with reassurance that medical professionals would ultimately acknowledge Joseph as Edwin's kin. He suggested, in recounting these types of interactions, that such behaviour should be taught consistently to service providers:

I guess that maybe, like when a nurse or a doctor or whatever would come in, I would never make an announcement that I'm his partner. I never thought that I should do that, or maybe I should have. They took the initiative in a very nice way. They'd say to Edwin, "I'm doctor so and so," and then they'd turn to me and say "oh, and who are you?" Or they'd introduce themselves, and I would say "Joseph," and they'd say, "what's your relationship?," in a nice way. It's training. Providers should learn how to, in a respectful way, discern who is this person standing beside the patient, just so they know.

Though the participant clearly discussed having had positive interactions with health care professionals while providing care to his ailing spouse, it is important to note that he nonetheless experienced some anxiety about the possibility of encountering homophobic or heterosexist attitudes by service providers during this time. Indeed, he suggested that each time he and Edwin would meet with a new specialist or other health care provider, he would have some uncertainty about the professional's level of openness to same-sex partnerships, even if subsequently the service provider would communicate with

the couple appropriately:

Every time you meet someone new, I think it's always in the back of my mind. Will there be any issue or – maybe even if there's nothing spoken – will there be something that bothers me or whatever? And it never happened. But maybe just being minority, you look for it, and you think about maybe the potential of it, that there might be something, and I never experienced that at all.

Given the participant's apparent experience of “living in the moment” during this period in time, it is understandable why perhaps health professionals' proactive mitigation of such anticipated homophobia and heterosexism may have been significant to both the care-giver and the care-recipient. Indeed, since Joseph continually suggested to me that he had little time to reflect on the many emotional difficulties he had encountered throughout this time, it is apparent that the demeanor of health professionals may have assisted the participant, at least to some extent, in settling sexuality-specific concerns he may have not been fully prepared to negotiate during a particularly busy and challenging period in his life.

Seeking Support and Re-Establishing Purpose: Life After Edwin. Joseph appeared to story an end to his narrative by describing not only the death of his spouse, but also the process of seeking support following this loss, and the countless attempts at constructing meaning out of this period of grief. Most significantly, Joseph described the end of Edwin's life as a sudden “finality,” specifically adding that because he had been so preoccupied with caring for his spouse amid the everyday progression of the illness, he had not been given an opportunity to really reflect on the possibility of death until it had finally arrived:

It felt so final. I knew for ten months that, yes, it's coming. But I never dwelled on what it would be like. I just knew it would be awful, but I didn't dwell on it. But then, when he did die, then that second, when you know that was the last breath, then it just felt so

final, you know? Well, it's over. And I think that was one of the first things when I phoned a good friend that night, and he answered, and I said, "well, it's over," and he said, "what's over?" He didn't know what I was talking about, so it's just, you know, the finality of it, that I knew it was coming, and now it's here, and it's happened.

Indeed, Joseph disclosed to me that he felt significant grief during this time, despite having had strong support from his friends and from Edwin's sons, and also in spite of his success in honouring Edwin's wishes of being brought home prior to his death. He suggested to me that although he had previously been reluctant to seek any formal support involving large groups, the magnitude of his grief at this time prompted him to access a support group for grieving family members. Interestingly, as with his experience interacting with health care professionals, Joseph explained to me that although his involvement in a group of primarily heterosexual adults had been positive during this time, he still harboured some initial anxiety about the possibility of encountering negative attitudes surrounding his sexual identity prior to fully engaging with the service:

I guess it's always in the back of my mind, or maybe any other gay person, that when you go into a situation of small group discussion where you'll be talking about personal feelings and your partner who died, and "gay" will be there. So maybe there's just sort of an assumption on my part that there might be someone who's judgmental and homophobic, and it didn't turn out that way. I guess that's in the back of my mind that the potential is there, but it wasn't.

It is important to note that Joseph suggested an overall lack of interest in group activities prior to his engagement with this support system, and that his sexuality-related anxiety therefore comprised only one dimension of his reluctance to access this resource. Nonetheless, he found the group particularly helpful near the end, when attrition in this support system left him in relative privacy with a lesbian woman. He recounted to me that he and this woman, at this time, began supporting each

other through some common elements of their grief, including fears of growing older without the support of a younger generation:

When he died, I'm thinking, well, okay, when my turn comes, who's going to look after me? ... Well, I don't have children. Edwin's children are very nice, but they're 5,000 miles away. I still think about that; like who's going to look after me when I'm sick? ... And in my therapy group, I told you that there was a lesbian there. When I mentioned this, she agreed right away ... I think any part of a partnership where one is left alone, and there's no obvious younger generation or whatever to be there that would look after them, I think it's a concern.

In light of the significant grief that Joseph had been enduring following Edwin's death, even during the time of my interview with him, it is understandable that he had attempted to locate meaning and purpose in his story as a gay care-giver. Joseph suggested to me that one particular source of meaning included the extent to which his relationship with Edwin enabled others (primarily heterosexuals) to become cognizant of the depth and commitment that may be found in same-sex partnerships. For instance, he told me that the couple's church community had never before been exposed as substantively to a same-sex couple, and due to their witnessing of Joseph and Edwin's commitment to one another (particularly during the course of Edwin's illness), they had gained insight into the equal worth and value of same-sex partnerships vis a vis heterosexual relationships:

We've had a long relationship, and a loving one, and I think they noticed that. That was just a good experience for them too. Like even this whole process of Edwin's death, I think just reinforced in their firsthand experiences that we did have a good life together. I think that impressed people, and hopefully it'll make it easier for other gay people if they come along, that these church friends will be nice to them too. Our experience might have sensitized them a little bit more.

Aside from feeling as though the couple had an impact on their church community, however, Joseph also discussed that he believed the couple had a positive effect on medical professionals they had interacted with during the progression of Edwin's illness, including the spouse's oncologist:

[The oncologist] was always so complimentary and impressed, just at the commitment that we had for each other, and me looking after Edwin. Now maybe he says that to all families. I have no idea. But I can't help but think that, if there were any sort of questions in his mind about gay relationships, I hope that I dispelled any myths that he might have had.

Joseph described to me that a final source of meaning, interestingly, included his understanding that Edwin had explicitly chosen to remain with him until the end of his life, despite the participant's earlier disclosure that he considered care-giving to constitute merely a natural extension of an intimate partnership, and not a product of deliberate choice. He recounted to me that, indeed, Edwin had expressed choice in spending a significant proportion of his life with the respondent, and that this conscious commitment had resonated with him as a sincere testament to the meaning and intimacy the couple had developed with one another throughout the years:

When [the relationship is] gone, you realize how fortunate we were. And as I mentioned, just how sort of honoured I was and am, that he chose to spend 27 years with me. Like I did the same obviously, but I think when the person dies, you realize he could've chosen someone else, but he chose to live until he died with me, and that was a real compliment in hindsight. And I guess, in terms of the ten months looking after him and whatever, it was very quality time; very low-key, and sort of gentle in that sense.

This element of choice is particularly important to note, since such discourse was pervasive in many of the constructions of “care” and “partnership” found in the stories of other gay carers in this study, and since even Joseph believed his long-term marriage to be somewhat bound by this reality.

Similar to other participants who invoked such language in their narratives, “choice” appeared to comprise a source of meaning and depth, signifying a conscious commitment to remain with a partner in the context of a relational field at times deemed unconventional by heterosexist standards. Joseph's story indeed seemed to be marked by not only a profound commitment to care for a partner as a natural extension of his spousal role, but also by a difficult grief process following this commitment, and then by an attempt to construct meaning out of the couple's choice to have built a meaningful and loving partnership during their time together. Though he may not have experienced the typical realities of homophobia and heterosexism found in qualitative studies of LGB carers (Hash, 2001; Hash & Cramer, 2003; Brotman et al., 2007), it is certain that some of his experiences indeed revolved around issues specifically related to losing a spouse in the context of same-sex partnership.

Mylo's Story

Mylo was the last participant to contact me for involvement in the study. Similar to other participants, he had initially been informed of the study after receiving a recruitment poster in his e-mail. Mylo explained to me that he had been caring for his partner Diego for approximately two years after he had endured a stroke. The participant told me that since Diego had required significant hospitalization at the onset of this condition, he began caring for his partner while he was still in hospital, and continued after he was returned home following his recovery at a rehabilitation facility. Mylo's caring role involved providing Diego with assistance on a wide range of activities ranging from instrumental tasks such as cooking and cleaning, to general supervision with mobility, and help with communicating (Diego had endured speech impediments following the onset of his stroke). At the time of the interview, Diego was at home with Mylo, and even stayed present during my first meeting with the participant. Though Diego was not present during my second interview with Mylo, this change did not significantly appear to impact the structure or content of his narrative. Since some of Mylo's narrative revolved around physical transitions in the couple's experience from home to

institutionalized care, Clandinin and Connelly's (2004) model provided me with a particularly interesting means of analyzing the effects of these changes on how the participant appeared to story his care-giving experiences.

From Private to Public in a State of Shock. Mylo began telling me his story by first recounting the feeling of shock he had experienced at the onset of his partner's stroke two years prior to the interview. He described to me that during a trip the couple had taken to Mexico, Diego had started behaving somewhat differently ("slowing down," according to Mylo), and in the hospitalization that followed this holiday, the respondent told me he was shocked to learn about the magnitude of his partner's medical condition. When describing these feelings, Mylo was also explicit in suggesting that he began seeing himself as a care-giver during this period, and that this process of self-identifying as a carer had felt natural in light of his commitment to Diego:

Okay, so I guess, it happened so quick. So I mean it was more of a shock. Like he had the stroke two years ago. It was just natural. I'm his partner. Of course, I'm worried, and you know, of course you want to look after them, and you want to make sure that he's getting the best care. So, you know, that's how it all came about.

Interestingly, though Mylo suggested that caring for Diego had merely constituted a natural extension of his commitment to his partner, he also described that he felt a profound sense of loss at hearing about the precarious state of his partner's life. Indeed, he nearly discussed this significant feeling of grief in physical terms:

It's my partner. I care about him, and something like this, it was like almost losing my right arm. I mean, it hurt. It was devastating. I just didn't know what to do. Am I losing 14 years of this? I mean, come on. We were so used to biking, and traveling all the time. So, it was a big change in our lives.

The presence of such emotional pain, however, combined with other experiences to render

Mylo's realities even more difficult during this time. He explained, for instance, that since he had been made aware that his partner's medical condition would likely require a lengthier hospital admission, he started living at Diego's bedside. This shift appeared particularly significant for the participant, since he not only experienced a physical toll on himself, but also since his life with his partner became increasingly defined by the realities of living in an institutional setting:

I lost a lot of weight, just from living in the hospital really. And yeah, it was just a learning process all the way along ... I mean, you go through these waves of being devastated because it happened, and then at one point, the hospital is telling you, "well, are you prepared that he may pass away," and I'm like, "you're kidding me, right?" ... So I lived at the hospital with him for, god, I think about three months? Yeah, three months ... So as time went on, and he became more aware, we got to know a lot of people in the hospital, that's for sure.

This period of time represented a transition from Mylo and Diego's relatively private life as a couple to their public reality in the context of institutional care, and it was accompanied by initial concerns about having the legitimacy of their relationship questioned by medical staff in this hospital setting. Mylo did suggest, however, that he soon discovered this fear to be unfounded after noticing that service providers appeared to acknowledge Mylo's position as Diego's partner:

I went into the hospital with my guard up, you know, just sort of say, "look, we need help, and god forbid you even ask, or question who I am," sort of thing. So I was pretty much demanding. No one really came out and said, "who are you?" No actually, a few times, in Emergency, people asked, "who are you?," I said, "I'm his partner." That's how I posed it. And in Emergency, it was like "oh, okay." But after that, it was normal.

Despite Mylo's primarily positive experiences with medical staff, specifically in relation to his sexual identity, the participant did describe examples of a few sexuality-related challenges he

encountered in the process of transitioning to his new life in an institutional setting. In particular, Mylo recounted that since Diego was often placed in rooms holding multiple patients, relatives of other patients would often question the nature of the couple's relationship. Indeed, Mylo described to me that some family members would often ask close-ended questions that would reflect heterosexist assumptions about the participant's relationship with his partner:

Some of the older ladies at the hospital, you know, coming in to see their family members, they would ask the stupid question, “oh, is that your brother?” I was tempted to say, “no, it's my gay partner.” And sometimes I did, and they were just totally floored. They were like “oh, okay,” and then they would walk away, you know? ... you know, assuming ... come on, he's not my brother, I don't even really look like him, so you know, what you're asking [is] “how are you two related?”

Mylo also, on occasion, perceived some medical staff to appear uncomfortable with the presence of a same-sex couple in a hospital setting, though he acknowledged that these manifestations were primarily subtle and covert. He also quickly explained that he believed these apparent expressions of homophobia to constitute anomalies amid a plethora of primarily positive experiences with hospital-based service providers:

I have to admit, there were some people that did work there [who] just totally ignored you because you could tell they were uncomfortable; some of the nurses. Didn't feel comfortable with the gay thing, and they knew you were gay, so their way of handling it was, “I'm not working in your section, but I have to work in this station, so I won't talk to you or acknowledge you,” sort of thing. “If you have a question, I'll answer it quickly, and then go away” sort of thing. You could see they were uncomfortable.

In light of the beginning of Mylo's narrative, it is important to note that although the participant did, in fact, believe his caring relationship to arise out of a natural understanding of his function as

Diego's partner, he also described the initiation of his care-giving role as a difficult transition comprising not only painful emotions, but also a complex transition into living the life of a gay carer in a hospital setting. It was apparent to me, as Mylo was recounting his story, that this period in time was rendered challenging due primarily to the participant's perception of this event as an incident of “shock” and grief, but also as a result of his transition into a new institutionalized reality as Diego's partner and care-giver.

“A Learning Process”: Providing Care in Institutional Settings. In hearing Mylo recount his experiences providing care to Diego during his hospitalization, one evident theme included his perception of having to learn how to provide care in this environment. More specifically, Mylo recounted to me that he had, upon Diego's hospital admission, been wary of others handling and providing personal care for his partner, and had to gradually learn to trust hospital staff with at least some of his partner's direct care needs:

Going to the bathroom, you know, just doing daily things, showering: [he] couldn't do any of that. So I did everything for him, and it was a long, grueling process. But I didn't want anybody else to touch him, I didn't want anybody to even handle him ... So I was always on my guard, so to speak. Yeah, it was a learning process.

Similarly, when Diego was taken to a rehabilitation facility to receive support with his physical and cognitive post-stroke recovery, Mylo suggested he needed to learn to trust the centre's staff with his partner's rehabilitation, even though he was reluctant to do so initially. He discussed remaining particularly cautious in the beginning stages of Diego's stay at the rehabilitation facility, specifically since he could no longer spend the night with his partner in this setting:

For me, to have to leave him somewhere, and let him do something on his own was really tough for me ... We did a lot of, you know, he had to go with physio, but it was time for me to sort of stand back a little bit, and let him do stuff. So I got sort of used to that, and

at the time, I had to go home in the evening, you know.

It is important to note that, despite the participant's reluctance to trust service providers with his partner, Mylo would frequently refer to medical and support staff as being helpful and attentive to Diego's needs. In light of this reality, I asked the respondent about his reasons for often having to learn to trust others with his partner's recovery, instead of simply assuming a level of confidence in their work. Interestingly, he answered this question by telling me that since his partner had lost his ability to communicate verbally following the stroke, he was concerned about his partner's particular vulnerability as a gay man without speech:

You always wonder how he's going to be treated when you know that he can't talk or he can't talk for himself. Like, he can't tell them what he wants ... At one point, [the gay issue] didn't really play a whole lot in my head, but at first, when we first went into the hospital, it did. I thought, "oh okay, here we are, a gay couple going into the hospital, we'll have issues"... And you know, we really didn't.

Given Mylo's apparent need to remain relatively protective of Diego during the couple's time at the hospital, and subsequently at the rehabilitation facility, it may be understandable that the participant placed great significance on being his partner's primary decision-maker at a time when Diego was still unable to consent to treatment. Indeed, he emphasized the importance of maintaining this role in an institutional setting, and suggested that this desire was merely reflective of what he perceived to be his partner's best interests: "I'm his partner, and of course, he feels more comfortable with me making a decision" (Diego, who was sitting nearby at the time, expressed agreement in response to this remark). However, despite Mylo and Diego's combined sense of confidence in the participant's suitability for representing the care-recipient's decisions at this time, Mylo indicated that Diego's sister had attempted to secure this role for herself during this period, primarily since she believed her kinship with Mylo's partner rendered her a more appropriate primary decision-maker:

Because I'm the person that he met a while ago, but still, not that anchored family member, she felt it necessary to [make decisions], right? That, "I'm the family member, I should be making decisions, not you; and I resent you making the decisions."

Mylo described to me that medical staff would ultimately defer to the participant as Diego's next-of-kin. However, the respondent suggested that this conflict was a source of unnecessary stress during this time period, particularly as he felt it necessary to maintain this role in accordance with Diego's interests. Interestingly, qualitative studies of LGB carers have commonly revealed tensions between care-recipients' families of origin and same-sex partnered care-givers, and so this experience may be consistent with existing literature (Brotman et al., 2007; Hash, 2001).

"A Different Type of Family": Diego's Recovery and the Quest for Informal Supports. At the time of my interview with Mylo, the couple had been living in their home for more than a year and a half. Though Mylo disclosed to me that his partner's speech impediment continued to persist, he also suggested that he had witnessed Diego making significant progress through various milestones that marked his recovery, and had gradually seen these events culminate in his partner's return home. These occasional incidents appeared significant to the respondent's care-giving narrative, particularly since Mylo had earlier experienced a profound sense of loss and grief, and since these events provided him with sources of hope to combat such feelings. Importantly, when the participant described these notable moments, he frequently quoted what he perceived to be Diego's thoughts during times in which his partner could not speak, and therefore indirectly suggested an understanding that both he and Diego shared sentiments of hope associated with these incidents. One notable example of such collective optimism accompanying a milestone includes the couple's rejoicing when Diego remembered how to ride a bike during his stay at the rehabilitation facility he had been taken to:

Well, he started to pedal, and one thing led to another. He went, "oh," and then he started crying. He started to squeeze the brake. He was pedaling. And then he came back to me,

and he said, “oh my god, bike, yes, a bike, oh, I remember this now, I remember this.”

And he started to go around in circles, and we videotaped it, and all the therapists just lost it. We all just lost it, because he was able to, he remembered a bike. That's how it came about. He started to squeeze the brake, and that's when he, yeah, you went, “oh my god, a bike.”

Mylo discussed a number of other similar events in storying his partner's recovery, as well as his own position within this process, and emphasized comparable manifestations of hope throughout most of these incidents. Notably, the participant disclosed to me that, throughout this series of milestones adorning his care-giving narrative vis a vis his partner's recovery, he placed particular value on informal sources of support that helped him not only to negotiate the difficult feelings he had experienced in the early stages of this process, but also to share in his celebration of his partner's recovery, and additionally to assist in practical terms whenever necessary. Interestingly, Mylo suggested that although several members of both his and Diego's families had offered assistance in various capacities throughout the span of the partner's stroke, a larger proportion of informal support had originated from “a different kind of family,” namely the couple's friends and colleagues:

You see the typical family members coming in. But my family members ended up being my friends. So when this all happened, his friends, my friends, everybody came together in support. So those people became my family ... overall, I think people have their brothers, sisters, mothers, dads coming in. We had ours, but it was a different setting, it was a different type of family.

In my second interview with him, after I shared my observation that informal supports appeared particularly central to the couple's collective experience of Diego's recovery, Mylo suggested that although such networks were indeed significant, they had dissipated to some extent over time. He explained, more specifically, that the couple had moved to a new neighbourhood, that Diego had

continued experiencing a number of challenges in his recovery at home, and that these two factors combined had prompted a number of friends and colleagues to gradually lower the level of support they had initially offered the couple. He noted, at the time of the interview, that whereas several formal sources of support continued being available to the couple, specifically including various rehabilitation therapists, the couple were struggling to reconstruct informal sources of support in their current state:

It's a different group of people who are in our lives now, because it's more speech therapists, music therapists, more people that are geared towards Diego's recovery. A lot of friends that Diego had are sort of gone to the wayside, and so, we don't see them a whole lot anymore ... I think what happens is people see that things are not the way they used to be, so it's nice to come and visit, but it's just a little awkward for them to see [Diego in recovery]. Because he can't talk, that's an awkward situation too.

Mylo indicated that although the couple had attempted to locate appropriate support systems in a variety of different settings, including recreation centres for persons with disability, the couple had often sensed some discomfort in accessing such venues. In particular, Mylo explained that Diego had expressed a lack of identification with other persons with disabilities, particularly after visiting a swimming pool catered to individuals living with physical impairments, and had indicated a disinterest in pursuing an active association with this and other similar community settings. Mylo, on the other hand, recounted his own experience of visiting this community resource, and suggested to me that he felt alienated among care-givers who appeared to be predominantly heterosexual female spouses, and who would often make heterosexist assumptions about his relationship to his partner:

I could see the care-givers beside [their partners at the swimming pool]. And putting myself in that category, as a “care-giver” and his “partner,” I don't see myself as the same as those people. It was a little awkward at the pool. A couple of times, where I see the old ladies that were carting their person around, and they're saying, “oh, is that your

brother?,” you know, questioning, “is that your brother?” And at one point, I thought, “I don't want to answer this,” and I said, “yeah, my brother, yes, mmhm, yeah, yeah, it's my brother.”

Accordingly, it is possible to suggest that Mylo appeared to end his story with his struggle of locating appropriate systems of support that would not only be mindful of his partner's condition, but ones that would also enable the couple's sexual identity to be respectfully recognized and acknowledged. In fact, when I asked Mylo specifically what he would most importantly want captured in his story as a gay care-giver, he described the abundant level of informal support he received from friends and colleagues in the beginning of Diego's stroke on the one hand, and the need for similar support networks in the couple's new life together on the other. He was implicit in suggesting that these two components of his story, combined, signified important experiences that some gay care-givers could encounter when families of origin might either be relatively unavailable, or at times when such relatives might question the legitimacy of same-sex partners' caring roles, as Diego's sister apparently had done earlier.

Chapter 5 - Discussion

In this chapter, I attempt to position the results of the study by first drawing attention to common themes invoked across the five care-givers' narratives, by then examining these themes in relation to both general care-giving research (including the three theoretical frameworks discussed earlier) and existing literature on LGB care-giving more specifically, and by finally suggesting implications of these findings on social work practice and on LGB care-giving research. In first discussing commonalities across the five stories, I engage in a form of cross-case analysis that draws on Clandinin and Connelly's (2004) three-dimensional model of narrative inquiry, and I therefore focus on elements of interaction, temporality and physical space that may have been found across various cases. Since Clandinin and Connelly have suggested that cross-case analysis may indeed reduce the richness of a narrative study, I attempt to counteract this possibility by consciously attributing examples of potential cross-case similarity to individual participants and their stories. In my analysis of relevant literature, I explore both general care-giving research, as well as quantitative and qualitative studies undertaken on non-heterosexual care, and in comparing the results of this study with the findings of previous research, I propose using a lens of intersectionality to help conceptualize the lives of the five gay care-givers featured in this piece of inquiry. I conclude this chapter, and the overall paper, with implications of this study on social work practice at various levels of intervention, with a reflection of the methods used in the current study, and with suggestions for subsequent related research, particularly in light of limitations specific to this attempt at understanding gay care-givers' experiences.

Across the Stories: Common Themes Invoked by the Five Care-Givers

Elements of "Choice" in Committing to Care. Though not all participants explicitly noted that they chose to care for their ailing partners, several referenced elements of choice in storying their positioning as care-givers. Pedro, for instance, was clear that Andrew disclosed his HIV status prior to the formal initiation of the couple's relationship, and that he gave the participant a period of time to

fully consider the implications of committing to a relationship that would likely involve the provision of care. Pedro initially felt some uncertainty in accepting this level of responsibility, but his partner mitigated this wariness by suggesting that the couple's commitment to one another would be reconsidered “day by day,” thereby conveying to him that a subtext of “choice” would continue defining the couple's togetherness. Remarkably, Rob recounted a similar milestone in his story of caring for Allan, as he too described being given time to deliberate on his commitment to the relationship at the onset of his partner's physical conditions. Both Pedro and Rob, in referencing elements of choice associated with their positioning as care-givers, implicitly described finding depth and meaning in this experience. Whereas Pedro, for instance, suggested that his conscious commitment to a care-giving role had appeared comparable to the significance of deliberately choosing to start a family, Rob believed Allan's offer of “choice” communicated his partner's respect and value for the support this carer would ultimately provide in the context of partnership.

Nick's case offered a particularly interesting example of deliberately “choosing” to commit to a caring role, specifically since this respondent had decided to offer such commitment at an apparent end to an undefined relationship he had had with William, and had left his relationship with the care-recipient predominantly unlabeled throughout his story as a care-giver. Interestingly, the participant was clear that despite the blatant element of choice underpinning his caring role, combined with the undefined nature of this relationship, he had found a profound sense of spiritual meaning in his care-giving position with William. More importantly, the participant was also clear that regardless of these factors, he had recognized himself as a primary decision-maker during William's hospitalization, and had cited his spiritual connection (versus the (un)labeled nature of his relationship) as a primary reason for being suited to this role.

Though Joseph and Mylo did implicitly make references to components of “choice” in their positioning as care-givers, these manifestations remained primarily subtle. For instance, though both

participants remarked that they believed their caring positions to have constituted mere extensions of their relational roles as partners, Joseph indicated that he had found meaning in understanding that his partner had actively chosen to remain with him through the entire length of the couple's partnership and through the progression of his illness. Indeed, in his words, he felt “complimented” by the fact that his partner had chosen to stay with him during the full span of the couple's time together. Although Mylo made no mention of “choice” in directly influencing his positioning as a care-giver, he did imply this factor by suggesting that he had chosen to firmly identify himself as Diego's partner at the start of his hospitalization, in spite of anxieties the respondent may have held in “outing” himself within an institutional setting. Despite these two participants' implicit constructions of “choice,” it is important to note that neither mentioned such elements explicitly, and that they would likely understand their caring positions more so as functions of kinship or familial responsibility.

Regardless of the extent to which participants explained care-giver positioning as a product of deliberate choice, it is significant to note that at least three of the five participants referenced this reality explicitly. As mentioned in an earlier section of this paper, emergent qualitative research on the care-giver positioning process has revealed that non-LGB care-givers may at times believe themselves to provide care as extensions of their existing relational positions (O'Connor, 2007), and may therefore not story “choice” into their narratives as much as some of these gay carers may have within the context of this study. In other words, it is possible to suggest that the theme of “choice” invoked in the scope of this study may be a characteristic specific to the experiences of some gay care-givers, whose relationships with care-receiving partners may or may not be as well-defined as carers located in conventional heterosexual caring partnerships. It is important to qualify this analysis, however, with an understanding that this piece of inquiry was only concerned with exploring the experiences of same-sex care-giving partners, and that LGB care-givers who support blood-related kin (e.g. including parents or siblings) may more likely report feelings of familial obligation, as has been uncovered by Hash (2001).

Anticipation and/or Experience of Discrimination in the Context of Public Space. Clearly, one theme that was shared by all participants included respondents' anticipation or experience of sexuality-specific discrimination. Significantly, these expected or felt manifestations of homophobia would often arise as care-givers would interface with formal systems of care in varying contexts of public space, ranging from primary care offices, to hospitals and rehabilitation facilities. The most apparent example of this theme was perhaps evident in Rob's narrative. In his story, the participant specifically recounted events in which he believed himself to experience overt homophobia in health care settings, particularly by not being permitted to accompany his partner into physicians' offices, and perceived this reality to reflect an undervaluing of same-sex partnerships in the context of formal medical spaces. Rob also suggested that, given his accompaniment of heterosexual female friends to medical appointments without any apparent questioning of his relationship with these women by professionals, he believed his experience in medical settings represented an inequality in how service providers would assume relational legitimacy among same-sex couples, versus heterosexual pairs.

Other participants did not convey overt expressions of homophobic hostility to the same extent as Rob disclosed in his narrative. However, several notable examples of homophobia were found in other stories nonetheless. The most compelling of these, arguably, could be considered Pedro's account of home support workers, whose apparently uncomfortable presence would often compel him to avoid showing physical affection to his partner Andrew. As already mentioned, this example appeared to suggest that Pedro felt a sense of “hyper-visibility” surrounding his sexual identity, particularly since he believed the couple's overt “queerness” would expose his partner to mistreatment by already homophobic service providers. This account also implied, perhaps more importantly, that the care-giver's usually affirming private residence would transform into a relatively homophobic public space upon contact by formal service providers, and therefore suggested that public spaces replete with discrimination could very well exist within a care-giver's own home.

Both Joseph and Mylo suggested that whereas they had anticipated homophobia by health care professionals, again within the context of public medical space, these fears had been mitigated by primarily positive experiences with service providers. Joseph, for instance, said that although he had had some limited anxiety surrounding how he and his partner would be treated by medical professionals, these fears were quickly proven unfounded when service providers asked him open-ended questions about the nature of his relationship with Edwin, and in so doing, provided him with assurance of their receptiveness to couples of different orientations. Mylo, similarly, suggested that he had experienced significant unease at the time of Diego's hospitalization, but was communicated with by medical staff appropriately, and subsequently felt confident in their respect for same-sex couples. Interestingly, despite Mylo's primarily positive experience in an institutional setting, he did suggest at times encountering heterosexist attitudes by family members of other patients while he and Diego were residing in a hospital setting, and additionally felt covert expressions of homophobic discomfort by some service providers within this context. Mylo's reality may suggest that although overt systemic discrimination may not be perceived within an institutional setting, ideological manifestations of homophobia and heterosexism may still subtly permeate day-to-day life within these public spaces.

Nick's story, perhaps in contrast to other participants, invoked the possibility that homophobia may be "flagged" as a concern by the care-recipient, as well as other parties, even when a care-giver's own understanding of an institutional context may render her/him relatively dismissive of the prospect. Indeed, though Nick disclosed to me that William had been fearful of entering a rural hospital setting as a gay HIV-positive man, and that he himself had been warned about his unconventional appearance by an AIDS advocate who was concerned about the care-giver experiencing homophobia, he appeared to remain largely indifferent to these possibilities until they were rendered salient by others. Nick's story is significant in implying that homophobia and heterosexism may underpin even situations in which a care-giver may neither be the subject of anticipated nor experienced homophobia, but may instead be

identified on as a potential target of such discrimination by friends and allies.

It is important to qualify all expressions of homophobia and heterosexism, as revealed in the stories of the five carers, by acknowledging that these realities would likely never be experienced singularly, but would instead combine with other factors to produce unique challenges, advantages, or other distinctions. For instance, in exploring the stories of Pedro and Nick, it may be evident that HIV stigma may have been at least comparable, as a source of discrimination, when juxtaposed with the participants' sexual identities. Similarly, Rob and Mylo both discussed issues of disability in largely distinct ways, and suggested that challenges surrounding disability impacted the respondents' experiences to a similar extent as sexuality-specific realities. Finally, Pedro briefly invoked the issue of race/culture, specifically in relation to experiencing a caring partnership with his White partner, and suggested that being Latino exposed him to unique variations on homophobia and heterosexism, the expressions of which would likely not be encountered by a non-racialized care-giver.

Despite the rich diversity of experiences reported by all care-givers, it is possible to argue that homophobia and heterosexism comprised significant elements of all their stories, to lesser or greater extents. It is important to note that these systemic expressions of discrimination may not only be overtly sensed, but are also likely to be anticipated, and that both the experience and anticipation of these realities may become particularly pronounced as carers interface with formal systems of care, including institutional settings. Clandinin and Connelly's (2004) model, by virtue of enabling an analysis of physical space, enabled me to explore the possibility that public physical contexts often influence the extent to which homophobia and heterosexism may be present for carers, and signified the potential need for proactive anti-discrimination interventions within institutional settings serving care-givers such as the five participants included in the study.

The Importance of Gay-Friendly Support Systems. Most participants discussed the importance of gay-specific support networks in helping them mitigate some of the difficulties they discussed within

the scope of the study. Some of these insights referred particularly to the relevance of suitable support groups. For instance, Pedro suggested that he would feel reluctant to access a mainstream care-giver support group for fear of encountering sexuality- and HIV-related stigma, and thereby implied the relevance of accessing a gay-specific group. Joseph, in contrast, suggested that he enjoyed accessing a mainstream support group, but also noted that he was respected as a gay man within this setting, and additionally that he was able to interact with a lesbian woman in the group who shared some of his concerns related to grief.

Aside from accessing established support groups, however, several participants also described the potential need for far more informal networks of gay-specific support. For instance, Pedro described his gay nephew's willingness to help with his partner's care on occasion, and suggested that the nephew's sensitivity to the couple's sexual orientation had likely prompted him to make himself available for this assistance. Nick and Mylo were also clear in delineating the value of such support. Whereas Nick, for instance, underlined his wish for a strong network of gay men to have assisted him in making spiritual meaning of his HIV/AIDS-based care-giving narrative, Mylo expressed the need for a system of informal friends and allies who would support the couple in the reconstruction of a new "family." Though Rob appeared to place somewhat less of an emphasis on the need for gay-specific supports, he would often make brief references to his friends and family as comprising strong sources of support in his life with Allan.

Regardless of the specific meaning that informal networks may have had for each of the individual carers participating in this study, it is apparent that such systems may be significant for care-givers encountering difficulties in the scope of their everyday lives. More importantly, given the stories shared by each of the respondents, it is possible to suggest that some gay carers may specifically prefer having access to gay-friendly support systems, be they formal or informal. In particular, since participants disclosed the tendency to either anticipate or even experience discrimination when

accessing mainstream services, it may be understandable that resources aimed at same-sex couples would perhaps be preferred for some care-givers and their partners.

Unique Constructions of “Family” and “Partnership” as Sources of Meaning. All participants appeared to place relative significance on the meaning they ascribed to their partnerships with care-recipients, specifically in light of issues they may have encountered in their lives as same-sex caring partners. For instance, as already mentioned, Pedro drew parallels between the depth of his care-giving commitment and the significance of starting a heterosexual family, and in so doing, appeared to suggest that he had constructed a meaningful rendition of “family” in the context of same-sex caring partnership. In addition to explicitly referring to the building of “family” as a source of meaning found in his care-giving narrative, however, Pedro also discussed his perceived “witnessing” role within the realm of the HIV/AIDS epidemic as being particularly fundamental to the meaning he ascribed to his partnership, and believed this dimension of his reality to reflect a positive distinction in his care-giving narrative as a gay man. Interestingly, though Nick never explicitly mentioned constructing “family” within his caring relationship, he did similarly make references to his perceived role amid the HIV/AIDS epidemic as a marker of distinction in his partnership with William, and additionally, he described this understanding as comprising a source of spiritual meaning for himself as a gay carer.

Both Rob and Joseph appeared to place great significance on storying their partners into their narratives as family, and also seemed to find depth in this process. In the case of Rob, the participant explained to me that, given the challenges he had survived with Allan, as well as the commitment he believed the couple had maintained to one another through these difficulties, he believed his partner comprised his most immediate family. Indeed, Rob understood this reality to be true despite a lack of legitimacy and recognition he had been granted by the medical system, and in fact, drew meaning from his tenacity to continue identifying his partner as family in spite of the presence of such barriers. Though Joseph's story was markedly different Rob's in many respects, he similarly appeared to find

purpose in storying his ailing partner as “family,” particularly when he discussed the impact his same-sex caring partnership had had on various church friends and professionals, many of whom he believed would have likely maintained some myths surrounding gay relationships in the absence of his relationship with Edwin.

Interestingly, Mylo explained that he had developed “a different kind of family” in the span of his care-giving narrative with Diego, specifically clarifying that he had come to rely on sources of support that extended beyond the couple's families of origin, and then subsequently revealed that he felt the need to construct similar networks in his future life with his partner. Mylo's experience is particularly interesting, since his story suggests that a gay care-giver's construction of “family” may very well exist beyond the parameters of his relationship with a partner to incorporate sources of support including friends and other allies. Needless to mention, Mylo found significance in building gay-friendly “family” systems during the beginning stages of caring for Diego, particularly since he overtly discussed his perceived need to seek and develop similar networks in the future.

Once more, all five participants appeared to story “partnership” and “family” differently in their individual narratives, though each also seemed to refer to gay-specific definitions of these constructs – evolving from within their narratives about care-giving – as strong sources of meaning and depth. This finding of the study suggests that notions of “partnership” and “family” may not necessarily fit heterosexist or conventional definitions within same-sex care-giving partnerships, but that these distinctions may nonetheless account for the significance that care-givers and their partners ascribe to their caring relationships.

The Findings in Relation to Relevant Literature

General Care-Giving Research. As mentioned in the literature review of this study, the contemporary study of care-giving arguably began with attempts at studying stress and burden in the context of care. Accordingly, it is understandable why a consideration of this literature may be

necessary in positioning the results of this piece of inquiry. Though stress and burden perspectives on care-giving may have been valuable in guiding research on care-giving for several decades, these models may present shortcomings in conceptualizing the findings of this study. Most importantly, since these frameworks arguably imply the need for quantifying and finding relationships between variables of “stress” and “burden” in large samples of informal carers (Pearlin et al., 1990; Zarit et al., 1980), they are likely to neglect a nuanced analysis of how these variables may be experienced individually among the gay men being studied. For instance, though participants in this study did disclose countless challenges that could be conceptualized as “stress,” they would often suggest that these realities were experienced uniquely in the context of their lives. Indeed, as a case in point, though Rob was clear in suggesting that many of his experiences at a medical office may have caused him great distress, the participant's understanding of this distress was closely related to his perception of homophobia, and not necessarily care-related “burden.” Though, accordingly, it is possible to suggest that stress and burden perspectives on care may be useful in acknowledging the existence of these factors in the lives of the men being studied, it is likely that this lens would nonetheless fall short of acknowledging the participants' realities as members of a sexual minority group.

In suggesting the relative shortcomings of stress and burden models of care-giving, specifically with respect to this study, it is important to note that these lenses have not been the only ones to predominate in contemporary care-giving research. Feminist frameworks, which have at least partly been premised on critiques of stress-related perspectives (Ward-Griffin et al., 2005), present yet another option for helping to adequately position the findings of this research. Though this study was primarily focused on issues of care in the lives of five gay men, feminist lenses may nonetheless prove applicable in discussing some of the findings. Namely, since feminist writers have indeed highlighted issues of power that may be present in the realm of care-giving (Hankivsky, 2004), these theoretical orientations may enable a recognition of some of the power-related realities discussed by the five participants. For

instance, as already mentioned, most of the participants discussed the presence of either anticipated or experienced homophobia/heterosexism in the context of their narratives, and they therefore suggested that their interactions with formal systems of care were often defined by complex relations of power. Many respondents also made reference to issues of power that existed beyond their identities as gay men, including factors related to disability, age, and race.

Despite the potential applicability of feminist lenses to the positioning of this study's findings, however, several shortcomings are important to note. Perhaps most apparently, since writers associated with these orientations have traditionally focused their analyses on how women's caring labour may be under-valued in the context of patriarchal power relations defining nuclear/heterosexual family contexts, these frameworks may not adequately acknowledge the sexuality-related issues that gay men may encounter as they interface with formal systems of care. Indeed, this shortcoming has been noted by Hash and Cramer (2003), who have suggested that feminist literature on care has predominantly focused on the experiences of either heterosexual female spouses, or older daughters assumed to be heterosexual, and has consequently neglected the experiences of LGB carers, located outside these conventional kinship roles, who often interact with hostile systems.

Thus far, both stress and burden perspectives on care-giving, as well as feminist lenses surrounding care, have been analyzed, not only in terms of their potential relevance to the findings of this study, but also in light of their possible shortcomings. One last set of analytical positions, whose tenets may be useful in conceptualizing this study's findings, includes constructivist approaches to studying care-giving. As discussed earlier in the paper, constructivist frameworks for understanding care may be most appropriately suited to examining the lives of gay carers, primarily because these experiences remain somewhat unexplored, and also because constructivist orientations enable inductive analyses of care that attend well to how little-known experiences are discursively produced and understood. Indeed, based on Adams' (2000) work, since constructivist frames of reference largely

necessitate the use of inductive qualitative methods to explore the experiences of giving care, such frameworks may be appropriately suited to researching a realm of reality not yet fully explored. For instance, in specifically discussing the results of this study, the theoretical position of constructivism would enable full attention to how the five men under study implied “choice” in their positioning processes, and additionally to how they may have ascribed unique definitions of partnership and family within the scope of their narratives.

Having discussed the applicability of constructivist lenses to the findings of this research, however, it is still important to note one apparent disadvantage inherent in these models. Namely, since these frameworks attend almost exclusively to how care is produced discursively in the context of interaction, they do not necessarily require a recognition of issues of power that may be relevant in the lives of the gay men under study. Indeed, although these lenses would enable some of this study's findings to be appropriately contextualized and understood as unique elements of the participants' stories, specifically in the context of their partnerships and their interactions with health professionals, the focus on such intersubjective processes would not necessitate attention to broader structural issues experienced by these five men. Even with a recognition of the discrimination encountered by the carers, specifically as products of the participants' interactions with medical systems, there would be little attention to these expressions of homophobia and heterosexism as potentially systemic issues that exist beyond the realm of single cases. In light of this critique, combined with my analyses of other care-giving literature, I argue that constructivist approaches may be best suited to positioning the results of this study, though the potential lack of structural analysis associated with these lenses may need to be acknowledged and addressed before actively drawing on these analytical frameworks.

LGB Care-Giving Research. In the preceding section, I attempted to outline the position of the study's findings within various bodies of literature related to the general study of care-giving. I now wish to describe the study in relation to research specifically focused on LGB care-giving. In starting

this discussion, it is important to begin with quantitative studies of LGB carers, particularly since no research had been made on this population prior to these attempts. Early quantitative research, as described earlier, was primarily focused on illustrating the prevalence of care-giving activities among LGB adults, primarily since assumptions had been made by earlier researchers that care-related responsibilities took place in predominantly heterosexual contexts (Fredriksen, 1999). Contemporary studies in this area have been primarily concerned with uncovering the prevalence of distress-related factors among LGB care-givers, particularly given a recognition that homophobia and heterosexism would present additional sources of strain to these carers (Fredriksen-Goldsen, 2005; Shippy, 2005). In other words, the few existing quantitative studies on LGB care today appear to be somewhat grounded in stress and burden perspectives on care, specifically in light of their emphases on measurements of distress.

Though it is understandable that some quantitative researchers have been primarily interested in determining the prevalence of strain among LGB care-givers, particularly given the realities of homophobia and heterosexism as additional sources of stress for these carers, the findings of the current study suggest that focusing on global measurements of strain and burden may be inadequate, in some respects, when examining realms of LGB care. Whereas some of the quantitative studies incorporated measurement tools that would specifically assess sexuality-specific distress indicators such as homophobia and heterosexism among care-givers (Fredriksen-Goldsen, 2005; Shippy, 2005), even these tools would perhaps not address the subtleties invoked in the stories of the respondents participating in the study. For instance, though several participants discussed feelings of strain arising out of their experiences with homophobia and heterosexism, their accounts also suggested that these realities varied significantly according to context (e.g. anticipated versus experienced homophobia), and that some carers additionally drew meaning from the difficulties they may have undergone as gay care-givers. In addition, since many of the participants storied the notion of “choice” into their

narratives as care-givers, it is likely that a focus on “burden” would be considered inapplicable to the lives of some of these respondents, since the construct may connote obligation or unwanted responsibility. Despite the possible disconnect between some of this study's findings and the results of past quantitative studies on LGB care, it is still important to note that the contributions of quantitative researchers may have prompted the emergence of this field of study, and may have additionally given this piece of inquiry a frame of reference for acknowledging the presence of discrimination in the lives of gay carers.

Aside from considering the relationship between this study and past quantitative research on LGB care, it is also highly relevant to explore the possible interrelations of this study's findings with those of other qualitative studies in this field of research. Past qualitative studies on LGB care-giving have been predominantly exploratory in nature, due most likely to the relative absence of non-heterosexual focus in care-giving research, and have uncovered a number of important themes related to the lives of LGB carers. As mentioned in the literature review of this study, this body of literature has overall found that non-heterosexual care-givers report: (1) lacking support from “family of origin” relatives, (2) encountering homophobic attitudes in interactions with service providers, (3) refusing to seek support due to a fear of discrimination, (4) keeping same-sex relationships secret to avoid conflict with potentially hostile medical professionals, and (5) not being legally recognized as same-sex couples in the United States (Hash, 2001; Brotman et al., 2007).

Interestingly, many of the themes surfaced in previous qualitative studies were found in this study as well. For instance, Pedro and Mylo both referenced lacking support from families of origin, virtually all participants discussed encountering either anticipated or perceived discrimination, Pedro suggested he had avoided attending support groups for fear of being stigmatized, and Rob disclosed to me that his relationship often felt delegitimized in health care settings, despite the legal recognition of same-sex partnerships in Canada. None of the participants explicitly discussed having to hide the

nature of their same-sex partnerships out of fear of being discriminated against, though Mylo did describe his tendency to occasionally “play into” heterosexist assumptions relating to his partnership, simply out of frustration of repeatedly having to correct these presumptions. Some of this study's findings, which perhaps may serve to complement the results of past research, have seemingly not been found in previous studies. These include the tendency for some of the care-givers under study to story “choice” into their positioning processes, the interplay of other non-sexuality-related factors (such as race and disability) in shaping experience, and the meaning that participants appeared to derive from their partnerships and constructions of family within the context of care.

In essence, previous quantitative and qualitative studies conducted on LGB care-giving may serve as frames of reference for this research, though the latter body of research may constitute a more applicable point of comparison. It is apparent, specifically after positioning the results of this study in relation to qualitative studies on non-heterosexual care, that further related research may need to be designed with an attention to not only care-giver positioning processes among LGB carers, but also to the relationship between sexual orientation and other dimensions of the self, and the tendency for carers to construct meaning and purpose as they negotiate the many difficulties they may encounter in their everyday lives. These issues appear to be relatively unexplored in related qualitative studies, and may require attention in the design of future related research. Arguably, since existing qualitative literature in the area of LGB care-giving has remained relatively descriptive and exploratory until this point in time, the future study of non-heterosexual care may require an analytical framework that adequately attends to these newly understood experiences as conceptual bases for further inquiry.

Intersectionality as a Lens for Conceptualizing the Study's Findings

In this chapter, after engaging in a cross case analysis of the study's findings, I attempted to position the results within the body of general care-giving research, and then more specifically within the limited expanse of literature on LGB care. During this discussion, I suggested that although the

three analytical orientations on care-giving appear to provide some insight into how the results of the study might be conceptualized, I also pointed to the various shortcomings associated with each. Similarly, whereas I discussed the relevance of quantitative and qualitative LGB care-giving studies to the current research project, and even explained the potential complementarity of the paper's findings to the body of related qualitative inquiry, I highlighted that some unique themes invoked in this piece of inquiry may have not been explored in past research. In conclusion, I suggested that a new framework, which would adequately attend to the realities invoked in this paper, may be needed to organize the findings of this study into conceptual bases for informing future inquiry in the area of LGB care-giving.

In this subsection of the paper, I wish to outline a lens, based upon the post-structural tenets of intersectionality (Yuval-Davis, 2006), that may be used to conceptualize the findings of this study, and that may consequently be used to inform future directions in this area of research. There are several reasons for pursuing the development of such a model. First, given the usefulness of feminist lenses for addressing issues of power found in the realm of care-giving, and additionally the applicability of constructivist approaches for inductively attending to care-givers' subjective constructions of reality, I acknowledge the importance of developing a model that seeks to encompass both a comprehensive analysis of power relations, and a recognition of complex subjectivities found in the realm of care. Second, given that this study's relatively original findings (in relation to existing qualitative studies) may not be adequately understood through either feminist or constructivist lenses alone, but rather by a combination of the two frameworks, it may be necessary to propose a model that will not only conceptualize the nascent issues invoked in the study, but will also, in so doing, create a conceptual framework encompassing attention to subjectivity and structural analysis for informing future research. It is with these justifications that I propose a lens based on the tenets of intersectionality.

Under a framework of intersectionality, each person is said to comprise complex identities with multiple facets that intersect at the interface of personal narrative and social context, and each

individual is therefore said to develop a complex and ever-changing subjectivity that is in part shaped by both personal and political dimensions of the self (Cronin & King, 2010; Yuval-Davis, 2006).

Though clearly the position of intersectionality loosely implies a constructivist foundation that may conflict with the epistemological origins of a more structurally-oriented feminist lens, it nonetheless addresses subjective experience without neglecting an analysis of structural or systemic issues of power. Applied to the findings of this study, this framework may serve as an appropriate lens for conceptualizing the experiences of the five gay carers under study, particularly since the care-givers' stories often revealed issues related to their complex intersubjectivities as care-giving partners of gay men, but also illustrated interrelated systemic issues that appeared to partly define these apparent subjectivities.

Pedro's story may reflect the suitability of using intersectionality as a lens for addressing and theorizing the realities invoked in this study. For instance, this participant's emphasis on his caring relationship as a manifestation of “family” denoted an intricate intersubjectivity located in the context of his partnership, and simultaneously, his experience with systemic interrelations of homophobia, racism, and issues of age appeared to form contextual bases for such constructions of “family” in the first place. Indeed, similar processes appeared to define Rob's narrative, particularly when he would refer to his relational construction of “family” as an enriching product of otherwise challenging systemic difficulties that would be marked by interrelations of homophobia, heterosexism and ableism.

To use other examples of how attending to subjective/relational processes and structural realities simultaneously might produce an adequate lens with which to conceptualize the findings of this study, it is possible to refer to Mylo's case. This care-giver acknowledged that he had anticipated experiencing an increased vulnerability to homophobia during his partner's hospitalization and functional decline, thereby immediately acknowledging a systemic reality defined by issues of sexual orientation and ability, but also suggested he had constructed a supportive relational context that had

helped him mitigate the intertwining difficulties of caring for a gay man with a newly-developed disability. Joseph recounted a somewhat similar experience, namely by disclosing that his structural context as a gay man had been very well mediated through his relational interactions with service providers, all of whom had apparently addressed himself and his partner appropriately during a time of crisis.

Nick's story provides a final example of how intersectionality may be applied to the findings of this study. In this narrative, the care-giver explained that he had derived significant spiritual meaning from acknowledging the collective position of gay men vis a vis the HIV/AIDS epidemic, as well as his own location within this reality, and expressed a wish to have had a gay-specific support network that would have helped him navigate these experiences during this time. In other words, the respondent described that he had immediately positioned himself in the structural context of HIV/AIDS during the process of identifying himself as a care-giver, had developed a complex subjective reality at that moment, and had hoped to share this reality with other gay men as a means of being supported through William's decline.

Accordingly, it is possible to suggest that a lens of intersectionality may serve as a relatively comprehensive lens for conceptualizing the results of this study. Further, in emphasizing the complex interrelationships between intersubjectivity and structural context that may have been located in the findings of this study, the framework may highlight the need for future related research to be conceptually based on an acknowledgment that non-heterosexual carers' realities may equally be shaped by relational processes and systemic issues of power. Indeed, given my analysis of the applicability of intersectionality to the study's relatively original findings, it is possible to argue that any future research arising out of this study's results may inevitably require an attention to both realms of reality.

Implications of the Study on Social Work Practice

Though, as mentioned previously, the results of this study may not be generalizable statistically, they nonetheless provide insight into how social workers could practice with gay carers whose lives may in some way bear resemblance to those involved in the study. Perhaps most apparently, at the direct practice level, it is important to note that discourses of “stress” and “burden” may not necessarily be applicable to the experiences of gay care-giving partners who may position their caring roles as functions of choice. Indeed, since a number of participants included in this study referenced conscious decision-making in identifying themselves as care-givers, using language that connotes obligation and conventional kinship may not necessarily apply to the experiences of some gay carers located in the context of partnership. Having discussed this implication, it may be equally important for direct practice social workers to acknowledge that, regardless of choice or obligation, gay carers may ascribe great significance to their relational roles vis a vis their partners, and that using appropriate language to address these sources of meaning may require attention to *how* gay carers express their ties to their care-receiving partners. It is important to note that this implication may not extend to gay carers who provide support outside the context of partnership, particularly as this theme of choice was specifically addressed in relation to the carers' intimate relationships with their partners.

Another direct practice implication includes the need for practitioners to be cognizant of the possibility that some gay care-givers may experience anticipated homophobia within institutional settings. As mentioned throughout various sections of this paper, even when gay carers would not encounter overt expressions of discrimination, many would still fear being exposed to such attitudes upon entering public spaces with their partners, and required some reassurance that same-sex relationships would be respected and recognized within these contexts. Indeed, Joseph even suggested the need for health care professionals to learn how to ask open-ended questions about the nature of relationships between care-receivers and care-givers, primarily in order to avoid making heterosexist

assumptions about same-sex couples, and in so doing, to mitigate anticipated homophobia/heterosexism.

One significant implication at the mezzo-level of social work practice relates to participants' emphasis on the importance of gay-friendly support systems. Indeed, since almost all respondents described either the value they placed on accessing these sources of support, or the retrospective wish to have had exposure to these networks, it may be highly relevant for social workers to consider that gay care-givers may either require information on gay-specific support services, or at the very least, exposure to support groups that are perceived to be gay-friendly. Whereas for social workers engaged in direct practice, this recognition may include a reconsideration of referrals, or (for group facilitators) measures to ensure the emotional safety of gay group members involved in a mainstream service, macro-level social workers may consider the relevance of community development initiatives aimed at creating gay-specific networks of support for care-givers and their partners.

In outlining institutional or macro-level implications for social work practice, it is first important to note that since none of this study's findings are generalizable, it may be important to consider these recommendations tentatively. Having provided this caveat, however, given the diversity in participants' definitions of "partnership" and "family," it may be important for social workers devising policy at the institutional level to recognize that conventional standards for establishing kinship may unfairly disadvantage some gay carers whose partnerships may diverge from heterosexist norms. In response, social workers may need to develop mechanisms for ensuring gay care-givers' ability to be primary decision-makers for their partners, or at least to be recognized as such, in the absence of formal legal arrangements such as marriage or common-law status.

In addressing anticipated and perceived homophobia/heterosexism at the institutional/macro level, one recommendation may include the need for social workers to develop educational opportunities for health care professionals engaged with gay care-givers. Indeed, for practitioners

working at the policy level, it may be necessary to advocate for initiatives that seek to train service providers on how to use open-ended questions, how to otherwise acknowledge same-sex partnerships appropriately, and ultimately, how to be proactive in mitigating homophobia/heterosexism. Though this recommendation may be considered far too specific, it is interesting that one participant (Joseph) placed great significance on the need for such relational competencies by service providers.

Reflection on the Use of Methods

As already mentioned, I adopted a constructivist position in designing the current study, and particularly drew on narrative approaches for conducting qualitative inquiry into the experiences of five gay care-givers. Specifically, I relied heavily on the work of Clandinin and Connelly (2004) for helping me examine how participants storied their experiences as functions of interaction, space, or time. As predicted early in the course of the study, the adoption of narrative methods enabled me to generate and analyze rich data specific to the experiences of non-heterosexual care among men. In particular, because the interview process enabled participants to share their personal narratives, and also because the process of analyzing data necessitated a strong attention to these individual stories, deeply subjective and complex experiences were recognized. For instance, Pedro's story revealed the potential that a gay couple's private space may be transformed into a public one when formal systems of care enter this realm. Rather than simply identifying "homophobia" as a broad category within which this experience would have likely been situated, a narrative approach to qualitative research arguably enabled a focus on how this participant experienced an institutional expression of discrimination in his own home, as his private residence became a public space.

Interestingly, since I relied on verbal interviews as sole sources of data, I may have been limited in the type of data I generated. As Clandinin and Connelly (2004) argue, narrative research often requires a commitment to gathering data from various sources, often times including "unconventional" texts such as photographs, participant-written journal entries, and illustrations. Indeed, since one

participant (Nick) made explicit reference to having written journal entries during his experience as a care-giver, my attention to this data would have likely enriched the scope of experienced I explored with the participant. It is after conducting the study that I recognize this shortcoming, and although I am assured by the richness of some of the data I was capable of gathering in the span of in-depth interviews, I am now convinced of the relevance of consulting various sources of “field text” in future attempts at employing narrative methodology.

Implications of the Study on Future Research

As already discussed, this study of gay care-givers evoked a number of themes that have not yet been explored in related qualitative studies of LGB carers. Namely, these themes included notions of “choice” embedded in the context of gay care, the possibility that other factors (such as race or disability) may interact with issues of sexual identity in marking the experiences of gay care-givers, and lastly, the meaning that some gay men may ascribe to their caring relationships as they mitigate challenges relating to their stories as gay carers. In analyzing these themes, in addition to other previously-uncovered experiences (e.g. encountering homophobia/heterosexism), it is possible to suggest that some gay carers may be grounded in realities that are constructed as intersubjective factors and structural realities interact in the realm of lived experience.

Given the above analysis, it may be relevant for future related research to examine more substantively how gay care-givers negotiate their structural realities within these intersubjectively constructed relational contexts. For instance, it may be particularly pertinent to more thoroughly focus on gay care-givers' positioning processes at specific stages in their care-giving narratives, and to determine whether discourses of “choice” are indeed applicable as markers of these experiences. Another possible direction for future research, in light of this analysis, may include an evaluative study of how proactive direct-practice interventions aimed at mitigating anticipated homophobia/heterosexism might impact gay care-givers accessing institutional settings.

Aside from the research implications listed above, which arguably relate to original themes invoked in the course of this study, it is also necessary to note research implications that relate more closely to the study's limitations. As is apparent, the study did not focus on the lives of all sexual minorities (e.g. for instance including lesbian women). Therefore, though the results of this study suggested that gay care-givers' lives may be underpinned by both intersubjective and structural realities, this overarching theme may or may not be applicable to the lives of other sexual minorities, and so an examination of this possibility may be highly relevant. Also, in discussing sampling limitations, since the study's recruitment process failed to attract relatively older participants (e.g. age 60+), it may be necessary to examine whether the findings generated in this study would indeed be transferable to older populations of LGB care-givers.

As has been repeatedly discussed, since this study has not produced results that are generalizable statistically, one last research implication may include the feasibility of somehow quantitatively determining the prevalence of “choice” in the positioning of non-heterosexual care-giving partners, of anticipated and perceived homophobia within this population, and of other issues explored in the scope of this study. Of course, it is also notable to mention the drawbacks associated with conducting such research, some of which may include losing the richness of care-givers' subjective experiences, unless inductive approaches to inquiry are somehow preserved. However, conducting such inquiry may provide a basis for illustrating the prevalence of these factors beyond a smaller sample.

Final Remarks

In this study, I attempted to gain insight into the experiences of gay care-givers, primarily by attending to how five Canadian care-giving partners of gay men storied their experiences. I first outlined the conceptual basis for the study by first introducing various terms related to the topic at hand, and then by providing an overview of literature related to the experiences of LGB care-givers.

Importantly, I specified the qualitative nature of this study, and explained my rationale for conducting a narrative study on the little-known realities of gay carers. Some themes that were invoked in the results of this research included the presence of “choice” in the positioning processes of the gay care-givers being studied, the possibility of encountering anticipated and perceived homophobia/heterosexism, the importance of locating gay-friendly sources of support for respondents, and lastly, the meaning that participants appeared to place on their partnerships. As mentioned in the latter sections of this study, perhaps the most significant revelation of this study included the notion that gay carers' experiences may be constructed intersubjectively in unique ways, but always within larger systemic contexts that may be defined by a complex interplay of homophobia/heterosexism and other factors. Indeed, it is my hope to have conveyed both social work practice implications, and recommendations for future research, that truly reflect this revelation.

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Appendices

Appendix A – Recruitment Poster

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work

2080 West Mall

Vancouver, B.C. Canada V6T 1Z2

Tel: (604) 822-2255 Fax: (604) 822-8656

www.socialwork.ubc.ca

CARE-GIVING PARTNERS OF GAY MEN WITH CHRONIC ILLNESS: CONSTRUCTING THEIR STORIES

I am a Master of Social Work student at the University of British Columbia's School of Social Work. As part of my thesis, I will be studying **how care-giving partners of gay men with chronic illness tell stories about their experiences**. Specifically, I want to explore how these care-givers experience the realities of giving care, and how they might communicate these unique experiences in the form of stories.

You are eligible to participate in the study if you:

- ⤴ Identify as a same-sex care-giving partner of a gay adult male with chronic illness
- ⤴ Are 19 years of age or older
- ⤴ Are a fluent English speaker
- ⤴ Are willing to commit to a 60-120 minute interview
- ⤴ Are willing to commit up to an additional 60 minutes, following the interview, to provide feedback on transcripts and on the way your story is represented in the study

A \$10 Starbucks gift certificate will be offered in appreciation of your participation.

The study is being supervised by Dr. Brian O'Neill, Associate Professor at the UBC School of Social Work.

If you're interested, please contact:

Hossein Kia, MSW student

*Appendix B – Consent Form***THE UNIVERSITY OF BRITISH COLUMBIA****School of Social Work**

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Consent Form

Care-giving Partners of Gay Men with Chronic Illness: Constructing their Stories

Principal Investigator: Dr. Brian O'Neill, Associate Professor, UBC School of Social Work

Co-Investigator: Hossein Kia, MSW Student, UBC School of Social Work

This research is being conducted as a requirement for a research class and for a thesis, a public document. The data may be used for scholarly presentations, manuscripts and publications. You will be informed regarding the use of and access to the information being provided. All identifying information will be removed from information collected during interviews.

Purpose:

To study how care-giving partners of gay men with chronic illness experience the realities of giving care, and how these carers might understand their experiences in the form of stories. Research on the narratives of gay care-giving partners could inform social workers, other health professionals, researchers and policy makers of the unique experiences and needs of this population.

Study Procedures:

Participation in the study will involve:

- ⤴ An individual 60-120 minute interview
- ⤴ Discussion of the following topics:
 - The story of how you came to see yourself as a care-giver
 - How your story, as the narrative of a gay care-giver, might be unique in terms of challenges you have encountered
 - How your story, as the narrative of a gay care-giver, might be unique in terms of rewards you have encountered

- The story of caring for a gay man with chronic illness
- ✧ A request to provide feedback on transcripts of your interview, and on how your story is represented in the study
- ✧ Giving feedback may require an additional 60 minutes of your time

Please note the following:

- ✧ You may decline to answer any of the questions being asked

Potential Risks:

No risks are anticipated for participants. However, you may ask the interviewer for a list of resources, should you require support after discussing potentially sensitive topics. Throughout the interview, I will remind you that you can decline to answer any question you may be uncomfortable with.

Potential Benefits:

No major benefits are anticipated. However, the experience of telling your story may feel empowering and validating.

Confidentiality:

Your identity will be kept strictly confidential. Any identifying information will be removed from interview transcripts. Audiotapes and written transcripts of the interviews will be kept in a locked filing cabinet. Electronic copies of transcripts stored on a computer will be password protected. Participants will not be identified by name in any reports of the completed study. Please note that although your identity will be kept strictly confidential, the contents of the study will be used for a thesis (a public document), and possibly in scholarly presentations, manuscripts and publications.

Information on the Rights of Research Subjects:

If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 604-822-8598 or if long distance e-mail to RSIL@ors.ubc.ca.

Contact Information for the Study:

If you have any questions related to the study, you may contact Hossein Kia either by telephone, or by e-mail.

Please note that you can also contact the Principal Investigator of the study, Dr. Brian O'Neill, at any time.

Remuneration:

You will be offered a \$10 Starbucks gift card at the end of the interview, in appreciation for your participation.

Consent:

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without jeopardy.

Your signature below indicates that you have received a copy of this consent form for your

own records.

Your signature indicates that you consent to participate in this study.

Subject Signature

Date

Printed name of subject