

**“WE EXPECT TO BE TREATED THE SAME”: A QUALITATIVE STUDY
WITH AGING SAME-SEX COUPLES AND LONG-TERM CARE**

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**“WE EXPECT TO BE TREATED THE SAME”: A QUALITATIVE STUDY
WITH AGING SAME-SEX COUPLES AND LONG-TERM CARE**

By

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Abstract

Using an interpretive, narrative approach this research study examined the perceived needs that same-sex couples expected if relocating to a long-term care facility. This exploratory study engaged couples in dialogue on their experiences with homophobia and heterosexism in society and within health care institutions. Semi-structured interviews were conducted with four same-sex couples. Results indicated participants were concerned that 1) homophobia and heterosexism would present barriers if moving into long-term care; 2) sensitivity and diversity training should be a mandatory practice in long-term care; and 3) participants found little difference between differential treatments they would expect compared to heterosexual couples. All of the participants expected to be treated with compassion, respect and professionalism that met their health care needs and their same-sex relationship and/or sexual identity should not compromise these needs. These findings suggested a need for long-term care facilities to examine and evaluate their current climate in order to provide services which are inclusive toward same-sex couples.

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Introduction

Canadian society has a long history of excluding individuals and groups who do not ‘fit’ the heterosexual mold. Homophobia and heterosexism contribute negatively to the health and wellness of Canada’s lesbian, gay, bisexual, transgender and queer (LGBTQ) community. Institutional and systemic discrimination is a reality many from this population have encountered at one time or another throughout their lifetime. Societal exclusion is not the only concern the Canadian queer¹ community struggles to overcome. Historically, LGBTQ populations have been ostracized from equitable participation in many aspects of mainstream society.

The health care system has been particularly notorious for creating barriers for the queer community. For decades, this population has been pathologized and stigmatized by the medical field. For nearly 80 years, the medical field has dehumanized and labeled queer people as being sick, ill, perverse, mentally ill and

¹ Queer is an umbrella term sometimes used in the literature to describe lesbian, gay, bisexual, and transgender (LGBT) persons/groups. I will use this term interchangeably throughout this paper.

sexually deviant (Brotman, Ryan, & Cormier, 2003). Further, queer populations have been controlled and manipulated by medical professionals into thinking they were mentally unstable (Brotman, Ryan, & Cormier, 2003; and Smith & King, 2003). Many older queer individuals have experienced homophobic ostracizing by the medical community. Many have encountered hazardous environments in which violence, shame, guilt, and despair were quite real (Cahill & South, 2002; Kochman, 1997; Rosenfeld, 1999). According to Brotman et al (2003), the aging queer population has grown wary of trusting health care services due to the years of the “medicalization of homosexuality” (p. 196) as an illness that can be treated and cured. As a result they often fear accessing mainstream health care services because they fear their personal health and well-being will be compromised.

Some older queer individuals simply passed themselves as heterosexuals and never felt they could proclaim their sexuality to a hostile and negative society. This appears to remain true for many in this population (McFarland & Saunders, 2003; Morrow, 2001). Many were ostracized and abandoned by family and friends forcing them to find comfort in others, such as partners, whom they eventually considered to be family (Brotman, Ryan & Cormier, 2003). Many

older queer people have lived successful lives resulting from their relationships with their partners and friends (Grossman, D’Augelli & Hershberger, 2000). A number of older queer persons have been involved in long-term relationships. These couples may find themselves in situations where disclosure will make them vulnerable and fearful under certain circumstances, such as moving into long-term care (Kaplan, 2002). In general, same-sex relationships have not been accepted by the mainstream, heteronormative Canadian society.

Canada witnessed a resurgence of societal homophobia and heterosexism with the public debates over the legislation of same-sex marriage. The debates encircling the legislation of same-sex marriage a few years back introduced the Canadian public to the right-wing, fundamentalist, homophobic rhetoric, which was being passed as the hegemonic, dominant discourse of how traditional marriage should be preserved. Yet a landmark Supreme Court decision in 2005 allowed Canada’s queer population the right to marry a person of same-sex. Currently in Canada, there is an estimated 34,200 same-sex couples (StatCan, 2001) living in Canada and approximately 12,505 (StatCan 2001) reside in Ontario.

The purpose of this study was to learn more about the care of aging same-sex couples in relation to the concerns they anticipate if, and when they engage with the long-term care system. Very little exists in the current literature detailing the experiences of older same-sex couples. The limited research that does exist primarily focuses on the experiences of aging lesbian and gay individuals, which I will discuss in the subsequent section. One of the main research objectives of this study was to give voice to a group who has not been represented very well in the current literature. There is importance conducting research with aging same-sex couples as they contemplate entering long-term care since very little is known about this population.

Literature Review

The following literature review will provide insight into the complexities and difficulties many older lesbian and gay persons/couples have encountered throughout their lifetimes. It will be sectioned in six parts: historical context of queer experiences; attitudes toward same-sex marriage; experiences of lesbian/gay persons/couples with the health care system and social service providers; experiences of older lesbian/gay persons/couples with the long-term care system; sexuality and intimacy; and the needs of lesbian/gay persons/couples.

Historical Context of Queer Experiences

There is documentation that same-sex relationships have always existed. In the Pre-modern Era, Ancient Civilization, the Medieval Period and the Renaissance Era, same-sex relationships were well-known (Tully, 2000). Although same-sex practices existed, there is a long history of these behaviours being condemned by the church and religious sects (Ibid). Most of these homophobic attitudes and heterosexist beliefs flourished in Europe and were assimilated into the “New World” when the English and the French invaded North

America in the 1600's (Ibid). These belief systems were brought here by our forefathers and foremothers. These colonists brought prejudices of sexuality with them from Europe. According to Tully (2000), colonizers were disgusted by First Nations communities and their beliefs about sexuality and nudity. Same-sex relations were respected in some First Nations communities prior to European colonization (Elliot, 2005). The colonizers believed that sodomy was an unspeakable act and they felt it went against the teachings of God. With colonizing the Europeans brought laws that criminalized sodomy in the 1800's (Tully, 2000). The term "homosexuality" was coined in the 1860's by a Hungarian doctor by the name of Karoly Benkert (Janoff, 2005); this "homosexual" label then enabled society to identify and forbid this form of sexualized behaviour. In the early 1900's North America began the medicalization of "homosexuality" as an illness that could be cured (Lahey, 1999). The medical profession labeled "homosexuals" as a population who were sick, sexually perverse, mentally ill and needing to be cured with aversion therapy or shock therapy (Janoff, 2005; O'Neill, 2006; Smith, 1999; Tully, 2000). Homophobic, heterosexist attitudes were the result of religious scripture, the criminalization of same-sex behaviours and the medicalization of homosexuality

as a psychiatric illness. These attitudes have contributed significantly to the struggles queer people have encountered in the past and today.

Queer people have been excluded from many aspects of social and political participation. It was in 1982 that Canada patriated its Constitution and added the Canadian Charter of Rights and Freedom. According to Smith (1999), section 15 of the Charter guaranteed equal rights for all Canadians. Although queer sexual orientation was not explicitly listed as a prohibited ground of discrimination in section 15, it was implied under the equality of rights for all Canadians (Hurley, 2007; O’Neill, 2006). According to the Charter and human rights legislation at the time, unequal treatment and discrimination were prohibited for persons based on “race, colour, national or ethnic origin, religion or creed, age, sex, family and/or marital status, and mental or physical disability (Hurley, 2007: p. 2). According to Smith (1999), the Charter documented the relationship between the government and the citizens of Canada. The Charter initiated the relationship between the queer community and government. Over the past thirty years many struggles for queer recognition have been battled.

Attitudes toward Same-sex Marriage

The basic premise of same-sex marriage is to accord the same equality heterosexual marriages are automatically granted. Queer activists and straight supporters hoped same-sex marriage would grant similar legal, political and social rights given to heterosexual marriages (Barclay and Fisher, 2003). Nearly two-thirds of Canada's population believed that same-sex couples should have the right to marriage; yet this issue has created conflicting arguments within the queer community and the broader Canadian society (Chapman, 2002). In 2002 a Canadian court found that denying same-sex couples the right to marry is overtly discriminatory and violates persons' rights as outlined in the Charter (Chapman, 2002). Since that decision, Canadian parliament has adopted the Civil Marriage Act instructing every province to legally recognize same-sex marriage; however, this was met with many challenges along the way.

Discussions on the rights to recognize same-sex marriages began over thirty years ago. Lahey and Alderson (2004) explored the issue of how marriage was defined in the 1960's. The authors highlighted a time when same-sex couples began to challenge the heterosexist discourse of marriage in the 1960's.

Government officials quickly amended marriage statutes to exclude queer people. In their book, Lahey and Alderson (2004) stated that politicians quickly shaped policy to protect the rights of heterosexual marriage. Despite what many people believe, same-sex marriage is not a new subject. The right to marry, for queer people, has a history. The first case that ended in victory for equality rights of same-sex couples wanting to marry was in 2003 when the Ontario Court of Appeal heard the case of *Halpern v. Ontario*. The case highlighted how the exclusion of same-sex couples from the definition of marriage violated persons' rights according to the Charter (Smith, 2007). The courts ruled that prohibiting queer couples from marrying was unconstitutional (Hurley, 2007). According to Smith (2007), the Ontario government refused to register the marriage citing the federal government's definition of marriage excluded same-sex couples. The case was ultimately heard at the Ontario Court of Appeal and the court ruled that the traditional definition of marriage violated the rights of queer couples (MacDougall, 2006; and Smith, 2007).

In the beginning the fight for same-sex marriage was a heated debate. It was a well-publicized topic and opponents, usually right-winged, Christian

fundamentalist groups were emerging. The Canadian Alliance introduced a proposal in the House of Commons to retain the traditional definition of marriage to include the union of opposite-sex couples, explicitly excluding lesbian and gay people (MacDougall, 2006). One of the compelling arguments, according to fundamentalists, was the fear the church would be forced to perform same-sex marriage (Institute for Canadian Values, 2006). Amidst the controversy the federal government stated that no church would be compelled to perform queer marriages (Hurley, 2007). The federal government announced that the Church would have “religious freedom” and were exempt from performing same-sex marriage.

Religious groups were, and continue to be, outspoken opponents of same-sex marriage. Important religious leaders and groups oppose same-sex marriage in two ways; “they help to define opinions on morality issues, and second, they often act as interest groups” that lobby and protest governments’ decisions and legal decisions (Barclay & Fisher, 2003). Quite often, these groups receive a great deal of media attention and they are provided a forum to propagate hate and violence towards the queer communities. Many religious leaders will state that

they do not have a problem with queer people but they feel that the sanctity of marriage must be reserved between a man and a woman (Lannutti, 2007; Mazur, 2002). Many religious groups, such as Catholics, Mormons, and Baptists have denounced decisions across North America as an abomination of God and His Kingdom (Mazur, 2002). According to traditional Christian morality, same-sex marriage must be denied and the queer community must be deprived of the fundamental right to marry as their heterosexual counterpart (Rigaux, 2003). Religious leaders continually perpetuate homophobic, heterosexist rhetoric freely within our society.

Experiences with Health Care and Social Services

Many studies have documented the homophobic, heterosexist experiences of queer people accessing health care and social services. Historically older lesbian and gay persons have encountered harsh experiences of inappropriate, insensitive, discriminatory practices when accessing services (Adelman, 1990; Anetzberger, Ishler, Mostade, Blair, 2004; Beeler, Rawls, Herdt, Cohler, 1999; Brotman, Ryan, & Cormier, 2003; Cahill & South, 2002; Kochman, 1997; Rosenfeld, 1999). Many of the aging queer population have encountered negative

experiences and this has contributed to their distrust with aged care services (Anetzberger et al, 2004; de Vries, 2006; Hughes, 2007; Platzter & Jones, 2000; Porter, Russell & Sullivan, 2000; Chamberlain and Robinson, 2002). For many of this population, being labeled as a ‘homosexual’ has been considered a deviant sexual act that needed to be treated and cured (Brotman, Ryan, & Cormier, 2003; Donahue and McDonald, 2005; Harper and Schneider, 2003; Pugh, 2005). Due to heteronormative socialization many aging queer people believed their sexual orientation to be a pathologized illness (Hughes, 2004). Non-heterosexual preference is seen as an “immoral, unnatural, psychiatric illness” (Eliason, 1993: p. 14). Health care professionals are rarely educated on the historical experiences and issues of older gay and lesbian persons (Thompson, 2008).

Many health care and social service environments do not provide opportunities for older gays and lesbians to feel safe and comfortable disclosing their sexual identity (Hughes, 2004). Many from this marginalized population have encountered “devastating exposures to cruel and thoughtless discrimination” (Fannin, 2006: p. 32) which contribute to the psychological challenges they have internalized when accessing aged care services (Grossman, D’Augelli &

Dragowski, 2007). Many are overwhelmed with anxiety at the thought of accessing these services. According to Quam and Whitford (1992), there is a strong fear of poor quality of care because of the lack of informed knowledge many professionals have exhibited in the past.

One of the greatest concerns highlighted in several studies was the insensitivity shown with the intake assessment documentation process many older gay and lesbian persons/couples have encountered (Callan, 2006; Eliason, ; Hughes, 2007; Johnson & Jackson, 2005; Platzer & James, 2000; Thompson, 2008; Ward, Vass, Aggarwal, Garfield & Cybak, 2005). One complaint expressed by lesbian and gay persons/couples relates to two questions in particular. On intake and assessment forms, people are usually asked about their relationship status and that question is followed by whether they have any children. When these questions are asked during an intake interview there is an overt and covert heterosexist assumption that being involved in a same-sex relationship is not acceptable (Callan, 2006; Eliason, 1993; Hughes, 2007; Johnson & Jackson, 2005; Platzer & James, 2000; Thompson, 2008).

Practitioners working within health care and social services need to re-evaluate intake assessment forms that perpetuate heterosexist assumptions.

Experiences with Long-term Care

Many aging queer persons are concerned with unjust treatment as they age. One concern relates to long-term care and who will take care of them in their later years. Discrimination and oppressive barriers in long-term care facilities are perpetuated through heterosexism and homophobia for this population (Brotman, Ryan, & Cormier, 2003; Cahill & South 2002; Edwards, 2001; Kaplan, 2002; Tolley & Ranzijn, 2006). Some long-term care facilities create barriers, such as heterosexism and homophobia, within the policies that prevent same-sex partners from sharing a room (Edwards, 2001; Kaplan, 2002). Policies such as these create fear and anxiety for older lesbian and gay persons and couples thus preventing them from accessing long-term care as an alternative to their deteriorating health (Brotman, Ryan & Cormier, 2003; Johnson & Jackson, 2005). Some studies have indicated that aging lesbian and gay persons/couples consider nursing homes to be undesirable and question whether they would be treated with equal respect and dignity as their heterosexual counterparts (Heaphy, Yip &

Thompson, 2004). According to Ward, Vass, Aggarwal, Garfield & Cybak (2005), incoming residents are all assumed to be heterosexual and there needs to be a focus “towards a wider consideration and exploration of sexualities” (p. 68) in long-term care facilities.

Older queer populations may be at an increased risk of encountering discrimination by front-line staff working in long-term care (Brotman, Ryan & Cormier, 2003; Tolley and Ranzijn, 2006). According to Johnson and Jackson (2005), older lesbian and gay individuals perceived they would encounter discrimination based on their sexual identity. According to the study conducted by Tolley and Ranzijn (2006), most staff working in long-term care are not exposed to queer people in this environment and this may contribute to the heteronormative beliefs they uphold. In a study conducted in Australia, participants also felt that they would encounter homophobia and marginalization in an aged care facility because many of them had encountered it in the past when accessing mainstream, heterosexist institutions (Hughes, 2007). According to a study conducted by Cosby (2005), participants, who were front-line staff working in long-term care, feared that queer individuals and/or same-sex couples would encounter differential treatment. These participants reported the safety and welfare of these residents would be compromised

if their sexual identity was known to other staff members. When aging queer populations experience homophobia and discrimination, they are less likely to access services in the early stages of their health concerns, resulting in their accessing services when it is too late (Brotman, Ryan & Cormier, 2003 and Hughes, 2007).

When queer people are reliant on health care services heterosexist assumptions and homophobia can “force people back in the ‘closet’ or undermine significant, longstanding relationships” (Swan, 1998: p. 27). Relocation to a long-term care facility increases the likelihood that lesbian and gay persons/couples would “veil their sexuality” (Ward, Vass, Aggarwal, Garfield & Cybak, 2005: p. 53). A report published by the Human Rights and Equal Opportunity Commission (2007) in Australia, documented the concerns of the aging queer community. The document reported that many aged care facilities are heterosexually biased and consequently many older queer couples are concerned their relationship will not be accepted and recognized by the administration and/or the health care staff. According to a study conducted by Brotman, Ryan & Cormier (2003), one older lesbian decided to change her last name to her partner’s name so the two of them could live together as siblings in long-term care without

being detected. This type of survival technique is representative of the extremes older lesbian and gay couples resort to in order to remain together in long-term care. Older lesbian and gay persons and couples have unique needs and mainstream long-term care facilities must address these particular needs (Cahill & South, 2002). Recognizing and acknowledging same-sex relationships must be ensured in order to challenge current heterosexist assumptions in long-term care.

Sexuality and Intimacy

Many older persons are categorized as “sexless or desexed” (Ward, Vass, Aggarwal, Garfield & Cybak, 2005: p. 51); however many older couples still have sexual needs and are sexually active (Fannin, 2006). Many staff members providing care in long-term care facilities believe that sexual activity between residents is wrong; the staff have negative attitudes towards sexual behaviour (Walker & Harrington, 2002). Very few facilities employ staff members that are open and accommodating towards residents who engage in sexual activity. Most staff members label residents as having behavioural problems. An estimated 60% of long-term care facility staff feels that residents should refrain from any form of sexual activity (Dickey, 1989; Hajjar & Kamel, 2003). Sexuality and sexual

activity amongst residents in long-term care facilities perpetuate fear, discomfort, and denial for staff members and residents' family members. Rarely does staff help to facilitate the sexual needs of clients, and many try to discourage or deny sexual activity amongst residents (Bonifazi, 2000; Dickey, 1989; Hajjar & Kamel, 2003; Rankin, 1989; Walker and Ephross, 1999; Zeiss and Kasl-Godley, 2001). According to Pugh (2005) sexuality is not recognized as an aspect of older peoples' lives and when it is acknowledged it is assumed to be based on opposite sex attraction.

While staff attitudes towards sexual activity amongst residents create barriers for sexually active older adults, other barriers also exist. One of the biggest concerns for heterosexual persons living and wanting to engage in sexual activity is the lack of privacy in long-term care living arrangements (Bonifazi, 2000; Hajjar & Kamel, 2003; Rankin, 1989; Zeiss and Kasl-Godley, 2001). According to Zeiss and Kasl-Godley (2001), many older adults feel inadequate in relation to sexual activity which also acts as a barrier. As well, attitudes from residents' family members contribute to some barriers that restrict older adults from engaging in sexual activity (Hajjar & Kamel, 2003; Zeiss and Kasl-Godley,

2001). According to a few studies, attitudes and privacy issues may create a hindrance to sexual arousal or sexual activity (Hajjar & Kamel, 2003; Rankin, 1989; Zeiss and Kasl-Godley, 2001). A great deal of the literature has focused on the sexual concerns of heterosexual persons living in long-term care facilities. Little, however, has been written about the structural barriers encountered by older lesbian and gay persons/couples living in long-term care facilities in relation to sexuality and intimacy.

Although residents and staff state that they personally do not have problems with “homosexuals”, many feel that this type of sexual behaviour should be avoided at all cost (Bonifazi, 2000; Hajjar & Kamel, 2003; Walker and Ephross, 1999; Zeiss and Kasl-Godley, 2001). These negative attitudes would definitely impact a lesbian or gay couple living in long-term care. This has the ability to reinforce social isolation, placing them at higher risk for self-neglect, and decreases the couple’s opportunity for a positive quality of life (Cahill & South, 2002; Kaplan, 2002). According to Kaplan, (2002) two gay males, who were lifetime partners, were intruded upon during sexual activity and forcibly separated; as a result one was sent to a “psychiatric hospital” and he was

physically restrained. Homophobia continues to dominate how long-term care environments respond to same-sex sexual behaviours.

Needs of Older Lesbian and Gay Persons/Couples

Many older lesbian and gay persons/couples find a great deal of comfort and security when people around them are supportive of their sexual orientation and relationships (Grossman, D'Augelli, & Hershberger, 2000). Many have lived through a lifelong process of non-acceptance and stigmatization which has contributed to difficulties in relation to health, loneliness, abuse and ageism (Johnson & Jackson, 2005). Recognizing and acknowledging “fictive kin” (Brotman, Ryan, Cormier, 2003: p. 12) relationships are very important to older same-sex couples. According to Dorfman, Walters, Burke, Hardin, Karanik, Raphael & Silverstein (1995), older lesbians and gays find support from their friends and partners, whereas their heterosexual counterparts obtain similar support from biological family members. Many of them live sheltered lives with partners and a few close friends and once the friends and partners die the persons may be subjected to isolation and loneliness (Langley, 2003). Health care professionals need to create environments where older lesbian and gay persons/couples are provided respect and dignity.

Although this population may have similar health issues as their heterosexual counterparts, they may have encountered problems with health care systems and the heterosexist assumptions inflicted by various health care services in today's society (Tully, 2000). When accessing mainstream health care systems older lesbian and gay persons/couples have encountered biased, insensitive and inadequate practices, due to health care providers being uninformed about the experiences and situations of this population (Duncan et al., 2000). There is a need for this marginalized population to receive appropriate care when accessing services and/or relocating to a long-term care facility (Porter, Russell & Sullivan, 2004). According to Fannin (2006), "there is an overwhelming need for acceptance, understanding and equality (p. 32) from those who care for older lesbian and gay persons/couples. According to a study conducted by Beeler et al (1999) the most noted need was for social interaction with other aging lesbian and gay persons/couples.

When seeking out services, older lesbian and gay persons/couples feel it is important to access services (e.g. long-term care) that are sensitive to their needs (McFarland and Saunders, 2003). Sensitivity and awareness about the historical struggles of this population is needed to effectively provide proper care for this

population (Kaplan, 2002). According to the study conducted by McFarland and Saunders (2003), many older lesbian and gay persons/couples are fearful of accessing mainstream health care services, such as long-term care because they do not feel that staff are knowledgeable and understanding to the concerns and issues of this population. The authors noted that if they are open about their sexuality prior to entering long-term care they may have to refrain from proclaiming it for fear of discrimination and negative repercussions from staff (McFarland and Saunders, 2003). Traditionally health care training does not address the concerns and holistic needs of older lesbian and gay populations and when it does the focus on any form of lesbian or gay issues is primarily on HIV/AIDS or certain risk behaviours (Duncan et al., 2000).

Very little research exists on the desired needs and concerns faced by older same-sex couples. This study provided same-sex couples the opportunity to provide information about their perceived and desired needs if they were faced with the decision to relocate to long-term care.

Research Questions

1. Under what conditions do same-sex couples, if encountered with the decision to relocate to long-term care, perceive their move to be a positive experience?
2. What are the anticipated social, psychological, and emotional needs of same-sex couples if they moved into a long-term care facility?
3. Do same-sex couples have unique needs that need to be considered when moving into a long-term care facility?

Research Methodology

Design and Instrumentation

I engaged in the use of qualitative methods of enquiry for conducting this study. According to Berg (2004), “qualitative research refers to meanings, concepts, definitions, characteristics, metaphors, symbols and descriptions of things” (p. 3). This research entailed semi-structured interviews that lasted between one to two hours using an interview guide that was developed by myself in consultation with my thesis supervisor. Hoepfl (1997) discussed that an interview guide “is prepared to ensure that basically the same information is obtained from each person, there are no predetermined responses, and in semi-structured interviews the researcher is free to probe and explore within these predetermined inquiry areas” (p. 47). I used the interview guide (See Appendix 1) in order to obtain rich, in-depth data for analysis.

The interview guide addressed the couples’ experiences in society in general and the health care system in particular; the perceived needs the couples anticipated if faced with the decision to relocate to a long-term care facility in their later years; and how long-term care facilities could appropriately

accommodate same-sex couples. The interview process was relaxed, conversational and reciprocal (Taylor & Bogdan, 1998). This research study was an extension of a current research project I have been involved in over the past two years. This has provided me with the opportunity to review some transcripts and interviews which I have conducted in the past. Subsequently, I have been able to refine my interview guide, and the interviews have informed me on ways to improve probes to obtain rich data that assisted me in the analysis stage. Insights, repetitive themes and issues that emerged from each interview assisted me in subsequent interviews and I was able to ensure in-depth data.

Sample

This study used the purposive, non-random sampling method (Hoepfl, 1997; and Neuman, 2003). According to Neuman (2003), purposive sampling “is less to generalize to a larger population than it is to gain a deeper understanding” (p. 213) of specific populations. Hoepfl (1997) argues that purposive sampling is used when a researcher is seeking to answer specific research questions and when she/he “seeks information-rich cases which can be studied in depth” (p. 43). I conducted four interviews in total.

Recruitment was conducted in a way that allowed participants interested in the study to initiate contact with the researcher as it was important that the potential participants did not feel coerced to participate in the research project. The process of recruiting participants for the study involved the use of various email listservs that provided information to aging lesbian and gay persons in Hamilton and Toronto. I contacted the various online organizations and social service organizations and asked if they would be willing to forward details of my research study to potential participants. The following organizations agreed to assist me with the recruitment process: The “519” Church Street Community Centre (Older LGBT Programme); Canadian Rainbow Health Coalition; and Gay Seniors Canada. The above organizations were provided with the letter of intent (See Appendix 2) outlining the purpose of the study, expectations of the participants, eligibility criteria required to participate (i.e. age, partnered relationship, and living in the community) and information on how to contact myself. The organizations forwarded the information via email listserv and/or posted the information at the agencies. Participants contacted me via email and I initiated a telephone conversation to further explain the research study. It is the ethical responsibility of the researcher to inform the participants about the

research prior to their decision to participate (Neuman, 2003). All participants agreed to participate in the study during the initial telephone contact.

The sample was composed of both male and female participants who are between the ages of 40 to 67, and all participants were currently in a relationship with a same-sex partner. I interviewed a total of 8 participants (3 females who self-identified as lesbian, 1 female who self-identified as bisexual and 2 males who self-identified as homosexual and 2 males who self-identified as gay), which was a relatively small sample; however, because this study is partial fulfillment of the requirements of my Masters degree in social work and I am limited by time constraints, this small sample will suffice. According to Patton (2002), when conducting qualitative research, a researcher should attain theoretical redundancy, where a saturation point is reached with no more new information being generated from the interviews; however, this will not be possible and is a limitation of my research study.

Another limitation associated with the recruitment process was not being able to locate more couples residing in the Hamilton region. Although the queer community has access to a new community centre, the centre does not provide

services for the aging queer population in this geographic region. When I finally connected with a couple who agreed to participate in the study, I initiated the use of snowball sampling (Neuman, 2003). According to Neuman (2003) snowball sampling is a method employed by qualitative researchers to use existing participants to recruit potential participants for the study. I asked the couple from Hamilton if they knew any couple that ‘fit’ my eligibility criteria and if so, would they be willing to pass the information along. Due to difficulty connecting with, and recruiting participants living in Hamilton I had to interview couples living in the Greater Toronto area and Vancouver, British Columbia.

Data Collection

As stated earlier, all interested participants contacted me, and I coordinated dates/times to conduct the interview. I invited the participants to select a convenient site to conduct the interview. I chose this procedure to ensure the participants felt comfortable and safe with their surroundings. As well, I wanted to make certain the place where the interviews were conducted ensured anonymity and confidentiality. At the participant’s decision six of the interviews

were conducted in the participant's home and two were conducted over the telephone.

At the beginning of the interview I explained the purpose of the research study and responded to any questions participants had about the research. I provided the participants with an informed consent (See Appendix 3) and demographics form (See Appendix 4). I read through the informed consent with each participant, asked them to sign the form and reiterated this study was voluntary and they could chose to withdraw from the study, without consequences, at any point throughout the interview. As well, I informed the participants that they could choose not to answer a question if they were not comfortable with the question. They were free to skip over any question that made them uneasy or uncomfortable. I let them know that they were not obligated to answer all the questions simply because they agreed to be in the study. I wanted to create an environment that did not subject the participants to discomfort. I asked the participants for their consent to audio record the interview to ensure I did not miss anything that we discussed. With the interview that was conducted on the telephone I sent the participants a copy of the demographics

form and informed consent with a letter stating they could contact me via email if they were still interested to participate. Once I received this confirmation I proceeded with the interview.

The participants were informed that their names or any identifying information would not be used in written transcripts nor would this information be used in any written report. This contributed to protecting the participants' anonymity and confidentiality. I explained to each participant that their involvement in the research would provide an opportunity to voice their concerns about the long-term care system, identify the needs they might anticipate as well as the opportunity to let others know how transition into a long-term care facility can be made as positive an experience as possible. Throughout the interview I periodically sought consent to continue with the interview to ensure comfort. At the end of the interview I asked each participant if they could provide feedback on the context of the questions. I wanted to see if there were additional questions I could be asking. No participants offered additional and/or alternative questions. As well, I obtained consent to contact participants in the future if I needed clarification during the analysis stage. I asked each participant if I could provide

my preliminary results to them in order to solicit feedback. I wanted to ensure accurate representation of their narrative.

One challenge that I encountered in my interviews involved interviewing the couple together. Although I strongly encouraged that I conduct the interviews separately, three of the couples requested I interview them together. Respecting their decision, I agreed. What I learned from this process was how one person in the relationship takes control of the interview. I attempted to maintain equal distribution of the questions, and I had to remind the participants that I needed to hear them both respond to the question. One other limitation I noticed when conducting group interviews with same-sex couples is the participants' comfort level when answering intimate questions in front of their partner without having previously discussed them. After consulting with my thesis supervisor, we agreed that in order to address this concern, we would provide the questions to each person prior to the interview for the remaining interviews. We asked the couple to look over the questions beforehand and they could discuss the questions amongst themselves to ensure either one was not surprised and felt comfortable responding with their partner present. My intent for this research project was to

legitimize same-sex relationships, and I hope I provided a space for my study to recognize and acknowledge the couple as a couple.

Data Analysis

Data analysis began during my data collection phase. Neuman (2003) highlights how emerging themes begin to formulate during the data collection phase and researchers need to be aware of this process. Qualitative data analysis does not begin as a final stage; it is “a dimension of research that stretches across all stages” (Neuman, 2003: p. 440). Throughout the interviews I identified themes and concepts that help me make sense of the emerging data. According to Charmaz (2003), this is a grounded theory model of analysis. Grounded theory is a process of analysis that is used to “develop analytic interpretations of data to focus further data collection” (Charmaz, 2003: p. 250). Grounded theory is the framework I employed when conducting this study.

Throughout the research process I was continually reviewing the interview transcripts to highlight emerging themes. I read over the transcripts in their entirety to gain a better understanding of what the participants were trying to communicate. The data were analyzed using the constant comparative method

(Strauss and Corbin, 1990). This involved line-by-line analysis using open and axial coding (Neuman, 2003). Using this method introduced me to recurring themes and common keywords used in each interview. I coded the data in the margins of the transcripts. Once I coded the data in the margins I coordinated them in categories and/or patterns.

I prepared a preliminary draft of the findings for member checks, which provided the participants an opportunity to look at my interpretations of the data they provided. Member checks are similar to what Neuman considers to be member validation. According to Neuman (2003), member validation is a process where the researcher provides the participants an opportunity to look at the preliminary findings in order to reflect on the interpretations of the interviews. Since one of my objectives was to bring voice to this subject, I wanted to be sure that what I was reporting was an accurate reflection of what participants meant to say. The member checks will enhance the trustworthiness and credibility of the data.

As well, after reviewing the transcripts I required further clarification from the participants in some areas. For example, one of the couples commented on

queer-identified staff, however, it was unclear whether having queer-identified staff working in a facility would make them feel ‘more at ease’ if relocating to long-term care. I contacted the couple via email and asked them to comment further on this issue. Both of them responded and provided a detailed description on their thoughts of queer-identified staff working in long-term care. This was the process I used when returning to the participants for member checks and further clarification.

Findings

In this section I will report the findings of the data from eight interviews I conducted with four same-sex couples. I have chosen to report the findings in the form of common themes and similarities from the data. Throughout the process of conducting the interviews many of the couples expressed concerns with attitudes of non-acceptance they experienced in society and/or from institutions they have accessed throughout their lifetime together.

My intention was to provide the reader with a greater understanding of the lives of each couple through the rich, in-depth narrative of the recurring themes. According to Neuman (2003), “the interpretive approach is the systematic analysis of socially meaningful action through the direct detailed observation of people in natural settings in order to arrive at understandings and interpretations of how people create and maintain their social worlds” (p. 76). By adopting this approach my intent was for the reader to gain a better understanding of the lived experience of each couple as well as how these couples define their experiences (Neuman, 2003). The following are the major themes that emerged from the data: *discrimination; disclosure; aging at*

home; queer-identified professionals; institutional (re)structuring; inclusive care; and self-advocacy.

Profile of Each Couple

Margaret and Dorothy

Margaret and Dorothy were an intergenerational, mixed race couple residing together in a large city in Southwestern Ontario. Margaret identified as a 67 year old Caucasian woman who was a lesbian. Dorothy identified as a 40 year old Chinese Canadian woman of colour who was bisexual. Both agreed that they were in a three year, long-term, monogamous, committed lesbian relationship. I interviewed this couple together in the home they shared. Margaret had a Graduate degree and identified herself as a retired professional who earned between \$20 000 and \$29 999 per year from government subsidies (e.g. Old Age Security). Dorothy had a diploma from a community college who was employed and earned between \$30 000 and \$39 999 per year. Neither one was currently engaged in the long-term care system; however Margaret stated she has had experience with family members engaged in the system. That experience provided her with some knowledge of the long-term care system in Ontario.

Margaret was open about her sexual identity and her relationship status with family members, friends and her family physician. However she mentioned that she was not open to her work colleagues when she was employed. Dorothy, who was currently employed, was open to her work colleagues, family members, friends and family physician about her sexual identity and relationship status. Margaret highlighted she was involved in a long-term heterosexual marriage for several years and had children.

Joseph and Kevin

Joseph (62 years of age) and Kevin (61 years of age) identified as a same-sex couple residing in separate dwellings in a large city in Southwestern Ontario. Joseph identified as a WASP, gay male who was in a partnered, non-monogamous relationship for 34 years. Kevin identified as a Jewish, Caucasian gay male currently in a coupled, non-monogamous relationship for the past 34 years. I interviewed this couple together in Joseph's home. Joseph had an Undergraduate degree, was currently employed in a professional career and was earning between \$30 000 and \$39 999 per year. Philip held a Graduate degree, was employed and was earning over \$60 000 per year. Neither Joseph nor Philip were currently

engaged in the long-term care system; however Joseph stated he had extensive experience with many family members living in long-term care facilities across Ontario. Both explained they have been open about their sexual identity and relationship status with family members, friends, work colleagues and family physician for several years. This was the only couple where one, or both, were not previously involved in a heterosexual marriage.

William and Philip

William (61 years of age) and Philip (59 years of age) were a self-identified same-sex couple residing together in a large city in British Columbia. Both identified as Caucasian, “homosexual” males who were in a 20 year, monogamous, committed, common-law relationship. I interviewed this couple separately via a telephone conversation. William had an Undergraduate degree, was currently employed and was earning between \$40 000 and \$49 999 per year. Philip graduated from a diploma program at a community college, was currently retired and was earning between \$30 000 and \$39 999 per year. Neither one of them were currently engaged in the long-term care system. Both stated they were open about their sexual identity and relationship status with family, friends,

colleagues and family physician. William was previously married in a heterosexual marriage and had no children. Philip was previously involved in a heterosexual, long-term relationship and had no children.

Janet and Lois

Janet (43 years of age) and Lois (57 years of age) were a same-sex couple residing together in a large city in Southwestern Ontario. Janet identified as a White, European woman who was lesbian and queer. Lois identified as an Italian woman who was lesbian. The couple stated they were in a monogamous, long-term, 16-year relationship. I interviewed this couple together at one of their workplaces. Both participants held a university Graduate degree. Janet was currently employed and was earning between \$30 000 and \$39 999 per year. Lois was currently employed and her yearly income was over \$60 000. Neither Janet nor Lois were currently engaged in the long-term care system. Lois stated she has had direct experience with family members residing in a facility; therefore she has some knowledge of the system and how it operated. Both highlighted they were open about their sexual identity and same-sex relationship with family members, friends, work colleagues and family physician. Lois identified as being in a

heterosexual marriage and having children. The following themes are reflected in the narrative stories of Margaret and Dorothy; Joseph and Kevin; William and Philip; and Janet and Lois.

Discrimination

All the participants have encountered discrimination in one form or another in their employment, in society and/or when accessing social services. They had experienced overt and covert homophobic, heterosexist behaviours from others. As we live in a hegemonic, heterosexist society that discourages any form of non-heterosexual behaviours and relationships it was not surprising when listening to their experiences.

Margaret and Dorothy

Margaret was actively involved in her church for many years; she explains how that has changed:

“It’s the Roman Catholic Church that seem to have a problem with it...my former family doctor, who was a Catholic explained to me that is was alright to be homosexual, alright to have homosexual friends, you just can’t have homosexual sex. That is the Roman Catholic

belief I guess....when people say that the Bible forbids this and that, it hurts because they are taking a one-sided view on the subject matter...there is a fallacy on what is right and what is wrong and if we are literally suppose to be living what the Bible says than we should all be in Jerusalem for offerings at the Temple.”

When same-sex marriage began a controversial discussion several years back, the church and religious groups were the first to exhibit overt signs of homophobia and discrimination. For years Margaret found a great deal of comfort with her Faith; however, she encountered outright disapproval which has altered her engagement with her church. Homophobia contributed to the hatred many older gays and lesbians have experienced throughout their lifetime.

Dorothy, who was currently employed, worked in an environment with daily interaction with the public. She recalled an incident that happened with a co-worker:

“I have had experience of discrimination from some co-workers and from time to time I do experience it from passengers who are strangers...I remember once speaking with a co-worker and she doesn't really like the term partner, yeah she was mad at me once for mentioning the term partner, as far as I know she was heterosexual...she would make reference to her husband and kids”

Dorothy stated she worked in an environment that advocated being non-discriminatory; however having protective policies may not always protect vulnerable persons.

Joseph and Kevin

Joseph and Kevin discussed types of discriminatory treatment they both encountered. For Joseph, discrimination was a “normal part” of his life. He recalled an incident which placed him in a vulnerable situation:

“I remember once incident was on Pride Day when we were coming home from Pride Day events, I remember a group of younger boys driving by us in different cars and yelling out faggots and it just destroyed all that positive stuff and suddenly to have that balloon burst from such idiocy...I did have a job in a university once where I was prevented from being promoted from an older army colonel and he was really trying to get me fired but I had a boss who came to my defense but I knew it was time to move on at that point”

Kevin experienced discrimination from his biological family members:

“I’ve been out to my family members for many, many years, all but my father. I didn’t come out to him until 17 years ago, he was the one that wasn’t very accepting of that which was difficult for me, which put me back into therapy for awhile...he disinherited me as a result of that and I had

some problems with my sister for a couple of years although I was out to her previously there were a couple of years of stress”

Both Joseph and Kevin described incidences of homophobic behaviours that they vividly remember. Whether it was walking down the street, in the workplace or with family members this couple encountered differential treatment based on their sexual identity.

William and Philip

When asked about discrimination both William and Philip stated they experienced it but rarely. According to William:

“I have no more than any gay person is going to if you are a gay person and you are out about being a gay person, then there are going to be total strangers who hate you. And you have no control over that but have I personally, rarely. You know, on occasion I’ve been blessed as I’ve never been gay-bashed. Have I been verbally insulted? Yes, of course I have because you know if you are gay then that’s just...unfortunately that’s just a part of your life... Well you know people yell, scream faggot at you”

William’s statement highlighted an important piece of information. He ‘normalized’ homophobic violence as an occurrence that every gay person

experienced; ‘it’s just the way things are’ type of statement. If you are gay then being discriminated against is a natural component of your life.

Philip’s experience was similar to Williams. He stated:

“Yeah definitely, what gay person hasn’t...I have at work, I have on the street, you know...on the street, yeah I’ve experienced the remarks, yeah”

Similar to Williams response, Philip expressed a sense of normalcy; if you self-identity as a gay person you should expect to be confronted with discrimination.

Janet and Lois

Lois explained a situation which her disclosure and proclamation of her sexual identity created a very hurtful discriminatory experience:

“In terms of my relationship with my family, I certainly saw that as a site of a great deal of discrimination...I mean I still have this memory of my mother saying if you hurt your children I’m going to come and take them away from you...it was just assumed, that after my sexual orientation was discovered, or I came out, who knows what sexually abusing would happen to the children”

Lois was confronted with a harsh stigmatization and labeled as a sexual predator and child abuser once she proclaimed her sexual identity to her family. She

experienced a great deal of isolation and ostracization from family members who treated her very differently after her disclosure. When proclaiming your sexual identity there is a risk that others around you will adopt beliefs and values that may be shocking and alarming. Many older lesbian and gay people have been directly impacted by a sense of loss and lack of belonging with their biological families.

Janet experienced discrimination in another way that is not uncommon to the narratives of the previous couples:

“When I was younger and relied on public transportation or rode a bicycle or I was walking I was frequently having people yelling at me from cars...I’ve been spat at, yelled at but now that I have the security of a car that doesn’t seem to happen as frequently”

Janet’s experience echoed similar situations the other participants previously discussed; homophobic behaviour can happen to anyone. An interesting point highlighted by Janet was when her class privileged changed she was provided with a sense of safety and security. Her socio-economic status had a direct impact on the homophobic violence she encountered.

Disclosure (Proclaiming Sexual Identity to Others)

Another recurring theme that was discussed in the interviews was the issue of sexual identity disclosure and when participants proclaimed their sexual identity to others. Most gay and lesbian persons are confronted with disclosure several times throughout their lifetime. For Margaret disclosing and proclaiming her sexual identity involved her partner from her heterosexual marriage and her children. At the time she was in her late 50's when she decided to proclaim her sexual identity. She has been exposed to this dilemma several times since:

“Well I was in a heterosexual marriage for quite a few years...the marriage didn't gel because I always knew I wanted to be with a woman...I come from a time when it is not accepted, a time when you have to be concerned about discrimination and prejudice...I am very selective with who I tell in order to avoid being judged and treated poorly...when I was working no one knew that I was a lesbian, I was afraid how they would react”

“I am in social situations and I am careful and cautious when people ask me about relationships...most people talk freely about their relationships yet I have to be more selective about it”

For Dorothy identifying herself as a lesbian with co-workers introduced selective disclosure decision-making:

“I am very selective... that is something that happened at my work...some of my co-workers attitudes changed toward me once they found out about my identity...in a negative way...I just try to avoid those people at any cost”

Disclosure for this couple was done on a selective and ‘need to know’ basis. They feared the consequences of differential treatment they would encounter once proclaiming their sexual identity. At times being in a same-sex relationship intensified the risk of being identified as lesbians for Margaret and Dorothy.

Joseph and Kevin

Both Joseph and Kevin were not concerned about proclaiming their sexual identity to others around them; however they only disclosed their sexual identity in situations where it is required. When they talked about whether they would disclose their sexual identity and relationship status to health care practitioners they were adamant; Kevin stated:

“Oh yes absolutely, I wouldn’t have it any other way...it would be a given to me, I would never keep that as a secret...yeah we don’t even think about it”

Joseph commented:

“Exactly the same way...because I am so out it is just there and at this moment in my life it is something I don’t even

think about...this is who I am...if they know it then that is just fine... I think the difference for us is we identify not as gay man but as men who happen to be gay...it is not the central piece about us it is just there”

Unlike the previous couple, Margaret and Dorothy, Joseph and Kevin were not selective in terms of who they disclosed this information. According to both being gay did not define who they were as people. They were two males who were gay that do not ‘hide’ their sexual identity or same-sex relationship. Both felt staff in long-term care would be aware of their situation.

William and Philip

Both William and Philip discussed how they rarely hide their sexual identity. They reside in a large city in British Columbia which is gay-friendly for the most part. Both had proclaimed their sexual identity and same-sex relationship to family, colleagues and friends. William discussed the acceptance he received from his biological family:

“My brothers and sisters, my nieces and nephews, everybody completely knows all about me, completely knows all about Philip and he is totally part of our family... I’ve never had to hide my sexuality or who I am since I have come out; so I have been very blessed that way”

William and Philip have been accepted and acknowledged as a couple. Their experience disclosing their sexual identity and relationship with one another exhibited a sense of belonging and recognition within their immediate circle. According to the couple they did not experience any differential treatment from most people they have come in contact with.

Janet and Lois

Janet and Lois talked about how their disclosure led to discriminatory, homophobic treatment with their family in their earlier years. Lois' encounter with her family was previously discussed; this is Janet's recollection of this process:

“When I first came out when I was a teen it was a really, really horrendous and bad, bad time; coming out was quite difficult and it took my family awhile to eventually accept my being a lesbian...now my family is very supportive and accepting of myself and my relationship with Lois”

Although some of the participants eventually gained the acceptance of family members, disclosing their sexual identity, for some, was a fearful and anxiety-building process. People from marginalized populations cannot control the attitudes and behaviours that surround them. Many people in society do not

accept people who self-identify as lesbian or gay and are reluctant to accept same-sex relationships. Proclaiming your involvement in a same-sex relationship would result in proclaiming your sexual identity, some of the couples were cautious and aware of the consequences of judgment and prejudice that may result from this disclosure. Entering a long-term care facility would definitely pose an issue for many same-sex couples.

Aging at Home

Another concept that emerged from the data was the desire to remain in their home for as long as possible. Most of the participants discussed the importance of accessing government/social services to assist them in home if and when their health deteriorates. For all participants long-term care was a last resort. Margaret, along with all of the other participants, knew she would hire homecare services as she aged. These services would hopefully provide her with the support she needed. She explained how she refused to be a burden to her partner:

“It (long-term care) is a place for accommodations that you may have your own apartment get your own meals, they may have a cafeteria, or they may have a nursing wing which you can go to if you are sick or if you are terminally

ill; basically you can go to them until you are finished (death)...if I had the choice, I would prefer someone come to my home to help me dress and bathe because she is younger than me and I wouldn't expect her to take care of me in that way...however they aren't too many alternatives so it worries me"

A stigma that currently exists in society is that long-term care is a place where older people enter in the final stages of life. For Margaret, it appeared to be a last resort. She had a wealth of resource knowledge and she would attempt to access home care services if it was an option. For Margaret aging at home would provide her with the autonomy and independence she currently experienced.

Joseph and Kevin

Both Joseph's and Kevin's beliefs about aging at home was similar to Margaret's story above. They expressed a strong desire to access home care services if faced with the decision to relocate to a long-term care facility. The couple stated they would not rely on government-funded home care. They stated they would hire privately in order for them to be in full control of who was providing the care. If they were faced with a care provider who was homophobic they would terminate her/his employment. They were financially privileged to afford private home care. Joseph elaborated on his point:

“Well it wouldn’t be home care in terms of the government supported, it would be finding private care, paying a fair fee for someone with skills and credentials...I don’t want to live in an institution anymore than I wanted to live in residence in university again I want some independence around when I eat, what I eat and who I have as friends and it is very difficult”

Joseph strongly desired to remain in his home for as long as he was capable. Both he and Kevin felt long-term care was quite regimented and the move to a facility would compromise their autonomy and independence. Joseph has experienced several family members living in long-term care therefore he was well-informed with the living situations in a facility. Joseph’s comments highlighted how their privileged socio-economic status provided them with the opportunity of choice. They are financially privileged to have alternative health care options rather than relocating to long-term care.

William and Philip

Similarly William and Philip, if given the opportunity and choice would choose to access home care services as an alternative to long-term care. Philip expressed concerns that the couple would be separated if they relocated to a long-term care facility. He stated:

“Our worse case which I don’t want to happen for us is to be separated that would be the worst for us to actually be physically separated and one of us living in a different facility...we’d prefer to stay at home, definitely”

All the couples who participated in this study exhibited a great deal of anxiety at the thought of relocating to long-term care. In the case of William and Philip, accessing home care services would maintain their longstanding relationship. If home care services could meet the health care needs of either partner, there was no question this would be their first choice.

Janet and Lois

Janet and Lois said that they would choose home care services rather than entering a long-term care facility. Aging at home for this couple would involve a caregiver who was respectful, accepting and preferably queer-identified.

According to Janet:

“I would prefer the person that was coming into my home to be lesbian...or at least a straight ally”

Lois commented:

“Again and this might not be the case for all women or all people but you do like to think of your home as your space where you are safe and free to be who you are and you

don't have to hide yourself; I know that that sounds like an idealized version of a home but if someone is going to enter it is very important that they don't violate that space by bringing their stuff in with them”

Both Janet and Lois were adamant that aging at home for them would involve bringing in a health care professional who was respectful, compassionate, understanding and aware of their sexual identity and same-sex relationship. They said they would be hyper-vigilant to recognize inappropriate behaviours and attitudes, as well as differential treatment. It is something they would definitely not accept and/or tolerate from a worker.

Queer-identified Professionals

For Margaret, having a family physician that self-identified as a gay male was very important. She had located her current physician on a website and had been very pleased with the care she received from him. Margaret's physician was not located near her, his office was located 45 minutes away but she refused to seek out another physician:

“I currently have a family doctor, which by the way is gay, which really helps...I enjoy going to him because he is aware of my sexual identity, my relationship with Dorothy and I feel very comfortable with him...he just understands

some of the difficulties I have had related to my being a lesbian...I don't have any problems with him..."

Margaret had a sense of comfort and safety with her family physician. She believed that his sexual identity provided him with the knowledge and awareness of the issues queer people encountered. Three out of the four couples I interviewed had primary care physicians who self-identified as gay. Most of them felt a strong connection with the practitioner based on their common sexual identity.

Joseph and Kevin

When I was interviewing Joseph and Kevin they explained to me that in the beginning of their relationship they both had a male family physician that self-identified as gay. Joseph, due to a lack of support for his medical condition, terminated this relationship. However, he explained reasons why he sought a practitioner who was gay:

“Well initially the man that Kevin sees was someone that I found and I went to him because I thought his sensibilities would be better because he was gay and he would be more aware of the particular issues that gay men encounter particularly the issues of sex and sexuality that come up and not to belittle him at all because that is exactly what he

brings...I don't deal with him anymore because I developed an illness that he didn't want to deal with at all and so I found another doctor who was willing to be a partner in the relationship with me"

Kevin agreed with similar reasons why he was with his present doctor:

"And with my staying with him I haven't had any medical concerns and I generally don't see him, mainly for two physicals a year, not much more than that; my feelings for wanting a gay doctor is similar to what Joseph talked about"

Having a family physician that self-identified as gay provided a sense of comfort for both Joseph and Kevin. According to Joseph he sought out the services of that practitioner based on the sexual identity of the person.

William and Philip

William and Philip as well had a family physician who self-identified as a gay male. Similar to the other couples, both were quite pleased with the care he provided. For William having a gay physician was a 'good thing':

"I just feel very blessed that this fine human being is my doctor and we also have that comfort level of him respecting my relationship with my partner and also if you are a gay man dealing with another gay man, there's a lot

of things that are basically a given; you don't have to explain”

William's statement definitely expressed a sense of closeness, trust and acceptance he and Philip received from their primary care practitioner. For him he could be open and honest with the physician and because of that the couple felt they experienced excellent quality of care. The couple felt safe and comfortable sharing information with their family physician and this has benefited their health.

Janet and Lois

Janet and Lois were the only couple who did not have a family physician who self-identified as lesbian or gay. Both had the same practitioner, however, Janet's experience with her employment within the health care system created a barrier with her accessing her physician unless it was necessary. Janet stated:

“Prior to my working within the health care system I would dutifully go to her once a year, do my physical and get all the benefits that I had; once I started working in that system and became aware of the abuses and all the bad things that happen within that system...as a result I haven't really seen her for eight years...we are very out to her...she probably could use some education and training”

Lois shared the same family physician with Janet and she too did not have a comfortable relationship with her; Lois commented:

“I have the same doctor...I haven't seen her in years...I try to avoid the system as much as possible...I don't have much of a relationship with my family physician but that probably has much more to do with who I am compared to who she is...we did have the conversation with her around who we are and we would expect no less from physician other than they be respectful”

Contrary to the other participant's need for a health care practitioner who self-identified as gay, this couple felt this did not impact the relationship whatsoever. They expressed no concerns, other than she would benefit from some type of training and/or education on queer issues, that her sexual identity acted as a barrier to accessing the health care system. It is important to note that Janet articulated how the system was definitely homophobic which contributed somewhat to their desire to only access health care services as needed.

Institutional (Re)Structuring

All of the couples who participated in the study expressed concerns that many of the institutions they have come into contact with over the years exhibited heterosexism and homophobia. Whether it was in the attitudes of health care

practitioners or documents such as intake assessments, many of them feared they would confront these types of challenges if faced with a move into long-term care. Every couple provided suggestions, based on their lived experience, that may counter heterosexism and homophobia.

Margaret and Dorothy

Margaret's experiences with discrimination and non-acceptance have made her aware of the complexities and difficulties she may encounter if contemplating a move into a long-term care facility. She is concerned that she would be treated in a non-professional manner:

“There is always the danger for anyone that is quote different to be treated differently. Some of our friends have been treated poorly when accessing various health care systems. We have had many conversations with friends about being treated poorly if living in long-term care”

Dorothy believed institutions, such as long-term care needed to have mandates and policies in place to protect the rights and safety of same-sex couples:

“In terms of long-term care facilities I would hope that there would be policies in place to enforce and say that no one could discriminate based on sexual identity”

Although Margaret agreed with Dorothy she expressed distrust with formal documents to protect the rights of lesbian and gay residents:

“Yes that is one step but I have always said, you can’t legislate morality and if someone out there is going to give you the evil eye there just going to deny and what are you going to say in that place...they didn’t look very friendly toward, who is going to respond to that? There would need to be training sessions, sensitivity training sessions... I think they would need to kick it off with an hour or so within the work day lasting about one week and then they can conduct follow ups and refresher courses on a yearly basis”

This couple felt the need for policy implementation, as well as some type of sensitivity training for all staff working in long-term care. An important piece that Margaret highlighted was the need for ongoing training.

Joseph and Kevin

Joseph and Kevin had a wealth of experience accessing health care institutions. This was a couple who experienced differential treatment on several occasions accessing health care services. They discussed in great detail the problems with health care systems. They were one of the only couples who had

recently accessed a hospital due to Joseph's fibromyalgia and chronic fatigue illness. In one recent hospital visit Joseph stated:

“What was irritating for me was when I was signing in they always ask your marital status, next of kin, do you have children and I am not any of those and I asked them to give me another category and it irritates the hell out of me... I mean that is what the world is it is all based on heterosexual, heterosexist assumption that's what irritates me”

Joseph mentioned in the interview that the tests he was taking had a one in three chances of complications which could result in death. Concerned about the health and well-being of Joseph, Kevin arrived, proceeded to the nurses' station and inquired about Joseph's health status:

“When we went to the hospital he had to have an angiogram and I went to find out how he was and I went up to the reception area to ask and I was asked whether I was family and I said no I am his partner, initially I was told that they could only release information to family members; I proceeded to make a fuss and eventually I was told how he was doing”

Clearly this experience exhibited the kind of heterosexist attitudes that continue to exist in the health care system. For Joseph he was denied a sense of oneself when filling out an intake form; it was all based on heterosexist assumptions. With

Kevin he was initially denied access to his partners health status; a person who he has shared his life with for 34 years. Health care systems can deny queer people the basic human rights of accessibility and quality care.

William and Philip

Institutional (re)structuring was a concept that all of the couples discussed throughout their interviews. For William and Philip their perception of institutional restructuring would be the availability of a gay-friendly long-term care facility. William stated:

“The only simplistic dream I would like to see care facilities that cater to gay couples or gay people, gay and lesbian people, just so that there wouldn’t...transition from your residence to care facility is frightening enough, or frustrating enough so to add the anxiety of wondering whether or not you know you’ll have basic acceptance is something that I don’t think people need to go through”

William introduced an interesting proposal, different from the participants in the previous interviews. He would like to see a facility that provided services in a positive way for older lesbian and gay persons/couples. Many of the participants would like to see the institution of long-term care improve and be gay-/lesbian-friendly.

Janet and Lois

When discussing the theme of institutional (re)structuring and what Janet and Lois would expect from a long-term care facility, the couple highlighted concerns with lack of training and lack of education of staff members. As with the other couples, they would want to be in a facility that provided queer-friendly spaces where they felt comfortable to be themselves. According to Janet when talking about staff members who have a duty to care regardless of one's sexual identity:

“It does speak to the lack of training and staff resources that are available to people and we keep on having to come back to it systemically that those kinds of attitudes are pervasive, I know they are and I would suspect that a lesbian or gay couple would be vulnerable”

For Lois institutional (re)structuring required people to challenge those sitting in the ivory tower:

“A lot of times training is conducted on a volunteer basis and this places women, who are over-represented in health care, in vulnerable situations... You know they are so many structural and systemic issues that have to be dealt with if we have a real commitment to diversity, we have to make a commitment to doing it and not doing it voluntarily”

Janet and Lois expressed similar sentiments as other participants in this research study. Facilities need to have some form of training for staff, yet the institution, at the administrative level, needed to commit to the training. Another important piece Lois highlighted was the need for governments to fund this type of training as a necessary educational component for all employees and administrators working in the long-term care system across Ontario.

Inclusive Care

Another recurring theme that emerged from the data was the social, psychological and emotional need to be treated with respect, compassion and dignity. All the participants wanted long-term care staff, residents and residents' family members to respect their right to inclusive and appropriate care which meets whatever health care needs they were inflicted with. One main component of fair and just care was the need for everyone within the facility to respect and accept their relationship with their same-sex partner. They would want to ensure that they were treated with the same type of care heterosexual couples would be granted. For many of the participants there was a constant battle for

acknowledgment of their same-sex relationship and they expected people involved in a long-term care facility to provide that.

Margaret and Dorothy

Margaret felt a sense of fear with the thought of entering a long-term care facility. She hoped the staff would first tend to her health care needs, to treat her with human dignity and respect her involvement with her same-sex relationship. It would be important that staff were aware of her relationship with Dorothy:

“Well respect for myself and respect for my relationship would be the number one thing for me...for me I am concerned with the staff who would give off the ‘you’re not welcome here at all’ attitude and believe you me I know that would happen...I want to be treated with respect, courteous, kindness...they should understand that they are such things as same-sex couples and that they are one of the many normal variances of human sexuality”

Dorothy agreed with Margaret’s need for inclusive care that welcomed an openness and respect for their same-sex relationship; however she expressed a concern that her sexual identity would not be the reason why she chose a facility. She expected to choose a facility based on her health care needs; not because it was a lesbian-specific facility. She commented:

“I pretty much agree with her...I want to move to a place that would meet my health care needs...I don't want to be placed somewhere just because I am a such and such, however once I am there I definitely want to be treated with respect and live somewhere without judgment”

For this couple inclusive care involved services that were respectful, compassionate and attentive to their health care needs. Margaret and Dorothy would like to ensure that practitioners behaved in a professional and appropriate manner. They hoped the care they received was based on their physical ailments and not on how they identified. However, they hoped that staff would be attentive and aware of differing sexualities that existed.

Joseph and Kevin

Joseph and Kevin expressed similar concerns of moving into a gay-friendly, compassionate environment that respected their relationship. Joseph discussed one need that he preferred:

“They put together a multi-purpose space which tends to be a dining facility, a café-torium which is not the model for me, there is no intimacy for me where you eat in these places and that doesn't make sense to, no privacy for us to have dinner alone outside of our rooms...I don't want to change all that at the end of my life just as I am getting ready to die; so I don't see us as using public facilities”

This was a very interesting need. Although Joseph stated he would definitely want socializing and interaction with other residents, he was adamant with his and Kevin's need to have more intimate times together. For him privacy would be compromised if he and Joseph relocated to a long-term care facility. Joseph explained how they would access a private facility because they were financially secure to have this option of choice.

Similar to Margaret's recommendation, Kevin stated:

“Certainly what needs to happen with all of these places where people rely on the care needs of others there must be mandatory diversity training for all of the diversity issues; I mean I think about my cousin who is living in the facility at the moment if we were to arrive there as a same-sex couple there would definitely be a ripple effect throughout the whole place, I mean a lot of the men who are living there would not be comfortable with us because it is a small town, a small place that has very different values”

An important component for an inclusive environment for Kevin was a facility that had mandatory diversity training. He claimed that smaller cities would not be open to a same-sex couple and they may experience differential treatment in rural areas. Kevin and Joseph felt that having staff who were trained on how to provide

inclusive care with people from marginalized populations may present a more welcoming environment for these populations.

William and Philip

In relation to inclusive care both expressed a desire similar to the other couples that they would be treated with respect and dignity. William and Philip stated if one of them were to move into a long-term care facility there would be a need for the other persons to move into the facility as well. For them inclusive care was a facility that permitted them to move into the facility together; a facility that respected and accepted their same-sex relationship. Philip stated:

“Just having lived my life in a gay atmosphere, you’re sort of cautious about where you end up I’d like to feel my way around first before I even went into some place...well I’d like to be able to take William with me; if I couldn’t then I would certainly like him to have access and if he had access then I’d like him to have access as a gay companion who could stay overnight or whatever”

William expressed a similar concern, he stated:

“I would need a facility that would allow me to, if Philip went in next week, I would need to have access to him as his partner; or if the position were reversed, if it were me, he would need to have access because we would need to

have the acknowledgment that we were a couple and we would need to have that respected.”

Both William and Philip discussed how inclusive care would be a facility that truly respected and recognized their relationship as a legitimate couple who loved and cared for one another. They expressed concerns that they would be separated in the long-term care system and this would be devastating for them to live apart.

Janet and Lois

Throughout the duration of the interview Janet and Lois were quite aware of what inclusive care meant to them. The environment definitely needed to employ staff who were capable and willing to work with people from differing diverse sexual backgrounds. Their experiences with a family member living in a long-term care facility informed their impressions about the present oppressive structure that existed. Janet commented:

“Respect and dignity and autonomy and recognition...it would be about really pushing that system to really recognize people’s relationships, their life needs and making sure that can happen regardless of sexual orientation and given some of the systemic barriers that would be facing us I would just want some particular attention making sure we are comfortable and we got some control of our lives”

Lois commented on the need toward acknowledgment of her sexual identity within the culture of the facility:

“I would expect to see who I am reflect in some of the programs they have; it may be as something simple as films they chose...it’s just what any group would want themselves to be represented in the movies; not a special lesbian night; it is just integrated into the programming that there is diversity and not just in terms of sexual orientation”

This couple provided some concrete examples of how facilities can create inclusive environments. Simply, a queer-themed movie night would send a clear message that the environment was open to diversity and inclusion. Many facilities do not include sexual diversity in their programming and this can potentially send a negative message to staff, residents and residents’ family members. By engaging in inclusive displays of acceptance the facility provides the opportunity for dialogue and discussion which increases the awareness of a queer-positive space.

Self-advocacy

Throughout the interviews I noticed a strong connection to advocacy and each person's ability to self-advocate for themselves in various settings and situations. This was another recurring theme that emerged from the data.

Margaret and Dorothy

Both of these participants discussed a few times when they had to self-advocate on behalf of themselves, more so Margaret than Dorothy. As a 67 year old woman who relied on Old Age Security, she has been confronted with ageist attitudes many times. Neither one of them would tolerate or be silenced if they encountered differential treatment as a same-sex couple. Margaret stated:

“Although I have expressed concerns and fears I may have if I move there it is definitely something I would be on my guard against and would not put up with; I am pretty assertive when I need to...currently I volunteer for a Conservative candidate and we all know their position on same-sex marriage; however I stay there because I want to represent the rights of lesbian and gay people”

Margaret expressed concerns that she would need to be vigilant and ‘on guard’ in relation to inappropriate treatment. This statement is concerning. At a time when

she would be in need of her basic rights to health care, Margaret has to be aware of differential treatment she may encounter based on her sexual identity and/or relationship status.

Joseph and Kevin

Joseph and Kevin stated they would not tolerate any form of differential treatment. This was the second couple who expressed the need to be assertive and vigilant when challenged by homophobia and heterosexism; Joseph explained:

“I have 60 years of lived experience...I want to be informed and I tell this with all the medical people that I come in contact with, I constantly tell them I want to be informed, as a well-informed patient I will be totally cooperative...if someone treated me or him poorly it wouldn't last long I'll tell you that”

After this statement Kevin laughed and stated, “Trust me, he wouldn't”. This was a couple who have lived experience that has contributed to their strong sense of self, as well as their rights to everyday services that heterosexual persons/couples are provided. This was a recurring assumption made by most of the couples that heterosexual people and couples were automatically granted special privileges

and they are automatically treated with kindness, compassion and professionalism.

William and Philip

William and Philip had a strong social support network, a committed relationship and a keen awareness of their rights as a couple living in Canada. William, as well, made a few comments on his role as a self-advocate. Similarly to the other participants in this study William would challenge the existing attitudes if he encountered any form of differential treatment; he stated:

“If I’d found myself a situation where people were disrespectful or homophobic I would have to react to that, I would not take that lying down...I would think that if something were to happen to one of us, we would have to go to a straight care facility and hope that we had sympathetic workers because we’re not about to, neither Philip nor I, change who we are”

William’s statement exhibited the role he would take if faced with inappropriate treatment. William would not allow his right to appropriate care to be compromised by individuals and/or institutions that disapproved of him or his partner. There appeared to be awareness that he would encounter homophobia if he and Philip entered long-term care. William would not tolerate this type of

behaviour. William’s statement “because we’re not about to change who we are” also highlighted a sense of historical discrimination many older lesbian and gay persons have encountered. There is a history of lesbian and gay persons having to succumb to and/or being forced into accommodating the heterosexist norms of society.

Janet and Lois

This was another couple who commented throughout the interview on ways in which they were informed consumers and they always felt empowered to challenge existing institutional and systemic oppression. At times Lois felt the need to express her intolerance of homophobic behaviours and attitudes within her workspace; she stated:

“In my work I have always felt quite empowered or to take on the people who make the homophobic jokes or comments”

Janet discussed ways in which she has built a positive environment in her life and she has little tolerance for people in challenging situations:

“We’ve worked so hard to create really high standards in our life and I would never allow anyone to chip away at that”

Lois interjected:

“Well and I would think that I am very, very clear as well, this is not about being dependent on their good will, I mean this is where I would use the power of the law because it is our legal right as well as our social right to be treated respectfully when accessing services; if I got a sense that anyone was reluctant I wouldn’t want them in my home...but I wouldn’t leave it at that, I would be making a lot of noise with the company”

All the participants in this study expressed very similar views in relation to self-advocacy and knowing when to confront homophobia and/or heterosexism. Most of the participants expressed a sense of being vulnerable to chance and the personal attitudes of individual workers; however both Lois and Janet resisted this formulation and offered a more politicized and rights based approach to the care they would expect to receive. The other couples looked at the situation(s) as an individual level struggle the two of them would need to challenge. In contrast, Janet and Lois took it one step further than the other participants and would demand an agency investigate and/or reprimand any health care worker exhibiting inappropriate behaviours. For them, there was an insistence on broader

institutional and systemic changes that would benefit the broader queer community.

Discussion

The narratives of the lived experiences of the couples in this study provided an opportunity for the participants to examine issues, concerns and recommendations they had if faced with the decisions to relocate to a long-term care facility. Several issues emerged from this research study. First, all of the couples interviewed felt strongly that discrimination, in the form of homophobia and heterosexism, presently existed in long-term care. Their experiences are consistent with the current literature that institutions, such as health care facilities have overt and covert forms of discriminatory practices (e.g. exclusion on intake forms) that are exclusionary toward aging lesbian and gay person and same-sex couples (Brotman, Ryan, & Cormier, 2003; Cahill & South, 2002; Hughes, 2007; Johnson & Jackson, 2005; Platzer & James, 2000; Thompson, 2008)

These types of differential treatment the couples have experienced throughout their lifetime contributed to the anxiety they would experience if contemplating a move to long-term care. These findings suggest the need for an organizational transformation that needs to begin in the long-term care system.

Changing current systems may provide a sense of safety and comfort for older same-sex couples who enter long-term care facilities.

Secondly, most of the older same-sex couples in this study experienced harsh consequences when disclosing their sexual identity to family members and colleagues. The participants who proclaimed their sexual identity in most aspects of their lives did proceed cautiously when disclosing this information. Environments (e.g. family) and institutions (e.g. hospitals) contributed to the anxiety they, at times, internally struggled with when proclaiming their sexual identity to others. Institutions, such as long-term care, need to develop strategies and procedures to welcome same-sex couples in order to lessen their fear of disapproval. Providing a space during the intake assessment process for couples to have a choice to provide that information may contribute to a welcoming environment inclusive to all persons from differing sexually diverse backgrounds.

Most of the research that has been conducted with aging lesbian and gay persons detailed participant's feelings of fear and resistance about entering a long-term care system (Brotman, Ryan, & Cormier, 2003; Cahill & South 2002; Edwards, 2001; Kaplan, 2002; Tolley & Ranzijn, 2006). All of the participants in

this current study expressed a strong desire to remain in their home for as long as possible. The couples felt they could control, regulate and monitor the services they required. Most of their fears stemmed from their personal experiences with the health care system in the past. Institutionalized care was seen as a ‘last resort’. Most of the couples were able to reflect on the possibility they may have to relocate to long-term care; however all would prefer a system that could provide similar types of care in the home. Aging at home needs to be re-examined by policy-makers and governments as an alternative option to long-term care. Currently the home care system provides minimal services and this needs to be re-evaluated as an effective component of our health care system. Independence, privacy and autonomy are highly valued by all the participants who took part in the research. All believed these aspects of their lives would be compromised if they moved into a long-term care facility.

Many older persons, regardless of sexual orientation, preferred the comforts of home. There is a stigma in society that long-term care is a space where people are placed; it is the final stop before death. Aging at home provides older queer people with a comfortable, safe space where they have greater control

with their care. Many lesbian/gay participants would be particularly concerned about entering a long-term care facility because they felt that they would be at greater risk of receiving inappropriate treatment by long-term care staff because of their sexual identity. Many were concerned that staff and residents would not accept their long-standing same-sex relationships and they may be subjected to differential care. Inclusive care that is respectful of same-sex relationships is important.

One important issue that was highlighted by most of the participants was the need for queer-identified professionals in the long-term care systems. The participants discussed how their relationship with their queer-identified family physician provided them with a sense of comfort, trust and understanding they believed they would not receive from a straight practitioner. The literature discussed ways in which people avoid health care systems because of heterosexist and homophobic attitudes and beliefs exhibited by staff and professionals (Brotman, Ryan, & Cormier, 2003; Tolley & Ranzijn, 2006). These participants had a communicative and open relationship with their health care practitioner because of the similarities of queerness they commonly shared.

The data suggests that professionals, such as queer-identified family physicians may provide individuals and couples the opportunity to openly discuss any issue or concern they may have. When a person does not have a positive, communicative relationship with their primary health practitioner they may be at a greater risk of neglecting their health care needs until it is too late to treat an illness. When health care practitioners self-identify as gay or lesbian, couples may experience a decreased fear and/or anxiety about disclosing their sexual identity and/or relationship status.

Institutions, such as long-term care need to have queer-identified staff which would provide persons/couples with an opportunity to access queer-friendly professionals (Barnoff, Sinding, and Grassau, 2005). According to one participant having an “all-straight staff would be a strong indicator that the facility may not be equipped to meet her needs’ as a resident”. One of the participants explained that having ‘out’ professionals is important; however they were concerned whether the institutions would support these individuals, a point also made by Barnoff, Sinding, and Grassau (2005). This participant expressed the need for ‘systemic protections and organizational commitment’ from the

institutions. Long-term care facilities who engage in hiring queer-identified professionals must ensure the safety of these people.

Consistent with the literature, the couples from this study were well-informed and quite aware of the complexities and difficulties with navigating homophobic and heterosexist health care institutions (Brotman, Ryan & Cormier, 2003; Cant, 2008). Heterosexist intake assessments and forms represent a type of differential treatment which promotes a non-welcoming environment that promotes exclusion and non-acceptance. Institutions such as long-term care need to re-examine their intake procedures and begin the process of institutional restructuring. Institutional restructuring and organizational change can be a lengthy process that requires a strong commitment that would involve internal and external support in the long-term care system.

Administrators and professionals committed to organizational change must begin the process of institutional restructuring. Policies, mandates and procedures need to be examined and altered to include older lesbian and gay persons' and couples' rights as residents. Addressing heterosexism and exclusionary policies and practices will help to create awareness that the facility is

open to residents from varying sexually diverse backgrounds. This may not be echoed throughout the entire facility but institutional restructuring and organizational change needs to have an entry point, which this could provide.

Another important component for the research participants was the need to have inclusive care integrated throughout the facility which is consistent with other research studies (Brotman, Ryan, & Cormier, 2003; Cahill & South 2002; Edwards, 2001; Hughes, 2007; Johnson & Jackson, 2005; Kaplan, 2002; Tolley & Ranzijn, 2006). Participants in this study wanted to be treated with respect, dignity, and compassion similar to their heterosexual counterparts. All of the couples hoped the services in long-term care would be professional, competent and appropriate. They expressed how priority should be given to their physical care needs and hoped that it would not be compromised based on the sexual identity and/or same-sex relationship. For all of the couples who were interviewed inclusive care involved a staff and administration that were knowledgeable, aware and sensitive in creating an environment that was non-homophobic and non-heterosexist. Every couple expressed the need for some form of sensitivity training on diversity and inclusion for all persons in the

facility. This was consistent with Brotman, Ryan, & Cormier's (2003) study found that traditional; heterosexist institutions need to train workers on the issues and barriers for people from marginalized populations. Something as simple as using the term partner for many gay and lesbian couples exhibits a sign of acknowledgement and inclusivity toward their sexual identity. Inclusive language has the ability to contribute to an inclusive environment.

Very little research exists on the experiences of older same-sex couples with health care systems. The couples expressed concerns that staff needed to respect their partnered relationship. Most of the participants talked about ways in which they wanted staff to recognize and accept them as a same-sex couple. There were concerns expressed by the research participants that staff working in long-term care would not respect the rights of same-sex couples as a legitimate couple. There was a consistency with hegemonic, homophobic, heterosexist societal views that same-sex couples were not afforded the same rights and privileges heterosexual couples were granted. Future research could involve a study examining differential treatment between same-sex couples and heterosexual couples in order to provide greater insight whether the former

experience differing challenges and barriers. One promising aspect of lesbian and gay people who are in healthy, partnered relationships is they are more likely to be emotionally supported by the person (Grossman, D'Augelli, & Hershberger, 2000). Therefore couples may have the comfort, support and safety of the other person when living in a long-term care facility.

According to one research study same-sex couples need to have some form of legal documents (e.g. advanced care plan) prepared if ever they were faced with health care concerns (Riggle, Rostosky, & Prather, 2006). All of the couples in the study made reference to fears that their partner would be denied access to them in a crisis situation. Only two of the couples had prepared Living Wills and assigned Power of Attorney to ensure their partner would be involved in any health decision-making or would have access to property in a crisis situation. Health care professionals and social service workers could initiate this process with same-sex couples to ensure estranged family members are not awarded rights based on biological relationships. In one case in Florida, a female was denied access to her partner when she was unexpectedly admitted to the hospital (Outword, 2008). Couples who are not legally married could encounter

this type of homophobic treatment in the long-term care system. If couples were to enter a long-term care facility and their capacity to make decisions was compromised by cognitive impairments this could pose a serious problem for both.

Although I stated previously that interviewing the couple was, somewhat of, a limitation, I wanted to provide the couple a space that acknowledged and recognized their coupleness. The data that was obtained primarily introduced their concerns about their losses and fears as a couple and how they hoped their relationship would be respected by staff working in long-term care. I strongly feel that interviewing them together had a kind of logic that provided them the opportunity to discuss their fears and concerns from the couples' perspective; not as an individual perspective in a same-sex relationship. All of the couples explained they felt the research was important and it provided them the opportunity to discuss issues they may not have considered in the past. Most of them felt that I respected their choice to be interviewed as a couple because they believed these issues impacted them as a couple and not as individuals.

Research Limitations/Strengths

Similar to other studies conducted with aging lesbian and gay persons, the sample in this research study consisted of well-educated, mostly white, middle- to upper-class couples who were well informed of the rights and privileges as citizens of Canada. This sample represents a group of individuals/couples who are privileged in Canadian society. As most of the participants in this study were middle- to upper-class this may present a limitation in terms of what this study was able to learn about the fears some couples may have when contemplating a move to long-term care. For the four couples in this study, relocating to long-term care was a last resort because they felt they could afford private home care services to meet their health care needs. The stories may not represent the anxieties and/or strategizing that comes along with having fewer choices which couples in a lower socio-economic status may encounter. This sample may not be representative of the aging queer population whose experiences may differ due to intersecting forms of oppressive barriers based on ethnicity, class, geographic location and education.

Another limitation of this study involved myself as an insider of the queer community. Reflecting on the interviews during the data analysis, I recognized situations where I could have sought further clarification from the research participants. For example, many of the participants, when asked if they have ever encountered differential treatment would say “yes, but that just comes along with being gay doesn’t it?” As a queer person who has experienced countless situations with homophobic violence, I noticed I would agree with the participants because I knew what they were referring to. I did not seek clarification because as an insider of the community, I identified with their experiences. However, if I sought out further clarification I may have obtained richer, in-depth data.

Although I encountered some limitations as a queer researcher, I did experience benefits as well. Throughout the recruitment process I was able to locate agencies, organizations and websites that disseminated my recruitment letter and recruitment poster. When I would contact these various places, some of the contact persons asked whether I was gay or not; at which point I self-identified. In doing so, I was permitted to have my information disseminated on their email listservs, recruitment posters posted in the organization, and

recruitment letters posted on the websites. I was granted privileged access to conduct this research because I was a member of the queer community. A heterosexual researcher may have encountered barriers and a great deal of challenges with recruiting participants.

A second benefit I experienced as a queer researcher was developing a sense of trust and respect with the participants based on our common sexual identity. According to Lasala (2003), “gay and lesbian respondents may be more likely to participate in research conducted by a lesbian or gay man because they believe the researcher is committed to deconstructing societal misperceptions about who they are” (p. 18). When the research participants contacted me I identified myself as a gay male. Most of the participants stated they felt comfortable talking with me because I was gay. Thus as an insider of the queer community I was granted accessibility to a community that heterosexual researchers may find difficult to access.

This research study had some strength which I feel necessary to discuss. Using the interpretive, narrative approach, I captured stories of same-sex couples who, to my knowledge, are under-researched. My intent was to conduct

exploratory research in an area where very little research exists in order to help address the issues and concerns of this population. I provided the opportunity for these same-sex couples to ‘tell their stories’ and inform others on ways systems could be improved to be inclusive toward them. This research was a form of resistance that was inclusive of the couple as a same-sex couple.

Directions for Future Research

These findings raised a number of questions that I struggled with which future research could focus on. Future research should focus on aging same-sex couples and their experiences with the Canadian health care system (e.g. hospitals, Community Care Access Centres, home care, and long-term care facilities). How would staff react to a same-sex couple living in a long-term care facility? What type of treatment would they receive? Would sensitivity training diminish personal values and beliefs of homophobia and heterosexism? What factors would move governments to fund some type of inclusivity training program or would they prioritize a need to allocate the funds elsewhere? Could a facility meet the needs of same-sex couples? If a couple were confronted with cognitive impairments would they be vulnerable to differential treatment by staff

if they were assertive and vigilant? Would couples who were reliant on long-term care providers be able and capable to maintain their self-advocating values and beliefs? Will they have the physical and emotional strength to challenge homophobic/heterosexist attitudes? How does the intersection of gender and sexual orientation impact on the roles and expectations of same-sex relationships when caring for a partner? Are gendered roles and expectations in same-sex relationships similar or dissimilar to heterosexual couples? Future research studies could focus on these questions to evaluate whether facilities and governments are prepared to provide sensitive services to Canada's aging queer population.

Dissemination of Findings

Most research is conducted in order to address issues and/or to effect social change. There is an expectation that research findings will be communicated in order for change to occur. According to Davis, Nutley and Walter (2005) research needs to make an impact. The knowledge gained from research projects needs to be transferred and researchers should consider how this will be accomplished prior to the research process begins. Baines (2007) argues

that knowledge transfer involves the concerted efforts of researchers to create an environment of exchange and dialogue of research findings. Simply disseminating the findings of research in the form of a thesis defense will not benefit anyone except for the student. As well I should not expect others to ‘seek out’ the findings I have prepared. Davis et al (2005) stated, researchers need to take an “active role in communicating their research” (p. 13).

According to Baines (2007), knowledge transfer involves the process of ways in which research is communicated, and the need to communicate research back to those being researched, as well as to external bodies/groups/organizations to effect change. Davis et al (2005; cited in Sinding, Gould & Gray, 2007), explained how research findings can “contribute not only to decisional choices, but also to the formation of values, the creation of new understandings and possibilities and to the quality of public and professional discourse and debate” (p. 6). The data collected from this research study will be integrated into a larger study in which I am currently involved. We will be continuing the research until we have reached saturation, then preparing an academic paper and submitting our work to various scholarly journals for publication. With the findings built into

each other, it is my full intention to disseminate my research in various ways to the community.

Over the past few years as a practitioner working in Hamilton I have developed numerous working relationships with various people in the community. My goal is to transfer this knowledge at the policy level, the practice level and individual level. Over the past year, I had the opportunity to meet with a senior administrator for the Hamilton, Niagara, Haldimand, Brant Local Health Integration Networks (LHINs). The LHINs is a corporation created by the provincial government who work with local health providers and community members to determine the health service priorities...they plan, integrate and fund local health services, including long-term care. One of the goals of the LHINs is to hear from service users about their needs in terms of health care. As a result of my connection with this senior administrator I was invited to present my findings once completed. I intend on presenting my findings in the form of a policy brief and short presentation. Policy-makers may be interested in gaining an understanding of the perceived barriers many same-sex couples highlighted if, and when, accessing the long-term care system.

A second strategy is utilizing my connection with the Ontario Long-term Care Association (OLTCA). The OLTCA members operate over 400 regulated long-term care homes across the province. The role of the OLTCA has four main functions to provide advocacy, communications, education, and member services. As part of the education piece the OLTCA strives to support members and their management staff in remaining current with leading edge developments in the delivery of long-term care services. As part of my connection with the OLTCA they expressed an interest transferring the findings to long-term care facilities across the province. A contact person there informed me that I will have an opportunity to communicate the research to her research team. I will prepare a short information letter in the form of a fact sheet for simple, easy reading for her to disseminate via her email members' list. A few months ago I was invited to develop an anti-homophobia, inclusivity training program for front-line staff working in long-term care which I have. My plan is to integrate these current research findings into my training program and to continue to disseminate this information to front-line staff working in long-term care.

Thirdly, I intend to disseminate the research findings to the organizations that assisted me with my participant recruitment. All have agreed to transfer the knowledge to their members, who are predominately queer people across Canada. I believe it is important for this marginalized population to gain a better understanding of today's aging population, particularly the concerns older same-sex couples have if faced with a decision to relocate to a long-term care facility. Disseminating the results of the research to individuals may give voice to a group of people who have been silenced. This research study has the potential to create dialogue, discussion and focus on the concerns and needs of same-sex couples. As well it is my intention to provide a copy of my findings to the same-sex couples who provided me the opportunity to conduct this research.

Personal Reflection

Prior to this research project I worked with many older adults who were internally challenged with self-advocacy efforts. I realize that I had internalized the stigma associated with many older adults as helpless and frail. Interviewing this group of couples provided me the opportunity to self-reflect on my biased assumptions, for which I am forever grateful. In any given heterosexist and/or

homophobic situation many of the participants expressed they would not tolerate differential treatment by professionals working in the health care system. All of the couples were well aware that access to inclusive care was a basic human right as a Canadian citizen.

After completing this research and highlighting the concerns and issues same-sex couples could encounter, one piece of legislation needs to be addressed which is exclusionary and directly related to the needs and rights of all lesbian and gay persons/couples who may become engaged with the health care system. This research has the potential to challenge the recent amendment to the Long-term Care Act. There was no acknowledgement of sexual diversity in the amended Act that was recently introduced. The Act states, “in assisting the applicant under subsection (3), the placement co-coordinator shall consider the applicant’s preferences relating to admission, based on ethnic, religious, spiritual, linguistic, familial and cultural factors 2007, c. 8, s. 44 (4)” (LTCA, 2007). There was absolutely no mention of sexual orientation anywhere in the Act. This promotes an exclusionary policy and there is great potential for this policy to be

challenged and amended for the equitable and equal treatment of older lesbian and gay persons/couples.

Appendixes

Appendix 1: Interview Guide

1. How would you describe your sexual orientation?
2. How would you define your relationship status?
3. How would you describe your health status?
4. Is your family aware of your sexual identity? If yes, would you describe your relationship with family members?
5. Is your family aware of your partner? Would you describe the relationship between your partner and your family members?
6. Are your friends aware of your sexual identity?
7. Is/Was your employer aware of your sexual identity? Relationship?
8. Have you ever experienced any form of discrimination based on your sexual identity? Prejudice? Differential Treatment?
9. Do you currently have a family physician? Could you describe this relationship?
10. Have you had to access health care services recently (i.e. hospital)? If yes, could you describe this experience?
11. When I mention the term long term care, what might you be thinking of?
12. If you had to access home care services, what might you need to consider, prior to a worker entering your home?

13. Have you considered entering long term care in later years? Could you discuss why/why not?
14. If you had to enter a long-term care facility due to unforeseen circumstances, what would you need to consider?
15. Would you have any concerns or reservations about using the long-term care system because you are lesbian/gay? Could you explain why/why not?
16. Would it be important that staff were made aware of your sexual identity and relationship status prior to entering long-term care?
17. If you did not want staff to know, could you explain why?
18. As a lesbian/gay person, what do you expect from staff in terms of service? Would you discuss any special needs because you are in a partnered relationship?
19. What type of care needs (social, physical, emotional/psychological) do you feel you/your partner may require from long-term care staff if one of you moved into long-term care? What if you both moved into the facility; what type of care needs do you feel you would require?
20. Would you discuss ways in which you/your partner's needs may differ from those of heterosexual couples?
21. To what extent do you feel that you/your partner being lesbian/gay may impact staff member's ability to meet your needs in long-term care?
22. Is there anything that could be done within the long-term care system to make you feel more accepted in terms of your sexual identity and that of your partner?
23. Are there any other questions that you think I should be asking participants in this study?

24. May I contact you in the future if I have any additional questions?

Appendix 2: Letter of Intent

School of Social Work
Kenneth Taylor Hall 226
Phone 905-525-9140 ext 23786
1280 Main Street West
Fax 905-525-4198
Hamilton, ON L8S 4M4



Hello,

A research team from the School of Social Work at McMaster University in Hamilton, under the direction of Dr. James Gladstone, is currently collecting data for a study concerning same sex couples involved with the long-term care system or couples' perceptions of long-term care.

Research Objective: To examine, and better understand, the social, psychological, and emotional needs of same-sex couples entering long term care.

Participants: We are seeking same-sex couples, (female and male), to participate in an interview, either in person or telephone (approximately 1-1 ½ hours in length per participant). Preferably one person in the partnered relationship is 50+ years of age. Participants can be living in the community or living in long term care or a combination of both. Couples participating in the study will receive \$25/per individual. Confidentiality and anonymity assured.

This study has ethics approval through the McMaster Research Ethics Board.

Interested participants please contact Robert Cosby, research assistant, through email cosbyr2@mcmaster.ca or by telephone 905 920-3030.

In case you have any questions regarding this study please contact Mr. Cosby or the principal investigator at the address/telephone number listed above.

Appendix 3: Informed Consent

School of Social Work
Kenneth Taylor Hall 226
Phone 905-525-9140 ext 23786
1280 Main Street West
Fax 905-525-4198
Hamilton, ON L8S 4M4



CONSENT TO PARTICIPATE IN RESEARCH

Project Title: NEEDS OF SAME-SEX COUPLES LIVING IN LONG-TERM CARE

You are asked to take part in a research project conducted by a research team from the School of Social Work. If you have any questions or concerns about the research, please feel free to contact Principal Investigator: Dr. Jim Gladstone at (905) 525-9140 extension 23786, e-mail: jwgladstone@rogers.com

PURPOSE OF THE STUDY

To identify the needs of same-sex couples living in long-term care.

PROCEDURES

The research assistant will meet with participants to discuss their experiences and ideas about same-sex couples engaged with long-term care.

If you volunteer to take part in this study you will be asked to do the following things:

First, the researcher will privately ask you a few questions to gather demographic information about your background. Next you will be asked to take part in a one-on-one interview that will last about 1 – 1½ hour.

You can choose not to answer any of these questions.

The interview will be tape recorded with your permission so that the researcher does not miss anything said. Interviews will take place at McMaster University or a location that is prearranged by the participant.

The following is an example of some of the questions you will be asked to respond to:

- When I mention the term long term care, what might you be thinking of?
- Would you have any concerns or reservations about using the long term care system because you are lesbian/gay? Describe.
- Would it be important that staff were made aware of your sexual identity and relationship status prior to entering long-term care?
- Would you discuss ways in which you/your partner's needs may differ from those of heterosexual couples?

POTENTIAL RISKS AND DISCOMFORTS

You may feel uncomfortable responding to certain questions and you may choose to skip any question you wish. If you feel you would like to speak with a counselor the research assistant can provide you with local service providers that can assist you.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

In Canada very little academic research exists on same-sex couples engaged with the long-term care system. The data collected from this study may be used to improve the quality of care same-sex couples would received when moving into long-term care.

COMPENSATION

You will receive \$25 in cash for participating in this study. Your signature signifies payment was received.

CONFIDENTIALITY

No names will be used in any of the written reports, nor will any identifying information be included. The only people who will have access to the interview data are the research assistant and the study investigators.

Interview tapes will be kept in a locked filing cabinet at McMaster University. Transcripts will not contain identifying information—transcripts will be stored at McMaster University.

Tapes will be destroyed after 1 years and transcripts after 3 years.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you do not want to answer and still remain in the study. If at any point you choose to withdraw from the study, any data that you have provided will be destroyed.

RIGHTS OF RESEARCH PARTICIPANTS

You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the McMaster Research Ethics Board (MREB). If you have questions regarding your rights as a research participant, contact:

MREB Secretariat

McMaster University
1280 Main Street W., GH-306
Hamilton, ON L8S 4L9

Telephone: 905 525 9140, ext.
23142
E mail: srebsec@mcmaster.ca
Fax: 905-540-8019

SIGNATURE OF RESEARCH PARTICIPANT

I understand the information provided above and my questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

Signature of Participant

Date

SIGNATURE OF INVESTIGATOR

In my judgment, the participant is voluntarily and knowingly giving informed consent to participate in this research study.

Signature of Investigator or research assistant

Date

Appendix 4: Demographics Form

DEMOGRAPHIC INFORMATION



In what year were you born?

What is your highest level of education completed?

Some High School _____

High School _____

Community College, Trade, Technical _____

University (Undergraduate) _____

University (Graduate or Professional Degree) _____

What is your income level?

\$0 to \$19,999 _____ \$20,000 to \$29,999 _____

\$30,000 to \$39,999 _____ \$40,000 to \$49,999 _____

\$50,000 to \$59,999 _____ \$60,000 or above _____

How would you identify your sexual identity?

How would you identify your gender identity?

How would you identify your ethnicity? _____

What is your current relationship status?

How long have you been in this relationship?

Are you or your partner currently engaged with the long-term care system?

Yes _____ No _____

If yes, for how long? _____

In what way?

- a) Contact with CCAC _____
- b) Receiving home care services _____
- c) Applying to nursing home/home for the aged _____
- d) Living in long-term care facility _____
- e) Partner living in long-term care facility _____
- f) Other _____

Who is aware of your sexual identity? (Check all that apply)

Family _____ Colleagues _____

Friend's _____ Physician _____

Who is aware of your relationship with your partner? (Check all that apply)

Family _____ Colleagues _____

Friend's _____ Physician _____

Appendix 4: Participant Recruitment Letter

School of Social Work
Kenneth Taylor Hall 226
Phone 905-525-9140 ext 23786
1280 Main Street West
Fax 905-525-4198
Hamilton, ON L8S 4M4



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