# Coming Out to Care: Caregivers of Gay and Lesbian Seniors in Canada

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Purpose: This article reports on the findings of a study whose purpose was to explore the experiences of caregivers of gay and lesbian seniors living in the community and to identify issues that emerged from an exploration of access to and equity in health care services for these populations. Design and Methods: The study used a qualitative methodology based upon principles of grounded theory in which open-ended interviewswere undertaken with 17caregivers living in three different cities across Canada. Results: Findings indicated several critical themes, including the impact of felt and anticipated discrimination, complex processes of coming out, the role of caregivers, self-identification as a caregiver, and support. Implications: We consider several recommendations for change in light of emerging themes, including expanding the definition of caregivers to be more inclusive of gay and lesbian realities, developing specialized services, and advocating to eliminate discrimination faced by these populations.

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Discrimination faced by gay and lesbian seniors and their caregivers in the health care system has only recently begun to receive attention within the field of gerontology (Brotman, Ryan, & Cormier, 2003). In Canada, a growing interest in gay and lesbian aging has resulted in several community-led initiatives documenting older gay and lesbian realities and challenging health care practitioners to respond to homophobic and heterosexist discrimination and to adapt their services to these populations. Homophobia is the fear, hatred, or mistrust of gays and lesbians often expressed in overt displays of discrimination. Heterosexism is the privileging of heterosexuality over all other sexual orientations and identities; although it is often subtle and invisible, heterosexism effectively works to create obstacles to achieving full equality for gays and lesbians (Brotman, Ryan, & Meyer, 2006).

Two notable Canadian organizations run by gay and lesbian community groups are the 519 Community Centre in Toronto and The Centre in Vancouver, both of which have highly organized and advanced programs for gay and lesbian seniors and their caregivers. Yet despite their efforts, policies and practices addressing issues facing gay and lesbian seniors in Canada continue to be marginal, particularly within mainstream health and social service agencies.

Given this reality, it is no surprise to find that identification of and responsiveness to those providing informal, unpaid caregiver support to these seniors is even further removed from the health care agenda. Faced with many of the same emotional and physical strains that often accompany caring for any disabled senior regardless of sexual orientation, caregivers of lesbian and gay seniors in Canada also experience unique challenges to identify themselves and receive appropriate care in an environment often marked by intolerance and avoidance. As a result, caregivers may experience a sense of isolation and invisibility in their attempts both to provide care to their loved ones and to identify support for their own needs. Because of the added burden of exposure to discrimination, caregivers may experience the challenges of providing care in the context of reduced support, rejection by family and society, and invisibility. Individuals who provide informal care support to gay and lesbian seniors remain hidden from view. If health care providers are to develop best practices to address the unique realities of gay and lesbian seniors, then the experiences of informal, unpaid family and friend caregivers must also receive adequate attention. For these caregivers, the experience of "coming out to care" must be given voice.

This article highlights the experiences and perceptions of caregivers to gay and lesbian seniors that emerged from a study exploring health care access and equity issues facing gay and lesbian seniors in Canada. The study addressed the issues facing gay and lesbian seniors living in the community who experience a loss of autonomy from the perspectives of three distinct groups: (a) gay and lesbian seniors; (b) their informal, unpaid family and

friend caregivers; and (c) providers of community and home care health services. Using qualitative exploratory interviews with caregivers that were undertaken between 2002 and 2006, we explored some of the critical themes that emerged in the interviews, including self-identity as a caregiver, the impact on caregivers of real and anticipated discrimination faced by gay and lesbian seniors in the health care system, coming out and the role of caregivers, and the need for specialized caregiver support services. (The term **coming out** refers to the process of identifying oneself to others as gay or lesbian.) This article addresses the unique perspectives of caregivers themselves and is an initial attempt to articulate issues from the standpoint of this population. Further explorations of data emerging from the standpoints of seniors and service providers are currently underway, and we hope, as a research team, to follow up this analysis with future articles comparing and contrasting perspectives and experiences in and between cohorts of participants (Brotman et al., 2003; Brotman et al., 2006). Hence, this article will draw exclusively from the voices of caregiver participants in the larger study. Finally, we consider recommendations for change in light of emerging themes expressed by caregivers.

The literature focused on individuals (regardless of their sexual orientation) caring for gay and lesbian seniors is limited. Rather than consider the experience of caring for a gay or lesbian older adult, the literature tends to approach the issue from the perspective of gay and lesbian caregivers, many of whom, admittedly, care for their gay or lesbian partners, friends, or, more rarely, parents (Cantor, Brennan, & Shippy, 2004; Cantor, Shippy, & Brennan, 2002; Coon, 2004; Frederiksen, 1999; Hash, 2001; Hash & Cramer, 2003; Moore, 2002; Shippy, Brennan, & Cantor, 2003; Shippy, Cantor, & Brennan, 2004). The majority of the literature that describes caregiving to gay and lesbian people focuses specifically upon HIV/AIDS caregiving and centers around the physical, psychological, emotional, social, and financial strains involved with caregiving for a partner with HIV/AIDS (e.g., Irving & Bor, 1995; Wight, Aneshensel, & LeBlanc, 2003). Apart from those in Shippy, Brennan, and Cantor's seminal work on HIV caregiving experiences among lesbian and gay elders, the individuals receiving care in most of studies on HIV and caregiving represent largely a young adult population (generally younger than 50 years old), and thus their usefulness for understanding the experiences of those caring for gay and lesbian seniors is limited. We were also unable to uncover any published research focusing on the experiences of children caring for ailing gay or lesbian parents. As a result, we know very little about their unique care experiences.

Overall, research on caregiving to gay and lesbian seniors is just beginning to emerge in the United States and Canada. Although researchers have explored a variety of issues and factors, the literature has demonstrated that discrimination plays a key role in the capacity for seniors and their caregivers to access health care services (Brotman et al., 2003; Brotman et al., 2006; Cahill & South, 2002; Hunter, 2005; Johnson, Jackson, & Arnette, 2005). Both the anticipation of discrimination and actual experiences of discrimination in health care services contribute to great tension and represent a challenge to the possibility of coming out to health care providers in order to receive appropriate care. This represents a significant challenge to seniors and their spousal/ partner caregivers. Several key authors who have published in the area have stressed the importance of expanding beyond the focus on burden and strain in order to examine the unique and positive aspects of caregiving and post-caregiving for this population (Frederiksen, 1999; Hash, 2001; Hash & Cramer, 2003; Moore, 2002; Shippy et al., 2004). The available scholarship has also reported that there exists significant experiences of heterosexist and/or homophobic discrimination at individual, social, economic, policy, and institutional levels (Coon, 2004; Hash, 2001; Hash & Cramer, 2003; Hunter, 2005; Moore, 2002; Wenzel, 2002).

The few studies on gay and lesbian caregiving have pointed to common issues consistent with the general literature on caregiving, including managing caregiving responsibilities, experiencing emotional and physical strains, feeling tension in partner relationships, and experiencing conflicts with employment responsibilities (Hash, 2001; Hash & Cramer, 2003; Moore, 2002; Shippy et al., 2003). Many respondents also noted positive aspects of caregiving, including the fact that caregiving gave them the opportunity to show love and maintain a commitment to a significant other (Hash, 2001; Shippy et al., 2003). Research has also highlighted the challenges of navigating the disclosure or hiding of their same-sex relationship to family, friends, and coworkers during both the caregiving and postcaregiving periods (Cantor et al., 2002; Hash, 2001; Hash & Cramer, 2003; Moore, 2002).

In these studies, most caregivers dealt with family members, friends, and professionals who did not provide them with the support they needed (Cantor et al., 2002; Cantor et al., 2004; Coon, 2004; Hash, 2001; Hash & Cramer, 2003). Support or lack thereof (if for reasons of not accepting respondents' relationships) seemed to greatly affect the caregiving processes (Hash, 2001; Hash & Cramer, 2003). Supportive family, friends, and professionals often served as buffers to caregiver strain, yet this support was not generally anticipated and respondents seemed to expect insensitive and unsupportive individuals (Hash, 2001).

Shippy and colleagues' (2004) more recent findings differed somewhat in that their examination of gay male caregivers presented a picture wherein caregivers received significant support from biological family members. This challenged the myth of the isolated gay male senior. Shippy and colleagues found that caregivers had both friends and family with whom they were close. Respondents asserted that, when present, biological family members were accepting and maintained contact. Nevertheless, the majority of respondents stated that, when in need of help, they were most likely to call on their partners followed by their friends. Remarkably, however, one

third of the respondents expressed the need for more adequate emotional support, and most called for the gay and lesbian community to fill the important role of caring for their elders.

Other work by the latter researchers echoed the call for psychological and emotional support for elder caregivers within gay and lesbian communities (Cantor et al., 2004; Shippy et al., 2003). In their groundbreaking research on caregiving among middle-aged and older gay, lesbian, bisexual, and transgendered New Yorkers, Cantor and colleagues (2004) found that of 341 participants who answered a mail survey, 46% had provided care to a family-oforigin member or a family-of-choice member during the past 5 years. In all, 24% of those individuals reported having cared for a person not related by blood. More than half of those caring for family-ofchoice members were caring for a partner or a significant other. Apart from the expressed desire for more psychological support, one third of the respondents also highlighted the need for more organized social activities for older lesbians, gays, bisexuals, and transgendered people (Cantor et al., 2004).

Respondents in many studies reported the commonality of homophobia and heterosexism visible either in attitudes of staff or in policies and practices (Coon, 2004; Hash, 2001; Hash & Cramer, 2003; Moore, 2002). Some caregivers expressed anger and hurt at how they were repeatedly denied acknowl edgement as family within policies such as visiting hours or parking (Moore, 2002). Often professionals would look to biological family members to relay information or discuss issues that arose (Hash, 2001). Respondents generally expected to face insensitive individuals and did not anticipate support from others (Hash & Cramer, 2003; Moore, 2002). Caregivers were apprehensive about seeking support from health professionals and services (such as groups or home care services; Hash, 2001). In light of this, respondents recommended policy changes and improved training in health and human services organizations (Hash & Cramer, 2003).

Studies have found that the majority of caregivers were apprehensive about disclosing the status of their relationship to health care professionals and that they would use generalized language hoping that, if professionals caught on, they would be alright with it (Hash, 2001; Moore, 2002). Finally, participants expressed that coping can be severely hampered due to the fact that partnerships cannot be openly acknowledged, shared, or disclosed. For example, in one study, caregivers expressed negative experiences with prior support groups wherein they felt unsafe or uncomfortable disclosing their same-sex relationship. Many expressed that their survival up to that point had been largely based on concealing their relationships and/or sexual orientation, making communication of feelings and thoughts impossible in the context of support groups (Moore, 2002).

In conclusion, several themes exist in the small literature currently available on caregiving to gay and lesbian seniors. These themes include anticipated and experienced forms of heterosexist and homophobic discrimination in the delivery of health care resources to gay and lesbian seniors and their caregivers; the challenges of identifying oneself as gay or lesbian, or as the caregiver of a gay or lesbian senior, in the context of receiving health care services; the management of caregiving responsibilities; the experience of emotional and physical strains; and the positive aspects of caregiving, including those related to a demonstration of commitment and the impact of informal support on the well-being of seniors and their caregivers. Previous research has also concluded that professionals currently know little about caregivers to gay and lesbian seniors because of the paucity of studies that address their unique needs and realities. These conclusions point to the need for further research on these often invisible populations.

## Methods

The findings presented in this article emerged from a larger study that investigated many aspects of accessing health and social services for gay and lesbian seniors in three cities across Canada. We developed a 3-year participatory qualitative research program that used an adapted grounded theory methodology (Glaser & Strauss, 1967; Strauss & Corbin, 1998) to uncover the multiple experiences of care that were reflected in service access and delivery with gay and lesbian seniors and their caregivers. The focus on seniors, their caregivers, and health and social service providers facilitated understanding of the potential dilemmas, gaps, similarities, and differences between the experiences of seniors and their caregivers and the ways in which service providers understand and make sense of that experience.

We determined research processes in conjunction with our local and national partner organizations, including those representing gay and lesbian community organizations, health policy bodies, home care organizations and caregiver groups. We established an advisory group made up of 10 national partner organizations from the onset of the study in order to enhance the trustworthiness (Denzin & Lincoln, 1998; Lincoln & Guba, 1985) and authenticity of the research (Erlandson, Harris, Skipper, & Allen, 1993). Our partner organizations were specifically involved in participant identification and recruitment, development of interview guides, review of data analysis, and member checking themes and patterns that emerged. Several separate meetings of local team members provided the research team in local areas with opportunities to undertake more in-depth regional outreach and analysis and to plan knowledge transfer strategies. We designed this research process to be a change process, and we intended that the involvement of an advisory group would move investigators' and

participants' understandings toward change (educative and catalytic authenticity). This was generally thought to be achieved.

Issues of sampling are particularly relevant in studies addressing sexual orientation (Brotman et al., 2003). The history of silence around discussions about the needs and realities of gay and lesbian seniors on the part of health care and social service providers as well as the reticence of seniors and their caregivers to come out to providers may have made some people hesitant to participate and often made recruitment quite challenging. This is particularly true for the current cohort of gay and lesbian seniors, who have a unique historical experience regarding oppression that is different from the experience of middle-aged and younger gays and lesbians today. Many older gays and lesbians lived their youths and young adult lives in very hostile environments prior to the development of the gay liberation movement that began in the late 1960s in Canada and the United States (Brotman et al., 2003). We cannot understate that gay and lesbian elders who grew up prior to the era of gay liberation faced considerable obstacles to coming out. Many experienced overt discrimination in their private and public lives. This has resulted in the need to stay hidden and has remained a prominent coping mechanism in the lives of many older gay men and lesbians (Bonneau, 1998; Cook-Daniels, 1997; Harrison, 1996; Harrison & Silenzio, 1996; Kochman, 1997; Krauss Whitbourne, Jacobo, & Munoz-Ruiz, 1996; Rosenfeld, 1999; Saunders, Tupac, & MacCulloch, 1988). This is particularly relevant in the context of health care research initiatives, which may have historically centered around the development of "curative" strategies designed to "fix" gay and lesbian people of their same-sex attractions (Brotman, Ryan, Jalbert, & Rowe, 2002). As such, recruitment efforts in the current study emphasized the importance of addressing this information and stressing the confidentiality of interview processes in order to respond to potential participants' concerns.

As is common in qualitative research methods, we employed a snowball sampling technique as the primary method of finding participants for the study (Bogdan & Taylor, 1994; Bryman, 2001; Neuman, 1997; Pulice, 1994). Snowballing techniques can be effective when a sample of interest is difficult to identify (Grinnell, 1993). This is pertinent with respect to gay and lesbian populations who, because of past and current experiences of discrimination, have remained largely invisible in health and social service environments. Unfortunately, one of the weaknesses of this technique is the risk that the sample will result in a relatively homogenous group of participants (e.g., friends refer friends, clients come from the same agency, or key informants suggest similar people). This emerged in the current study, with many participants coming from referrals from a small number of agencies or from within the same community or circle of people. For example, our female participants were largely activist in orientation, having come from an experience of feminist community organizing. Also, our participant group was relatively young. Still, caregiver participants represented a wide range of people with different relationships to the senior they were caring for (partner, child, friend, other relative), living arrangements (with and away from the care receiver), gender, and sexual orientation, and with a variety of caregiving tasks and frequencies and durations of support (see Table 1). We placed special attention on establishing a climate of confidence to facilitate participant involvement. This included engaging in a prolonged manner both in the field (through partner agencies) and in the interview process itself (Lincoln & Guba, 1985, p.

Overall, recruitment proved to be very challenging throughout the research process, particularly in Halifax, where we succeeded in interviewing only 2 caregivers. In Montreal, we identified only 5 caregivers for participation in the study. This directly points to the level of invisibility of this population and the variation of support in different parts of Canada. In Vancouver, for example, where a unique organization directed toward the needs of

Table 1. Demographic and Relational Chart

Duration	1 year	6 months	k 8 years	24 years	4 months	N/A 6 years se	5 years k 10 years	k 10 years	k 12 years	5 years	3-week	¢ 4	2 years	13 years
Frequency	Daily	Daily	3-4 times/week	Daily	6-hour shifts around the clock	Daily Progressively more intense	to dally 1 time/week 1–2 times/week	1-2 times/week	2–3 times/week	Daily	Daily when	4–5 times/week Daily	Daily	Daily
Form of Caregiving	Hospital visits	Cooking, cleaning, medication, personal care	Functional support, instrumental tasks,	companionship Cooking, cleaning	Groceries, cooking, personal care, medication	Household tasks, cooking Personal care, shopping, cleaning	Grocery shopping Instrumental tasks,	Phone support, decisions,	occasional meal Household tasks, phone	support Household tasks, accompaniment to	medical appointments Cleaning, cooking, phone	Cleaning, groceries Accompaniment to medical appointments, personal care,	Accompanisment to medical appointments, instrumental tasks,	emotional support Decisions, accompaniment to medical appointments,
CG's Relationship Status	Single	Single, widow	Divorced	With partner	Single	With partner Single	Divorced With partner	With partner	With partner	With partner	Divorced	Married Divorced, with partner	With partner	With partner
CR's Health Status	Recovering from	Unclear	Confused, colitis, arthritis, glaucoma,	intestinal problems Disabled in a wheelchair; multiple sclerosis	Cancer	Unclear Cancer, then died	Cancer, then died Unclear	Unclear	Unclear	Unclear	Unclear	Unclear In a wheelchair	Brain hemorrhage, aphasia, then slow recovery	Breast cancer
CR	Gay father	Partner	Gay male tenant	Partner	Lesbian friend	Partner Gay father	Gay father Gay friend	Gay friend	Gay friend	Partner	Lesbian sister	Lesbian mother Partner	Partner	Partner
Relationship to CR	Child	Partner	Neighbor	Partner	Friend	Partner Child	Child Friend	Friend	Friend	Partner	Sister	Child Partner	Partner	Partner
Sexual Orientation	Gay	Gay	Heterosexual Neighbor	Gay	lesbian	Lesbian Heterosexual	Heterosexual Gay	Gay	Gay	Lesbian	Heterosexual	Heterosexual Lesbian	Lesbian	Lesbian
Age	33	+09	61	52	79	62 46	47	58	42	61	57	37	09	72
Gender	M	M	ΙΉ	M	Ţ,	H X	Ħ M	M	M	ΙΉ	ΙΤ	ᅜᄺ	Ħ	ഥ
Interview	Montreal 1	Montreal 2	Montreal 3	Montreal 4	Montreal 5	Vancouver 1 Vancouver 2	Vancouver 3 Vancouver 4	Vancouver 5	Vancouver 6	Vancouver 7	Vancouver 8	Vancouver 9 Vancouver 10	Halifax 1	Halifax 2

Note: CR = care recipient; CG = caregiver.

community-residing gay and lesbian seniors exists, recruitment of both seniors and their caregivers was far more successful. The concern of having to identify as a gay man or lesbian (in the case of spouses and partners) or as a child of a gay or lesbian senior (in the case of adult children) in order to participate in the study may have also contributed to difficulty in recruitment. Still, we must consider the possibility that gay and lesbian seniors in these locations have fewer avenues of informal support or that there exists a lack of identification on the part of those who provide support to gay and lesbian seniors with the term Caregiver. Our team theorized that those caregivers who form part of a friendship or fictive kin network with gay and lesbian seniors may not identify themselves as caregivers, particularly given the narrow definitions used in mainstream service agencies that focus primarily on advancing a caregiver agenda for heterosexual spouses or adult children. This may be a subject for future research initiatives.

Interviews lasted approximately 1.5 to 2 hr and were audiotaped and transcribed. We developed the interview protocol in a two-stage process in conjunction with the research advisory group. First we developed interview guides and tested them with a small number of caregiver participants. The interview protocol was semistructured, with open-ended questions in several theme areas that provided participants with the opportunity to discuss issues important to them. The interview was based upon four broad theme areas: (a) description of the caregiver role and relationship, (b) experiences of access to health care on the part of gay and lesbian seniors and the impact of these experiences on the caregiver role and relationship, (c) caregiver needs and issues, and (d) areas for future change. Included in the first theme discussion was a question designed to allow participants to explore their identity as a caregiver, whether they defined themselves as such, and their feelings regarding caregiving. Section 2 of the interview focused more specifically upon experiences of caring for a gay or lesbian senior in the context of access to and equity in health service delivery (i.e., caregivers' perceptions of the kind and quality of care the gay or lesbian senior received and what this meant for their caregiving role and responsibilities). Section 3 focused upon participants' own health care and service needs with respect to their caregiving role. Finally, Section 4 asked participants to talk about what services were needed, with respect to both the gay or lesbian senior as well as caregivers. Participants had the option of having a copy of the interview guide during the discussion. In addition, participants received a 1-page sheet on which the major themes were highlighted in order to provide them with an idea of where the interview was heading. All participants signed a consent form and were assured of confidentiality in conformity with ethical procedures of research. Interviews were undertaken by the same interviewer in two of the three regions, allowing for interviewers to learn from their experience and transfer knowledge from one interview to the next over the entire period of the study. This supported integrity in the research process. The guide itself was meant to be open, allowing participants to focus on specific areas that they found meaningful while ensuring that they covered the major themes. Although some change in interviewers occurred in one region over the 3-year period, all interviewers were trained and were provided with support, feedback, and ongoing training to ensure consistency in the interview process across all regions.

We undertook analysis using the grounded theory method outlined by Glaser and Strauss (1967) and Strauss and Corbin (1998). Grounded theory is a popular research methodology developed as a model for theory generating research. The goal of the analysis is to identify themes and the relationships between these themes (patterns). The researchers worked closely with the advisory group at this stage to ensure the credibility of the analysis and the applicability of the emerging concepts to practice (Lincoln & Guba, 1985). Various members of the investigative team simultaneously undertook content analysis of transcripts (Gilgun, 1994) using the constant comparative method (Strauss & Corbin, 1998). Members met regularly to compare and contrast their analytic themes. Blind review of coding occurred with a select sample of transcripts to ensure consistency in analysis and coding. We conducted qualitative analysis of data on an ongoing basis as the research proceeded, alongside data collection. In fact, analysis informed data collection in an iterative process. In the first pass, we analyzed the transcribed interviews in order to come up with working concepts and hypotheses that informed future phases of the work. At this stage, broad concepts such as what the caregivers said about their experiences, the experience of interventions by health and social service providers, and caregivers' needs and perspectives with respect to service intervention formed the basis of the analysis. Several interviews were completed and themes analyzed in order to determine the characteristics of further cohorts or themes we wanted to address in subsequent interviews. Therefore, interviews occurred throughout the 3 years in stages that sought to enhance the analytic depth of, and the comparison in and between, cases. The use of N6, a qualitative data software program, facilitated both data coding and analysis.

Finally, in order to ensure that the research process and the findings were authentic with respect to the voices and meanings of participants themselves (Lincoln & Guba, 1985), we employed techniques such as member checking (going back to participants and other key informants to check that our analysis made sense to them and reflected their original intent), referential adequacy (referring back to the literature and to experts in the field to ensure the analysis was consistent with both interview transcripts and previous research), and prolonged engagement (staying in the field and continuing to interview for a prolonged period of time to ensure both adequate context and content for analytic purposes).

### Results

# Description of Participants

A total of 17 caregivers participated in the current study. These included 5 from Montreal, 2 from Halifax, and 10 from Vancouver. Participants in the study included 4 adult children (3 of whom identified as heterosexual and 1 as gay), 7 partners (5 lesbian, 2 gay), 4 friends (3 gay, 1 lesbian); and 1 sister and 1 neighbor (both heterosexual). The gender breakdown of the participants fit the expected finding of more women caregivers (10) than men (7). The age of the caregivers ranged from 33 years to 68 years, with an average age of 63 years for the partners and 41 years for the adult children.

The caregivers in the study reported a range of durations in the caregiving role. Some had only been caregiving for less than a year, whereas others had been caregiving for up to 20 years. Five of the caregivers had provided caregiving support for other family members and friends prior to the relationship in question. The frequency of contact varied from 24 hours a day to 2 points of contact (calls, visits) per week (see Table 1).

# Self-Identification as a Caregiver

Research in the general caregiving literature (reflecting the heterosexual caregiving relationship) suggests that those family members who provide unpaid instrumental, physical, financial, and emotional support to older family members do not often identify themselves as caregivers. This is particularly true of spouses who see caregiving as a natural extension of their spousal role, something done out of love or obligation or as a result of a reciprocal relationship with the care receiver. Caregivers in the current study identified with this reality, providing clear indications that caregivers of gay and lesbian seniors have the same sense of motivation and identity (self-identification as a caregiver) as caregivers of heterosexual seniors. The following quote exemplifies this:

I'm not really a caregiver, it's a relationship based upon love. I love my partner, I was always with him, we will always be together.... It has been 30 years that we are together, so I take care of him. ... (Partner, gay)

One aspect of caring for a gay or lesbian senior may include the notion of community identity and commitment as a motivating factor for providing care. This positive aspect of caregiving emerged in two of our interviews with caregivers in specific reference to lesbian communities where a value of solidarity stemming from previous involvement in feminist organizing may have contributed to other forms of caregiver identity for these participants. This pointed to a unique strength of the gay and lesbian community that could potentially influence the caregiving experience. One lesbian partner caregiver reflected on how her friends in the lesbian community might perceive themselves: "Not as ... caregivers, but there would be rallying within the community to say we need to put support around

[her]."This notion of community challenged the idea

that older gay men and lesbians were, because of their sexual orientation, more isolated than their heterosexual counterparts. In fact, some research has suggested that older gay men and lesbians successfully engage in friendships and experience a wide sense of community throughout their lives that follows them into their senior years (Shippy et al., 2004; Thompson & Richardson, 2002).

What was made evident in the current study was that, for gay and lesbian seniors, the opposite was equally true. Although some seniors had large support systems, there were also those who lived in relative isolation, such as this care receiver before the lesbian caregiver network mobilized around her:

... we found out that she was very ill and had a terminal cancer.... I was working at the bookstore ... and she used [to] often visit. ... And then we realized we weren't seeing her anymore, and we asked around and we heard she was ill.... Then someone I met by accident said to me, "She's always in her apartment.... She's very ill and ... there's really no one looking after her."... She wasn't eating, you know, she was too weak to eat ... and really take care of herself. (Friend, lesbian)

Mediating this reality was a sense of connection to a wider community exhibited prior to getting older that facilitated the coming out process, as well as limited experiences of discrimination faced over time that may have reduced the fear of connecting to others:

In her last round of cancer ... there were a number within the lesbian community who in different ways put support around her. ... There were lots of things that came to the door.... The lesbian community, her friends, made ... lots of attempts to carry her through that time.... She would name it as being held in a womb.... The women's community, in that way, uh, was very supportive for her. (Partner, lesbian)

Finally, the existence of ageism in the gay and lesbian community may have diminished the sense of community felt in younger years leading to potential areas of vulnerability as people aged:

I think that, the biggest worry was getting older ... because like he says, when you're young, you swing, you have friends ... but when you start to lose your hair, then you're less sexy and you are alone. (Female neighbor, heterosexual)

Overall, few caregivers identified outwardly with the term Caregiver. Although the reasons vary, expanding definitions of Caregiver to include experiences of those caring for gay and lesbian seniors have the potential to challenge more narrow definitions legitimated only through biological connection or heterosexual marriage currently held paramount in the field of gerontology.

## Discrimination

Previous research in Canada and the United States has identified the discrimination faced by gay and lesbian seniors in accessing health care and social services (Brotman et al., 2003; Kimmel, Rose, & David, 2006). The current cohort of gay and lesbian seniors articulated this discrimination in two distinct ways. First was the actual discrimination that these populations encountered in the health care system. Second was the anticipation of discrimination experienced by seniors prior to accessing health services that mediated their willingness to come out to health care providers or to access services altogether (Brotman et al., 2006). This anticipated discrimination was largely based upon previous negative encounters in the health care system as experienced by gay and lesbian seniors in their younger years, but also included such realities as hearing stories of discrimination from others or experiencing discrimination in other contexts (such as family, school, or workplace settings) that might have caused a person to develop a generalized expectation of discrimination.

Caregivers in the current study affirmed both of these realities. For a majority of caregivers interviewed, both experienced and anticipated discrimination played an important mediating role in the willingness to access resources

Speaking of the general distrust of health and social services as a major factor in a care receiver's reluctance to use services, these caregivers explained

I am certain [that being gay or lesbian affects the quality of service one receives].... It's for sure that he won't have confidence in the health care provider. ... He is afraid of everything. (Female neighbor, heterosexual)

My dad's generation was more conservative, more guarded... So they are [more] reluctant to accept help.... My dad wouldn't want to be stigmatized as a gay. (Son, heterosexual)

Almost all of the respondents cited at least one discriminatory incident with a health or social ser vice professional. For example, when asked whether he thought the needs of gay and lesbian seniors were understood by health and social service providers, a gay son caregiver to his gay father remarked, "They told me that it would be better to hide this aspect... the identity of my father.' Problems related to current experiences of discrimination (whether overt or covert) seemed particularly acute in relation to workers coming into care receivers' homes:

I do know people in home care services who, if they know a person is lesbian or gay, will refuse and say, "You must send someone else because I'm not comfortable with that situation."... But they could also not treat you very well because they have to do the job ... especially when it was to do with personal care, so yeah ... I think it's a concern not just to [my partner] but to me and others, too. (Partner, lesbian)

Many caregivers expressed that discrimination was often covert or subtle, thereby making it difficult to identify, address, or respond to. This factor highlights the difficulty in distinguishing between subjective feelings or expectations of discrimination and actual acts of discrimination. For example, the following two quotes highlight the subjective feelings these caregivers had regarding health care providers' treatment in the form of "inferences" and "negative energy":

It's a bit of a grey area, it's hard unless somebody says something.... [The care receiver] was aware of her inferences ... and he felt uncomfortable having her around. (Friend, gay) [Sighs] Yeah, [we experienced homophobia] just in terms of energy around us.... Sometimes we'd laugh about it and sometimes we would get irritated. I do think we had one experience of a nurse being more grumpy or sharp or impatient ... her responses were just more sharp. And I think it had something to do with her being homophobic. (Partner, lesbian)

These subjective feelings and anticipated forms of discrimination played an important role in the ways in which caregivers responded to and experienced their caregiver role. For example, more than half of the caregivers spoke of the worry they had in leaving the care receiver unattended during interactions with health care professionals for fear of rendering the care receiver more vulnerable. One lesbian partner caregiver stated, "She's going to have continued care from this person on the night shift.... She is more vulnerable. ... I wouldn't want to—to leave her there on her "The fear of facing discrimination when accessing health services rendered the caregiving experience more complex. Of particular importance was the requirement of caregivers to mediate the coming out process, both with respect to care receivers, and in many cases, themselves. Partners discussed their concerns regarding respecting the care receivers desire to keep their sexual orientation private in the

context of interactions with the health care system, thereby rendering the relationship between the care receiver and the caregiver invisible. Previous research has identified the common occurrence of older gay and lesbian couples identifying themselves as "friends" or "roommates" as a coping mechanism related to their generational experience of privacy and to mediate negative treatment by others (Brotman et al., 2003). This may make it increasingly difficult for caregiving partners to show affection, provide care when others were present, or gain recognition as the care receiver's spouse. For example, one caregiving male partner described having to carry his ailing partner into the bathroom so as to give him a hug away from the eyes of others. Efforts to advocate on behalf of the care receiver were also more difficult as, by doing so, one risked outing the care receiver. Adult children addressed the difficulty in advocating for appropriate care for their parent in the context of attempting to keep the sexual identity of their parent private. As a result of discrimination experienced, adult child caregivers may have chosen not to discuss the sexual orientation of their parents with others:

I think that's probably why my sister and I didn't openly talk about it to certain people. Because I think they judged a lot more what's going on in the bedroom, and I don't think that was really important for my dad. When you talk to people, when you tell them he's gay ... they want to know more details and that sort of thing ... what goes on. They wouldn't ask the same sort of questions of a straight couple. And [my dad would get] frustrated with it. So I just don't bring it up unless it's close friends or something... We just have a dad who just happened to be gay, that's all. (Son, heterosexual)

Needless to say, negative experiences of discrimination resulted in reduced trust in health and social service systems and the practitioners who work within them:

... being in the hospital, in terms of access for my partner, all those questions are there.... How will the medical staff respond to us? Who's going to withdraw good care, or shift care if they have homophobic [attitudes] or have a sense that they're uncomfortable in the room? (Partner, lesbian)

Being vocal enabled both care receivers and caregivers to advocate for better service. Five caregivers gave testimony as to how the care receivers openly voiced their concerns and demanded professional, respectful care with both medical professionals and/or home care staff. When questioned whether he felt that sexual orientation affected the quality of health care and social services that the care receiver would receive, one gay friend caregiver responded

I think, you know, fortunately he's able to voice his concerns and express ... what he wants ... whereas there are people that, I'm sure, aren't able to, or are intimidated and they would just accept the status quo and ... not even necessarily [as good as] the status quo ... (Friend, gay)

In addition, caregivers also expressed that being out and having higher self-esteem made advocating for services easier:

I think the difference [is that] now ... we have more of an expectation that people will be more tolerant or more open than they were [back] then.... And we are also in a different place because we're more comfortable, and ... we can initiate something in terms of making change ... (Partner, lesbian)

I think that she [homemaker] was [religious] and she just says it's wrong, and she didn't want to acknowledge the relationship.... And, I don't think she was there very long, 'cause I think he just contacted the agency [and told them] that she's not welcomed back at the house anymore. (Friend, gay)

Finally, having the support of others who could help to navigate the system and identify supportive allies was an essential coping mechanism for mediating negative encounters among caregivers. For example, one caregiver to her lesbian partner found it helpful to have her son help them navigate the health system:

My son would know who was open to gays and lesbians in their [medical] practices, and who would not be ... or he might have more of a sense [of how] to navigate through. (Partner, lesbian)

Adult children providing care to gay and lesbian parents may have found themselves in a unique place with respect to the coming out process. Two children expressed that their parents being out may have led to assumptions about their own sexual orientation, thus exposing them to experiences of discrimination by association despite their own heterosexual orientation. One caregiver stated:

"What [does it mean] if someone's parent is gay?"... They would probably ask that. And then they probably question, "What is your own sexuality?"... which is a common question you hear. And it's kind of frustrating after you tell it about 20 times and it goes on and on.... It's my dad, my dad's partner, it's [not me]. (Son, heterosexual)

This highlights the reality that caregivers who are put in a position of having to advocate for their loved one may find themselves exposed to discrimination.

# Support

Support can have an important mediating effect on the negative experiences of caregivers. Although approximately one fourth of the caregivers interviewed reported having satisfactory to significant family support, they also pointed to the importance of "chosen family" (friends and community members who are present to provide support and love in the absence of biological family).

Overall, interviews revealed that when people had come out to their families, under the condition that they were accepted once out, more potential existed for a wider breadth of support. Alternatively, when care receivers and caregivers were not well received by family and did not have other avenues of support, they may have had to rely on family members who may not have had the sensitivity, level of acceptance, or courage to advocate adequately for them. In this context, support from family members may have been more complex and/or stressful. One caregiver described how she and her partner dealt with their families:

... some of them are still learning what to do with her sister being in a lesbian relationship. And some of them did try to find ways to make connection, and [for] others it was just silence. [I helped] her to think through how she might want to talk to her family and identify what she needs from them and doesn't need from them. (Partner, lesbian)

Another caregiver expressed the difficulty gay and lesbian seniors faced when isolated from family. A lesbian friend caregiver discusses her friend's situation as follows: "The family rejection ... and not being able to have access to her child [was very difficult for her]. When care receivers were connected to a gay or lesbian community, the support gap may have been filled by chosen family or community members. One lesbian friend caregiver explained, "... and she was very happy, you know, to see all these lesbians who were around, and I think that's very important ... because we were her family, you know. This broadened sense of community as family is not always understood by mainstream health care providers who continue to view caregivers as biological family members. Anyone outside of this model is subject to misunderstanding, as one lesbian friend caregiver stated: "And it was funny ... the nurses asked her from what sect we were. They thought we were a religious sect, you know [laughs]... Needless to say, regardless of whether it is through social involvement or through community groups, the more connection a care receiver or caregiver has with his or her community or with gay or lesbian friends, the more potential exists for a wider network of support; consequently, the more potential exists for diffusion of caregiver responsibility and mobilization of caregiver support. Individuals who are isolated will be more vulnerable and thus deserve the particular attention of service providers and systems.

The issue of finding supportive environments for caregiving children may have been more complex, however, as participants' friendship and family circles did not necessarily contain individuals who were gay friendly and, thus, these caregivers may have felt isolated in their role. Those who have managed to identify support for themselves did so through a pathway familiar to gay and lesbian people. Four caregivers interviewed expressed that they themselves received support from other members of their family network (including children, siblings, and nieces or nephews) as well as from within their friendship circle. This reality confirms that caregivers can also experience feelings of support from a broader network, just as gay and lesbian seniors do. Generally, they locate those members of their community, family, or friendship network who are supportive of gay and lesbian people and who have some knowledge of the community. In fact, 3 of the 4 caregivers of gay and lesbian seniors who themselves identified as heterosexual expressed the importance of selecting friends who were supportive of gay and lesbian people. An adult heterosexual son caregiver explained the source of most of his support: "Probably my friends, you know. I have a good, close network of friends, and they know that my dad is gay."

## Services

Given the important role that caregivers of gay and lesbian seniors play, it would seem essential for there to be some supportive services made available to them. Unfortunately, caregivers expressed a lack of awareness within mainstream service settings regarding their needs or realities. One caregiver stated:

I guess there's not many organizations that you can go to as a caregiver and say, you know, "Can you help me out? You know, I'm stressed out," and stuff like that. I would never do that. I would probably go to my friends. ... I don't know if there's any support group for ... sons and daughters looking after their [gay] parents. (Daughter, heterosexual)

Several caregivers also stated that, although they could identify a caregiver support group in their geographic area, they were reluctant to join because of fears of being ostracized, discriminated against, or isolated within the heterosexist

environment. Indeed, previous research has indicated that many caregiver support groups are implicitly limited to a heterosexist framework (Moore, 2002). The following adult child caregiver reinforced this point:

... of course, [it] would be great to have ... a support group. [You] can go and talk about the caregiving needs of your dad or his partner and not be given the same sort of stigmatism.... If I went to a support group, it would probably be more of a straight group ... and they would get into issues about your dad being gay and [ignore] his care needs. I find that frustrating. I probably wouldn't go back. (Son, heterosexual)

The following caregiver drew the connection between her partner needing a support group specifically for lesbians and the fact that she herself might also benefit from a similar group for caregivers:

... I know that [my partner] has attempted, even through the health care system, to find a support group where she could talk about what it's like to be a lesbian [with an illness]. And for her it carries some differences.... There isn't a place where she can talk about what it means, as a partner to a woman and in her own sense of herself as lesbian.... Perhaps that would have been helpful for me, too, because [lesbian] partners carry [the] journey differently. (Partner, lesbian)

#### Discussion

In the current study, caregivers shared their experiences of caring for a gay or lesbian senior from a variety of perspectives and positions. Participants addressed discrimination in care, both from the perspective of what the care receiver experienced as well as in the context of caregiver support. For the most part, caregivers expressed that both actual discrimination and the fear of being discriminated against (what we have described as the anticipation of discrimination) have an impact upon how seniors use services and how caregivers interact with services in order to protect care receivers from potential harm. Anticipation of discrimination can be based upon many experiences (e.g., those of seniors and their caregivers in previous encounters or in their younger lives, or those they have heard from others). In addition, although experiences of hostility were more common in historical accounts, there continues to be discrimination, albeit often more subtle, in the form of negative attitudes, comments, or, as one caregiver put it, "energy"that surrounded their treatment. In the end, when care receivers are reluctant to access health and social services because of real or anticipated discrimination, the consequences for caregivers are numerous. First, if care receivers are alienated from services, then it is reasonable to assume that caregivers might also refrain from making the most of services available in an effort to protect and/or respect the wishes of their loved ones, or to avoid discrimination themselves. Second, the less care receivers make use of health and social services, the more is demanded of their caregivers. In essence, caregivers of gay and lesbian seniors may provide care for individuals who might otherwise receive care through the longterm-care or home care network. There are several aspects to specialized services that could be considered. These include such issues as the development of mandatory training sessions on the needs, realities, and issues facing gay and lesbian seniors and their caregivers; the hiring of gay and lesbian health care workers; specialized support groups or telephone support lines for caregivers caring for gay and lesbian seniors; and community outreach programs designed to invite gay and lesbian community health professionals onto boards and committees within mainstream agencies.

In order for experts to address the important concerns revealed by this study, caregiver participants made several recommendations for current health and social service agencies and providers in the senior services sector. There was an expressed need for specialized senior services, including those found in the voluntary, home care, and residential sectors. Whether these are identified and created within existing publicly funded services or developed through the voluntary or private sector remains an important question for consideration, particularly with respect to access and equity. Several caregivers pointed to the debates within the gay and lesbian communities as to whether it is possible to advocate for the creation of specialized services through the public sector. As one caregiver stated in reflecting on retirement and nursing homes

With gay couples going into retirement more and more, I would hope someone would open up a gay seniors home one day.... And then the [question of] public versus private ... in the public system, which is funded by government dollars, [you] probably couldn't impose ... but private health care, because it's private, they might be able to open a gay home.... (Friend, gay)

The issue of financing is paramount in order to ensure the development and delivery of services and equitable access. It is essential that gay and lesbian community organizations, as advocates for the eradication of homophobia and heterosexism, be financially supported to develop expertise to address the needs of gay and lesbian seniors and their caregivers as the most appropriate place to begin change-making efforts. Findings also point to the need for the development of services, including support groups, targeted for caregivers. Five caregiver respondents either anticipated or had experienced support groups operating within heterosexist frameworks, and this served as enough deterrent for them not to access those support services that may have been available.

All of the caregivers highlighted education and training of health and social service professionals in hopes that these practitioners could learn acceptance, address heterosexist assumptions, and confront homophobia. Also, individuals who work with seniors in the health and social service sector would benefit from learning to identify the more subtle clues behind individuals' reluctance to access services so that they may proactively address potential problems, concerns, or needs.

Caregivers who felt comfortable advocating for care receiver rights to full and equal access to services tended to have a sense of entitlement to and assurance of their own rights as well as a comfort with being out as gay or lesbian themselves, as was the case with partners and/or friends providing care. The implications of this finding for health and social service professionals entail working toward empowering seniors and their caregivers as well as developing explicitly gay- and lesbian-friendly services or safe spaces for those caregivers and care receivers who might still be "in the closet." This includes but is not limited to such issues as training employees at all levels so that they provide a warm and welcoming environment; using gender-neutral language in discussions about relationships, life history, and identity; providing opportunities to celebrate all forms of diversity; ensuring confidentiality in communication; supporting the wishes seniors have regarding care planning and making sure that they are understood and respected; and engaging in dialogue with gay and lesbian community organizations to enhance integration and knowledge transfer.

Findings indicate that, overall, support tends to mediate negative experiences, especially when it comes in the form of advocacy around potentially discriminatory behaviors or policies. The gay and lesbian caregivers in this study were mostly out to their families, and this seemed to be an important factor in garnering more support for the care receiver. When care receivers are less out in their gay or lesbian communities or are isolated from the potential of community, they may have to rely on inadequate family support or force more responsibility onto the relatively isolated shoulders of the caregiver. Here it is also important to address situations in which adult children (or other biological family members) are in conflict with a gay or lesbian partner in the care of an older adult. In some cases, the partner may be unlikely to have legal rights, and a biological family member who is not comfortable with a relative's sexual orientation might command power that alienates the partner. Although this reality has changed in Canada, where the legal recognition of same-sex partnerships has given legal rights to partners, these partners might not always be vocal, identify as a conjugal partner in the public realm, or be prepared to advocate for himself or herself in the context of a disagreement between the partner and the biological family. Family structures and relationships are complicated, and there may be some instances when heterosexual family members either get involved even though they are not entirely comfortable with the care receiver's sexual orientation or exclude a supportive partner or ally from decision-making capacity. The implication for health and social service professionals again involves sensitivity to the needs of caregivers and care receivers as well as to the potential reasons for conflict in families regarding care and decision making. This puts the responsibility on health care providers to engage in family conflict resolution or to advocate for the same-sex partner in cases in which the older person cannot speak on his or her own behalf. It also points to the necessity of educating older gay and lesbian people about the need to create living wills and/or mandates to ensure that their care desires and needs are understood, to provide care givers with adequate documentation as to their role, and to provide further assurances that these will be respected in emergency situations.

Finally, specific attention is warranted to the unique issues and realities facing heterosexual caregivers, particularly children, caring for gay and lesbian seniors. This population has not received much attention from researchers or practitioners to date. The current study points to shared concerns with other caregivers of gay and lesbian seniors, most notably regarding the role they play in mediating discrimination, advocating for appropriate services, and providing hands-on care. However, adult children who are heterosexual may also be exposed to homophobic and heterosexist discrimination as a result of their roles as caregivers; these are forms of discrimination that they may be ill equipped to face. For example, they likely have not experienced these forms of discrimination first hand. In addition, compared to gay and lesbian partner or friend caregivers, heterosexual caregivers may have fewer contacts with individuals or communities who can provide a supportive environment in dealing with this new and difficult experience. Only one of the heterosexual caregivers in the current study made mention of having supportive relationships within the gay community. Two other heterosexual care givers spoke of having close friends who knew of the sexual orientation of the care receiver. Helping build connections to people who can help heterosexual caregivers deal with and respond to discrimination would surely reduce stress and provide opportunities to learn how to address both the experience, and anticipation, of discrimination. Although caregiver support services and voluntary caregiver organizations must be made more welcoming for caregivers of gay and lesbian seniors as a whole, it may be best to offer adult children a space to discuss their unique experiences and to connect with one another.

The results of this study clearly indicate that although experiences of caregivers to gay and lesbian seniors often echo those of caregivers to heterosexual older adults, differences do exist. These revolve primarily around the real and anticipated discrimination confronted from professionals, and programs and policies that not only do not take these populations into consideration but often deter them from making themselves visible. The legitimate fears that seniors have of encountering homophobia and heterosexism in health and social services may mean that caregivers are called on to care more intensely and for a longer period of time than other caregivers. This

points to a need for involving gay and lesbian health activists in organizations, services, and policy development to ensure that issues of overt and subtle discrimination are seen, highlighted, and addressed effectively.

The inclusion of gay and lesbian caregivers in already existing diversity agendas within mainstream senior services and caregiver organizations is a necessity in order to advance responsiveness and support to them. This could be facilitated by an expansion of the often narrow definitions of caregiving currently in place in both professional and popular discourse that prioritize recognition of those biologically related or married to the care receiver. Indeed, the sense of solidarity and community that lead some to the caregiving role in gay and lesbian communities can provide a new model of care beneficial to all seniors and their caregivers. Understanding under what conditions the development of such a sense of community solidarity can lead to a decision to care can help professionals enhance and support options that are truly community driven and responsive to all older people in society.

Finally, given the paucity of research on caregiving to gay and lesbian seniors, we suggest that much more research needs to be undertaken to explore these important and pressing issues. Our study was limited by several factors, including sampling processes that contributed to a lack of diversity in participants on the basis of race, ethnicity, and class. We also were unable to a large degree to identify caregivers in smaller regions. In addition, issues regarding identity as both a caregiver or as gay or lesbian contributed to difficulties in recruitment. In this study, several participants told us that they did not identify themselves as caregivers (as is consistent with all caregivers), but simply as family or loved ones. In light of this, future studies must adapt outreach and recruitment strategies to identify people through the widest lens possible in order to ensure inclusion of those who would otherwise not come forward because of lack of identification with the targeted population. Using terms that describe people's role in the context of care and not simply the Caregiver label might help to increase the diversity of participants. Finally, the study was also limited by the use of gay and lesbian identity labeling for outreach and recruitment purposes. As with much research on gay and lesbian populations, those who were most comfortable identifying themselves as gay or lesbian were most likely to agree to participate. This resulted in a lack of representation of those who do not identify with these labels or who are not out to others. Most people we interviewed were comfortable either with being out or with their care receiver being out. As a result, the current study missed the most invisible cohort of caregivers. Caregivers who were not part of this study because of even greater distress, greater disconnection, or greater distrust of the research establishment might have had even more serious limitations and problems. Certainly, the combined factors of not identifying as a caregiver and being private about the orientation of the care receiver as gay or lesbian posed some problems with respect to recruitment efforts. Future research areas include some proposed previously, such as a comparative analysis of gay and lesbian caregivers, heterosexual caregivers, and other minority caregivers (including ethnocultural minority populations); caregiving to pre- and post-liberation seniors; experiences in rural contexts and with respect to diverse social variables, such as race, ethnicity, and class; legal and financial concerns in the context of rights-based discussions across jurisdictions; caregiving to gay and lesbian seniors in institutional settings; and caregiving issues for bisexual and transgendered seniors.

There are many unexplored avenues of caregiving to gay and lesbian seniors. In Canada specifically, the possibilities for funding and institutional support for research and the interest in advocating for practice and policy changes to support gay and lesbian seniors and their families are slowly increasing. Researchers must be encouraged to undertake projects in a manner that prioritizes resource sharing and partnerships with community and health care organizations to ensure that results are communicated to health care professionals and community activists. In this way, research findings can contribute to the development of a commitment to change on the part of gay and lesbian communities and mainstream health care sectors in order to guarantee that gay and lesbian seniors and their families find support, comfort, and services designed to meet their needs as they age.

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