

# “Could We Hold Hands?” Older Lesbian and Gay Couples’ Perceptions of Long-Term Care Homes and Home Care\*

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## RÉSUMÉ

Cette étude qualitative décrit les attentes, les préoccupations et les besoins en matière de services de soins de longue durée et de soins à domicile de 12 couples de lesbiennes et de gais plus âgés qui habitent au Canada. Nos résultats reflètent quatre grands thèmes: la discrimination, l’identité, les dépenses d’énergie, et les soins nuancés. Discrimination a été caractérisée par des préoccupations concernant une discrimination déguisée; perte d’amortisseurs sociaux lorsque l’on vieillit; diminution de la capacité de plaider pour soi-même et l’autre conjoint. Les questions d’identité ont inclus le risque prévu sur la divulgation de son identité sexuelle; l’importance centrale d’être identifié comme un partenaire dans une relation couplée; et l’importance d’avoir accès à des groupes de référence constitués d’autres aînés gais. Nous concluons que les partenaires sont accablés par le travail émotionnel de dépenser de l’énergie à cacher une partie de leur identité, l’évaluation de leurs environnements de discrimination et d’apaiser autres. Les participants suggèrent que les soins nuancés sont nécessaires, ce qui implique sentir à l’aise avec les fournisseurs de soins de santé; ayant fournisseurs sentir à l’aise avec eux; et une dualité de nécessité entre vouloir être considéré comme le même, tout en même temps également reconnu comme unique. Ces thèmes informent ententes de services de soins et de soins à domicile à long terme pour les couples lesbiens et gais plus âgés.

## ABSTRACT

This qualitative study describes expectations, concerns, and needs regarding long-term care (LTC) homes and home care services of 12 older lesbian and gay couples living in Canada. Our findings reflect four major themes: discrimination, identity, expenditure of energy, and nuanced care. *Discrimination* involved concerns about covert discrimination; loss of social buffers as one ages; and diminished ability to advocate for oneself and one’s partner. *Identity* involved anticipated risk over disclosing one’s sexual identity; the importance of being identified within a coupled relationship; and the importance of access to reference groups of other gay seniors. We conclude that partners were burdened by the emotional effort expended to hide parts of their identity, assess their environments for discrimination, and to placate others. *Nuanced care* involved a mutual level of comfort experienced by participants and their health care providers. These themes inform understandings of LTC homes and home care services for lesbian and gay older couples.

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Lesbian and gay couples contribute meaningfully to society yet are often treated unfairly and denied opportunities for equitable participation. Although they are protected in Canadian legislation, an ongoing concern for lesbian and gay couples is that they still experience various forms of discrimination and cultural violence (Janoff, 2005). As same-sex couples grow older, they may be even more vulnerable to social forces like heterosexism and homophobia, which produce both outright and covert discrimination that can impact their health and well-being.

This exploratory, prospective study provides a qualitative description of what lesbian and gay couples anticipate their experiences will be like with long-term care homes and home care services if and when they need them. We asked: what do couples think about entering a long-term care (LTC) home and using home care services? What are their expectations? What kind of care do they feel they need, may come to require, and deserve? In this study we refer to long-term care as a system of care over the longer term for an individual. An LTC home is a facility where people reside who can no longer live independently. Home care refers to a variety of medical and non-medical support services – both publicly and privately funded – for people who are able to live otherwise independently in their own home.

## Background

### *Discrimination against Lesbian and Gay Adults in Health Care*

Over the past century, lesbian, gay, bisexual, transgender, queer, and two-spirited (LGBTQ2) people have mobilized advocacy movements, gained substantial ground in acquiring human rights, and formed a unique identity within the Canadian cultural mosaic (Smith, 2009; Warner, 2002). However, despite these gains, LGBTQ2 people continue to experience social exclusion from many public institutions, including the Canadian health care system. It is widely documented that sexual minorities are excluded from health care systems in Canada, the United States, and Australia (Brotman, Ryan, Jalbert, & Rowe, 2002; Daley, 2005; Hughes, 2007; Kimmel, Rose, & David, 2006). Given that homosexuality was pathologized and considered to be a mental illness until 1973 (Greenberg, 1997), many gay older adults recall experiencing discrimination in the health care system and, as such, continue to harbor deep distrust and fear towards its professionals (Anetzberger, Ishler, Mostade, & Blair, 2004).

In addition to discrimination that is enacted or public, such as the denial of marriage rights and refusal of services, covert discrimination on the basis of sexual orientation can be subtle or hidden. Croteau, Lark,

Lidderdale, and Chung (2004) reported that “covert” or “elusive” heterosexism can happen through silence or by not affirming, acknowledging, or recognizing same-sex relationships, or assuming someone is straight without asking. Nadal (2013) recently proposed the “sexual orientation microaggressions” concept that includes covert discrimination. Nadal argued that when environments are deemed to be unsafe, even if there is no evidence of public discrimination, the feeling of being unable to disclose one’s sexual orientation suggests the existence of microaggressive environments influenced by heterosexism and hegemonic power.

To date, the concept of covert discrimination has been understudied in populations of older same-sex couples, who, given the aging of society, may increasingly require services such as home care and LTC homes.

### *Health Care Encounters*

Qualitative research has drawn out some of the experiences of lesbian and gay older adults’ encounters with health care providers. Brotman, Ryan, and Meyer (2006) conducted cross-Canada focus groups about the health and social service experiences of gay and lesbian older adults and their families who reported they experienced virtual invisibility as well as barriers to care (historic and current) and discrimination by service providers.

Likewise, Brotman et al. (2002) conducted focus group research in rural, mid-size, and urban Canadian communities on the impact of coming out on accessing health care services, and found that participants identifying as lesbian, gay, bisexual, transgender, queer or two-spirited indicated that they encountered barriers to health care related to personal safety, lack of education among health care practitioners about sexual identity and diversity, and discrimination.

Lesbians may be particularly vulnerable to discrimination in health care. Platzer and James (2000) conducted 12 focus groups and 23 in-depth personal interviews with lesbians in the United Kingdom and found that these women encountered hostility, avoidance, physical and verbal abuse, and voyeurism from health care providers (2000, p. 194). These experiences were reported to cause delay in seeking further health care. Echoing this, Sinding, Barnoff, and Grassau (2004) interviewed 26 lesbians living in Canada accessing cancer care, and also found that some participants were targeted, denied standard care, or had aspects of their identity and social context relevant to their care dismissed, while most experienced a lack of care sensitive to their identities as lesbians. Together, these studies show that discrimination against lesbian and gay older adults is characteristic of encounters with the health care sector.

*Long-term Care Homes and Home Care Expectations of Older Lesbian and Gay Adults.* Lesbian and gay older adults are concerned with who will take care of them in their later years, particularly with respect to home care and LTC homes (Brotman, Ryan, & Cormier, 2003; Cahill & South, 2002; Tolley & Ranzijn, 2006). The undesirability of entering into an LTC home is an almost universal opinion among older people; however, lesbians and gays may be even more concerned (Heaphy, Yip, & Thomson, 2003). Brotman et al. (2003) conducted four focus groups with stakeholders including gay and lesbian “elders”; their families, and their service providers in three Canadian cities, and identified the fear and discomfort associated with accessing health care or living in an LTC home as an individual. Several authors have highlighted individuals’ common fear of going back in the closet and feeling that they have to conceal their sexual identities (Seraphin, Smith, & Keltz, 2013; Stein, Beckerman, & Sherman, 2010; Teaster & Harley, 2016, p. 660). A recent needs assessment survey conducted with 38 gay and lesbian older adults found that they questioned whether they would be treated with respect and dignity equal to that of their heterosexual counterparts (Smith, McClasin, Chang, Martinez, & McGrew, 2010). Lesbian and gay adults might feel that they would encounter homophobia and marginalization in an LTC home because many of them had encountered it in the past when accessing mainstream care (Hughes, 2007). Similarly, caregivers of lesbian and gay older adults have reported apprehension around accessing services like home care supports and other resources (Brotman, Ryan, & Collins, 2007; Hash, 2001).

When seeking out an LTC home and/or home care services, lesbian and gay older adults have reported that it is important to access care that is sensitive to their unique needs (McFarland & Saunders, 2003). Although this population may have similar health issues as their heterosexual counterparts, some encounter more difficulty with elements of care in an LTC home or in their own homes.

*Service Provider Perspectives.* Lesbian and gay older adults may be at an increased risk of encountering discrimination by front-line LTC home staff and home care service providers (Brotman et al., 2003; Tolley & Ranzijn, 2006). Some staff working in long-term care fear lesbian and gay individuals and same-sex couples might encounter discrimination and reduced safety (Cosby, 2005). Most staff working in long-term care had not previously experienced caring for openly lesbian and gay older adults, or they generally assumed that clients were heterosexual (Tolley and Ranzijn, 2006). LTC home staff have often reported negative attitudes towards sexual behavior generally, and when it has been acknowledged by staff, it was likely assumed

to be based on opposite sex attraction (Pugh, 2005). Therefore, human sexuality remains a taboo topic within these environments (Bonifazi, 2000; Bouman, Arcelus, & Benbow, 2007; Dickey, 1989; Hajjar & Kamel, 2003; Kaplan, 2002; Roach, 2004; Walker & Harrington, 2002; Ward, Vass, Aggarwal, Garfield, & Cybak, 2005).

*Issues of Identity.* As aging lesbian and gay couples are becoming more reliant on health care services, heterosexist assumptions and homophobia can prompt a fear of identity disclosure and, in some cases, may force people back in the closet, adding unnecessary strain to relationships (Teaster & Harley, 2016, p. 660). Many health care and social service environments do not provide opportunities for older adults to feel safe and comfortable disclosing their sexual identity (Hughes, 2007; Knochel, Quam, & Croghan, 2011).

Recognition of same-sex partnerships is paramount to quality care for lesbian and gay older adults. Hughes (2007) highlighted concerns with heteronormativity and “the lack of understanding of same-sex partners as persons to notify or next of kin and a trivializing of lesbian and gay relationships” (2007, p. 203). Some long-term care homes may have policies that prevent same-sex partners from sharing a room (Movement Advancement Project, Services & Advocacy for Gay, Lesbian, Bisexual, & Transgender Elders, & Center for American Progress, 2010). There are also concerns over lack of privacy in LTC home living arrangements (Bonifazi, 2000; Hajjar & Kamel, 2003). For example, Parsons’ (1995) report has presented anecdotal evidence that one gay couple were forcibly separated from each other and prohibited from having sexual relations.

*Importance of Social Relationships.* Lesbian and gay older adults’ social lives and significant relationships are important to consider in the study of their concerns about entering an LTC home and/or accessing home care services. These older adults have been reported to find a great deal of comfort and security when people around them are supportive of their sexual orientation and their relationships (Grossman, D’Augelli, & Dragowski, 2007).

Lesbian and gay older adults find support through shared culture and friends, or “fictive kin” (Brotman et al., 2003, p. 12). They may be more likely to derive support from their partners and friends, whereas their heterosexual counterparts might obtain similar support from biological family members (Dorfman et al., 1995).

Many lesbian and gay adults report living private lives with partners and a few close friends but once these social agents die, isolation and loneliness occur (Stein et al., 2010). Stein et al. interviewed participants living in LTC homes, and noted that this group expressed their concern of feeling alone because “they could not



talk to anyone about their lives, their partners and their grief" following the death of their same-sex partner (2010, p. 430). Shared recognition, acknowledgment, and remembrance of these significant others and affirmation of a variety of types of social relationships are very important to these older adults. Beeler, Rawls, Herdt, and Cohler (1999) noted that affirmation includes providing spaces for social interaction with other aging gay and lesbian adults to provide a sense of community. Of concern is the possibility that some health care providers might be uninformed about the social lives of this population, which could lead to lack of quality of care (McFarland & Saunders, 2003; Quam & Whitford, 1992).

In summary, there is still relatively little information available about lesbian and gay older adults' expectations or needs concerning LTC homes and home care services, particularly with regards to lesbian and gay older *couples*. Our research recognizes that same-sex older couples, by merely identifying as a couple, would be proclaiming their sexual identity prior to moving into an LTC home or accessing services, and that this situation has been understudied. The perspectives of couples are important. Lesbian and gay older couples likely experience tensions similar to heterosexual couples (Gladstone, 1995) but may not have the same resources (because of systemic discrimination) to deal with them.

Recent changes to marriage laws in Canada now permit legal partnerships that LTC home environments legally must acknowledge; however, it is unclear how this might play out, since the option of being public about one's sexuality, or "out" within a coupled partnership, is a relatively new development for some older adults (Humble, 2013). As life expectancies increase and same-sex couples become more socially accepted, we can expect that more of these couples will require services.

## Methods

### *Design*

This study provided couples with the opportunity to share their expectations, concerns, and needs should they be faced with the decision to use home care services or enter into an LTC facility. The research team utilized a grounded theory approach guided by the interpretive paradigm (Strauss & Corbin, 1998) where thematic categories were derived inductively from the data. The team sought same-sex couples (female and male) to participate in an interview, either in person or by telephone (approximately 1–1 1/2 hours in length per participant). At least one person in each coupled relationship was age 50 years or older. There were no other inclusion criteria. The researchers gathered data through active interviews (Holstein & Gubrium, 1995)

which reflected a collaborative and interactive process that involved both researcher and participants – mainly participating in dyads – in the co-construction of knowledge. In conducting the interviews in dyads, we were trying to recognize these partnerships, and to appreciate and respect participants as couples. The research team identified themes through dialogue with research participants and were not necessarily restricted to responses given to any one question.

### *Procedures*

This study was approved by the McMaster University Research Ethics Board. Researchers recruited participants through posted details about the research through LGBTQ2-friendly identified websites (Gay Okanagan, McMaster University). The team also utilized snowball sampling and encouraged participants to refer appropriate others to the study (Patton, 1990). The research coordinator made initial contact with one member of the couple who contacted the coordinator by telephone and/or email. The research coordinator then explained the nature of the study in detail, and if the participant was still interested in participating, an interview was arranged. Couples were presented with the questions from the interview guide prior to the interview so they could discuss in advance the issues of home care and LTC homes together, to think about their responses beforehand, and know what they would be asked.

The coordinator gave the participants the option of being interviewed individually or in dyads. Of the 24 participants, 22 opted to be interviewed in coupled dyads, and two opted to be interviewed individually (due to scheduling conflicts between the interviewers' and participants' schedules). Due to geographic distance between interviewers and participants, the researchers conducted nine interviews over the telephone using digital technology to record the interviews, with both participants on the line at the same time. Seven of these nine telephone interviews were conducted with dyads, and two were conducted with partners of the same couple separately. The research team conducted four face-to-face interviews with local couples with both parties of the relationship present at the same time. Three of these interviews were conducted in the participants' homes and one interview in a space requested by the couple.

The team offered participants an honorarium of \$25 to participate. The researchers audio-recorded and transcribed the interviews with participants' consent. The team gathered qualitative data using an interview guide that included questions about their health, family, employment, experiences of discrimination, health services, LTC homes and home care, specific needs they might have, and suggestions for improving care.

Social workers previously trained in interviewing skills conducted the interviews.

### Demographics

The research team drew findings from qualitative data gathered from 12 couples (24 individuals making up four male same-sex couples and eight female same-sex couples) living in Ontario, British Columbia, and Alberta, Canada. One partner in one of the couples identified as transgender. The participants ranged in age between 39 and 75 ( $M = 63.58$  years, median age 65). Education level ranged between high school and university-graduate level. Participants reported a variety of relationship types: married (4), common law (3), coupled relationship (3), and long-term relationship (2). Relationship length ranged from 3 to 34 years, with the majority of couples (8) reporting having been coupled 20 years or more. Most participants identified as white, Caucasian, Anglo-Saxon, European background, and one participant identified as Chinese-Canadian. Income levels identified by participants ranged from \$0–\$19,999 to \$60,000 and above. Couples all lived in the community. All but one of the couples stated they had not previously had experience with LTC home services.

### Analysis

The research team inductively derived categories using the constant comparative method (Glaser & Strauss, 1967). Data analysis was continuous. The team first read transcripts of data in their entirety with notations made in reference to emerging categories (Luborsky, 1994). The team then conducted a line-by-line analysis (Strauss & Corbin, 1998). Categories were distinguished by identifying key words, phrases, or common ideas. The team created additional categories through comparison of themes presented in the couple-level data already analysed with those revealed in new data. The team members established trustworthiness by discussing categories and properties until consensus was reached. This process was continued until the central categories became distinctive and inclusive of all data gathered (Strauss & Corbin, 1998).

## Results

Our qualitative findings are organized around four major categories: discrimination; identity; expenditure of energy; and nuanced care. When thinking about the prospect of accessing home care services or an LTC home, participants expressed concerns about covert discrimination against lesbians and gays; loss of social buffers as they age; and diminished ability to advocate for oneself and one's partner. In terms of identity, participants anticipated risk over disclosing one's sexual identity and noted the central importance of being

identified as a partner in a coupled relationship; they also acknowledged the importance of having access to reference groups consisting of other gay seniors. We argue that lesbian and gay couples are burdened with the work of hiding parts of their identity, assessing their environments for discrimination, and placating others. Participants desire nuanced care which they characterized as involving feeling comfortable with health care providers; having providers feeling comfortable with them; and a duality of need between wanting to be seen as the same while at the same time recognized as unique as any resident regardless of sexual orientation. We present each of these themes in this section. Pseudonyms were assigned to protect the anonymity of these participants.

### Discrimination

Participants were wary of discrimination that they might face if their or their partner's health declined and they required home care services or entered an LTC home. Three properties were associated with this category: covert discrimination; loss of buffer; and diminished ability to advocate.

Most of the participants did not expect to encounter overt discrimination, if only because legislation over the years has protected them from being targeted. Their concern, rather, was that they would be subjected to a more covert type of discrimination if they entered an LTC home or if they used home care services. As Natalie put it, "you can't legislate morality." This type of discrimination could come about in an indirect way, such as being disparaged, even if the participant wasn't physically present. Cassandra, for example, had recently been in hospital but didn't disclose her sexual identity, saying:

I think it's just easier if you don't ... because my experience being in the medical field is I've heard how people talk behind people's back, you know? Not that they don't necessarily get the same care, but they do a lot of talking and joking and that sort of thing.

It appears that Cassandra, a former health care worker, felt obligated to participate in withholding her sexual identity to avoid possible embarrassment.

Pina stated:

I think the cultural image of sort of, well, lesbian, gay, or any sexuality being just about sex and kind of either funny or disgusting is still alive and well. So I would worry that that would happen, as opposed to sort of ridicule or horror or dismay or something.

Pina's experiences of being stigmatized may also link to covert homophobia grounded in taboos about sexuality and sexual expression.

Covert discrimination could also come about when care providers, albeit unintentionally, make presumptions about participants' relationships with their partners. Cassandra, for example, recalled a colleague talking to a patient at work:

She said to this woman "you and your husband" and she said "I'm not married. I live with another woman." She said "oh, your sister." Immediately it was *your sister*. And so I thought, I wish I had the opportunity or the ability in some way to say "it's okay, you know, it's okay if you identify them." Because I know that it wasn't her sister.

A few participants saw their professional status at work as being a potential buffer that would protect them against discrimination. Their concern was that as they aged and if their health declined to the point that they needed home care, this buffer would be removed and they would be more open to discrimination. Pina explained:

I sometimes am sort of conscious that as long as I am at work, I have a sort of work-derived status and being lesbian is part of that. But give me 15 years and arthritis and low status – it will put me in a different context and that will all change very quickly.

Several participants had advocated for themselves or for others over the years. In some cases, participants worried that declining health would cause them to lose their ability to advocate for themselves or their partners. Enna, for example, talked about being "guarded" around her sexual identity at work. "If I shared that information and knew that they would try to accommodate it, then I would." Asked if she would disclose her sexual identity to a home care worker, she commented that "you have the sense that older people become kind of vulnerable anyway and so, would someone be respectful of trying to accommodate that?" The implication was that deterioration in health would leave her less able to counter possible discrimination in the future.

Julio referred to entering an LTC home as a transition where a diminished ability to advocate could have negative consequences for his partner and himself:

I hear these stories of gay couples who are forced to split up and live in different facilities and I think, oh yeah, we're gay and it would be really easy for people to do that to us. And if we're at the stage where we are moving into a facility, we may not be in a position that we are strong enough to fight back against it as much as we should.

Daina indicated that she and her partner would depend on one another to advocate for each other's needs. She commented, "I would hope just that we were not equally incapacitated at the same time and one of us was able to navigate on behalf of the one who needed the help or mediate or something."

Some participants felt that discrimination would be even more likely to be experienced in smaller or rural communities. This could be related to greater acceptance typical of, or to the greater likelihood of social support being available in, a more cosmopolitan centre. Carmela, for example, stated:

I live in [town] which has a population of about 35,000 people. I think Vancouver or Toronto, maybe even Ottawa to some extent, but I think perceptions where you've got a lot more diversity in communities and you've got, you know, support groups and activities, people are a little bit more aware ... There is very little diversity here. It is very white.

Here Carmela also expressed a concern over white privilege. Interestingly, the majority of our participants had not experienced overt discrimination directly. There were exceptions, such as Annette, who said that:

I lost my job and I think it was because I was pushing the envelope and being very openly lesbian. We had a crisis in [my partner's] health and I just realized I couldn't say "oh, my friend is having a crisis." I needed them to know that this was the woman I loved.

The concerns around covert discrimination were more often rooted in stories that had been heard, observations or anecdotal stories of the way others had been treated, and personal experiences in the past. As Pina stated, "In some respects we've been lucky, or are privileged in certain kinds of ways, where for the most part, the worst things to happen to us are silences and indirect dismissals. They're not 'kick your face in'."

Although participants may not have felt stigmatized at the moment, the anticipation of discrimination is a profound experience that shades one's expectations about care. Also, the thought of accessing health care services might have re-kindled memories from the past. As Kent explained:

It has always been okay in my life and my experiences in the last 30 years of having come out. But in the formative years, you know, as a child, ah, it's the worst thing one boy can call another, you know: faggot, cock-sucker, or so on. And I carry that fear with me still ... you know, the fear of being seen as a bad person.

Here Kent is noting that requiring care in older adulthood opens up revisiting being vulnerable again to discrimination based on stigma.

### *Identity*

Participants spoke about the importance of retaining a gay or lesbian identity if they accessed an LTC home or home care services. Three properties were associated



with this category: disclosing identity; identification as a partner in a coupled relationship; and importance of a reference group.

Most participants were clear about their need to retain their identity as a gay or lesbian person. As Annette said, "I feel like I'd be back in the closet if I didn't." Not all participants, however, would be comfortable disclosing their identity to health care providers. Daniella, for example, stated, "I would prefer to not have to mention it [identity] until I really have to. Again, it all depends on the situation and I would not tell any more [people] than I have to." This sentiment appeared to be related to the fear of discrimination, for Daniella later added:

Because I am a transit driver, I am dealing with many different types of people, whether it is kids or elderly people. I think I cross a lot of people and some of them are really prejudiced and they use a lot of name calling. Because of the nature of my job, this is really unavoidable.

Daniella's story does not clarify in what situation she would feel compelled to come out; and we question, for instance, how likely Daniella would be to come out in the event of a health crisis.

One factor related to participants' comfort level, especially with home care, was whether one or multiple care providers were entering their home. Kent stated:

I would be concerned also if it was going to be different people coming over. If it's one person, the same person, you know, I could see getting a comfortable relationship. I don't know – a bunch of different people, I think I'd have to go through an attitude adjustment.

This is possibly because, in Pina's words, she would have to "explain it over and over and over and over".

Participants emphasized their need to be identified as a partner in a coupled relationship. As Enna pointed out, "your relationship with your same-sex partner matters just as much as somebody's relationship with a, you know, other-sex partner." Participants recognized that some of the issues that they could face would be the same for other couples, such as "going into long-term care and leaving their partner behind or their partner needs to go into a facility but it's not at the same level." Although their needs might have been similar to those of straight couples, participants were worried that their needs might be less likely to be met because of their sexual orientation. Carmela, for example, was concerned about moving to an LTC home:

Let's say that we both had to go. Would we be living together? Could we hold hands? Could we put our arms around each other watching television when everybody else is straight? I mean, socially it

would be totally uncomfortable. What would it be like if my partner came to visit? How would we visit that would be acceptable to the rest of the facility?

Carmela's concern about discomfort at public displays of affection between her and her partner provides further evidence of how heterosexism can be enacted in microaggressive ways in long-term care.

Being in a lesbian or gay coupled relationship also meant that participants were concerned about the needs of their partner as well as their own needs. Asked, for example, what she would have to consider if she moved into a long-term care facility, Carmela commented:

I'd have to consider how my partner would be accepted when they came freely to visit for dinners, that she is involved just as somebody's husband or wife would be involved in any events that go on ... knowing that my partner will be the person that's called first, not my sister or my dad.

Participants also spoke about the importance of being around other gay or lesbian people if they entered an LTC home. Retaining contact with a reference group appeared to be a way of maintaining identity and feeling affiliated. As Enna stated, "if socially you were always put in with straight people who are doing straight activities and you can never sort of interact with your own social group, that would be difficult."

Having gay or lesbian people on staff would also contribute to this sense of inclusiveness. Annette noted that "they would have an understanding of what it's been like [living with prejudice] ... if not out-and-out homophobia." Annette recounted the story of a woman she knew who met a gay staff member in the facility where she was living "and it's the only place she has where she can express her lesbianism and get any kind of response that's meaningful to her. Anyone else, it's "okay, well sure."

### *Expenditure of Energy*

Participants reported having to expend a great deal of energy to ensure their well-being in care environments. Three properties were associated with this category: hiding identity; assessing their environments for discrimination, and placating or educating others. Participants actively looked out for cues signalling emotionally uncomfortable situations for which they tried to be prepared. This was expected to continue if home care and LTC home services were utilized.

Unlike other themes that emerged from interviews where participants spoke about their fears concerning discrimination or their level of comfort with identifying themselves as lesbian or gay, this theme refers to energies that were expended by participants in their efforts to protect themselves or their partners from

actual or perceived threats. Some participants spoke about hiding their identity when caregivers came to their home. Kent, for example, said:

I guess I would probably put some pictures away [slight laugh]. To de-gay the household a bit. I would be a little concerned that maybe the level of care wouldn't be as good [otherwise].

Kent's challenge to "de-gay" his environment to conceal his identity may be an example of "passing" as straight for service providers who are assumed to be heterosexual. Participants described continually assessing for discrimination. Enna, for example, observed that "you listen to people talk, you listen to the jokes they tell, you listen to the comments they make, and you pretty quickly learn to assess the risk." In some cases, the threat of being discriminated against was associated with the fact that participants were in a coupled relationship. Carmela, for example, was one of several participants who were "nervous" about being dismissed by health care providers or not being given information about her partner's medical condition because she was not in a heterosexual relationship. She said:

You never know how a doctor or the staff will react to two females coming in as opposed to a man and wife. So there's always a nervousness about it – that someone might say "you can't go because you're not, you know, a partner" or something like that.

Kent's comments about discrimination took a different form but one that was also related to his being in a coupled relationship because his worry concerned his partner as well as himself. As Kent put it, "I would feel I would sort of need to be on guard to make sure that every word that I say is, you know, not going to make them treat me or Jordan badly." Participants also spoke about having to expend energy in order to placate or educate others in order to gain a sense of acceptance. Daina explained:

You learn to bury your feelings and honour theirs in the hope that they'll meet you halfway. It becomes your job and yours alone to explain, to ignore, to forgive over and over again. Well, I mean that just sums up what it is like to be a gay person in a straight world, it seems to me. You're always the one who has to, you know, soften the corners, make things right. And it takes a great deal of work and a great deal of effort.

Referring to the possibility of moving someday to a gay-positive facility, Marcella explained that it would be an advantage because she wouldn't have "to do the educational awareness." She added "it's just a relief because you work your whole life ... you know, being an advocate or working in human rights and it's like,

I'm retired and I'm sick and I don't want to do it." Marcella's story does not tell us who she expects to take over this advocacy work. Carlos talked about educating a professional in a very different way, through role modelling what a loving relationship can look like between two gay partners. Carlos's partner was in the hospital when a nurse approached him and said:

"I'd like to thank you." And I said "what are you talking about?" And she said "thank you for teaching me about relationships." I was just flabbergasted by her kindness. We hadn't treated each other any differently than we would have if we were home but I guess that she had never seen a gay couple. That just blew me out of the water because it was hardly a place – when you are in a hospital, you are hardly a role model.

These findings speak to emotional work – hiding, assessing environments, and placating others – which these study participants felt they must undertake.

### *Nuanced Care*

Three properties were associated with this theme: feeling comfortable with health care providers; having providers feeling comfortable with participants; and duality of need. It was important for the study participants to feel comfortable with their health care providers. As Carmela remarked:

I would have to consider their awareness of a gay lifestyle. I think I'd have to consider their knowledge of my lifestyle which is different than theirs in some ways. I'd have to ensure that they were tolerant and that they were accepting.

This need for comfort went beyond having a health care provider who didn't convey prejudice. Participants were looking for health care providers who could respect their lifestyle and empathize with their concerns around receiving care from someone who was not lesbian or gay. At the same time, the desire was for the health care provider to act in a natural and sincere way and not to show acceptance in an overly solicitous or exaggerated manner. Pina, for example, referred to earlier years at work where she felt that her colleagues "wanted to be liberal but didn't get it ... they wanted to be kind but they didn't understand." Her concern was that this history might repeat itself if she or her partner accessed home care or entered an LTC home.

Participants felt that it would be essential that health care providers feel comfortable with them. Annette, for example, who had ongoing health issues and was currently using health care services, commented that "if it's someone who's going to be a long-term person, I just say that I want you to know that Alessia and I are lesbians ... my thing is, if you don't like it, don't come back."



Jordan pointed out that being in a dependent position with regards to receiving health care services can itself be uncomfortable. A health care provider's ability to "banter" in a gay-friendly manner could help offset the embarrassment that he might feel:

I hope they'd have the ability to banter. It's an embarrassing situation. It's being in a situation where you are a client and someone else is taking care of you is inherently embarrassing. So you've got to be able to joke about it.

The comfort that study participants wanted to feel was associated not just with the way that individual health care providers responded to them, but also with the attitude of the organization as a whole. Participants were looking for the organization to have a deeper appreciation and understanding of what it means to be gay or lesbian. Annette, for example, said that when her mother entered a nursing home, she told the administration that her mother was "gay positive and needs support for that". Their response "makes me cross: 'We've got a gay person on staff, we're fine with it.'... I mean, no questions about what would that look like: 'How could we be of any help?'" As Enna stated, acceptance on the part of the facility

has to come from the top down in any organization, where it has to be part of the philosophy ... There are things that you can do that can be written in a mission statement ... what they put up on the walls, pictures that don't just always give back visions of straight people all the time.

For many participants, there was a duality between wanting to be treated just like any other person receiving health care services, and at the same time, wanting to be recognized as a lesbian or gay person with needs that were unique. Carlos, for example, stated that he would like to be treated "the way professional staff would treat anybody. I wouldn't accept any special treatment, but I wouldn't accept substandard treatment because of my sexuality." Or, as Carmela stated, "I would expect nothing more than what they would provide to a non-lesbian person."

Pina's comments, on the other hand, pointed to "nuances" that may be attached to unique needs that lesbians receiving home care or long-term care services, may have. Asked whether she felt that a lesbian couple may have any long-term care needs that differ from a heterosexual couple, Pina replied:

In some ways I'm tempted to say that the answer is "no," that we don't need anything different. Except I think there is something wrong with a "no" because the context is different ... There might be nuances that need smoothing or that they need to work on.

The "nuances" that Pina referred to might not be linked so much to physical care as to the social or preservative (Bowers, 1988) care that would be provided. The study participants wanted the same standard of physical care, as well as the respect and dignity, given to any heterosexual person receiving health care services. What stood out as unique was that health care providers needed to be able either to understand, or be genuinely interested in learning about, the life situation that lesbian or gay people have experienced, in order for them to provide the type of preservative care that would be meaningful. Marcella's fear of being in an LTC home speaks to this need:

I don't know about outright discrimination which you could be scared of, but I think that it would be more that no one would really care about your life and your family. They would be so uncomfortable they would never talk about it ... That to me would cause stress and anxiety and worry and isolation.

## Discussion

Our study yielded several important findings related to the expectations concerning LTC homes and home care of lesbian and gay older couples in Canada. Participants clearly reported a great deal of uncertainty about availability of appropriate services. Despite being protected by Canadian legislation which also legalizes same-sex marriage (Elliot, 2005), couples expected covert discrimination which was of particular concern for couples living in smaller cities. Previous work has drawn attention to the role of "silence or not taking an affirmative stance" in covert discrimination (Croteau et al., 2004, p. 147). An example of covert homophobia is failure to recognize gay and lesbian employees in the workforce (Tully, 2000, p. 87). As Nadal (2013) suggested, in addition to lacking recognition, lesbians and gay men may be subject to non-verbal, non-intentional, but nonetheless powerful macroaggressions. In this article, we have extended this thinking in two ways: first, to older lesbian and gay couples, and second, to LTC home facilities and home care services.

These data provide some clues about how intersecting identities may lead to some of participants' perceptions of care. For instance, the confluence of sexual identity, gender, and race, along with ageism, are all important considerations that inform constructions of vulnerability associated with the sick role (Parsons, 1951); and these intersections may help account for the different care lesbian and gay older adults might experience.

Couples' stories suggested a complicated discourse involving visibility. Although it is important that gay and lesbian adults be recognized as service users,

disclosure of their sexual identity was felt by the study participants to be risky because of potential persecution and homophobia. Issues relating to concealing, managing, and disclosing sexual identity were of concern. For instance, some participants noted a fear of having to go back into the closet or having to come out over and over again. Potential undermining of same-sex relationships was also of concern. Recognition of partnerships in long-term care homes was uncertain as was availability of reference groups of other gay and lesbian people which were framed by some of these participants as needed to create a sense of community.

We argue that participants' various strategies to thrive in care involved expenditure of energy on activities such as hiding their identity (i.e., removing identifying photos in their homes before service providers arrived), continually assessing the terrain for risk, or placating others' heterosexism. These findings may reflect "emotion work" (Hochschild, 1983) and "identity work" (Rosenfeld, 1999) that older lesbians and gay men may need to perform in planning their futures.

We also note that older lesbian and gay persons in our study raised issues around using home care and LTC home services that were related to their being in a coupled relationship. Participants talked about depending on their partners to advocate for them, as well as their fear that declining health would result in their not being able to advocate for themselves or their partner. Participants spoke passionately, not just in terms of being recognized as lesbian or gay consumers of health care services, but in terms of being in a coupled relationship. Participants were concerned that their social needs might not be met, that their partners would not be consulted on medical decisions, or that their partners would not be given information about their health care needs because their same-sex relationships would be ignored or invalidated by health care providers. Participants were also concerned that their partners' social and emotional needs be met, as well as their own.

Many participants were asking for services that would be no different from those afforded to heterosexual couples. Pina's comment that "the context is different" for lesbian and gay couples, however, was striking in terms of whether lesbian and gay couples require unique care. The context Pina was likely referring to is a heterosexist society which is not as accepting of diversity and same-sex coupled relationships. Partners in heterosexual relationships might also find themselves advocating for one another (Schmidt, 2008), but not necessarily to the same extent or for the same reasons, such as fighting for the right to receive information about their partner. Heterosexual couples living together in LTC facilities might also experience intolerance as reflected, for example, in staff's attitudes towards

sexual behavior (Bonifazi, 2000; Bouman et al., 2007; Roach, 2004). But in the case of same-sex couples, as Carmela asked, "could we [even] hold hands?"

For older lesbian and gay persons, honoring their relationship with their same-sex partner could require them to reveal their sexual orientation to health care providers. In a very simplistic way, lesbian and gay persons have the option as to whether they want to do this. In reality, however, older lesbian and gay couples do not control the "field of choice" (Parenti, 1978) because unlike heterosexual couples, they are not being given a choice as to whether they want to be put into this position in the first place.

Much as we had observed, Brotman et al. (2003) similarly highlighted the fear and discomfort many older gay and lesbian individuals may experience discussing their sexuality with staff working in long-term care. Our research makes visible how couples, who by virtue of their partnership have "outed" themselves to care – or otherwise face possible separation – might think about long-term care and home care services.

In this original research, we interviewed the majority of participants in dyads about their expectations on planning to enter an LTC home or to use home care services. This reflects life course perspectives (Elder, 1994). For instance, the idea that older adults' lives are linked to social agents – partners, families, caregivers, friends, service providers (Hutchinson, 2005, p. 150) – is well represented in our study. Moving into an LTC home or requiring home care can represent a turning point, and this can impact the developmental trajectory of the couple (2005, pp. 144–145). Aspects of this process (i.e., entering into an LTC home) can have a similar impact on any couple, regardless of sexual orientation. However, the trajectory of lesbian and gay older couples might be uniquely affected because of discrimination and the need for expenditure of energy disproportionate to that undergone by heterosexual couples.

Given the histories shared by the study participants, it is also important to factor in embeddedness of gay and lesbian aging in historical time. Cohort membership is important, and sensitivity and awareness about the historical struggles of this population are needed to provide proper care for this population who may have experienced homosexuality as a discredited identity during their life course (Rosenfeld, 2003). Several participants noted that the thought of seeking and planning for care in the future brought back past memories of being vulnerable to discrimination rooted in stigma based on heterosexism and homophobia, which contribute to health and social burdens such as loneliness, abuse, and ageism (Adelman, 1990).

Given the social change that has occurred for lesbians and gays in Canada, this generation of lesbian and gay older couples will have paved the way for more inclusive LTC homes and home care in the future.

#### *Limitations and Future Directions*

This study does have several limitations. Our sample size is small, although it has been suggested that for such a marginalized group, the sample may be sufficient to draw out some key themes (Luborsky, 1994).

Although we interviewed couples, the study did not explore the degree to which being coupled serves as a protective buffer to withstand societal stigma. We also did not examine how solving social problems collaboratively within a partnership might benefit overall aging (Dixon, 2011). Most of the participants were interviewed in dyads; however, it is unknown what impact being part of a dyadic interview had on self-censuring or response agreement, between the partners.

As older lesbians and gay men may be more likely to age alone and experience social isolation (Fredriksen-Goldsen, 2011; Dorfman et al., 1995), future researchers will want to focus on differences between couples and individual experiences. In addition, perceptions of aging-related services for bisexual and transgender individuals and couples should also be considered.

Lesbian and gay identity is suggested to be “situationally contingent” (Rosenfeld, 2003, p. 76); however, this study did not factor in the partners’ health statuses to determine the likelihood that each couple might come to require entry into an LTC home and home care services in the near future. U.S. census data show that although some lesbian and gay couples raise children, the majority do not (Kurdek, 2005). Unique family dynamics for each partner and couple are relevant but did not emerge as key categories in this study. Age differences between partners should also be factored in, as well as the stability and nature of same-sex relationships in later life.

The role of discrimination and social stigma in LTC homes and home care should be further explored in future research, particularly in relation to past burdensome experiences this age group might have become accustomed to over time. Although the mean of age of these participants was 65, it will be important to seek out older adults (age 70 and older) from previous cohorts of lesbian and gay adults who perhaps could not come out. Also, because of the unavailability of programming aimed specifically at LGBTQ2 older adults at the time of the interviews, we were unable to discern whether these couples preferred to access gay-specific or mainstream services.

Although our study examined the expectations, concerns, and needs of aging lesbian and gay couples thinking about their future, future research needs to focus on the actual experiences of couples who are currently receiving home care services or are living in LTC facilities. A particular issue is whether lesbian or gay residents living in LTC facilities are subjected to homophobic attitudes on the part of other residents or their family members and, if so, how staff intervenes in these situations.

#### *Practice Implications*

Our study observed several implications for direct practice with lesbian and gay older couples. According to the study participants, nuanced care involves feeling comfortable with health care providers; having providers feeling comfortable with participants; and duality of need. Recognition and acknowledgment of same-sex relationships is a first step to challenging current heterosexist assumptions in LTC homes and affirming older gay and lesbian people in care. As articulated by some participants, non-heterosexist banter is welcomed, but this may require delicate attention. Participants also expressed a duality of need: lesbian and gay couples want to be treated just like any other person but at the same time, they want to be recognized as unique.

We argue that nuanced care desired by some of these participants fits well with Bowers’ (1988) model of preservative care, namely, maintaining the person’s family connections, dignity, hope, and sense of control. Connections can be assured by affirming that same-sex couples will remain together and intact; dignity, through providing affirmative space for queer people; hope, by publicizing these types of programs to people to alleviate concerns prior to accessing LTC homes and home care services; and a sense of control, by encouraging agency and choice in couples care. People who identify as bisexual, transgender, two-spirit, and intersexed likely also have particular needs that require nuanced care. Research should be conducted across these axes of sexual identity.

Participants’ stories reflected the idea that health care providers should assess their personal biases, attitudes, and beliefs about aging gay communities (Donahue & McDonald, 2005; Fredriksen-Goldsen, Hoy-Ellis, Goldsen, Emlet, & Hooyman, 2014; Kochman, 1997). Eliason (1993) suggested that there is a spectrum of acceptance of gay identity among service providers, which ranges from viewing homosexuality as unnatural/immoral/pathological/acceptable, if kept private/celebrated and valued. (1993, p. 14). We need to do more as service providers to encourage the affirming end of this spectrum.



Practitioners working within health care and social services need to re-evaluate intake assessment forms and practices that perpetuate heterosexist assumptions. In fact, by not asking about sexual and gender identity, providers inadvertently participate in a type of “erasure” of queer identity (Namaste, 2000). Desire to have lesbian and gay-identified service providers is common for lesbian and gay adults (Barnoff, Sinding, & Grassau, 2006; Cosby, 2008). Our finding that coming out repeatedly is stressful suggests that consistency of care providers may be particularly important for this population.

Traditionally, health care training does not address the concerns and holistic needs of older lesbian and gay populations and tends to focus primarily on issues associated with HIV/AIDS (Duncan et al., 2000). This lens needs to be expanded for clinician education on lesbian and gay aging. As our participants noted, this may need to start from the top down in service organizations.

Drawing on a comment from Julio’s interview, we ask: how can those in helping professions empower gay and lesbian seniors to be “strong enough to fight back” for social change? Recognizing that personal and individual factors – as well as structural forces such as racism, gender discrimination, and economic marginalization – may impact access to service for older lesbian and gay adults (Porter, Russell, & Sullivan, 2004), service providers can work with older lesbian and gay couples who may be planning for contingencies involved in their care. Specialized LGBTQ2 family counselling services are needed to help older lesbian and gay couples prepare for LTC homes and home care services.

Cultural competence in practice with older lesbian and gay adults has only recently been elucidated (Fredriksen-Goldsen et al., 2014). Interdisciplinary care teams may benefit from sensitivity training (Dickman-Portz et al., 2014; Knochel, Quam & Croghan, 2011). Additionally, intersectional thinking about available baskets of relevant services for aging and LGBTQ2 communities should be considered when working with this population (Hughes, Harold, & Boyer, 2011).

### Policy Implications

The participants in our study noted that organizational attitudes are just as important as those of individual service providers. We echo other authors who have observed a failure by health policymakers to recognize sexuality as a relevant issue within the health policy arena (Daley, 2005, p.45). Inherent in health care policy and practice remains a presumption of heterosexuality that is neither valid nor constructive to providing culturally appropriate services. More work is needed to

better understand the systematic social exclusion of lesbian and gay older adults in health care. Policy work is needed to bridge sectors of LGBTQ2 and aging-related services.

Several strategies have been deployed to increase the visibility of and accessibility for sexual minorities within the Canadian health care system. Examples include framing the battle for social inclusion as a rights-based challenge as outlined in the Canada Health Act; and the establishment of several health initiatives directed specifically towards sexual minorities. Both rights-based advocacy and community-focused programming have proven effective in reducing social exclusion of lesbians and gays (Smith, 2009).

In summary, we found that older lesbian and gay couples anticipating the need for LTC homes and home care services are concerned about future discrimination and complex challenges related to their sexual identity and couplehood. They expect to have to expend emotional energy while experiencing the need for nuanced care. We believe this study identifies the need to further examine how lesbian and gay older adults plan for and experience home care and LTC home environments, which factor greatly into health and well-being in later life.

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