QUE(E)YRING HOME CARE: OLDER LESBIAN AND BISEXUAL WOMEN'S EXPERIENCES OF ACCESSING AND RECEIVING HOME CARE SERVICES

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ABSTRACT

This exploratory study examined the impact of sexuality, gender and aging on older lesbian and bisexual women's access to home care services and their experiences of receiving home care. This study had three objectives: (1) to learn about the experiences of older lesbian and bisexual women who currently access home care services in Ontario, (2) to gain an understanding of the impact of sexuality and sexual orientation on home care experiences, and (3) to explore older lesbian and bisexual women's definitions of quality home care and the factors that enable (or hinder) quality care. This study used a qualitative case study design and was guided by a feminist political economy framework and the critical sexuality and LGBTQ studies literature. Semi-structured interviews were carried out with 16 women who have accessed home care services in Ontario in the last five years. These interviews were subsequently transcribed and analyzed using an iterative thematic analysis. The findings of this thesis reveal that attitudes around gender, sexuality and sexual practices affect individuals' need for home care, their access to care and their experiences of receiving home care. This study highlights the necessity of incorporating a consideration of gender, sexuality and sexual orientation into home care policy and delivery, as well as into the training of home care workers and case managers. These findings may be useful in the development of respectful and effective home care services that are sensitive to diverse experiences and to those of lesbian and bisexual families.

DEDICATION

For my family of choice and my family of birth

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Chapter 1: Introduction

The Problem

The rapid increase in the Canadian population over the age of 55 combined with the expansion of the lesbian, gay, bisexual, trans and queer (LGBTQ) community means that a significant lesbian and bisexual older population is emerging in Canada. However, despite advances in civil rights and the redefinition of the family in Canadian law, health care and social services systems have been slower to change and to include a consideration of sexual diversity in their policies, practices and delivery models (Daley, 2006; Smith, 2006; Mulé, Ross, Deeprose, Jackson, Daley, Travers, & Moore, 2009).

Although women's and feminist health care activism and research in the last 60 years has exposed gender bias in medical treatment and the medicalization of women's bodies, less attention has been paid to the experiences of older and non-heterosexual women (Barker, 2004; Weitz & Estes, 2001). In addition, while LGBTQ liberation movements have been very active in Canada and have had many successes, they have paid little attention to older LGBTQ people's issues until very recently (Brotman, Ryan & Cormier, 2003; Brotman & Ryan, 2008; Fredriksen-Goldsen & Muraco, 2010; Herdt & de Vries, 2003). While older lesbian and bisexual women, like their heterosexual peers, are vulnerable to poverty and discrimination as a result of the prevalence of their gender and age, they have unique challenges as a result of the prevalence of homophobia and heterosexism in society. The former is a fear and hatred of those who are, or are assumed to be, homosexual, while the latter is the belief that heterosexuality is the superior form of sexual orientation (Morrow, 2001).

While little research to date has explored LGBTQ persons' needs and experiences of home care services, there is some evidence that LGBTQ people may have a higher need of publicly funded care services as a result of poverty, lack of familial caregivers and fear of institutionalized care facilities (Grant, 2010; Brotman, Ryan, & Meyer, 2006). Moreover, at present there is no national standard or mandate for including gender and sexual orientation sensitivity training for home care providers and organizations in Canada. As a result, LGBTQ people may be vulnerable to discrimination and poor quality care when accessing home care services. Research into the current experiences of older lesbian and bisexual women can be used to better understand their home care needs, as well as to identify potential policy changes and training that may need to be implemented to ensure quality of care.

Home care services are a particularly interesting context within which to explore the intersection of sexuality, equity and quality of care for a number of reasons. First, like other long term care services, home care services in Canada are not explicitly regulated by the *Canadian Health Care Act* (*CHA*) because they are classified as extended health care services and are therefore not necessarily funded by the provincial health care systems. As a result, the organization, delivery mechanisms and scope of services vary among different provinces and territories within Canada. Second, research has shown that Canadian social policies, and the organization and delivery of social services in Canada, privileges the nuclear heterosexual family model and is based on the assumption that women (and in particular wives and daughters) will assume the primary responsibility for caregiving within families (Grant, Amaratunga & Armstrong, 2004; Gazso, 2009; Daley, 2006; Smith, 2006). Carabine (2004, 3) further adds that "in policy, welfare analyses and practice, sexuality is taken as given, as something that "just is,"

and welfare subjects are assumed to be universally heterosexual. The idea of heterosexuality is left unproblematized & unquestioned." A study of the experiences of older lesbian and bisexual women home care users can reveal the implications of these types of policy assumptions for individuals and families who do not neatly fit this type of family configuration.

Purpose of the Study

As the title of this thesis suggests, the purpose of this study is two-fold. It seeks to query, that is to investigate, home care, as well to queer home care, that is to make the familiar in home care strange, by examining its underlying assumptions and foundations with respect to sex, gender and sexuality. In combining these two words, the title indicates that this study seeks to both investigate and uncover what is queer about home care by exploring the experiences of a group of queer individuals, older lesbian and bisexual women and explore the ways in which their experiences reveal assumptions about sexuality, gender and the responsibility for care that are embedded in current policies and structures of the Ontario home care system.

The primary purpose of this study is to explore the lived experiences of older (> 55 years old) lesbian and bisexual women who access home care in Ontario. Specifically, this study has three objectives: (1) to learn about the experiences of older lesbian and bisexual women who currently access home care services in Ontario, (2) to gain an understanding of the impact of sexuality and sexual orientation on women's home care experiences, and (3) to explore older lesbian and bisexual women's understandings of quality home care and the factors that enable (or hinder) quality care in order to provide recommendations that can be used in the creation of health care policy, planning and delivery.

Theoretical Framing

This study is guided by the understanding that care is relational and contextual and that experiences of care are shaped and constructed through social, cultural and state structures and practices (Armstrong, Amaratunga, Bernier, Grant, Pederson & Willson, 2001; Carabine, 1992; Daley, 2003, 2006; Doyal, 1995; Morrow et al., 2007). Furthermore, a key assumption of this study is that sexuality is an important organizing principle that shapes individuals' identities and social lives, as well as their access to resources (Altman, 2001; Andersen, 2005; Carabine, 2004; Mule et al., 2009).

In terms of theoretical framework, this study is framed within a feminist political economy perspective (Armstrong & Connely, 1989; Coburn, 2001; Vosko, 2003) and is informed by LGBTQ and sexuality studies frameworks (Stein, 1997; Carabine, 2004; Daley, 2006). Feminist political economy (FPE) is an approach that argues that power and economic control are interconnected and that individuals' health and wellbeing are shaped by the social, political and historical contexts in which they live. In particular, this approach argues that gender and gender relations influence, and are in turn influenced by, socio-economic and political structures, processes and ideologies and that these are important for understanding individuals' choices and access to resources. This approach has been used to show that the neoliberal reform of health care and caregiving in Canada has downloaded the cost and the responsibility of care unto families, and in particular onto women (Armstrong et al., 2001; Grant et al., 2004). FPE has also been used to problematize the state's claim that these reforms have improved the cost effectiveness, equity and quality of care by bringing forth the perspectives of health care users and front line health care workers (Choiniere, 2011; Armstrong et al., 2001;

Armstrong, Boscoe, Clow, Grant, Guberman, Jackson et al., 2011; Grant et al., 2004; Aronson, 2006).   Consequently, this approach is well suited to exploring the lived experiences of an underrepresented population of health care users and their perspectives on accessing and receiving home care within the current home care system.

Situating my study within this analytical tradition encourages me to consider how home care policies and organizational processes construct and shape older lesbian and bisexual women's need for care services, as well as their access to care. Furthermore, the use of this approach allows me to explore how material and contextual factors, such as access to income and social supports, interact with gender and class to influence participants' experiences. Finally, the incorporation of sexuality and critical LGBTQ frameworks alongside FPE also allows me to consider how sexuality and sexual orientation interact with and intersect with gender and other contextual factors to shape older lesbian and bisexual women's relationships and interactions with home care professionals.

Outline of the Chapters

The next chapter, chapter two, presents an overview of the historical and current organization of long term care and home care in Canada and Ontario and reviews research on the impact of recent neoliberal reforms on quality and women's access to home care services. This chapter provides the necessary political, economic and historical context informing the analysis of this thesis. In chapter three, I review what is known about older lesbian and bisexual women's health and the impact of heterosexism and heteronormativity on their health and their use of social services. This chapter provides context for the specific population which is the focus of this thesis and situates the thesis in relation to the broader literature on older

lesbian and bisexual women's experiences of health and care. In chapter four I present the theoretical framework underpinning this study and the methodology that I use, including the research questions, the processes of data collection and the steps taken in the data analysis. In this chapter I also outline the bounds of the case study, which structure the parameters of the data analysis, and discuss the limitations of the research.

In the following chapter, chapter five, I present an analysis of the factors that affect the conditions under which older lesbian and bisexual women access and receive home services in Ontario. I begin the chapter by examining participants' health and their demographic and socio-economic characteristics. I then connect these characteristics to their health, their support needs and their social support networks. In chapter six I present an analysis of participants' experiences of accessing and receiving home care services and identify factors that mediated their access to and their experiences of receiving home care services. In chapter seven, I focus in more detail on sexuality and analyze the meanings that individuals ascribe to their sexualities and sexual identities in their everyday lives and explore their role in their home care experiences and in their interactions with caregivers. In chapter eight, I focus on quality and present an analysis of participants' definitions of quality in home care and the factors that they identify as enabling or hindering quality. Finally, in chapter 9, I conclude the dissertation by discussing the overall analysis and findings of the thesis, the significance of the findings for academia and policy and their potential implications for home care services' planning, delivery and training.

Chapter 2: The Policy Context

This chapter provides an overview of the status of health care and home care in Canada and the policy context informing the analysis of the study. While this study focuses on a particular social group, time period and geographic location in Canada, the specific setting is and continues to be shaped and affected by polices and restructuring that occur in other areas and levels of government as well as in other times. As a result, it is necessary to situate the present study of home care experiences within the context of broader Canadian health care organization, policy and reform. I begin this chapter by providing a brief introduction to the historical development of the current health care system and discussing the changes and reforms that have occurred over the past twenty-five years. This historical background is necessary in order to understand the current organization and delivery of home care, which I discuss in the latter half of this chapter. Next I discuss the concept of quality as it relates to care, which is a key theme of this study. Finally I take up the specific issue of caregiving, long term care (LTC) and home care organization in Canada, and in particular in Ontario. As I illustrate throughout this chapter, the recent neoliberal restructuring of health and home care has negatively affected home care availability and services provision, which has had particularly negative consequences for older women, who are the primary users of home care.

As feminist political economists argue, health care systems and policies are not neutral or random. Rather, they result from particular social and historical processes that are context-specific and based on particular values and assumptions about governments' and individuals' responsibilities and rights to care (Armstrong & Armstrong, 2010; Aronson & Neysmith, 1997; Coburn, 2001; Vosko, 2003). In Canada in particular, the current organization and structure of

home care services has been the result of 30 years of restructuring that has been guided by

neoliberal values of reducing labour costs and maximizing profits. The resulting reforms have

reduced government spending and oversight for public social programs, such as health care,

while increasing their regionalization, decentralization and devolution (Armstrong, Amaratunga,

Bernier, Grant, Pederson & Willson, 2001; Daly, 2007; England, 2007; 2010; Glen, 2010).

Neoliberal reforms in Canada have changed how health care is organized, managed and

delivered across Canada and have increased its privatization. Some parts of the health care

system in Canada are and have always been privatized; for example most doctors typically work

in private practice and for the most part hospitals are not owned by the state. Although doctors

in Canada do get paid by the state (or other actors), they are paid on a fee-per-service basis.

Consequently, while recent reforms to health care have not privatized it, they have increased

the intensity and scope of privatization in health care. For instance, recent privatization

strategies have included the downsizing of care within public institutions such as hospitals, the

contracting out of health services to private for-profit companies, the shifting of more

responsibility for care to individuals and families and the adoption of for-profit management

strategies in public health care. Research on the effects of these reforms has shown that

instead of reducing cost and increasing efficiency, the neoliberal restructuring of health care

has instead decreased the system's efficiency, quality and public accountability, while

increasing its administrative costs (Armstrong et al., 2002; Grant, Amaratunga, Armstrong,

Boscoe, Pederson & Willson, 2004; Armstrong & Armstrong, 2010). Finally, as I discuss in more

detail below, these reforms have also changed the *nature of the care* that is provided both at

home and within health care institutions (Armstrong et al., 2001; Armstrong, Armstrong &

Coburn 2001; Grant et al., 2004). In particular, these reforms have contributed to the privileging

of acute technical medical care over supportive social care and the provision of more medically

complex care at home for longer periods of time.

In Canada today, health care funding is regulated by the *Canada Health Act* (*CHA,* 1985).

The *CHA* is responsible for ensuring that publicly funded health care services throughout all the

provinces and territories follow five principles. These are universality, public administration,

comprehensiveness, portability and accessibility. According to the *CHA*, these five principles

have to be fulfilled by the provinces and territories in order for them to receive federal funding

for health care. However, while on paper the *CHA* guarantees *all* Canadians the right to

"medically necessary" (*and doctor and hospital provided*) health care services, researchers

have shown that women in Canada face multiple barriers to accessing appropriate, timely and

quality health care services due to systemic inequalities (Morrow, Hankivsky, & Varcoe, 2007).

Home care services in Canada are one component of the Canadian health care system.

However, these types of services are considered to be "extended health services" and are thus

not publicly insured by the *CHA.* Thus, although "home care is a key part of our health care

system that has the potential to affect all Canadians," it is "not an insured service under the

Canada Health Act" and therefore "there is no obligation on the part of governments to provide

a minimum basket of services" (CHCA, 2009). As a result of this liminal status in federal policy

and the fact that health and health care are primarily the responsibility of provincial

governments, home care services vary dramatically across the country in terms of organization,

payment structure, types of services offered and the delivery of care.[1] In fact, an article on this topic in the *Journal of the Canadian Medical Association* noted that "when it comes to using home care, it can be a crapshoot as to where you live and what services are available" (Angus qtd. in Seggewiss, 2009). Given that this study is concerned with the experiences of home care in Ontario, I focus the bulk of my discussion of home care in this chapter on the Ontario context.

Before moving on, it is important to mention that Canada's current health care system is based on the allopathic or biomedical model of care, which is focused primarily on curing disease through medical, pharmaceutical and surgical interventions (Morrow, 2007; Rioux & Daly, 2006). Biomedicine has often unnecessarily medicalized women's bodies and has frequently been found to be insufficient in addressing the chronic health needs of women (Morrow, 2007; Hankivsky, 2007; Cruikshank, 2009).[2] This model of health has also guided much of neoliberal health care reform in Canada and has contributed to the privileging of acute medical and technical care over supportive care in long term care.

Health Care Systems and Reforms in Canada

Since the 1970s, the Canadian health care system has undergone several major economic and political reforms that have negatively affected women working in health care and women receiving health care (Aronson & Neysmith, 1998; Armstrong et al., 2000; 2002; 2012; Armstrong & Armstrong, 2003; England 2010; Fuller, 1998; 2001; Wiktorowicz, 2006). Prior to this period, the dominant approach to health care and other social care services was a "welfare

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[1] While some parts of health care are legislated federally, it is the responsibility and right of each province and territory to decide the scope of health care services and the way in which they are organized and delivered.
[2] Medicalization is a process by which bodily symptoms or behaviours become defined medically as problems that have to be cured or treated with surgery or pharmaceuticals (Bourgeault, 2006).

state" approach, which is characterized by the belief that these services are a public good and a human right and that it is the responsibility of the state to provide these for its citizens. While this approach to social welfare began to unravel in the 1970s, since the late 1990s health care reforms have become particularly intense in Canada.

During the 1990s there was a paradigm shift in how health care was conceptualized on both provincial and federal levels, moving from a progressive welfare paradigm to a neoliberal paradigm (Armstrong 2001, 121; Aronson & Neysmith, 1997; CCPA 2000; England, Eakin, Gastaldo, & McKeever, 2007; Glenn, 2011). Under this neoliberal framework, the health care system was reframed as a "business" to be managed, and often along for-profit-lines, rather than a public social good that is the entitlement of all Canadians. This paradigm shift has allowed the federal and provincial governments to push successfully for health care reforms premised on the idea that health care costs have to be "better managed" in order to increase the system's efficiency and to make it more "cost-effective," while providing optimal consumer choice (Armstrong et al., 2001; Fuller, 1998; Daly, 2007; England, 2010).

Hospitals have become a key site of restructuring under the neoliberal reforms as they constitute a major health care expense and are protected by the *CHA* (Armstrong et al., 2001; Fuller, 1998; Grant et al., 2004). Much of hospital reform has focused on reducing access to care within hospitals by restricting admission eligibility criteria and decreasing the amount of time patients can spend within hospitals. Other cost-saving strategies include the reduction of the overall number of acute care beds; the general downsizing of the number of employed, non-physician health care workers such as nurses; and the contracting out of ancillary services, such as meals and laundry, to external private, for-profit companies.

The downsizing of care within hospitals has placed severe limitations on the ability of hospitals to provide quality care by reducing workers' time to care, to learn and to teach new health care professionals on site (Armstrong & Armstrong, 2005; Armstrong & Kitts, 2004). Alongside these limitations, the kind of care that has come to be primarily valued in health care is technical care, with less recognition given to the necessity and value of health care workers` non-technical skills, such as caring (Armstrong & Armstrong, 2001; Grant et al., 2004). As caring is an important component of providing services, these limitations have had negative consequences for the quality of care that workers are able to provide to clients (Grant et al., 2004; Armstrong et al., 2001).

As a result of this restructuring of care, large numbers of chronically sick people have been moved out of hospitals into long-term care facilities or into homes to be cared for by their families, often by women, with little infrastructure or support provided to families to manage increasingly complex medical conditions (Grant et al., 2004). Consequently, instead of reducing overall health care costs, these reforms have merely "moved," or offloaded, the care costs from the public sphere (institutions) to the private sphere (families) and made it more difficult to see the effect of these reforms on individuals (Aronson & Neysmith, 1997; Armstrong et al., 2000; 2001; Fast, Williamson, & Keating, 1999; Fuller, 1998; Grant et al., 2004). These changes to health care are important, for as I discuss later, they have also significantly altered the provision and delivery of long term care and home care services in Canada.

Home Care in Canada

Home care is defined by Health Canada as "an array of services which enables clients, incapacitated in whole or in part, to live at home, often with the effect of preventing, delaying, or substituting for long-term care or acute care alternatives" (Health Canada, 1999). Services considered to be home care can include medication administration, wound care, house-keeping, meal preparation and therapy services, among others.

Home care in Canada is defined by the location of services provided, in the home, rather than by the nature of the service. This is important to note as the kinds of services that are provided and the limit on how much care can be provided in the home varies across the country (CHCA, 2009; Grant et al., 2004). For example, while Quebec covers all necessary medical supplies, equipment and pharmaceuticals for home care clients, Ontario only provides some equipment coverage and some pharmaceuticals, and there is evidence that the need for this coverage exceeds the amount allotted (CHCA, 2011; Auditor General of Ontario Report, 2010; Ontario Health Coalition, 2011).

Long term care, as an area of health care, is almost completely invisible at the federal policy level and has no targeted federal funding (Banerjee, 2009). Furthermore, although home care was mentioned briefly in the 2003 *Romanow Report on the Future of Health Care in Canada*, which argued that the government should include home care under the *CHA*, the report suggested that the focus of funding should be on acute types of home care and palliative care. This is a problematic stance, given that the majority of users of home care are those who have long-term chronic conditions. As a result of the Romanow report, the federal government, in 2004, agreed to pay "first-dollar coverage for[a] basket of services for short-

term acute home care [two – weeks], including acute community mental health and end-of-life care" (CHCA, 2009, 27). However, this funding agreement was set for a period of 10 years only and to date there has been no word about LTC funding after 2014.

Currently, provinces and territories get block funding for all health care expenditures from the federal government and then decide how much to allocate to various services. However, nationally, home care is seen as the best possible solution, both for reducing federal and provincial health care expenditures and for care recipients (Aronson and Neysmith, 1997; 2001; Armstrong et al., 2001; Armstrong and Kitts, 2004; Armstrong and Banerjee, 2009). Furthermore, there is a desire to cut costs in LTC despite the fact that public funding for LTC services such as residential care is considerably less than what is spent on inmates in jails and detention centers (Banerjee, 2009).

Long term care has become "an important site for profit making" and there has been a shift in LTC policy to more and more individual responsibility for care provision. There has also been a push towards more care provided in the community and private homes, rather than within public long term care institutions such as residential care facilities or nursing homes (Armstrong et al., 2001; Grant et al., 2004). This was done under the assumption that community and home care would be more beneficial for all, both in terms of the quality of care and in terms of cost effectiveness (Armstrong et al., 2001, 78). However, although each province has had a slightly different restructuring of long term care under these assumptions, there has been a steady increase in user fees for LTC services, a shrinking in the amount of services provided and a deterioration in the level of care provided in all provinces and territories in the last 30 years (Aronson, 2004; Aronson & Neysmith, 1997; 2001; Armstrong et

al., 2009). In particular, there has been a sharp decrease in the amount of non-medical services provided in home care, such as housekeeping, cleaning and bathing, and priority given to providing more "medically necessary services" instead, such as wound care and medication dispensing. These changes have had a particularly deleterious effect on older women, who are more likely to have chronic health issues, have more need of supportive, non-medical "social care services" as a result, and are often unable to pay for these out of pocket (Aronson, 2004; 2006; Daly, 2007).

As Kitchen et al (2011) and others (Canadian Home Care Association, 2008; Grant et al., 2004, Seggewiss, 2009; Williams, 1996) have noted, home care use has increased dramatically in the last 30 years in Canada, with 5% of all Canadians using these types of services, or an estimated 1.2 million people, in 2003 (CIHI, 2003). In Ontario alone, the number of home care users increased from 350,000 clients in 2004 to 586,400 clients in 2009 (Auditor General of Ontario, 2010). The funding for home care has not matched the increase in clients, despite the growth in service use over this period. In Ontario, between 2004 and 2009, the amount spent on home care increased by 40%, while the number of clients during this time increased by 60% (Auditor General Report, 2010).

Nationally, home care is seen as the *best* possible solution for reducing health care expenditures and providing care for chronically ill people by both provincial and federal health care authorities (Armstrong et al., 2001; Armstrong & Banerjee, 2009; England, 2010; England et al., 2007; Seggewiss, 2009). In Canada, less than 2% of all Canadians live in long term care residential facilities and strict eligibility and availability criteria make it difficult to get into these places (Banerjee, 2009). The majority of Canadians requiring supportive care live in their

homes. Furthermore, 85-90% of all the care that is provided to Canadians is done informally, primarily by unpaid female family members (Guberman, 2004; Ontario Health Coalition, 2011). While some care services are provided outside the home, there are no community care services *per se*. Rather there are a small number of patchwork, mostly volunteer-based, community programmes such as `Meals on Wheels` and day centers that provide some social programming and activities that supplement the care that is provided in the home. As Guberman (2004) notes, as a result of this, the reference to "community care" in long term care discussions "is often a euphemism for unpaid family care" (76).

Home Care in Ontario

Ontario has experienced several harsh neoliberal health care reforms in the wake of the 1995 election of a Conservative Party provincial government led by Mike Harris (Armstrong et al., 2001; Aronson, 2004; Daly, 2007; Randall & Williams, 2005). In the early 1990s, LTC was regulated by the *Ministry of Community and Social Services* and home care was mainly provided by not-for profit organizations. Home care services in Ontario were administered by several local home care program and placement coordination services (Kitchen et al., 2011; Williams et al., 1999). In 1994, Ontario, then governed by the New Democratic Party, introduced the *Long Term Care Act,* which formally specified what is meant by home care and proposed the creation of multi-service agencies that would both assess care need and provide home care services. The following year, the newly elected Conservative Party repealed the *Long Term Care Act* and replaced it with the *Home Care & Community Services Act*, which designated the administration and allocation of home care services to Community Care Access Centers (CCACs; Kitchen et al., 2010; Armstrong & Armstrong, 2006; England et al., 2007). However, this legislation did not

establish any formal guidelines for how home care service need should be assessed, allocated

or capped.

In 1999 the Conservative Ontario government passed a formal regulation on the amount

of home care individuals can receive and reduced access to services by placing limits on care-

provision. This regulation was passed without any inspection of long term care agencies or any

rationale for the limits set and did not establish any way for CCACs to address quality or client

complaints (Armstrong & Armstrong, 2006; England et al., 2007). In terms of current limits on

home care, personal support/homemaking services are provided up to a maximum of 60 hours

per month or up to 120 hours for adults with physical disabilities. Nursing services can be

provided for up to 28 visits per week (CHCA, 2009). In practice, however, the number of hours

that individuals receive is much lower than that and the allotment of services has been shown

to not be fully responsive to users' need (Ontario Health Coalition, 2011; Auditor General

Report, 2010; Kohli, 2009 [thesis]). Furthermore, as a result of cuts in funding and reductions in

services, formal home-care has increasingly come to mean increasingly short-term acute

medical care services, leaving those in need of other types of supportive services to make up

the difference in care need themselves (e.g. Aronson & Neysmith, 2001; Daly, 2007; England,

2010; Grant et al., 2004). In line with this, a recent report on long stay home care recipients

over the age of 65 has found that 98% of all home care clients who received home care services

also received care from an informal and unpaid caregiver such as a spouse or child (CIHI, 2010).[3]

For 75% of the non-married home care recipients, the primary caregiver was a child. This is an

important trend to note, as I discuss in the next chapter, because older lesbian and bisexual

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[3] Long stay home care recipients, as defined by the *Canadian Institute for Health Information,* are home care clients who have used, or are expected to use, home care services for more than 60 days.

women are more likely to live alone and to not have children, compared to heterosexual

women.

The management and delivery of home care services in Ontario today is coordinated by

the CCACs mentioned earlier. The CCACs are not governed by the *Ontario Ministry of Health &*

Long Term Care (MOHLTC) directly, but rather by their own independent, incorporated, non-

profit boards of directors; they do, however, have a service agreement with MOHTLC and are

accountable to MOHLTC (MOHLTC, 2006). They receive block funding from the Local Health

Integration Networks, which receive it from the ministry, and the LHINs are responsible for

deciding how to allocate these funds in terms of service provision.[4] The CCACs do not provide

any direct home care services, but they are responsible for case management and referral. The

CCACs determine eligibility for receiving services and decide what kind of and how much service

will actually be provided to an individual. Thus, aside from case management and referral, all

the care services are contracted out to not-for-profit and for-profit home care companies.

Information is not publicly available on exactly how care need is calculated by the CCACs

and there are no provincial or federal guidelines with respect to how need and relevant service

allocation should be calculated. There is evidence, however, that increasingly less and less paid

home care is allotted per individual and for the most part it is short-term acute medical care

only that is provided (e.g. Kohli, 2009; Daly, 2007). Moreover, there is some suggestion that

access to home care services varies across the province and that there are differences in the

type and amount of home care available between rural and urban areas (Kitchen, Williams,

Pong, Wilson, 2011). The most recent Auditor General's report on home care further noted that

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[4] Local Health Integration Networks, or LHINs, are local health organizations in Ontario that are responsible for integrating and coordinating health care services in their geographical region.

there are marked differences among the 14 CCACs in terms of levels of home care funding,

services allocated and guidelines for service duration. However, 11 of the 14 CCACs currently

have lists of people who are waiting to receive home care services with some waiting as long as

262 days (Auditor General of Ontario, 2010).

A recent Ontario study of priority setting in CCCAs further shows that CCACs and

individual case managers ration existing services when evaluating how to allocate services to

clients (Kohli, 2009). As Kohli notes, care *need* is a "moving –target" and a value-based concept,

rather than a specific definition for CCACs, and varies across organizations and individual case

managers. Services are primarily allocated based on a biomedical definition of functional status,

such as a client's continence, cognition and risk for falls. However, no internal guidelines,

policies or regulations exist that determine how case managers should translate a functional

status rating into hours of service. Kohli found that case managers often distinguished between

"wants/wishes" and "needs" when making these decisions and justifying their allocation of

minimal service levels. Clients' evaluation of service need was typically seen as a want or a

wish, rather than a *need,* and was therefore considered less relevant to case managers'

decision-making.

Currently, Ontario is the only province in Canada where all home care services are

contracted out to private not-for profit and for-profit companies, through a competitive bidding

process called "managed competition." In a competitive bidding process, companies bid for the

right to offer services and the emphasis is typically placed on reducing the care cost through a

reduction in either labour or paid work time. Managed competition has been shown to

negatively affect home care users and providers. Research on the impact of this type of

privatization in Ontario (Armstrong, 2007; Aronson & Sammon, 2000; Daly, 2007; Denton, Zeytinoglu, Davies, Hunter, 2006; England et al., 2007; England, 2010; OHC, 2008; Randall & Williams, 2006) has shown that it has increased the commercialization of not-for-profit home care companies and has led to the casualization of work, shorter contracts, rapid staff turnover and lower pay for home care workers. It has also negatively influenced the quality of care that is provided by decreasing continuity of care, as a result of staff turnover and loss in contracts from year to year. Overall, competitive bidding, the push to lower costs to remain competitive, and cutbacks in home care funding have led to decreases in the number and duration of home care visits provided to clients and reduced providers' education and training opportunities (Armstrong et al., 2000; 2010; Choiniere, 2011; Mykhalovskiy, Armstrong, Armstrong, Bourgeault, Choiniere, Lexchin, Peters, & White, 2008).

Acute medical care has increasingly come to be valued over preventative and supportive social care in home care and less and less of the latter is allocated by the CCAC and provided to home care users (Aronson & Sammon, 2000; Daly, 2007; Kohli, 2009). The focus on acute care is seen as a way to manage high demand for home care and decreases in funding as well as more crucial to supporting clients' health. The valuation of medical over social care has long-term health implications, as access to supportive social care is considered to help prevent acute medical conditions by decreasing individuals' isolation and supporting their physical and mental health (Daly, 2007; Health Canada, 1999; CHCA, 2009).

In Ontario, as elsewhere in Canada, government provided non-medical home care services are considered to be an "add-on" option only and this is stated clearly in provincial home care policy documents: "publicly funded home care services are designed to complement

and supplement, but not replace, the efforts of individuals to care for themselves with the

assistance of family, friends and community" (OHCA, 2010). Furthermore, home care

expenditures in Canada amount to only 1.5% to 7% of all health care spending in Canada, with

Ontario spending about 4% of its health care funding on LTC in 2009 (Home Care Association,

2010; CHCA, 2011). The resulting reliance on unpaid "family care" has important consequences

for older women who may not have familial supports due to longer life spans, more chronic

illnesses, or sexual orientation, as they may have to rely entirely on formal home care services.

Gender and Care

Women are the majority of unpaid caregivers and care recipients, especially of home

care services (Morris, 2004; CHC, 2009; OHC, 2011). Older women in particular are the

overwhelming majority of those who require home care services and the majority of those

living in LTC residences. In Ontario alone, older women accounted for 76.6% of all LTC

institutional residents (Banerjee, 2009) and 60% of all home care recipients (CIHI, 2011). One

possible reason for this is that women live longer than men and are thus more likely to be

widowed and single in older years, making them more vulnerable to poverty. Women also often

play the caregiver role within the family (Aronson, 1992; Grant et al., 2004). As a result, when

women need care themselves in older ages, there is often no one in the family who can care for

them, or no family at all and they often cannot afford to pay for privately- arranged care. Thus

they are more likely to depend on home care services and be institutionalized as they age.

Morris's (2004) review of home care research shows that while women on average give

more hours of unpaid care than men do, they on average receive fewer hours of formal care

than men do and receive less short term, post-operative care. She argues that this suggests that

certain assumptions about women and their caregiving duties may play a role in how caregiving

services are distributed by long-term care organizations. Research also shows that even when

women have paid jobs, they have more unpaid care responsibilities than men do in the home

(Cranswick, 1994; Keating et al, 1999; CHCA, 2009). On average, more women than men also

provide more demanding and personal types of care and travel further and more often to

provide care (Cranswick & Dosman, 2008; Keating et al., 1999). Not surprisingly, then, it has

been found that caregiving affects women's health and economic wellbeing more negatively

than that of men. A recent study of women and men caregivers found that more women than

men had indicated that caregiving resulted in negative physical and social and emotional

outcomes and resulted in them reducing their work hours and their incomes (CHCA, 2009).

However, despite the obvious gender differences in care provision and use, the majority of

caregiving research and policy does not take gender into account, let alone other factors such

as types of family arrangements, sexual orientation or ethnic and cultural background (England,

2010; Morris, 2001; 2004).

Researchers have shown that current caregiving allowances and policies assume that all

Canadians have at least one family member who is willing and able to take care of them

(Armstrong & Kitts, 2004; Aronson & Neysmith, 1997; 2001; Morris, 2001; Morris et al., 1999).

In mainstream LTC discourse and government policies, typically "families are pictured as warm,

supportive environments that can and want to care… or if they do not, they should" (Armstrong

& Armstrong, 2001, 25). Therefore, there is both a push on families (and women in particular)

to assume the responsibility for care and a policy assumption that they wish and are able to do.

In Ontario, some guidelines for home care services state explicitly that people are not eligible to

receive home care services until they have exhausted the support capacities of their family and friends, with little regard as to whether their caregivers may be employed or not (Armstrong & Armstrong, 1999; CCAC, 2011). In fact a recent report by the Canadian Home Care Association (2010) stated, "publicly funded home care services are designed to complement and supplement, but not replace, the efforts of individuals to care for themselves with the assistance of family, friends and community. A fundamental component of home care is that family and/or friends will provide care to supplement the formal service provision" (4).

This "familization of care" (Bezanson & Luxton, 2006; Gazso, 2009) dichotomizes care into "good care," which is family provided, and "bad care," which is government provided (Guberman, 2004). In dichotomizing care in this way, the government erroneously assumes that all those requiring care want to stay at home with their family and that all families have at least one available person who will gladly "assume the responsibilities for care that the state wants to transfer" (Guberman, 2004; 79). Furthermore, the assumption that all families can provide a good care environment and thus do not need to be regulated by the government is in itself problematic. Assuming that care is always better provided at home leaves both care providers and care recipients potentially vulnerable to harm and isolation within the home (Armstrong & Armstrong, 2001; Lang, MacDonald, Storch, Elliot, Stevenson, Lacroix et al., 2009).

I could find no research focused on the experiences of lesbian and bisexual women accessing or receiving home care services or on their experiences of living in long term care residences. I found only one published research study on the experiences of lesbians receiving informal care in Canada, but it included the experiences of both caregivers and care recipients and the sample included both younger and older women (Aronson, 1998). Aronson showed

that lesbians, like other women who need care, experience a "layer of marginality" due to their lifelong socialization as women in a sexist society. The women in her study reported that they did not want to be a burden, were not used to asking for care, and thus felt ashamed when they needed help. Furthermore, they had experienced negative reactions when accessing formal health care services in the past. Feelings of fear and shame consequently caused them to delay accessing formal caregiving services, thus placing a greater burden on themselves and their partners.

Quality

While the dominant neoliberal health care model and recent health care reforms are concerned with improving the "quality" of health care, quality is defined in very narrow, biomedical terms and the emphasis is typically on the measurement and subsequent improvement of quantitative biomedical outcomes such as life expectancies, wait times for surgeries, rates of falls, number of pressure ulcers and days spent waiting for home care (Armstrong & Armstrong, 2010; Armstrong, 2001; Health Canada, 2010; Health Quality Ontario, 2013; Mykhalovskiy, Armstrong, Armstrong, Bourgeault, Choiniere, Lexchin et al., 2008; Sutherland, Leatherman, Law, Verma, Petersen, 2012). These kinds of outcomes cannot measure all aspects of quality, such as the emotional and interpersonal aspects of care, nor illustrate how care recipients themselves perceive the quality of care that is provided to them (Armstrong, Boscoe, Clow, Grant, Guberman, Jackson, Pederson, Seely, Willson, 2011; Jackson, Pederson, Armstrong, Boscoe, Clow, Grant, Guberman, Willson, 2004; Dubé, Ferland, Moskowitz, 2003; Sinding & Wiernikowski, 2008).

The emphasis in current quality reforms, based on these kinds of outcomes, is typically on standardizing care by ensuring that all patients have the *same* access to the *same* type of treatment regardless of their particular needs, social locations or circumstances. "Sameness," however, is not the same as equity, as it does not account for the importance of location and context, which can influence both women's care needs and their definitions of quality. Individual women have different needs and may experience barriers to care as a result of systemic and structural discrimination resulting from poverty, racism, sexism and homophobia (Armstrong, 2001; Eliason, 1996; Jackson et al., 2004). For instance, as I discuss in more detail in the next chapter, lesbian and bisexual women face multiple barriers to quality care as a result of negative and sometimes violent health care interactions and a general lack of knowledge by providers about LGBTQ health and wellness issues (Solarz, 1999; Matheison, 2007).

Quantitative quality measures also cannot demonstrate the "felt and the material dimensions of exclusion" that individuals may experience as a result of how services are (re)organized and (re)structured, which may result in a "dis(connection) between what people need and what they get from health care services" (Sinding, 2010, 1657). Consequently, such measures may miss subtle examples of inequity and exclusion that may occur in the absence of examples of direct and blatant discrimination or poor quality care (Sinding, Barnoff, McGillicuddy, Grassau, & Odette, 2010).

 In fact, some common quantitative measures of quality, such as patient satisfaction surveys, often yield more positive results than qualitative measures, even when there are experiences of dissatisfaction with the provided care (Williams, 1994; Sinding, 2003). Therefore, to fully understand the impact of neoliberal home care reforms based on these types of

evidence, we need to explore the experiences of those who are typically excluded in this type of evidence gathering— the care recipients themselves. This study adds to this gap in the evidence base by exploring how older lesbian and bisexual women define "quality home care" and how they experience the process of accessing and receiving home care services.

Conclusion

The provision of home care in Canada is largely seen as private issue, rather than a public health care problem, and consequently it receives limited government money or attention as compared to other areas of health care and social services (Armstrong, 2007; Armstrong et al., 2009). When we "gender" home care need and use patterns, we find that there are inequalities and inadequacies in how these services are organized, legislated and delivered in Canada (Armstrong et al., 2001; Grant et al., 2004; Hankivsky et al., 2004; Morris et al., 1999; Ontario Health Coalition, 2008).

While the increasing privatization of home care services in Ontario (and Canada) has had a negative effect on all women, certain populations of women are even more vulnerable to hardship as a result. Older lesbian and bisexual older women in particular may have an increased need of government funded home care services as a result of poverty and lack of unpaid caregivers such as spouses, children or biological kin. In the following chapter, I focus on this issue in more detail and the necessity to consider their unique home care experiences and needs.

Chapter 3: Literature Review

In the previous chapter, I reviewed the neoliberal reform of home care in Ontario and Canada and introduced the policies and assumptions that guide how home care is distributed and delivered currently. In this chapter I narrow in on the population that is the focus of this study - older lesbian and bisexual women - and review what is known about their health and aging and their access to care. This is necessary to illustrate the rationale for the research focus of this study and to contextualize the analysis presented in the following chapters. I begin the chapter with what is known about lesbian and bisexual women's health status and experiences in Canada and the United States. I then examine the literature on aging and women's health and what is known about the health of older LGBTQ (lesbian, gay, bisexual, transgender, queer) people, and specifically older lesbian and bisexual women. Finally, I take up research on care provision for LGBTQ people and specifically older lesbian and bisexual women's home care needs. As this review illustrates, although older lesbian and bisexual women may have a higher need for formal caregiving services such as home care than other populations, very little research to date has examined their care experiences or needs. This thesis aims to fill this gap by examining the home care experiences of a group of older lesbian and bisexual women in Ontario.

The literature reviewed in this chapter focuses on material that has been published in English in North America in the last 25 years. This period was chosen because even though a large body of research exists on women's health, sexuality and aging have for the most part not been a particular focus of analysis until very recently (e.g. Barker, 2004; Herdt & de Vries, 2004; Kimmel, Rose & David, 2006; Shankle, Maxwell, Katzman & Landers, 2003). Although this thesis

focuses on the Canadian context, due to the limited amount of Canadian research available on the topic, I also discuss literature from the United States. While the United States and Canada have markedly different health care systems, research has shown that lesbian and bisexual women in both countries face many similar obstacles in accessing quality health care due to systemic homophobia and heterosexism, and raises important questions for Canada (e.g. Barker, 2004; Daley, 2003; 2006; CLGRO, 1997; Mathieson, 2007; Mule, Ross, Deeprose, Jackson, Daley, Travers & Moore, 2009). Research has also shown that LTC provision is an important concern for LGBTQ people in both contexts for many similar reasons (e.g. Brotman et al., 2006; Grant, 2010; Outing Age, 2006). While this review acknowledges that it can be problematic to compare health and experiences with health care across different systems, it is useful to do so in this case to further illustrate the entrenched nature of prejudices faced by older lesbian and bisexual women as a result of their sexualities, age and gender.

In selecting literature, I reviewed published scholarship on aging and health, as well as work that was women- and LGBTQ-specific. The LGBTQ-specific literature either explicitly focused on lesbian and bisexual women or included them as a specific population in the analysis. Therefore, literature that only focused on gay and bisexual men or transgender people was excluded. While lesbian and bisexual women and gay and bisexual men share some commonalities as a result of their sexual minority status, their experiences and health issues can be very different due to sex and gender differences, which form "real, persistent structural differences in style, ideology and access to resources among men and women" (Stein, 1997, 388). As a result, it was more useful to consider, whenever possible, the experiences and needs of lesbian and bisexual women in isolation from gay and bisexual men and trans people.

Sexualities and Identities

Given that this study focuses on a population with a particular sexual identity or orientation, it is important to address some of the theoretical and methodological tensions that exist around defining sexualities, desires, behaviours, identities, and orientations. Both LGBTQ and mainstream theorists have struggled with how best to measure sexual desire, behaviour and identity and to define what they mean when using the terms "lesbian" or "bisexual" (Bauer, Jairaim, 2008; Garnets & Peplau 2001; 2006; Stein, 1997b; Weston, 2009). They have noted that defining sexuality is not an easy task as it is context-specific, individually and historically-based and can vary across dimensions of desires, behaviours, identities, and relationships. In different periods, cultures and spaces, individuals who today may be classified as lesbian or bisexual have chosen instead to identify in a variety of other ways such as gay, queer, or heterosexual, or to not identify or label their sexuality at all. Furthermore, recent research on female sexuality across the lifespan suggests that many women may not have stable sexual identities and many identify their sexuality based on their current relationship partners rather than their lifelong experiences, attractions or behaviours (Diamond, 2008; Garnets & Peplau, 2001; 2006).

Research on lesbian and bisexual sexualities is further complicated by the fact that many women also adopt a gender-based identity that is connected to their gender expression. These identities can include butch, femme, and androgynous. These gender identities are typically organized around particular dress and bodily styles, behaviours and presentations and are based on, without being reducible to, traditional differences in masculine and feminine gender norms (Rubin, 1992; Kennedy and Davis, 1993; Halberstam, 1998). Historically, butch and

femme cultures emerged in the early part of the twentieth century, but were later rejected by

many lesbian feminists in the 1970s who argued that they reinforced patriarchal gender norms.

In the 1980s, butch-femme identities became popular again and they remain visible in

contemporary lesbian communities. Very little research exists on gender identity in relation to

women's health, but it is likely that women's gender expression, style and presentation affect

health care interactions and quality of care. Women who are read as more visibly "queer" as a

result of their (masculine) appearance and presentation may be more vulnerable to overt

homophobic discrimination (Levitt, Horne, 2002). In line with this, a recent study found that

butch identified women were less likely than femme identified women to access routine

gynecological care and more likely to report experiencing poorer treatment in health care

settings (Hiestad, Horne, Levitt, 2007).

Given that this is a qualitative study that is interested in understanding women's

subjective experiences in Ontario today, it is conceptually appropriate to focus on women who

self-identify as lesbian or bisexual, rather than determining their sexual identity or orientation

through other means (such as quantifying past sexual experience or using a standardized

questionnaire). However, within political economy analyses of sexuality, sexuality is also

understood to be more than an identity or practice, as it is seen as being historical, relational

and contextual (Lancaster & di Leonardo, 1997; Altman, 2001). The focus of this study on a

particular sexual identity group is thus a "starting point" that can be used to explore in more

details the ways in which sexuality matters in the context of policy and social life. As Valverde

(1985) argues, "Sexuality is not something we 'have', our personal property that we might

choose to 'share' with others, but rather is a process in which the powers of the state, of the

scientific and moral establishments, and the sexist ideology of male defined pleasure, are

constantly meeting resistance from individuals and groups. The experience of individuals gives

them a starting point to challenge the ideas and power of those who create oppression" (17).

As a result, while I have chosen to focus this thesis on older lesbian and bisexual women, I

recognize that these may be problematic terms that are a product of recent Western culture

and discourse.

Nevertheless, I would argue that despite the indeterminacy and conceptual difficulty in

using sexuality categories, sexual identities do matter as they signal particular social relations

and are constructed in relation to dominant normalizing and organizing social processes. Thus, I

use these terms (lesbian/bisexual) strategically, to examine the material conditions and lives of

women who self-identify as lesbian or bisexual while acknowledging that in doing so I may

exclude women who have engaged in same-sex sex in the past, or are engaging in same-sex sex

in the present, if they do not self-identify as lesbian or bisexual.

The literature reviewed in this chapter has taken many different approaches to resolving

this methodological tension, including imposing sexual identity/orientation labels on

participants based on their behaviours (e.g. studies that define lesbians as women who report

having sex with women), measuring sexuality using dimensions of desires and behaviours (e.g.

studies that determine sexual identity through a combination of desires, behaviours, and

intimacies) and relying on self-identification. This review refers to all of the research collected

as research about lesbian and bisexual women, regardless of how particular research studies

have defined this category, and it uses the terms sexuality or sexualities when discussing

women's sexuality more broadly.

Social Policies and Women

To understand how older lesbian and bisexual women are affected by health and care policies, it is necessary to consider how women in general are constructed within public policies. Notwithstanding significant changes in women's roles and status in Western society in the last 50 years, traditional ideas about women continue to be influential in many contexts. In particular, many contemporary social policies and institutions depend on traditional ideas and expectations of women as mothers and (unpaid) caregivers who are inactive in the paid workforce (Bezanson & Luxton, 2006; Gazso, 2009; Carabine 1992; 2004). Some examples of these types of assumption can be seen in Canadian caregiving, labour and welfare policies that do not recognize women's unpaid caregiving as work. For example, typically this type of work is reimbursed through minuscule income tax credits, rather than through a monetary payment or through a publicly insured care program. Similarly, maternity leave policies in Canada allot individuals only 55% of their regular income and are restricted to permanent employees only. Pension supports in Canada are also income- based, such as RRSP contribution allowances and pro-rated employment pensions (Hanson, Hanson & Adams, 2001; Brodie and Bakker, 2007). While these types of policies are typically labeled as "gender-neutral" in state documents and discourse as they do not explicitly address gender, in practice these policies favour men as men are less likely to be primary caregivers and are more likely to have permanent and well-paying employment than women, who more often rely unilaterally on state support if they are the primary caregivers and/or are poor. Similar assumptions can be seen in Canadian home care policies that assume that all families will have an (female) unpaid caregiver who can provide care as needed and therefore only allot care services after family care options are exhausted.

As shown in the previous chapter, this is sometimes explicitly stated in provincial and federal

policy documents.

While all women are affected by these gender assumptions in public policy, lesbian and

bisexual women (like all LGBTQ people) are also affected by another set of expectations that

are institutionalized in public policies and systems: the assumption that the only appropriate,

healthy and normal type of sexuality is normative heterosexuality. While in Canada, same-sex

marriage has been legal since 2003 and sexual orientation has been included in the Human

Rights code since 1996, LGBTQ people in Canada continue to experience homophobic hate

speech, bias, prejudice, discrimination and outright violence and bullying in all areas of society.

In part, this occurs because of the privileging of normative heterosexuality in our social policies

and public attitudes with respect to sexuality, kinship and health (Warner, 1991; Berlant &

Warner, 1998; Morrow, 2001; Smith, 2006; Hudak, Giammattei, 2010). Warner has called this

heteronormativity. Berlant and Warner (1998) argue that "like class relations…

heteronormativity is a fundamental motor of social organization" and "a founding condition of

exploitative relations throughout even straight society" (564). Heteronormativity can be seen

operating in social policies that do not recognize diverse, non-nuclear families (e.g. birth

certificates with more than two parents or partner benefits that are extended to more than one

partner), in the continual censoring of LGBTQ materials in publishing and in social and

educational settings, in legal regulations such as age of consent laws that differ based on the

type of act (e.g. higher age for anal sex), in ongoing challenges to established LGBT rights and

hate crime legislation, and in immigration and refugee laws (Smith, 2006; Stein, 2012).

Evidence of heteronormativity can also be found in the practices and organization of our health care systems. For example, LGBTQ people and their health issues continue to be largely invisible in Canadian medical curricula and public health promotion campaigns, and the vast majority of health care admission forms, pamphlets, posters and national reporting systems continue to be heterosexist and cissexist (Goins, Pye, 2012; McDonald, McIntyre, Anderson, 2003; Mule, Ross, Deeprose, Jackson, Daley, Travers, Moore, 2009; Morrison, Dinkel, 2012).[5] All of these policies and practices continue to support the belief that only heterosexuality is "normal" or "natural" and negatively affect lesbian and bisexual women's health and well-being directly and indirectly through reduced access to health care and other social determinants of health.

While there is a significant body of literature on lesbian and gay men's health in North America, recent reviews have argued that much of this work has focused on younger adults and has primarily examined health and health seeking behaviours in primary health care settings (Boehmer, 2002; Snyder, 2011). These reviews also note that many studies to date have concentrated on quantifying rates of disease and on identifying factors that contribute to ill health rather than on examining health and health seeking behaviours with attention to intersectionality and macro and micro polices, processes and contexts (Boehmer, 2002; IOM, 2011; Mule et al., 2009). As a result, we still know little about how social determinants of health, such as age, intersect with sexualities and sexual identities, about older LGBTQ people's health, and about bisexual or transgender people's health in general.

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[5] Heterosexism refers to the belief that everyone should be heterosexual and that all other sexualities are "unnatural or deviant" (Morrison, Dinkel, 2012). Cissexism refers to the privileging of cisgender/cissexual people over transgender/transsexual people (Serano, 2007). Examples of these include admission forms that only have male/female options for gender identity and married/widowed/single for relationship status.

The available research (Brotman, Ryan, Jalbert & Rowe, 2002; CLGRO, 1997; Daley, 2006; Ramsay, 1994; Stevens, 1993), however, has consistently shown that lesbians and bisexual women seeking health care face "deeply entrenched" prejudice and stigma, as well as providers' ignorance with respect to the specificities of their lives. These prejudices include negative assumptions and stereotypes about lesbian and bisexual women, lesbian and bisexual sexualities, and lesbian and bisexual health and health needs.

Historical Context and Homosexuality

In part, the discrimination that lesbian and bisexual women encounter in health care environments stems from the historical construction of homosexuality as a mental illness that was thought to be the result of early childhood trauma or a congenital abnormality (Abelove, 2003; Herek, Chopp & Strohl, 2007; IOM, 2011; Kochman, 1997; Kimmel, Rose, Orel & Greene, 2006; Knauer, 2009). Prior to the 1970s, homosexual people were defined as essentially "mentally ill" and homosexuality was considered a psychiatric diagnosis by the American Psychiatric Association and included in its Diagnostic and Statistical Manual (DSM). While it was removed as a stand-alone diagnosis in 1973, some forms of homosexual behaviour remained in the DSM under the diagnosis of "ego-dystonic homosexuality" until 1987. Some aspects of homosexual behaviour in North America were also historically criminalized under various sex laws, including sodomy laws (Stein, 2012). As a result, many people identified as homosexual or caught engaging in same-sex behaviour were jailed, imprisoned, institutionalized and/or "'treated' with electro-shock therapy, aversion therapy, drugs, and even prefrontal lobotomies" (Knauer, 2009, p.320). As a result, many older lesbian and bisexual women grew up in a time

when homosexuality was defined as an illness to be hidden or cured, and this history has an effect on their current experiences and practices.

While homosexuality is no longer explicitly constructed as a mental illness or a criminal activity, negative and pathologizing attitudes towards LGBT people continue to exist in the general population and in the minds of medical professionals in particular (Brotman, Ryan, Jalbert & Rowe, 2008; IOM, 2011; Kimmel et al., 2006; Shankle et al., 2009; Wilton, 2000). Studies of providers' beliefs and attitudes with respect to homosexuality have consistently shown that although fewer providers today report having outright homophobic attitudes, many continue to report being "uncomfortable" with treating homosexual patients (Chapman, Watkins, Zapia, Nicole, Shields, 2012; Eliason, Raihem, 2000; Rankow, 1995; Tellez, Ramos, Umland, Palley, Skkiper, 1998). As mentioned earlier, these attitudes persists as a result of the entrenched ideology of heteronormativity in health care and other social institutions, which continues to influence ideas about "health" and normality. Furthermore, with the emergence of the AIDS crisis in 1980s, homosexuality has been re-pathologized and the focus in LGBT health care training and research has primarily centered on the prevention and treatment of sexually transmitted infections and HIV/AIDS and related medical issues rather than more broadly on health and well-being (Boehmer, 2002; Smith, Mathews, 2007).

According to Wilton (1998; 2000), the prejudices that lesbian and bisexual women encounter in the health care system is also linked to how medicine and health care systems have historically defined women's "proper sexuality" and sexual behaviour. Wilton (1998) argues that since the nineteenth century, medical science has medicalized and pathologized women's sexuality and sexual desires and that this pathologization has been especially negative

for lesbian and bisexual women, whose same-sex desires were labeled "deviant" and "sick."

While feminist and LGBTQ activists have successfully challenged much of the medicalization of

their lives, attitudes about women's sexuality and sexual behaviour have been slow to change.

Wilton and others (Daley, 1998; 2006; Ramsay, 1994) have shown that there is still little

attention paid to sexuality in general in the training of medical personnel and in the health care

system and that current health providers continue to be influenced by prejudiced views of

women and ideas about (their) "normative" sexual behaviour.

As part of this prejudice, within the medical system, sex is usually narrowly defined as

heterosexual "penis-in-vagina" intercourse and there is a "continuing silence and ignorance

about female sexuality" (Wilton, 1998, 150) and sexual behaviour in general. Within the

biomedical model of health, when women's sexuality is discussed, it is often still defined in

relation to their heterosexual reproductive abilities (Wilton, 1998; Dolan, 2005). Lesbian

women within this model of sexuality are thus by definition unhealthy or "deviant," as they are

not engaged in "reproductive sex" and are not considered to be able to or interested in having

children. These assumptions persist despite the fact that many lesbian and bisexual women do

have children through interactions with men, the use of assisted reproduction services and

through adoption.

A 1997 survey of LGBT people's experiences with health care in Ontario (CLGRO, 1997)

has found evidence of this prejudice and has shown that self-identified lesbian and bisexual

women often face systematic discrimination in health care systems in Ontario and that there is

a general lack of awareness of LGBT health issues. Experiences of discrimination that were

identified included instances of physical violence, homophobic comments and denial of care.

The participants also reported experiences of receiving inappropriate care as a result of heterosexist assumptions about women's sexual behaviour and non-heterosexual women's health related risks.

A more recent study of Canadian providers' knowledge and experiences with older lesbian and gay people has shown that this marginalization and lack of knowledge continue to exist and affects LGBT people throughout their lifespan and across Canada (Brotman et al. 2006; Brotman & Ryan, 2008). Brotman et al's study found that heterosexual health professionals were reluctant to discuss homosexuality with their clients and overall felt that sexuality was "irrelevant" to their care plans. Many did not have any knowledge or training about LGBT health issues and lives and did not feel that such knowledge was necessary, as they would treat all patients "the same." This is problematic, as treating all patients the "same" ignores systemic inequalities and prejudices that prevent individuals from being able to access appropriate care and ignores the distinct health care needs of lesbian and bisexual women.

Research on lesbian and bisexual women and their health care behaviours (Anderson, Healy, Herringer, Isaac, & Perry, 2001; Barbara, Quandt, & Anderson, 2001; CLGRO, 1997; Peterson and Bricker-Jenkins, 1996; Stuart, 2008) has shown that lesbian and bisexual women generally face barriers to receiving quality health care that is based on "trust, respect and confidentiality" (Jackson et al., 2004, 17). As a result of these types of experiences, many lesbian and bisexual women avoid accessing health care and receiving preventative care. In line with this, a recent Statistics Canada analysis of health care use by LGB Canadians (Tjepkema, 2008) found that lesbian and bisexual women were more likely than heterosexual women to

not have a regular doctor and report having an unmet health care need in the past year, and to

not have had a Pap test in the last three years.

Jackson et al (2004) and others (Andersen et al., 2001; CLGRO, 1997; Mathieson, 2007)

have also drawn attention to systemic heterosexism within the health care system, which acts

as a structural barrier that prevents lesbian and bisexual women from disclosing their sexual

identity and sharing important details about their lives. The lack of disclosure can affect

women's ability to receive appropriate medical care directly. For example, not coming out in

situations involving contagious disease, psychological health and drug and alcohol abuse may

mean that women do not get important information, immediate intervention and access to

specialists. Lesbian and bisexual women can also experience negative health outcomes

indirectly as a result of non-disclosure if given erroneous information about safe-sex practices

and improper gynecological care because of heterosexist assumptions. Furthermore, hiding and

the experience of fears related to disclosure have also been shown to contribute to poor

emotional and physical health outcomes and dissatisfaction with health care in general as a

result of increased feelings of stress, fear and the avoidance of health care interactions

(Brotman, Ryan, Jalbert, Rowe, 2002; IOM, 2011; Solarz, 1999). Given the period in which they

grew up, older women have an historical legacy that may well make it worse for them.

According to Daley (1998, 106), "the assumption of heterosexuality is a powerful force,

which shapes the experiences of lesbians [and bisexual women] and functions to limit the

quality of their health care interactions." Reviewing hospital records in Toronto, she notes that

knowledge about lesbian health and concerns is often fragmented and that women's sexuality

is typically seen as something that is relevant to a medical diagnosis on an individual level,

rather than as representing a community with similar health concerns and stresses. Moreover, heterosexuality is still assumed to be the norm, until found otherwise, putting the onus on individual women to come out to their health care providers.

Research in both U.S. and Canadian contexts (Andersen et al., 2001; Brotman, Ryan, Jalbert & Rowe, 2003; Mathieson et al., 2002; Petersen & Bricker-Jenkins, 1996; Stevens, 1993) has shown that past experiences of homophobia and violence in the health care system often cause lesbian and bisexual women and other GBTQ people to be wary of coming out to their health care providers, choosing instead to "pass as heterosexual" when accessing or receiving care. However, by "passing," lesbian and bisexual women often receive improper and uncomfortable treatment and care. This often puts women in a "double-bind" and affects their ability to access health care and support (Daley, 2010).

Multiple studies have found evidence of lesbians and bisexual women receiving prejudicial, improper or poor quality health care (CLGRO, 1997; Daley, 2010; Eliason, 1996; Eliason & Schope, 2001; Lesbians and Breast Cancer Project, 2004; Mathieson, 2007; Mravcak, 2006; Saulnier, 2002; Sinding, Barnoff & Grassau, 2004). These affect both women who identify as lesbian or bisexual, and women who do not, but who engage in sexual behaviours or relationships with women. These include inappropriate guidance regarding birth control, sexual health and reproductive care, as well as limited access to preventative screening measures such as pap smears and mammograms as a result of assumptions about health risks. Upon disclosure of a lesbian or bisexual sexuality, women have also reported being subjected to homophobic behaviours such as demeaning comments, avoidance of physical contact and even breaches of confidentiality (ibid). Furthermore, a common finding across studies of lesbian and bisexual

women's health care experiences is that disclosure is often also met with the negation or dismissal of lesbianism or bisexuality as a valid identity, which can compromise women's ability to get supportive and appropriate care.

While there are no illnesses that are unique to lesbian and bisexual women as compared to heterosexual women, there is some evidence that lesbian and bisexual women may be more at risk for developing chronic health problems as a result of having higher rates of several risk factors and the avoidance of health care interactions (Dibble, Eliason, Christiansen, 2007; IOM, 2011). For example, lesbian and bisexual women have been found to have higher rates of smoking, alcohol and drug use, higher body mass indexes and lower pregnancy rates than their heterosexual peers (Andersen et al., 2001; Bergeron, 2003; Denenberg, 1995; IOM, 2011; Mathieson, Bailey, & Gurevich, 2002; Mathieson, 2007; Solarz, 1999). All of these are known risk factors for cardiovascular disease, stroke, cancer and other chronic illnesses. There is also some evidence that as a result of these risk factors, lesbian and bisexual women may have higher rates of cervical and breast cancers than heterosexual women.

There have not been any large scale, longitudinal, or epidemiological studies of lesbian and bisexual women's health to date (Solarz, 1999; IOM, 2011). However, a recent survey of cancer prevalence in California (Boehmer, Miao, & Ozonoff, 2011) has found that while lesbian, bisexual and heterosexual women have comparable rates, lesbian and bisexual women report significantly poorer health outcomes after accessing cancer care. It is possible that lesbian and bisexual women have poorer health than heterosexual women as a result of higher risk factors, poorer access to health care, or a combination of the two. Lesbian and bisexual women, like other GBTQ people, have also been found to experience high rates of sexual violence and abuse

and poor mental health, which have a negative effect on health and quality of life (Bergeron, 2003; Denenberg, 1995; Andersen et al., 2001; Mathieson et al., 2002; Mathieson, 2007; Solarz, 1999). A recent review by Diaz-Granados, Ross, Azar, Cheng, Coulombe, & DesMeules et al (2006) suggests that lesbian and bisexual women may experience a higher vulnerability to depression than heterosexual women as a result of experiences of homophobia and barriers in accessing mental health services.

Bisexual women in particular have been shown to experience marginalization as a result of biphobia within mainstream and LGBTQ organizations and services (CLGRO, 1997; Dobinson, MacDonnell, Hampson, Clipsham, & Chow, 2005; Tjepkema, 2008). Biphobia is the fear and hatred of bisexual people, or people who experience sexual and romantic feelings towards, and form relationships with, both men and women. One example of biphobia is the labeling of bisexuality as an "immature" or transitional sexuality, rather than a stand-alone and valid sexuality or sexual orientation (Diamond, 2008; Ochs, 1996). Some bisexual people may internalize biphobia and feel that they need to hide their bisexuality and publicly identify as heterosexual or homosexual, depending on their current partner. In general, we know less about bisexuality and bisexual people's health than we do about gay and lesbian sexualities and health, and the existing research on bisexual health has primarily focused on mental health and HIV/AIDS (Kaestle & Ivory, 2012). The available research shows that bisexual people generally experience higher rates of anxiety and depression than both heterosexuals and gays and lesbians (Fredriksen-Goldsen, Huyn-Jun, Barkan, Balsam & Mincer 2010; Jorm et al., 2002; Davis & Wright, 2001). Research has found that bisexual women are more likely to experience mental distress and poor health than lesbian women (Fredriksen-Goldsen et al., 2010; Steele, Ross,

Dobinson, Veldhuzien & Tinmouth, 2009; Tjepkema, 2008). Bisexual women, like lesbian women, also report discriminatory treatment and often receive inadequate health care as a result of assumptions about their partners and sexual health (CLGRO, 1997; Dobinson et al., 2005).

Sexual Minority Stress

It has been suggested that as a result of experiencing negative and violent reactions LGBTQ people often engage in identity management processes, which involve deciding when and how they will disclose their sexual identity and when it is "safe" to do so in various social situations and contexts (Laaser & Tharinger, 2003; Jenkins, Walker, Cohen, & Curry, 2010). This type of identity surveillance may contribute to LGBTQ people's everyday level of stress and negative mental health outcomes.

Some researchers have further argued that the stress and isolation that lesbian and bisexual women (and GB men) experience as a result of living in a heterosexist and homophobic society should be considered a health determinant in and of itself (IOM, 2011; Mathieson, 2007; Meyer, 2003; Meyer & Northbridge, 2007; Solarz, 1999). These authors argue that as a result of direct and indirect forms of discrimination and violence, lesbian and bisexual women may experience a lifetime of high rates of stress, which can negatively affect their ability to maintain good health and quality of life. The lifetime of high stress and limited access to health care and other social determinants such as income may have a particularly negative effect on lesbian and bisexual women as they reach older ages due to the cumulative effects of experiencing a lifetime of poor health and stress (Brotman & Ryan, 2008; Brotman et al., 2006; Cruikshank 2009; Grant, 2010).

Race, Racialization, Ethnicity and Culture

Much of the research on lesbian and bisexual women in North America has focused on white, English-speaking, middle-class women and our knowledge of the experiences and challenges faced by women of more diverse racial/ethnic, class and cultural backgrounds is limited (Cruikshank, 2009; Greene, 1997; Wilson & Yoshikawa, 2007). As a result, the ways in which race/ethnicity and culture affect older lesbian and bisexual women's experiences of aging and health and their experiences of gender and sexuality has largely been unexplored (Greene, 1997; Cruikshank, 2009; Mathieson, 2007). This is problematic, as these are considered to be important social determinants of health and are "major dimensions around which people organize their assumptions about who they are in the world" (Greene, 228, 1997).

Research on women's health and health care in general has shown that racism, nativism and language barriers all negatively influence women's health and their ability to access quality health care services in Canada (Greene, 1996; Hyman, 2009; Morrow, Hankivsky, & Varcoe, 2007; Nestel, 2012). As a result of these barriers, racialized women in Canada experience poorer health status and have higher rates of chronic illnesses such as HIV/AIDS, diabetes, cardiovascular diseases and cervical cancer than white women. Immigrant women and racialized women have also been shown to be less likely to have a regular physician and access to preventative health care services such as cancer screenings and mental health services (Hyman, 2009; Nestel, 2012). As a result of experiencing multiple traumas, violence, stress and social isolation, immigrant and refugee women in particular have poor mental and physical health outcomes (Hyman, 2009; Farmanova-Haynes, Bose & Vissandjée, 2006). It has also been shown that racism (like homophobia) indirectly influences women's health by affecting their

access to social determinants such as education, housing, job opportunities and income

(Hyman, 2009; Nestel, 2012).

Data on the health of racialized LGBTQ people is sparse and a recent review of LGBTQ

health studies revealed that 85% of the studies reviewed did not mention race or ethnicity in

their analysis (Boehmer, 2002). A recent report on LGB health in the United States, however,

noted that racialized LGB people are more likely to delay seeking medical care and getting

prescription medications and less likely to have access to routine health care and preventive

screening measures such as mammograms than white LGB people (Krehely, 2009). Research on

racialized lesbian and bisexual women has shown that they have lower rates of health care use

and report higher rates of victimization and risk factors, such as tobacco and alcohol use, than

white lesbian and bisexual women (Balsam & D'Augelli, 2006; Grant, 2010; Mays, Yancey,

Cochran, Weber, & Fielding, 2002; O'Shea, 2009). They have also been shown to experience

high rates of major depression and anxiety disorders (Krehely, 2009; Ramsey, Hill & Kellam,

2010; O'Shea, 2009). Furthermore, a recent study of Hispanic lesbian and bisexual women has

found that they experience higher rates of smoking, asthma, and disability as compared to

Hispanic heterosexual women, that Hispanic bisexual women have higher rates of lifetime

mental distress than white bisexual women, and that Hispanic lesbians had higher rates of

asthma than white lesbians (Kim, Fredriksen-Goldsen, 2012). These findings suggest that both

sexuality and racialization can exert specific and negative effects on the health of racialized

lesbian and bisexual women.

Racialized lesbian and bisexual women may experience homophobia and isolation not

only in relation to mainstream society, but also in relation to their ethno-racial communities,

which may be particularly harmful as these communities provide protection from racism experienced in the rest of society. Greene (1994) and others (Stevens, 1998; O'Shea, 2009; Kim, Fredriksen-Goldsen, 2012) have suggested that racialized lesbians women are subject to multiple stigmas and stressors as a result of their intersecting marginalized status. They propose that these multiple stressors negatively affect their mental health. It is likely, therefore, that racialized older lesbian and bisexual women may be even more likely to experience poor health as a result of multiple, intersecting oppressions and the cumulative effects of a lifetime of unequal access to social and health determinants such as education, housing and income.

Class and Income

Class, which is often defined in terms of access to income, has been shown to have an impact on lesbian and bisexual women's health (Cruikshank, 2009; McDermott, 2006; Meyer, Frost & Schwartz, 2008). While access to health care in Canada is less dependent on income than it is in the United States due to Canada's universal health insurance system, income still affects Canadians' ability to pay for prescription medication, dental care and other extended health care services that are not publicly funded in Canada. This includes some home care and supportive care services, nursing home care, rehabilitation services, assistive devices and some medical procedures. As mentioned in the previous chapter, while some home care services are paid for in Canada, the type of service and eligibility criteria vary across the provinces and territories. Furthermore, publically paid home care services in Canada are rationed, and there is evidence that the demand for services exceeds the amount provided (CHCA, 2011; Auditor General of Ontario Report, 2010; Ontario Health Coalition, 2011; Kohli, 2009 [thesis]). As a

result, it is likely that women who need additional medical or supportive care at home may experience worse health outcomes if they are unable to purchase care privately. Finally, income level can also affect individuals' health indirectly, through access to nutritious food, quality housing and effective education.

There is evidence that older lesbian and bisexual women are generally poorer than older heterosexual women and that lesbian couples are poorer than heterosexual or gay couples (Albeda, Badgett, Schneebaum, Gates, 2009; Wallace, Cochran, Durazo, Ford, 2011; Fredriksen-Goldsen, Kim, Emlet, Muraco, Erosheva, Hoy-Ellis, Goldsen & Petry, 2011). A recent Canadian survey of gay and lesbian people over 65 years old has also found that 42% of older lesbians reported incomes below the poverty line, as compared to 14% of gay men (McKee, 1999). Moreover, given that there is evidence that LGBTQ people continue to experience discrimination in employment and that women historically tend to earn less than men and have less access to occupational pensions, it is likely that older lesbian and bisexual women are poorer than heterosexual women or gay and bisexual men.

Some researchers have further suggested that "class mediates experiences of health" (Fish, 8, 2008) for LGBTQ people and that access to higher incomes can also ameliorate some of the negative consequences of racism, sexism and homophobia (Cruikshank, 2009; Fish, 2008; Gabrielson, 2009; Krieger, 2001; Solarz, 1999). This amelioration may explain why some studies of LGBTQ health that have primarily focused on the experiences of younger, more affluent and educated adults have not shown as many negative health outcomes or as much underutilization of services as researchers had expected (Brotman et al., 2003; 2008; Gabrielson, 2009; Hash, 2001; Massini & Barret, 2008).

Class, however is more than just access to material wealth and can affect one's health in more ways than influencing access to goods and services. Class also mediates other aspects of one's identity and experiences and relates to one's ability to advocate for oneself, seek appropriate help as needed and "be taken seriously" by health professionals (Cruikshank, 2009; Krieger, 2001; McDermott, 2004; Mayer, Bradford, Makadon, Stall, Goldhammer, & Landers, 2008; Portacolone, 2011; Sinding, Hudak, Wiernikowski, Aronson, Miller, Gould & Fitzpatrick-Lewis, 2010; Taylor, 2005). Upper and middle-class people are privileged as they have both "cultural capital" (Skeggs, 2004), which includes the knowledge of how to access and navigate social systems, and economic capital, which can supplement the care available in the public sphere. As a result, class status may confer privilege on and support some older lesbian and bisexual women, while leading to problems for others.

Aging

Within mainstream and gerontological discourse, all older people are seen as potentially in need of care (Arber, 1998; Higgs & Jones, 2009). Aging in western societies is typically constructed as pathological and treated as a medical problem, rather than as something that is simply part of the life-course. Older people are also often seen as economically and socially redundant and as a burden on society. This dominant view of aging as a problem is the result of widespread ageism in our society, which can be defined as discrimination and structural disadvantages based on negative attitudes associated with advancing age (Arber, 1998, 57; Higgs & Jones, 2009). These beliefs about older people and their care needs are important to note, as they are often used to justify neoliberal reforms and cuts to care services that I discussed in the previous chapter (Gee, 2002; Glenn, 2010; Health Canada, 2010).

Within the Canadian health care system, emphasis is placed on preventing death and treating the clinical problems that are associated with age, a phenomenon that has been labeled the *biomedicalization of aging*. This type of care paradigm privileges the use of medical, pharmaceutical and surgical treatments over supportive care and often ignores how social, environmental and behavioural factors can influence "the process and experience of aging" (Arber, 1998, 58). The resulting focus on acute intervention in the health care system has had an especially negative effect on older women, who often experience chronic illnesses and disability (Armstrong et al., 2001; Cruickshank, 2009; Grant et al., 2004).

Important differences exist in the experiences of aging for men and women. Women's roles in pregnancy, childrearing and caregiving within families, for example, influence their health and quality of life as they age (Armstrong & Kitts, 2001; Calasanti & Slevin, 2001; Cruikshank, 2009). Women's life experiences as they age are also shaped by their greater longevity and their lifetime vulnerability to poverty (Calasanti & Slevin, 2001; Morris, 2001; Morris, 2004; Morris, Robinson & Simpson, 1999). Women have different rates of diseases such as cancer, cardiovascular disease and osteoporosis and experience different symptoms and disease progression (Bierman, 2007; Bierman, Ahmad, Angus, Glazier, Vahabi, et al., 2009). While women generally live longer than men, they are more prone to suffer from chronic diseases in older ages, which negatively affect their quality of life and well-being (Belgrave, 1993; Henderson, 1998; Maxwell, Leger, Hirdes, Ellis-Hale & Tjam, 1998). All of these factors contribute to older women's vulnerability to poor health and their increased need of social and health care support services as they age.

Older women experience different health symptoms and disease patterns and behaviours than men do (Belgrave, 1993; Cruikshank, 2009; Doyal, 1995; 2001; Henderson, 1998). For instance, women are more likely to suffer from chronic, debilitating day-to-day symptoms while men are more likely to develop life-threatening illnesses (Belgrave, 1993; Cruikshank, 2009). Older women have been found to visit doctors more often and access more preventative services than men (Henderson, 1998). Women are more likely than men to be institutionalized in old age, have longer lengths of stay in hospitals and fill the majority of nursing home beds (Banerjee, 2009; Henderson, 1998). Older women are also over-prescribed drugs in general and consume twice as many tranquilizers, sedatives, hypnotic drugs, vitamins, diuretics and laxatives than do older men (Henderson, 1998; Maxwell et al., 1998).

Ageism in the health care system has been found to affect women's patient-doctor relationships in several ways. Older patients are typically viewed as more difficult to deal with than younger patients and physicians tend to spend less time with older patients and attribute pathological problems to the normal aspects of aging. Physicians also tend to view older women's symptoms as being the result of "natural aging decline" or psychogenic processes, rather than attributing them to treatable medical causes, making prevention and/or aggressive treatment less likely to be employed (Sharpe, 1995; Henderson, 1998; McCandless & Connor, 1999; Cruikshank, 2009).

The fragmentation of health care and the biomedical focus on "curing disease" does not adequately equip physicians to treat older women's chronic conditions, which may be complicated by specific social and emotional contexts (Belgrave, 1993; Cruikshank, 2009; Henderson, 1998; Higgs & Jones, 2009; McCandless & Connor, 1999; Sinding & Wiernokowski,

2008; Weitz & Estes, 2001). Furthermore, recent evidence suggests that despite the pressing

need to consider how age matters in relation to individuals' experiences of health and to health

care provision, geriatric education in medical schools in Canada remains minimal at best

(Monette & Hill, 2012).

Myths and stereotypes also exist about the sexuality and sexual behaviour of older

people. This includes the belief that older people are sexually undesirable, are unable to have

sex, have inappropriate sexual feelings or have no sexual desires (de Vries & Blando, 2004;

Kaye, 1993; Brotman & Ryan, 2008). Barker (2004) notes that "there is a general tendency to

de-sex and de-sexualize the elderly as well as to depict them as a bundle of health problems

waiting to happen, if not already being manifest, [which] results in a view of old people as

androgynous, dependent and ineffectual" (53). Consequently, older people in general and

older women in particular are erroneously believed to be asexual or not interested in sex

(Hodson & Skeen, 1994). Contributing to this general inability to conceive of elderly people as

having a sexuality is the widespread assumption of heterosexuality in social policy and social

research on older people (Carabine, 1992; Daley, 2006; Heaphy, 2007). Due to these myths and

assumptions, traditional gerontological research has paid little attention to non-heterosexual

aging and the experiences of older LGBTQ people (de Vries and Blando, 2004; Fredriksen-

Goldsen & Muraco, 2010; Heaphy, 2007; Morrow, 2001; Shankle et al., 2003).

The existence of lesbian and bisexual elders in society raises the issue of sexuality

directly, as lesbian and bisexual women are differentiated by their "non-normative" sexuality

(Barker, 2004). Lesbian and bisexual women are thus somewhat of a "paradox" for

gerontological literature as older women are generally thought to be "asexual," while lesbian

and bisexual women are defined by their "unusual sexuality" (Fullmer et al., 1999). Both feminist and mainstream research on women's aging and health has historically assumed that heterosexuality is the norm and has devoted little attention to non-heterosexual women's aging. Few studies have also considered how processes and experiences of aging are constructed by and affected by sexuality and sexual identities (Barker, 2004; Cruikshank, 2009).

Furthermore, although in recent years the scientific literature has paid more attention to non-heterosexual aging, some of this research has "lumped" the experiences of lesbian and bisexual women with those of gay and bisexual men and/or transgender people. This lumping of LGBTQ populations is problematic, as while LGBTQ people may share oppression on the basis of sexuality, they may have markedly different patterns of aging and disease as a result of gender (Barker, 2004; Grant, 2010).

For example, recent surveys of older LGBT people in the United States (Wallace, Cochran, Durazo, Ford, 2011; Fredriksen-Goldsen, Kim, Emlet, Muraco, Erosheva, Hoy-Ellis, Goldsen & Petry, 2011) have found that older lesbian and bisexual women were poorer and have more psychological distress and physical disability than gay and bisexual men. Women were also more likely to delay seeking care and obtaining prescription medication. Consequently, it has been suggested that lesbians and bisexual women and gay and bisexual men need to be examined separately as the latter group may have higher incomes and greater access to social support in the LGBTQ community, partly as a result of historical community building and activism around HIV/AIDS (Brotman & Ryan, 2008).

When considering the experiences of older lesbian and bisexual women today, it is important to bear in mind the relevance of cohort. The current cohort of lesbian and bisexual

women aged 55 years old and over grew up and reached adulthood prior to the decriminalization of homosexuality in North America and during a time of major changes to LGBTQ and women's rights. Consequently, much of the gains that have been made for LGBTQ civil rights have occurred fairly recently in the lives of older people and have not had the same kind of effect on them that they have had on younger LGBTQ people (Brotman & Ryan, 2008; Cook-Daniels, 2008; de Vries & Blando 2004). As a result, the legacy of a lifetime of persecution and pathologization lingers and affects many older LGBTQ people, who are often more closeted and isolated than younger LGBTQ people (de Vries & Blando, 2004; MetLife, 2006).

Cohort differences also matter in relation to women's gender and sexuality identities and practices. Depending on the context where women developed their sexuality, the particular labels that they choose to identify with and the degree with which they may be connected to LGBTQ communities and be "out" varies. Accordingly, while this is a cohort that for the most part reports being happy and stable, it includes many people who retain the fear and shame of being "outed" as homosexual, which can affect their ability to access quality care and social services (Brotman & Ryan, 2008; Cook-Daniels, 1997; D'augelli & Grossman, 2001; Grossman, D'augelli & O'Connell, 2001; Morrow, 2001).

While some studies of older LGBTQ people have touched briefly on the health and wellbeing of older women (e.g. Grant, 2010; Brotman et al., 2003; 2006), these have primarily been small scale studies which were survey or focus group-based, rather than large interview-based, ethnographic or epidemiological studies (Barker, 2004; Brotman & Ryan, 2008). As a result, we still know very little about how older lesbian and bisexual women experience health and their unique issues outside of primary care. Research on lesbian aging and on younger

lesbian and bisexual women's health suggests that older lesbian and bisexual women's health is negatively affected by a lifetime of experiences of homophobia and heterosexism and the avoidance of routine health care services (Brotman & Ryan, 2008; Grant, 2010). It is likely, therefore, that older lesbian and bisexual women experience marginalization and discrimination in older age and may have poor health and quality of life as a result.

The available research on older lesbian and bisexual women health has shown that they, like younger women, avoid using formal health care and social services (Brotman et al., 2006; Brotman & Ryan, 2008; CLGRO, 1997; Grant, 2010; Ross, Scott & Wexler, 2003; Richard & Brown, 2006). Many report being subjected to discrimination and insensitive treatment by health care providers when they do attempt to access care (Boehmer & Case, 2004; Hash, 2006; Brotman et al., 2003; 2006; Cook-Daniels, 1997; Jowett & Peel, 2009; Ross, Scott & Wexler, 2003). Older lesbians have also been found to be more likely not to have children and to live alone in older age than heterosexual women, which may make them more vulnerable to poverty and social isolation (Grant, 2010; Morrow, 2001; Solarz, 1999). In addition, there is evidence that attitudes and experiences of aging and health vary widely among older lesbians and may be linked to social inequalities such as race and class (Barker, 2004; Cruickshank, 2009; Ross, Scott & Wexler, 2003; Reid, 1995).

Brotman and Ryan (2008) have proposed that older LGBTQ adults tend to overestimate how good their health status is and their ability to cope with the challenges of aging, as a result of mistrust of formal services and a pattern of lifetime self-reliance. Davies et al (Davies, Addis, MacBride-Stewart, & Shepherd, 2006) have further added that LGBTQ people are "less likely to complain about the quality or appropriateness of services because of fears of being out-ed

against their will" (43). As a result, older lesbian and bisexual women may delay accessing care

when they need it or not complain about receiving poor care and become more isolated and ill

as a result.

Sexuality and sexual orientation have been shown to be "missing" in current Canadian

(and American) LTC policies and in the training of LTC workers, case managers and health care

providers (Brotman et al., 2006; 2007; Fredriksen-Goldsen & Hooyman, 2007; Harmer, 2000;

Morris et al., 1999; Morrow, 2001). This gap in research and policy persists despite evidence

that sexual orientation in general is seen as a barrier to accessing supportive housing and care

services by older LGBTQ people, many of whom feel that they would have to "go back into the

closet" when entering a care home (Brotman et al., 2006; Chamberland, 2003; De Vries,

2005/2006; MetLife, 2006; Stein, Beckerman, & Sherman, 2010).

While LTC provision is an important concern for many older LGBTQ people, older lesbian

and bisexual women may be more likely to require these types of services due to their patterns

of longevity and the greater use of such services by women than men (Banerjee, 2009; Grant et

al., 2004). The current cohort of older lesbian and bisexual women is also less likely than their

heterosexual peers to have had children who could assist with caregiving (Brotman et al., 2006;

Grant, 2010; Morrow, 2001; Solarz, 1999). Moreover, as older lesbian and bisexual women may

be more likely to be poorer than older gay and bisexual men as a result of women's greater

vulnerability to poverty, they may require government assisted LTC services more than other

populations (Calasanti & Slevin, 2001; Cruikshank, 2009; Gabrielson, 2011; Morrow, 2001).

As far as I can ascertain, there are currently no assisted-living residences or adult day

care programs in Canada (and only a handful in the United States) that are specifically for

LGBTQ people and few that are outwardly LGBTQ friendly (Cahill & South, 2002; Brotman et al., 2006; 2007; Moore, 2009). While there is one hospice, *Casey House*, in Ontario that is LGBTQ-friendly, it is HIV-AIDS specific. There have also not been any published studies that have examined the experiences of LGBTQ people in these types of LTC environments in Canada or that have explored what (if any) sexual and gender diversity policies and training exists within LTC provider agencies and residences. However, a recent survey of LTC workers' attitudes in a U.S. residential care facility (Hinrichs & Vacha-Haase, 2010) has found that staff reacted more negatively to vignettes describing potential non-heterosexual sexual contact among LTC residents than to vignettes describing heterosexual contact. LTC workers were also found to be less accepting of the possibility of non-heterosexual contact among residents in general, regardless of individual workers' knowledge of aging and sexuality.

Conclusion

The purpose of this chapter was to review relevant literature on lesbian and bisexual women's health, aging and access to health care. The literature reviewed above suggests that older lesbian and bisexual women using LTC services currently may experience barriers to accessing care, marginalization and homophobia. Furthermore, it is likely that many women may opt for home care as a way to stay in their homes and avoid possible discrimination or abuse in a residential care environment (Aronson, 1998; Brotman et al., 2006; Grant, 2010). However, as Morris et al (1999) notes, home care recipients may be more vulnerable to abuse as "prejudices and stereotypes are especially prevalent in home care, where the focus is on very personal and intimate services provided in someone's own home" (64).

Given that there is no national standard or mandate for including gender and sexual orientation sensitivity training for LTC providers in Canada, older lesbian and bisexual women may be especially vulnerable when receiving home care services (Brotman et al., 2006; 2007; Moore, 2009; Morris et al., 1999). As older women are the primary users of home care in the general population, it is likely that older lesbian and bisexual women may have an increased need of these services than other LGBTQ people. As a result, it is necessary to examine the current experiences of older lesbian and bisexual women who are receiving home care to determine whether they experience any barriers to quality care and whether the current organization and delivery of these services adequately supports them and their communities.

Chapter 4: Methodology and Methods

In this chapter I describe the methods that I have used in this study. I begin the chapter by providing an overview of the conceptual frameworks, the objectives of the research and the research questions that guided the data collection. I then describe the research design, the single case study and the measures used to collect the data. I also review the participant recruitment process and timeline. I then discuss the steps taken to collect, transform and analyze the data. Finally, I discuss the issue of theorizing about sexuality and sexual orientation and present some details with respect to variety of identities and home care experiences captured in this study. A description and detailed discussion of the socio-demographic characteristics of the study participants is provided in the next chapter.

Conceptual and Theoretical Framework:

This study is informed by a feminist political economy perspective (FPE) (Armstrong & Connelly, 1989; Vosko, 2003; Bezanson & Luxton, 2006) and builds upon earlier feminist critical analysis of women's health and aging (for examples, see Armstrong et al., 2001; Armstrong & Armstrong, 2003; Doyal, 1995; Grant et al., 2004; Morrow et al., 2007). Feminist political economy is an approach that argues that political power and economic control are deeply interconnected and maintains that it is necessary to examine gender and gender relations within different socio-economic and political structures, processes and discourses (Armstrong, Armstrong & Coburn, 2003). Further, FPE links reproduction and caregiving activities to production and attends to women's voices and experiences. As Murphy (2009) further argues, such an approach "reveals and clarifies how gender determines or influences the social and

political relationships and structures of power, and the differential economic effects that flow

from these relationships and structures." (4)

   This is a particularly useful theoretical framework for examining health care, as it

supports a critical investigation of the dominant neoliberal assumptions that are embedded in

our current health care policies, systems and delivery mechanisms. These assumptions include

the belief that health care should be managed and organized based on for-profit business

models and that health is an individual responsibility, rather than a social right. Consequently,

adopting an FPE approach ensures that analyses of policy attend to the historical, social,

cultural and political contexts that shape systems, relationships and spaces of care.

   FPE is a suitable theoretical framework to use in this study as it allows for the

investigation of how contemporary policies, discourses and organizational processes construct

and shape the home care experiences of older lesbian and bisexual women. The attention to

policy is especially relevant for this study as this project examines an area of health care that

has undergone major restructuring under the assumption that this would improve the quality

and efficiency of care. However, as discussed in chapter 2, these changes were implemented

without considering the full effects that they may have on users of home care. The use of this

framework allows for the inclusion of care users' perspectives as "evidence" that can be used to

challenge the neoliberal assumption that underlie these reforms and bring forth users'

definitions of quality care.

   Alongside FPE, this study also incorporates LGBT and queer studies frameworks to

address health, care and LGBTQ people with a specific focus on lesbian and bisexual women.

This allows me to explore how sexuality and gender are socially constructed through current

social practices and policies, as well as show the material effects of these on individual

women's lives. As Lancaster and di Leonardo (1997) argue, this type of historical political

economy analysis "neither reduces sexual expression to a consequence of 'material life' –as if

sexual bodies were not material—nor imagines that human sexual and reproductive lives can

be considered apart from the changing political economies in which those lives are embedded"

(4). The inclusion of these perspectives is especially relevant to this project given the literature

review presented in chapter 3, which showed that the widespread heteronormativity and

heterosexism in the health care system and in everyday life, along with neoliberalism, has

material effects on lesbian and bisexual women's health. The integration of LGBT and queer

studies scholarship also ensures that the analysis of sexuality in this study is grounded in an

understanding of sexuality as relational, historical and contextual.

Study Objectives and Research Questions:

This study is an exploratory project and has three main objectives. The primary goal is to

investigate the experiences of older lesbian and bisexual women who currently access and use

publically provided home care services in Ontario. The secondary objective is to investigate the

impact of women's sexualities and sexual identities on their experiences of accessing and

receiving home care services. The third and final goal is to investigate how older lesbian and

bisexual women define "quality home care" in order to provide recommendations that can be

used in the creation of health care policy, planning and delivery in the future.

As mentioned in the previous chapters, little research exists on this topic, despite

evidence that this group of women may face challenges in accessing and receiving appropriate

and competent care in other areas of health care services. This study aims to fill this gap by

obtaining rich and thick description of the experiences of a group of older lesbian and bisexual women living in Ontario. However, to ensure that the data collection and analysis were able to address the three study objectives, the data collection was also guided by seven questions (See Appendix C).

Research design

I chose to use a qualitative research design in this study. A qualitative method was the most appropriate choice for this study for two reasons. First, this is an exploratory study that is interested in obtaining an in-depth description and understanding of an experience, rather than in classifying, quantifying or testing out a particular theory. Second, this is a study of a population that is typically obscured and invisible in health care research and policy. The choice of qualitative methods was therefore useful to foreground the voices of this group of women by examining their experiences using an interpretive approach that seeks to understand individuals' lives by focusing on their voices in their real-life settings (Denzin & Lincoln, 2000).This methodological approach also fits with the conceptual framework for this project, as it allows me to explore the meanings that individuals ascribe to their experiences, while being conscious of how particular social, economic, and political contexts and processes inform this meaning (Maxwell, 2005). This supports an approach to policy research that is "bottom-up," one that is interested in exploring the perspectives of individuals who are affected by policies and systems of power or "policy actors."

Case Study Design

Given that this is an exploratory study, an embedded single case study design was chosen as the methodological approach (Yin, 2003). This was chosen over other qualitative

approaches such as grounded theory or institutional ethnography as the aims of this study were to obtain a description of a particular experience (home care) and to apply a particular theoretical framework (FPE) to this experience. Given that the aims of this study are also framed within a particular historical and theoretical context, the case study is the most appropriate methodological approach. As Yin (2003) argues, case study designs are particularly useful when the research is guided by an explicit theoretical framework and when the goal of the research is to "deliberately cover contextual conditions—believing that they might be highly pertinent to your phenomenon of study" (13).This type of research approach seeks to answer "how" and "why" questions within a particular context.

The Case Study. For the purposes of the case study, the case in question is the experience of older lesbian and bisexual women receiving home care in Ontario currently. The case is therefore bounded by a particular age (over 55 years old), gender (female), sexuality (lesbian or bisexual), geographic location (Ontario), care type (public home care) and time period (received or accessed services from 2004 to 2012).[6] Establishing these particular parameters ensured that participants' experiences were constrained by a similar policy and delivery context and increased the credibility of the analysis.

Using Yin's (2003) description of the application of the case study method, this research followed five steps that were used to ensure rigour and provide a "logical model of proof" for this study (Nachmias and Nachmias, qtd. in Yin, 2003, 21). First, the study's questions were formulated through an initial review of the literature on LTC, health care, sexuality, gender and political economy. Second, the propositions were developed using the review of the literature

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[6] Age 55 was chosen as the minimum cut-off as this is the age at which one becomes eligible to receive 'senior' community services in Canada.

and the conceptual framework. These propositions were then developed into the study objectives and were used to determine the questions in the interview guide. Third, the unit of analysis was defined as a single case study with multiple, embedded units of analyses. The units of analysis are the experiences of individual participants in the study who are considered to be key informants with unique and specific information pertaining to the case study questions. The embedded design was chosen over the holistic single case (single unit of analysis) design in order to increase the complexity of the analysis and to incorporate multiple individuals' perspectives, thus increasing the intersectionality and complexity of the analysis. Step 4, linking the data to the study propositions, and step 5, establishing criteria for interpreting the findings, are described in more detail below.

Research Procedures

Participant recruitment began once ethics approval was obtained, starting in March 2011, and continued until 16 interviews were completed and saturation was reached (Guest, Bunce, & Johnson, 2006). The first interview was held in May 2011 and the last one in July 2012 (see Appendix A for interview dates). Given that the population in this study is a sensitive and hidden population (Platzer & James, 1997), achieving a random sample was impossible. Furthermore, as this was an exploratory study, having a random sample of participants was also not necessary. Instead, a mixture of snowball and purposive sampling was used to obtain the group of study participants.

Initial recruitment consisted of identifying agencies, social and community groups and clubs serving older adults and LGBTQ people in Ontario[7]. These were then contacted by email and/or in person and electronic and printed flyers were distributed in the locations where permission was granted to do so. Information about the study was also distributed electronically via a variety of Ontario-based women's, LGBTQ and older adults' list serves and online forums (see Appendix H for list of all groups and organizations where information was distributed). To increase the diversity of perspectives in the data, I also specifically targeted social and service organizations that primarily served marginalized, racialized and aboriginal people.

Additional contacts were also made with health professionals, community members and service organizations at three conferences while presenting preliminary data from the project (Ontario Long Term Care Research Day in November 2011; Rainbow Health Ontario Conference in April 2012; Institute of Gender and Health Conference in October 2012); information about the study was subsequently distributed over email to these contacts. Finally, at the end of each interview, participants were asked about relevant service agencies or community organizations and were provided with paper flyers with study information to pass on to other potential participants.

This study has the following inclusion criteria: (a) gender identity: participants had to self-identify as women (transgender and transsexual women were eligible to participate in the study but none were recruited and as a result all of the participants in the study are cisgender women); (b) age: participants had to be at least 55 years old; (c) sexual orientation: participants

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[7] See Appendix for a list of all agencies, groups and list-serves that were contacted and where information about the study was distributed.

had to self-identify as lesbian or bisexual (or a related term, e.g. gay); (d) geographical location:

participants had to have lived in Ontario when receiving public home care (because home care

is provincial); (e) time period: participants had to have attempted to access and/or received

home care services in the last five years (2008 - 2012)[8, 9] Public home care services were

defined as any type of care service that was provided in the home to participants by formal

caregivers, rather than only by friends and/or family; these services included therapy,

homemaking, nursing and any other medical or supportive care that was not paid for privately.

All participants underwent a telephone screening to ensure that they met these criteria before

an interview was scheduled.

Data Collection

Multiple sources of data were collected for this study. This was done for the purposes of

data triangulation, or the practice of collecting multiple types of data and integrating these

together in the analysis in order to develop and validate themes and patterns observed in the

data. This allows the researcher to develop complimentary and "converging lines of inquiry,"

thus addressing the issue of credibility and the trustworthiness of the data analysis (Yin, 2003,

98; Golafshani, 2003).

The data for this study were collected over a period of 13 months, from May 2011 to

July 2012, and included the following: an extensive literature review, the results of which are

described in chapters 2 and 3, interview data, contextual information (e.g. demographic

questionnaires) and field memos.

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[8] Cisgender is a term used to describe individuals who identify with the gender that they were assigned at birth, or are not transgendered.
[9] The time period and geographic location of care was an inclusion criterion in order to capture a particular temporal and geographic context (Ontario); these parameters were important in order to be able to focus on the Ontario policy context.

Data

     Interview data. The primary data source consisted of semi-structured interviews that were done with 16 study participants in their homes (see Appendix F for detailed socio-demographics of the participants).[10] For the most part, the interviews lasted between 60 and 120 minutes. The majority of the interviews were done in one sitting. However, several of the interviews required two or three visits to complete when participants wanted to stop before finishing the interview and reschedule as a result of a medical appointment, or the arrival of their caregiver. To ensure rigour and reliability in the data analysis, a semi-structured interview guide was used to guide the data collection (see Appendix B for instrument). To maximize understanding of diverse experiences, the questions were semi-structured and open-ended. This allowed for a conversational style that enabled participants to give as much detail as they wanted. Probes were used to explore areas of little information, to obtain more detailed understanding and to explore novel issues or topics that came up for some participants during the interview.

     To help establish rapport and familiarity with the research experience, the beginning of each interview focused on general health status, support needs and familial and community connections. I then moved on to questions that specifically addressed participants' experiences of accessing and receiving home care and obtained detailed information on the type of care provided, the caregivers and both negative and positive experiences with home care. The last portion of the interview explored the concept of quality and focused on participants' views on quality home care.

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[10] One participant requested that the interview take place in the courtyard of their building instead. All participants were asked where they preferred to do the interview: in their home, at York University or at another location of their choosing (library, coffee shop, etc.).

Contextual data. Contextual data for this study included demographic questionnaires, detailed field notes and research memos, as well as an extensive literature review of the history of home care policy, services and discourse in Ontario and its neoliberal restructuring in the last 20 years (See Chapter 2).

Demographic questionnaires. All participants completed a demographic questionnaire at the end of their interview. This questionnaire included a combination of fill-in and multiple choice questions about their age, gender, sexuality, income, relationship status, class identity and racial/ethnic background. This information provided important contextual information about participants' current social locations and socioeconomic status and enhanced the interview data. These questionnaires were filled out by participants on their own, or with my help or their partner's help for those participants who indicated that they wanted assistance (see Appendix B for instrument). The questionnaires were given to the participants after the interview in order to makes sure that rapport and comfort was established with participants before requesting from them detailed socio-demographic information.

*Field notes and research memos***.** Detailed field notes and researcher memos were used to record information about the interviews, details about all contacts made with study participants (and potential participants) and potential recruitment resources that they mentioned. Background information about the participants (e.g. their appearance, demeanor and living arrangements) was gathered throughout the data collection period. The information collected in these memos did not directly relate to the research questions; the memos instead were used to create depth and specificity, and to understand more clearly the nuances of participants' responses to interview questions. The field notes were also used to track if there

was any additional information that was obtained during the interview, any questions that participants did not wish to answer, and any instances where challenges occurred in establishing rapport with participants.

These notes and memos were also used to develop early impressions, organize thoughts before and after interviews, reflect on the interview process and develop initial analytical themes. Finally, these records were used to think about how participants' identities, abilities and care needs related to their class and social support networks, as well as how individual geographic and living spaces shaped their home care experiences (Williams, 2002). In essence, the information gathered in the field notes and memos was used to "create texture and variation [while] avoiding the flatness that comes from generality" (Emerson, Fretz, & Shaw, 1995).

Protection and Ethics

Ethics approval was obtained prior to commencing the study and before contacting any organizations and/or potential participants (see Appendix G for certificate). Detailed information was provided to all participants about study procedures and participant rights prior to commencing the interview. All of the participants in this study provided written informed consent to participate in the study (see Appendix G for consent form). Each participant was also given a $20 gift card as an honorarium for participating in the study. Prior to commencing, verbal consent was obtained from each participant to audio record the interview using a digital recorder.

Participants were informed during the interview that they could read the transcript of their interview, if they wished, after the interview was transcribed. This was chosen as an

optional procedure to decrease the burden of work on participants and to ensure that their

continued involvement in the study was not coerced. Only one participant indicated that they

wished to do so and they were mailed a copy of it as soon as it was available.[11] This study also

used a modified member checking procedure, whereby initial thematic analysis was presented

at three conferences during the data collection phase (see above for dates) in order to ensure

that emerging themes were validated by other relevant stakeholders (health care professionals,

home care users and health care researchers).

Data Management

A chain of evidence of all of the study documents, field notes, procedures and

description of recruitment efforts was maintained throughout the study period to enhance the

credibility and trustworthiness (or validity) of the analysis. This included electronic records that

were password protected and written paper copies of all of the documents, memos, notes, and

discs of digital interview files and transcripts. All of the interviews were audio-taped and

verbatim transcribed by a professional transcriptionist. Each transcript of the interview was

then checked against the interview recording to ensure accuracy of transcription. Appropriate

punctuation was then inserted into transcript excerpts to enhance readability and clarity. In the

following chapters, excerpts of the participants' quotations are presented verbatim. Ellipses (...)

are used to indicate an omission of text in the middle, square brackets [] are used to indicate

insertion of a generic word that stands in for an identifier (such as the name of a person or city)

or a non-verbal utterance [laugh] or an explanatory word. Two dashes (--) are used to indicate a

participant's pause in the transcript, after which they began a new sentence.

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[11] This participant approved the transcript and did not want any changes or deletions made to it.

Analysis

Data analysis was an iterative, reflexive and ongoing process that occurred throughout

the data collection phase. It followed "a loop-like pattern of multiple rounds of revisiting the

data" (Berkowitz qtd. in Srivastava and Hopwood, 2009, 77). In particular, three strategies were

used in the analysis of the data. These were relying on theoretical propositions, defining and

testing rival explanations and developing a case description (Yin, 2003). These strategies were

used to develop themes and build towards pattern-matching explanations. Data analysis was

inductive and guided by the study objectives and the theoretical framing and followed the OTTR

(observe, think, test, revise) method (Yin, 2003). Interviews were listened to after every

interview and contextual information was reviewed to identify preliminary themes or

categories of information and to explore any gaps in information obtained in order to focus on

these subjects in subsequent interviews. These themes were developed by examining

participants' answers against the study's propositions (as specified by the theoretical

framework), the guiding questions and the literature review. Themes were "recurrent unifying

concepts or statements about the subject of inquiry" (Bradely, Curry, Devers, 2006) and were

derived from examining participants' "answers" to guiding questions and contextual data

against the study aims and theoretical framework. Themes were identified when participant's

responses "capture[d] something important about the data in relation to the research

question" (Braun & Clarke, 2006). The development of themes involved reflecting on

individuals' responses, social locations and supports, relationships and feelings, processes of

access, types of care and overall support needs. These themes were used to develop

preliminary themes, which were then tested in subsequent interviews by exploring a particular

aspect of the theme or participants' experience in more detail. If subsequent participants' answers confirmed the theme, it was retained and tested again in the following interview; if it was not confirmed, this led to the revising of the original theme or hypothesis. Additionally, subsequent interviews led to development of novel emergent themes, which were tested in the following interviews (See Appendix E for examples of preliminary themes).

After all of the data were collected and initial themes were developed, a further analysis of the data was done by developing a more through definition of the identified initial themes and hypotheses, comparing these against the literature and developing alternate or rival explanations for the identified themes. An initial step in this process consisted of re-familiarizing myself with the data by listening to the interviews again while reading the transcripts and examining the contextual information within each interview and across interviews. Using the interview data and the contextual information, a detailed description of the case was developed and a book of codes was created (see Appendix D for the list of codes). Following this phase, all of the interview data were inputted into a qualitative software program (NVivo 2) that was used to organize and collate all of the collected data according to the initial themes. This was done as a data management technique and was used only to categorize the data once the initial set of themes was already developed.

Once the data were coded, they were also examined for differences and similarities across participants' responses according to the identified themes and additional themes were developed as necessary. Finally, I looked for larger patterns in the data and relationships across the themes and the interview, a process defined by Yin (2003) as pattern matching. The identified patterns were interpreted against the central aims of the project, the collected

literature and theoretical review (chapter 2 & 3) and the theoretical framework to develop an understanding of their significance and meaning in relation to the overall aims of the project, the existing literature and future policy development and research.

Limitations

Although strategies were used to ensure the "trustworthiness" and credibility of this study, several limitations must be noted. Given that this project consisted of interviewing older adults who are a hidden population about a sensitive topic, it is possible that interviewees did not feel comfortable in sharing as much detail as they could have with someone closer to their age, as I am 25 - 42 years younger than my participants. To minimize the impact of this bias, I interviewed participants in their homes and spent the beginning of each interview establishing rapport by explaining the rationale of the study and answering any questions participants had about the study and my reasons for choosing to focus my thesis on this topic. In addition, I began the interview by asking participants general questions around their health, everyday needs and families, before delving into potentially more difficult and vulnerable details of their experiences with home care. Throughout the interviews I used a variety of probes to elicit more detailed information and obtain a thick description of participants' impressions and experiences (e.g. "Can you tell me about that?"; "Can you tell me what that means to you?").

Despite my attempts to ensure demographic variability through the purposeful recruitment methods described above, the group of participants is fairly homogenous; the majority are white, relatively young (< 65 years old) lesbians, who have some post-secondary education and live in a major urban center in Ontario with services for LGBTQ people. Furthermore, given that participants had to identify as lesbian or bisexual to participate, the

results of the study reflect the experiences of women who are at least somewhat "out" and identify with a lesbian or bisexual identity. As a result, the perspectives captured in this study may not reflect the experiences of individuals from more rural areas who may not have access to a LGBTQ community or LGBTQ affirming care services, may not be out in their communities and may not identify with a lesbian or bisexual identity. Notwithstanding this limitation, the group of participants in this study includes representation from a variety of ethnic/racial, occupational and economic backgrounds and captures a diversity of experiences with home care services.

Sexualities, Sexual Orientations and Identities

As I have discussed in chapter 3, sexualities and sexual identities are complex and contextual and encompass desires, behaviours, feelings, relationships and communities. Furthermore, women's sexualities and sexual identities are also shaped by heteronormative and sexist social practices and sexual and gender norms. Sexual and gender norms include attitudes about bodily physical appearance, clothing, exhibited character traits, as well as sexual behaviours and practices. Women who do not conform to these norms in terms of behaviour and appearance experience social stigma and are subject to discrimination.

Some researchers have further suggested that sexual identities, such as "lesbian," may be different from sexual orientations, that is same-sex/opposite-sex or both (Golden, 1996; Diamond, 2003, 2005). Specifically, it has been suggested that while individuals may choose to identify with a specific identity, their decision to do so may not necessary match their sexual orientation or behaviour over their lifetime. Women in particular may choose to identify with different sexual identities over their lifetimes as a result of situational differences,

such as a particular partner and/or whether they identify an identity as being a political, sexual or social identity (Golden, 1996; Diamond & Savin-Williams, 2003). Additionally, research has shown that the ways in which individuals who experience same-sex desires and relationships may identify in terms of their sexual identity can vary across class, race, national and other types of identities. Thus, whether individuals choose to identify with a particular sexual identity such as "lesbian" or "queer" may have as much to do with the particular time and place where they grew up and came out as it does with their sexual behaviours.

Given that most of the participants in this sample are white, Canadian and in their early sixties, it is likely that they share a common generational cohort experience that shapes how they view their sexuality and sexual identity. For example, the women in this study likely came of age and experienced same-sex desires prior to the decriminalization of homosexuality and the lesbian and feminist movements of the 1960s and 1970s. As a result, it is likely that the history of pathologization and overt discrimination affects how they choose to identify, as well as when to disclose their sexuality. For instance, individuals of this cohort may be less open about their sexuality than individuals of later cohorts (Barker, 2004).

While my analysis in the following chapters explores some of the commonalities in participants' experiences, it also highlights differences between them that may be the result of differences in how they understood their sexualities and their relationship to sexual identity labels. For example, my analysis demonstrates that while all participants identified as lesbian or bisexual for the purposes of this study, they did not necessarily share a common understanding of what these identities meant. While some women in the study saw themselves as exclusively oriented to women, others did not and viewed themselves as lesbian primarily because they

were in a romantic relationship with a woman, rather than as a result of having an innate

orientation to women. The varied meanings that participants ascribed to their identity and its

role in their lives has implications for their decisions with respect to disclosure of sexuality and

their experiences with home care. These differences also caused them to employ different

strategies to resist heteronormativity and homophobia in their everyday lives and in their

interactions with home care caregivers.

The multiple meanings of sexuality and sexual identity are evident in the ways in which

study participants chose to identify on the demographic forms and during the interviews.

Although my study focuses on "lesbian and bisexual women," the recruitment materials

indicated that this could include a broader array of identities, including gay, lesbian, bisexual

and queer. Many of the participants chose categories other than or in addition to lesbian or

bisexual to label their sexualities as can be seen in the demographic characteristics table (see

Appendix F). Although a majority of the participants identified themselves as either lesbian or

bisexual during the interviews, many picked a variety of additional identity categories, including

queer and gay, on the demographic questionnaire. The use of multiple sexual identifiers

suggests that many participants did not feel that any of these identities on their own captured

how they felt about their sexualities and/or sexual identities.

In terms of gender expression, or lesbian-specific gender identity, the majority of the

participants chose not to qualify their gender by picking "butch" or "femme" or any other

categories, instead preferring to identify only as "female." In fact, although I included a specific

question with respect to this on the demographic questionnaire, most of the participants (n =

13) did not understand what I meant by the term "gender identity." After I explained that this

term referred to the practice of some individuals identifying as "butch/femme" or "gender-queer," most participants indicated that they didn't identify with any of these labels and that these had no meaning for them. Only two of the participants identified as either butch or femme after my explanation, and one identified as being "in between." [12] However, none of these individuals used these terms to describe themselves or others during the interviews.

In fact, only two of the participants (who only identified as female on the gender-identity question) discussed gender identity or gender presentation explicitly during the interviews and did so only in passing. For example, P14 described a previous lover as being "butchy" and P16 had said that she was "not everyone's cup of tea in terms of femininity." These examples suggest that while most of the participants did not self-identify with gender identity-based terms, these terms may nonetheless hold some meaning for them. This is supported by other research on lesbian identity that has similarly shown that while these categories are hard to define and identification with these may vary across class lines, these concepts may be important to how some lesbians understand gender and sexuality (Weston, 1996; Taylor, 2005b).

In part, judging how and why some individuals chose to identify is beyond the scope of this study. The majority of the women in this study were also similar in class, race and immigration background, so it is difficult to gauge how differences across these other identities affected how and why they chose to identify in terms of sexual identity. In fact, I would argue that the participants were more similar than different in that the majority identified as lesbian or bisexual and their narratives suggest that they did so as a result of having long-term social

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[12] Two identified as being "butchy" and one as "femmy."

and emotional connections to women, rather than as a result of viewing lesbianism as a political identity. Therefore, participants' dis-identification with lesbian gender-roles and/or a political lesbian identity may again be a reflection of their cohort and the historical stigma attached to homosexuality and butch/femme roles.

Home Care Service Experiences

Finally, it is important to note that this study captured a spectrum of home care access experiences and included experiences of accessing home care for a few weeks to over 10 years. As can be seen in the demographic table in Appendix F, the majority of participants (n =9) used home care for a short period of time, a few weeks to 2 months after experiencing an acute health episode such as a surgery. The rest of the participants were long term home care users, (used services for more than 6 months) and had received home care for a chronic health condition such as complications from stroke, osteoarthritis, brain tumor or polio. Several of the participants also had multiple periods of accessing home care (or attempting to access home care) and had accessed both nursing and/or supportive home care services. However, none of the participants had accessed both types of home care services at the same time.

Conclusion

In this chapter I described the conceptual framework for the project, the projects' aims and its guiding questions. I also described all of the relevant study procedures, methodologies, methods and data analysis steps. This was an exploratory qualitative case study, which used semi-structured interviews as the primary data source. Additionally, I discuss the issue of analyzing sexualities and provide some background on the home care experiences captured in this study. In the following chapters I present a more thorough discussion of the study

participants and their processes of accessing, initiating and receiving home care, which entails

some analysis of the interview data in their health status.

Chapter 5: Caring Subjects

I mean you realize that health care needs are very tied to your own experiences as an individual and as a social class. (P3, Jewish, 65 years old, middle-class, on long term disability)

In the previous chapter I described the methodology, design and procedures of the study. In this chapter I begin to present the results of the research. Specifically, the focus of this chapter is on the analysis of factors that affect the conditions under which older lesbian and bisexual women access and receive home services in Ontario. I begin the chapter by examining participants' health and their demographic and socio-economic characteristics. I then connect these characteristics to their health and support needs and their social support networks. Although a summary of their demographic and socio-economic characteristics is reported in Appendix F, a qualitative case analysis within a FPE framework necessitates that these characteristics are linked to the context of individuals' lives and their particular experiences. Such an analysis can reveal the importance of considering how individuals' specific needs and experiences affect their care needs as well as their ability to access care.

This focus on individuals and their lives also provides the necessary background to understand their experiences of using home care services within the current system in Ontario, which is the focus of the next chapter. Furthermore, focusing on the specific conditions of individual women's lives helps illustrate the strategies and mechanisms that participants use in order to secure care for themselves. These strategies and mechanisms are necessary despite recent reforms that have been implemented in order to improve "efficiency and timely access" to long term care services in Ontario (e.g. *The Local Health System Integration Act*, 2006; The

Community Care Access Corporations Act, 2001; Ontario Action Plan for Home Care, 2012).This

analysis thus also contributes to feminist care research that seeks to resist neoliberal care

restructuring and policies that fail to support the state's responsibility for providing care that is

responsive to the diversity of care recipients.

Health

To understand the effects of care allocation or access under the current home care

policies and systems, it is important to examine how the need for care is determined and

allocated. According to current federal home care policy, the aim of home care services is to

enable individuals with health and support needs to live at home (CHCA, 2009). However, as I

discussed in earlier chapters, there are few guidelines that specify exactly how much care

should be allotted per individual and how decisions about home care provision are to be made.

Additionally, as shown in Chapter 2, there is evidence from across the province and country

that the demand for home care is greater than the amount that individuals are able to access

(Ontario Health Coalition, 2011; Auditor General Report, 2010). Consequently, to understand

the impact of current policies that support the rationing and restriction of home care services,

it is necessary to examine the study participants' everyday health and support needs.

When asked about their overall health, most participants used a biomedical perspective

and assumed that being healthy was defined as the absence of disease. This meant that when

they were asked to describe their current health, most gave a list of current health conditions

and symptoms. Participants in this study reported a variety of both physical and mental health

issues including fibromyalgia, arthritis (rheumatoid, psoriatic or osteoarthritis), diabetes,

chronic pain, stroke, heart attack, post-polio syndrome, cancer, bipolar disorder and

depression. The majority of participants reported having dual or multiple chronic conditions

that affected their ability to perform everyday activities of daily living, such as personal care

(e.g. dressing, grooming, bathing, eating), meal preparation and housekeeping. [13] Many

individuals also struggled with ongoing pain, fatigue and difficulties with balance and mobility.

Some also experienced difficulties with vision, memory, speech and hearing. All of these health

symptoms and difficulties represented challenges for individuals' ability to do routine everyday

tasks, to work, to participate in activities inside and outside their homes, and to maintain social

connections with their communities.

One participant illustrated the cumulative impact of having multiple health conditions,

the nuances of everyday life for such an individual and the isolation and challenges they face

while trying to have social contact and continue participating in their communities:

The hearing loss is a difficulty because it excludes you from society in many ways.

People look at you. They don't understand what hard of hearing is. They understand if

you have a device in your ear, but they still disregard you. In a public meeting you're

constantly asking to have people miked or for people to speak directly to you and they

don't have it yet. They just think, "Oh yeah, it doesn't matter. You're only one of the

group." Well as we age, the person who can hear is going to be the one in the group

because it happens with aging and for whatever reason. It's like losing your sight. If you

lose your sight, you're excluded because you can't see to do things anymore. You can't

drive, you can't walk. You can and we see people with Seeing Eye dogs and that's really

wonderful that they're able to cope with that. Not every one of us is that capable at

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[13] I use the term "chronic" here to refer to health conditions that are long developing, ongoing and often incurable.

that time in your life. If you said to me, "I'm going to give you a Seeing Eye dog" and I

had to deal with all the other stuff, I don't know if I could cope with all of that. I have

enough. And most of what I have is invisible. And we're doing this interview at home

today, so I don't have my wheelchair out or my scooter or my canes because I'm in a

safe place and I have this place set up for me. I can reach the wall. I have a telephone

next to me. I have my safety secured. If I leave here, then it's more work for me to

secure my own safety. I have to think about it more. Like who knows I'm leaving the

house? Where am I going? Am I able to drive? Do I have enough money in my wallet to

get a cab home? Do I have identification in my wallet that says who should be notified?

I don't know if the average person has to think all that out before they leave. Energy

draining. And you have to have the ability to think about it. There's where the cognitive

stuff comes in and the memory. I walk with a cell phone. I'm not busy tweeting back

and forth, which might be kind of fun. Because I can't see it, I can't learn it. So what I

need to rely on is the old voice method of using the telephone, so some of that new

technology is lost to me because of the learning disability. Life gets a little complicated

over here. (P6, 65 years old, post-polio syndrome, fibromyalgia, diabetes,

osteoarthritis)

Despite describing these types of challenges to their health, most participants

attempted to maintain a positive outlook and often minimized the impact of their health

conditions on their everyday lives:

I have osteoporosis. I have cirrhosis of the liver. I just finished a bout of severe psoriasis

and psoriatic arthritis-- I have a physical disability due to falling down the stairs in my

home--I cannot walk more than 10 minutes or sit for more than 10 or 15 minutes

because my disability is in my legs. They get really stiff and my joints get really painful.

What else? Well I would say that I've recovered from brain surgery--I have sleep

Apnoea. (P5)

Another participant noted that while they didn't consider themselves healthy, they felt that

they were "doing fine" given that they weren't terminally ill. When asked to describe her

health, this participant responded:

Well it's not great. I'm diabetic. I have arthritis and fibromyalgia. I've lost all the toes

on my left foot from the diabetes and I've just had surgery and it's healing, but slowly. I

had a bone that's infected in my foot, so more digging. I'm more relaxed than I've ever

been in my life. My blood pressure is very good. And I'm obese and I smoke, so I'm not

in great health. But I'm not dying of anything. And arthritis and fibromyalgia and all the

rest of it, it's not terminal so I'm doing fine. (P7)

Some participants who accessed home care for a temporary acute health episode and were no

longer receiving home care services at the time of the interview reported that their overall

health is currently good:

Other than my ankle, it's great… I don't really have arthritis per se. You know, I get

aches and pains and that sort of thing, but I don't have chronic arthritis or anything. I

don't have any outstanding medical things pending. I'm not on any meds and haven't

been. (P4, broken ankle)

Overall health is good. Actually I just went for a major physical and my overall health is

O.K., is good… I don't have any major diseases--I'm not diagnosed with any disease.

Blood pressure is O.K. Heart is O.K. Everything is O.K. So like I haven't been diagnosed

with any like big disease. (P2, knee replacement)

Several participants described their health as being "good" or "fine" prior to their

seeking home care and reported that needing home care came as a surprise given that they

were able to "manage" prior health issues without it. For many participants, being healthy was

also tied to physical fitness, self-reliance and independence:

It [my health] was good. It was good. I was a bit overweight but I rode my bike every

day and I exercised. I was pretty healthy. We walked a lot. We camped. Car camping.

But still we have two kids so we did stuff. It was pretty good. (P1, age 64)

Prior to that my health was just fine. I was in excellent shape. Prior to getting the

psoriasis in 2000 I was fine. (P5, age 57)

However, several participants also described experiencing a "narrowing of horizons in

terms of social activity" (Aronson, 1991, 141) as a result of their worsening health difficulties

prior to accessing home care. Many of the participants in this study also had multiple chronic

health conditions which negatively affected their mental and physical health. As a result of

these, many participants needed ongoing support with managing everyday self-care and

housekeeping activities.

Age and ageing

The age of the participants in this study was relatively young compared to the national

profile of older home care users and ranged from 55 to 72 years old, with just half the sample

over 65.[14] This may be because younger individuals were more likely to respond to calls for

participation in this study or because older individuals may have been less aware of the study

as a result of being more isolated and/or house-bound. The aging process, however, figured in

several participants' narratives in relation to when they first began experiencing challenges

with mobility and/or the ability to do every-day personal care activities. One participant

reflected on her realization that she wanted to discuss the events that led her to access home

care with a "counsellor," who she later identified as being a social worker:

> I want to talk to her. I want to talk to her because I don't know how to live my life. All
>
> of these things that are coming to me are new because I'm aging and I think I'm aging
>
> and doing life a whole lot differently than the average 67 year old female and I need to
>
> express myself. I need to talk about it. I need to reflect upon it and I need to have
>
> somebody that I admire and respect their abilities. (P6, age 67)

Given that this study focused on *older* home care users, the finding that for many home

care use coincided with experiencing more complex health issues as they aged is not surprising.

In fact several individuals had multiple chronic conditions that intensified as they got older. For

others, the need for home care was the result of an acute health episode that necessitated

daily medical treatment (such as an IV drip or wound dressing). While in the past such complex

health needs were managed in a hospital setting, the development of medical technology has

allowed for much of this type of care to be done at home, and it has been promoted by health

care reforms (Grant et al., 2004).

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[14] According to the *National Home Care Reporting System,* over 90% of all (long term) home care clients in Ontario in 2011-2012 were over 65 years old (Home Care Reporting System, 2011–2012, Canadian Institute for Health Information).

However, many participants associated getting older with increased need for care and expressed worry about their ability to pay (or continue to pay) for supportive services and assistive devices while subsisting on a reduced income. In fact, all but one of the participants cited financial concerns and worries about their ability to pay for necessary care and/or assistive equipment in the future. When asked if they had any concerns about needing more care in the future, one participant explained:

> Well of course I have a concern because I rely a lot on X [my partner] for a lot of the activities of daily living, like I mean I wouldn't be able to-- I can throw the cover on my bed but I can't change the sheets. I can't do stuff like that… Like I have a walk-in shower and so on so I mean I can do my own showering and everything but I really need somebody to change the beds, to do the cleaning, and apparently you can't get that unless you pay, do it privately but my income is going to be quite low and so it's a concern about how you get the kind of care you need and the cost of that. I think that's an ongoing issue for a lot of people. (P3)

While this participant was able to access home care once in the past, during their most recent attempt to access care after hand surgery they were unable to get a case manager from the Community Care Access Centre (CCAC) to come and do an assessment. As a result she relied primarily on her partner to assist with everyday care tasks. Similarly, reflecting on the issue of needing more care in the future, P4 noted:

> But I mean it's only natural that I'm going to age and I'm going to need more help, but it's not going to be available and I don't have the financial wherewithal to pay for it. (P4, age 70)

Another participant observed:

> All the things for older people are very expensive… So that again, that's not necessarily a
>
> thing [that is] necessarily gay. You can be a straight person and be poor. Poverty is an
>
> equal opportunity disease, right? So it's not only a gay issue or lesbian issue. But yeah.
>
> If you don't have a lot of money and you try to access all the services, you have to pay
>
> through the nose. So I hope if it ever comes that way I hope I'm dead before that.
>
> [laughs] Then I won't know. (P2, age 55)

Most participants anticipated that they would need more care in the future and that their

access to publicly funded care at that time would be more limited and/or inadequate to

support their needs.

Despite the worry about income and access to care, none of the participants described

aging or getting older as negative in and of itself. Furthermore not all participants described

getting older as something that would necessarily involve reduced functioning and health. As I

discuss below, most of the women instead had the expectation and hope that their health

would improve in the future. This view of aging is in direct conflict with the dominant discourse

of aging as a process of progressive and inevitable decline, as I discussed in Chapter 3. However,

while most of the women in this study didn't explicitly discuss ageism in relation to home care,

they were aware of it and discussed it when describing their efforts to access other health care

services for themselves and others. As P13 describes, "looking older" and having difficulty

communicating sometimes resulted in caregivers treating clients in a paternalistic manner:

> My mother was 90 when she died. Most of the people treated her well but occasionally
>
> when she was in the hospital because she had a hearing aid and she couldn't see

without her glasses and she was blind in one eye, when you took those things away

from her you took away all her communication stuff and people treated her like she was

an idiot and she's not. Now you've taken her hearing aid and her glasses, you've made

it so she can't hear or see you and she's afraid and you're talking to her like she's a

puppy. And she's not. She's an 80 year old woman who has seen a lot more life than

you have. And when I was sick I looked old and occasionally you get a nurse who treats

you like you're stupid. And you don't need to be treated that way because you're not

stupid. So you need to be treated with respect in that way, respect as a person. (P13,

age 59)

Similarly, P2, in discussing caregivers, described what she thought was important:

That they don't talk down to you, that they don't talk to you like you're retarded and

that they don't--I hate to use the word but that they don't talk to you like you're feeble,

right? You're not. Well even if you are feeble that they talk to you with respect. (P2)

This suggests that while participants did not view aging and getting older as negative, they were

aware that being older is viewed negatively in society. As a result, they were vigilant about such

behaviour in their caregivers.

Families and circles of care

Seven of the participants were single at the time of the interview and lived alone, while

nine were married or in common-law relationships and lived with their partners/spouses.

Regardless of relationship status, all of the participants described having a variety of chosen

and kinship-related families that they were connected to in their daily lives. However, many had

also experienced recent losses of parents, siblings and friends, which had a significant impact

on their social circles and their potential for drawing on these connections for receiving

informal support in the future. As P3 described:

> I do still see A [a friend] but B [another friend] was the person I was closest to. But she's
>
> gone now. So it seems like a lot of people I've known, like my friend, this woman here
>
> whose husband I knew since we were kids, he died. He was 51. B just died. She was 60.
>
> Another really close friend from Montreal died at 55 of breast cancer. So there's been a
>
> lot of losses, so there are very few people that I really have any attachment to. A is one,
>
> but A's is a very different life than me. Very different life. So did B, but we were a lot
>
> closer. A and B and I and all these people, we all grew up on the same street. We've
>
> been friends since we were three years old, but B was more my closest friend, like I said,
>
> like sisters. She's gone now. Kind of leaves you a bit alone. (P3)

For many, their relationships with members of their natal families were complicated and

at times strained as a result of their families' ongoing homophobic attitudes and behaviour

towards participants and their partners. This finding is not surprising and is supported by other

research on LGBTQ families and relationships that shows the historical and contemporary

prevalence of negative familial attitudes and violence towards LGBTQ family members

(D'Augelli, Hershberger, & Pilkington, 1998; Weston, 1997; Ryan, Huebner, Diaz, Sanchez,

2009). This research documents historical and ongoing familial homophobia and rejection of

LGBTQ family members and its association with higher rates of self-harm, poor health and

homelessness for LGBTQ youth. As a result of these types of negative familial attitudes, while

participants considered these individuals family, they did not typically wish to (or necessarily

could) rely on them for providing instrumental or emotional support. Reflecting on her

relationship with her brother, one participant reported:

> He thinks that the reason I got cancer is because I was gay. So like I asked him, I says,
>
> "Well you've got MS. What did you do wrong?" My sister in Portland, we don't talk to
>
> each other. My sister that's in Seattle, she's totally against gays, but she absolutely
>
> adores me and she adores my wife. (P15)

Other participants noted that while they did have natal family members, none were close

and/or supportive enough for them to feel like they could ask them for support if they needed

something:

> Well neither of us have any [family] in the city. I have a sister. She lives in another
>
> country and we have a rather tenuous relationship at the moment. Tenuous at the
>
> moment, which is better than it was a few years ago. She's a challenging person. (P1)
>
> Oh my family. My parents are both dead. I have a sister and two brothers. I've not
>
> spoken to my two brothers in probably 15 years, since my mom died … I don't like them
>
> and they don't like me and when I came out as a lesbian, they liked me even less. My
>
> sister-- my sister and I see each other maybe every two years or so. We talk on the
>
> phone occasionally. Her children are adults now, but when her children were younger I
>
> wasn't allowed near them because I was lesbian. (P7)

Many participants said that they considered their close friends, who were typically also LGBTQ,

as family reflecting past research findings that typically LGBTQ people form communities based

on sexual orientation and shared social identities or connections, rather than biological ties

(Weston, 1997; Muraco, Fredriksen- Goldsen et al., 2011):

But I think I consider more my friends my family-- I mean your family is family, but my parents are dead. I have an old brother who died three years ago and I'm the youngest, so I have left a sister and a brother and one niece I talk to once a month or so. The rest, they don't live in this country. One is in Scotland and one is in the States, so we converse occasionally and e-mail. (P13)

My family, I have two families. I have a blood family and I have friends family (P4)

The friends in X [in a nearby city], I can go several days without seeing them but they really are like family. When I was in hospital last summer, when I was diagnosed, they were there every day and looked after this place and my cats. I have two cats. So everything was totally prepared for me to come home. Came to visit every weekend after that until I felt quite comfortable doing whatever had to be done. So I would say they are like family. (P12)

Several participants identified that while they had supportive friends and family members and valued those connections, they did not feel that they could or wanted to rely on them to provide them with care. Many noted that their friends were also older and had health issues themselves and thus may not able to help:

Most of my friends are dead or more disabled. Most of my friends that are alive are in their 60s, 70s and 80s. I wouldn't ask some of them to pass me the salt. You know what I mean? They want to know how I'm doing, I tell them I'm doing great. Why would I burden them? And family? I mean come on. My family is dead. I don't have mommy and daddy. (P16)

We never have relied on other people to assist us. We've always done it ourselves or

had somebody come in, paid somebody to come in and do for us. It's just I'm very

independent, always have been, so I don't like to rely on other people because if I want

it done, I want it done when I want it done, where if you rely on a family member or a

friend, it's kind of at their convenience and that might not be convenient to us, O.K.?

(P8)

The discomfort of relying on natal or chosen family members, friends and neighbors for

care was a salient theme across the narratives. This was particularly true for individuals who

lived alone and were single. While participants appreciated being able to draw on these

connections in the past, they were hesitant to do so again in the future as that would change

their relationship with these people. Reflecting on her experience with receiving help from her

friends, one participant said:

And they were wonderful. And I really didn't want them-- I didn't want to be dependent

on them. I'm a very independent person. And I didn't want them to feel responsible for

me. I wanted them to be my friend, not my caregiver. (P14)

Similarly, another participant explained:

I have a neighbor who is willing to be supportive, but I prefer her next door, not here. I

have friends who live over there [an area in the city east of her building]… I can call

them, [but] I try to be self-reliant. (P12)

In contrast to the national data on home care that shows that the majority of informal

home care provision for older adults in Canada is done by adult daughters (CIHI, 2010), most

participants did not rely on their children to provide care. In fact, the majority of the sample (9)

did not have children. Again, this reflects existing research on LGBTQ families, which has shown

that lesbian and bisexual women have lower birthrates than heterosexual women and are less

likely to have children. Furthermore, of those participants that did have children, most had

adult children who lived typically at least an hour away and were not considered to be a

primary caregiver.

> I have a daughter that's 41. She'll be 41 this month actually. And she's in Vancouver.
> And she's there most of the time. I think she's been back here to X [a city in Ontario]
> maybe twice in the last 10 years. (P8)

> Yes I do. He's 42. He'll be 43 on Monday. He's got severe agoraphobia... So he lives
> with us. (P7)

> I have the three children and they're in Seattle. I have 11 grandchildren. They're in
> Seattle. And I have a sister. She's in Seattle. I have a brother in Idaho and a sister in
> Portland, Oregon. So all of my family is west coast, U.S. So no one local. (P15)

Additionally, none of the participants who had children voiced the expectation that their

adult children would become their primary caregiver in the future. As one participant

explained, while she didn't have any living children, she did not think that even if she had

children that she would want them to provide her with care, nor that they could provide the

kind of caregiving that she needed:

> I did [have children] and they're dead, not that it matters. I mean one shouldn't expect
> that children can do it. Most people my age who have children, their children have
> children. They have careers and children. They don't have time. It's the society we live
> in. I mean there's probably the odd individual, but I've watched it and it's pathetic. You

know, the kids, they just don't have a clue of how to do very much. It's a rare exception to find someone who (a) knows how to assess me and (b) to respond appropriately. That's what home care was supposed to provide. (P16)

In fact, only four of the participants described receiving some informal support from their children at the time of the interview. Of these, one participant had a son who was living with her and providing help with food preparation: "My son makes my lunch and supper" (P7). Primarily, however, the type of support that participants received from their children was occasional and not personal or "hands-on" care.

My son in Winnipeg, every once in a while he'll surprise me with a few bucks in my account or I'll get a fast phone call. "I dropped some money in your account. O.K.? Bye." [laughs] But the other poor one in London, he's my poor baby… I send him stuff, cards and money and stuff like that. (P11)

He [my son] does our lawn maintenance. He does home maintenance for us. He's a phone call away, a text away. He just checks on us or he'll say, "I'm going to be here next Tuesday to mow the lawn," and then he'll call on Tuesday and say, "Well do you think I need to mow the lawn or do you think there's something else you want me to do?" And he'll dress accordingly to do whatever we need. (P15)

They [my son and daughter] both do errands and things like that and fetch and carry. X [my son] can cook and does-- Well he's been away at university over the school year, but he's back now so he can cook, which is great, and he's our barbequer in chief… They both do their own laundry. I will say that-- They clear the table-- take out, assemble and take out the garbage and recycling every week. (P1)

Coupled participants, all of whom lived with a female partner, described relying heavily on their partner's emotional and instrumental support for personal care tasks and filling in the gaps between home care visits. However, they reported that their partners also often continued to engage in paid work responsibilities alongside providing this caring labour and performed the bulk of housekeeping activities. It is possible that participants felt more comfortable relying on their female partners for support, rather than drawing on other sources of informal support such as their friends, as result of gender role assumptions about women's caring and responsibility for household tasks. Previous research has also shown that lesbian caregivers may also feel that it is their sole responsibility to provide this type of support as a result traditional gender role stereotypes and the desire to protect their partners from potential homophobia in formal health care services (Aronson, 1998). As a result of these dynamics, older coupled participants may experience additional stress and burden and may not be able to rely on this support long-term. For example, referring to housekeeping responsibilities, one participant noted:

> I would have to say we try to make it a 50/50 thing, but my wife definitely does more because we found out that bending forward puts extra pressure on my knees, so like picking something up on the floor it's going to stay there. Or I can get the broom and the dustpan because they have long handles that I can sweep it up to be able to do that. My wife does the cooking and I'll do the dishes and then I'll go downstairs immediately, put my feet up. (P15)

Similarly, when asked who they received everyday support from, other participants said:

I rely a lot on X [my partner] for a lot of the activities of daily living, like I mean I

wouldn't be able to-- I can throw the cover on my bed, but I can't change the sheets. I

can't do stuff like that. I can't do a lot of the physical work around the house, so as I age

I mean my health will be uncertain. I guess it is for everybody, but I also know that I

have more limitations and without X as a support system, I would have to get home

care. (P3)

Well you see X [my wife]? [laughs] She helps me walk, get up steps sometimes. She

makes most of the meals, although I can. I made muffins the other day. I can make a

mean grilled cheese sandwich and stuff like that, but X does most of the stuff around

the house now that I used to do. Getting down and back up is not an easy thing. It's

probably due to the weight, too, but it's definitely not an easy thing. (P8)

As with relying on friends and neighbours, participants reported that while they relied

on their partners for assisting with their everyday care needs, they did not feel comfortable

doing so. Many participants also reported feelings of ambivalence and tension with respect to

their partner taking on a caregiver role in the relationship. As P3 describes:

So I mean the fact that X is sort of-- we've got the double whammy of having a physical

disability as well as mental health issues and it's like, you know, it's a lot. It's a lot for

me, but I live with it. But it's a lot for anybody who is sharing that life, you know,

because I mean the physical stuff is really, I mean you're living with chronic pain all the

time. (P3)

Similarly, two participants whose spouses were nurses noted that it was important that their

spouses did not help them with necessary medical care:

And X [my spouse] shouldn't have to do that. I mean that's the kind of boundaries. She is a nurse. She's not my nurse. So she does know medical things, but she shouldn't be giving me medical care because she's not my primary caregiver. She's my wife. (P1) And although she's a nurse practitioner and she does some of my medical stuff, there's lots of medical stuff she wouldn't do, like having, what I needed the CCAC for was I needed hydration in the pump and she wasn't going to get involved in that. I needed another nurse, an active nurse, to come in and do that so X [my spouse] didn't offer to do that. Nor should she have. And that was good. So those are the kinds of boundaries we have. She doesn't try to do everything for me and I wouldn't try to do everything for her, but I would do what I could. And I also know from both of us, it's important to be at home. Like that's why I came home when I was sick. We talked about where I would die because I didn't want to die in the hospital and she was O.K. with me coming home to die. Depended on how sick I got, but essentially that's what I did. (P13)

The finding that participants did not necessarily want to rely on their spouses, friends and natal family members for care, suggests that the common assumption made by home care policies that *all* home care users *prefer* to be cared for by their families, and especially by women, instead of by caring professionals is inaccurate. Furthermore, these findings provide additional evidence that existing norms and assumptions around care provision may not be applicable to LGBTQ individuals and families.

Despite expressing ambivalence with respect to relying on familial-based care provision for support, many participants described providing care for their friends and family, both currently and in the past:

I mean I took care of a partner for 16 years. My resources are deplete (P16).

Well I help her [my spouse] out-- There's lots of physical things that she can't do any more so, you know, it has become my job. Her medications and her pain levels at times make her confused and so then I have to help her out with getting her meds or reminding that this is eight o'clock in the morning on Tuesday [laughs], not, you know, eight o'clock on Monday. Things like that. You know, physically certainly there are times when I have to help her, to steady her. She has trouble walking, things like that. (P8)

And I helped care for my stepmother when she was dying of a brain tumour. We kept her at home. And some of my stepbrothers and sisters and myself and my sister at times stepped in to take care of her. (P10)

This finding is supported by research on LGBT and heterosexual caregiving that suggests that women typically have high rates of informal familial caregiving throughout their lifetime and that they provide care to both immediate family members and extended and chosen family members (Aronson 1998; Fredriksen, 1999; Grant et al., 2004; MetLife, 2006; Shippy, 2007). As a result, they may not have similar resources to draw on when they themselves need care in older ages.

Race, Racialization and Culture

The majority (N = 12) of the participants in this study self-identified as having a white European background. One participant identified as a woman of colour and three others identified as Aboriginal.[15] This represents a higher percentage of Aboriginal identified

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[15] The specific racial/ethnic identity of each participant is available in Appendix F.

individuals and a lower percentage of visible minorities than has been found by the Census for

the population of Ontario.[16]

While I did not ask specific questions with respect to race, racialization or culture in this

study, two of the study participants directly discussed racialization in relation to their identities

and care experiences during the interview. One of these, P5, noted that being a woman of

colour was an important component of her identity and influenced her expectations of care:

> I'm a woman of colour. I'm lesbian. And I have all these health issues. And if they can't
>
> treat the whole package then I have nothing to do with them. (P5)

Furthermore, she explained that being a woman of colour also negatively affected her

experiences with some caregivers who were racialized women as a result of their cultural and

heteronormative assumptions with respect to her sexuality. Describing an experience that she

had with a caregiver, she says:

> So she walks in. I get down here, she walks in and she says, "Hmm, but house." And
>
> she's like this. So I said "You're here to help me with the shower, right?" "So you live
>
> here alone? You married? You have a fiancé? You have any children?" I said, "I think
>
> you're asking too many questions." "Well you want me to help you or not?" So I was
>
> stuck with her. And luckily she only came once a week because back then I was only
>
> getting two days a week so I got her and I got somebody else. So I told them "Do not
>
> send her to me anymore." So they sent somebody else. The same thing. "Oh, living in a
>
> big house by yourself." (P5)

When asked why she thought that these caregivers asked these questions, she explained:

---

[16] In 2011 in Ontario Aboriginal individuals represented 2.4% of the population and visible minorities 25.9% (Statistics Canada Census, 2001).

They were women of colour. They were Filipinos. So to find out that a woman is living

in a house, a woman of colour is living in a house, obviously you can't do it by yourself.

There must be a man in the picture and if there's not a man in the picture he has left.

But you must have had children by this age. So there are these stereotypes that, I guess

I used to be like that, we have of each other as women of colour. So to see me getting R

[home care company name] help and I'm living in a house by myself, a big house, so

what's going on with me financially and how am I supporting myself and why do I need

care? (P5)

Similarly, another participant noted that as a result of being Jewish and experiencing anti-

Semitic discrimination, she was more attuned to the possibility of homophobic discrimination in

home care services and other areas of her life. Referring to her sexuality as a "lifestyle", P3

explains:

You know fast enough if someone is prejudiced, okay? I'm Jewish. That comes in terms

of prejudice that's certainly on a par with the lifestyle. Lifestyle is often more accepted

than religion. (P3)

In terms of nativity, most of the participants (12) were born in Canada and four were

born outside of Canada (Trinidad, Wales, the Netherlands and the United States); however, all

had been in Canada for longer than ten years and spoke English fluently. None mentioned any

difficulties or issues related to immigration or citizenship status in their everyday lives or home

care experiences. One immigrant, however, described having difficulties accessing care services

not covered by Ontario's health insurance as result of having their application to the Canadian

Pension Plan (CPP) denied; this difficulty was experienced despite the fact that she had been in

Canada for over ten years and was married to a Canadian citizen. Discussing her need to have someone cut her toenails, she explained:

> But it's twenty dollars if you have somebody come in and do it and I'm unemployed.
>
> I've applied for CPP. I haven't received it. I've been declined twice now. (P15)

These narratives are important for understanding the intersections between gender, sexuality, age, class, race and nativity and their effects on older lesbian and bisexual women's home care experiences. However, given the small number of study participants who identified as being racialized, Aboriginal or a recent immigrant, and given that this was not an explicit focus of the study, it is difficult to theorize the impact of racialization and nativity on other socio-demographic characteristics and/or on home care experiences in general. Conversely, given that all participants who identified as being racialized, Aboriginal or an immigrant also reported having a low income ($20,000-29,000), and most of these participants lived in subsidized housing, it is likely that these participants experienced restricted access to housing, income and other social determinants of health as a result of racism and racialization. Additionally, as I will illustrate in later chapters, issues of race and racialization were present in both racialized and non-racialized participants' narratives when they emphasized their desire to be able to communicate with their caregivers, many of whom were racialized women, and in their worries about encountering religious-based homophobia in home care contexts. As a result, it is likely that these are significant factors that affect access and receipt of home care services.

Class, Income and Education

In terms of socio-economic class, eight of the participants self-identified as being middle-class, seven identified as working class and one individual did not wish to identify. However, class identification did not necessarily have a strong relationship to participants' incomes, educational attainment or chosen occupation. In fact, several of the individuals who identified as middle class had current annual incomes of less than $30,000, did not have more than a high school education and reported an occupational history of service work. This suggests that establishing class identity by asking people to self-identify may not be a reliable measure of assessing socio-economic status.

Participants' annual household incomes ranged from $20,000 to more than $60,000. However, incomes varied sharply between single women and partnered women and higher household incomes in this sample were the result of a partner's/spouse's full-time employment income. Most single participants reported annual incomes ranging between $20,000 and $30,000, which was slightly less than the average individual income for Canadian women under the age of 65, which was $33,500 in 2008 (Stats Canada, 2009). Married or common-law household incomes ranged between $50,000 and over $60,000 and were similar to the average annual income for Canadian married couples, which was between $59,400 and $86,000.[17] The majority of participants (15) were not working for pay at the time of the interview and most participants' primary source of income was either their public retirement pension or provincial disability support benefits. As mentioned earlier, regardless of income, the majority of

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[17] Statistics Canada. Income and Wellbeing Report, 2010.

participants expressed financial worry, in particular about their current and long-term ability to pay for necessary care and health services such as home care, therapy and assistive equipment.

Several participants expressed feeling fortunate that they currently had some benefit coverage, allowing them to afford some assistive equipment and/or social support services not covered by provincial insurance, such as massage therapy and occupational and physical therapy. However, they still experienced financial worries and difficulties in accessing these benefits. In particular, living on a limited and fixed income often meant an exhausting set of tasks related to balancing payments, filling out forms and anxiously waiting for reimbursement:

My medication before I turned 65 we were paying for and getting reimbursed through our employers. And X, my partner, works for the provincial government. So did I. So we had really good benefits package so we were not having monies taken out of our pockets. If I need a new brace I get a new brace. But it becomes a taxable benefit when we pay our federal tax money, so it's not free. We're taxed on it. But we have the benefit that we can have it now and then tax later. The problem with it is there is so much work for my medication, my braces, the scooter, whatever it is that I need, she is spending two to three hours a week doing that paperwork in order to get it paid for. Then it comes back from one company and it goes to her company so that the balance is paid. So that's two times. Instead of just having a card that says "give it to her," she has to fill in the forms. How friggin archaic is that? And what seems to be her biggest complaint is that she's constantly doing that and constantly having to make sure that we got the money back so that we can go forward. Like if you're popping out six or eight hundred bucks a cheque, that's a lot of money out of our budget. Yeah. And to get it

back in a timely manner when we had that little postal strike, that was kind of tricky. So

if I didn't have her to do that I would have to find somebody on a voluntary basis or I

would have to pay someone. When I go to the home or some kind of care, I'm hoping

that she's still able to do that. If she isn't, I don't know who picks that up for people in

the home into the future. That's a good question, isn't it? (P6)

Similarly, single participants who lived on one income expressed worry about being able to

continue to subsist on their income when they retired because their pension would be

significantly lower than their current incomes:

I have a disability benefit from Great West Life that I paid for when I was working and I

have CPP disability and both of those benefits only go until I hit 65. So I have to start

thinking now because that's eight years down the road. What am I going to do with a 30

percent decrease in my income? (P5, age 57)

The only thing I couldn't ask my friends for [is] money. Money is only me. Like I work or

I don't work. (P2, age 55, currently working)

Another participant who lived alone in a subsidised seniors' housing and depended on

home care for all of her care and support needs described the connection between income and

care more explicitly. When asked what her expectation was for the future in terms of her

health, she noted that she didn't expect anything different from her current health care unless

she won a million dollars. She stated that a million dollars would be helpful because it would:

Buy personal medical attention. I think money can buy health although we're not

supposed to believe that. I think there are situations that money can buy all kinds of

extras that contribute to healthier living. I think that's probably true. So I don't foresee

any miraculous turnabouts in my case. (P12, annual income of $20,000 - 29, 000)

Despite the range in incomes reported in this study, money and the ability to pay for

care featured in all participants' discussions about being able to access care in the future. This

concern with needing to pay for care in the future indicates that many participants were aware

of the public discourse about the affordability of home care and the national "concern" with

care costs. This finding is in line with other studies of older home care recipients (Aronson,

2000; 2006; Aronson & Neysmith, 2001; Sinding & Wiernikowski, 2008) that have found that

home care users are very aware of the discourse of affordability in home care. As a result of

this, older home care clients often downplay or deny their experience of restriction and denial

of care. It also has been suggested that older women who are particularly vulnerable to poor

health are less likely to complain and/or ask for formal help with care as a result of their

gendered socialization as family caregivers. As I illustrate in Chapter 8, the internalization of the

neoliberal discourse of "affordability" and the emphasis on individual rather than state

responsibility for care has implications for home care users' ability to articulate complaints with

respect to service quality and accessibility. While the emphasis on self-reliance or personal

"hardiness" reflects the resilience and resourcefulness of study participants and their families,

reliance on informal care may be problematic in the long-term.

In terms of education, the majority of the participants had a college or undergraduate

diploma and some had graduate training. Five participants had a high school degree or less. The

majority of participants (n = 15) were not currently working and their occupational histories

primarily consisted of "pink" collar service work in the areas of social services, education and

health or in manual labour jobs.

The only participant who was employed at the time of the interview explained that she

was working in a "second career" as a personal support worker (PSW). This finding is supported

by research that suggests that in general lesbian women have less access to income than

heterosexual women and men do and are more likely to experience poverty in older age as a

result (Calasanti & Slevin, 2001; Cruikshank, 2009; Gabrielson, 2011; Morrow, 2001). Thus, most

of the women in this study lived on limited fixed incomes and worried about their ability to

access needed care in the future.

Spaces and Living Environments

In terms of living environments, most of the sample (n =10) lived in a large urban centre

in Ontario (population over 2 million), 4 lived in a medium urban centre (population around

100, 000) and two participants were in a northern rural area (population of <12,000). All of the

individuals who lived in the large urban centre lived near the downtown core. As a result, most

participants lived in areas where the amount of available health and social support services was

greater than in more rural areas in Ontario (Coyte, 2000; MacDonald, 2011; ROMA 2011). While

this does not necessarily mean that participants were able to access home care (or other social

services) in a timely and responsive manner, it suggests that their experiences do not

necessarily reflect the experiences of older lesbian and bisexual women living in more rural

communities, where access to medical and supportive care for older people may be more

restricted.

The majority (N = 11) of the study participants also lived in a house or a condominium; one individual lived in a rented apartment, another in a cooperative housing apartment and three lived in subsidized community housing for seniors.[18] All of the participants who lived in the rented apartments or subsidised housing had incomes less than $29,000, lived alone and were either Aboriginal or a recent immigrant to Canada, suggesting that these individuals may be even more vulnerable to poverty in the future.

For several participants who lived in multi-level homes, the architectural layout represented a challenge in terms of everyday mobility. Stairs in particular presented a challenge and participants tried to arrange their lives around using them. Reflecting on her ability to manage without home care services, one participant who lived alone in a multi-level home stated that she was worried about the potential for injury. Given that she had sustained an injury from falling down the stairs in her home the previous year, re-injury was a considerable worry:

> Now I have to do the laundry myself so that's going to be tricky because I'm not supposed to go up and down the basement stairs when there's nobody in the house because the risers on the basement steps are a lot narrower than regular stairs. I'm more at risk going up and down those stairs. (P5)

Others participants who lived with family members relied on the family members to help them manage getting around their physical environment:

> She [my spouse] hikes up and down the stairs for me if I need my medications or if I need anything. We've got nine stairs going to the basement and sometimes it's like a

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[18] These are residences owned by the city that are offered at reduced rent as compared to market value for individuals on social assistance/disability; seniors' residences are further restricted to individuals over 55 years old.

whole staircase. Once I go downstairs I don't come back up until it's bedtime so if there's any up and down the stairs or if somebody comes over it's like, "Oh my god. I've got to climb those stairs again. Just bring them downstairs," you know. (P15)

I need the kids and X [my spouse] to sometimes go upstairs and get things for me. If I've already run up and down stairs several times when this knee, now that it's acting up. I have what's called a Baker's cyst on the back of the knee, which is really just a fluid that's building up in the knee because of something else kind of pushing out to the back of the knee. I learned this the other day.   And sometimes it makes it really painful to go upstairs, which I do anyway. I mean we live in a four story house if you count basement so there's a lot of up and downing but sometimes I will ask especially the kids, "Would you please go up and get something for me" or "Take this" or whatever. And they're generally very amenable about doing it, although I occasionally get rolled eyes from our daughter who is at that age. (P1)

Accessibility and the ability to get around their environment was a common issue for many of the participants who used walkers, wheelchairs and/or canes in their daily lives. As one participant explained, depending on how her balance was, she could alternate between using a walker or a wheelchair. However, using the wheelchair sometimes meant that she wasn't able to access certain spaces in her community. As she lived in a small rural community with limited access to health and social services, if she was not able to enter a building in her wheelchair, she couldn't access an important health service:

Days when I'm not the steadiest on my feet I can take a wheelchair into the dentist's office but it's just a hassle. In fact the doctor's office I can't get into in the wheelchair.

My dentist's office is difficult, not impossible but difficult to get in and out of with the

wheelchair. The drugstore, you know, where I get my prescriptions and so on is difficult

to get in and out of in the wheelchair. The mobility store is difficult to get in and out of

with a wheelchair. I don't know where—Oh, when I was doing massage therapy I

couldn't get in there and out with a wheelchair. It was stairs. If I couldn't handle the

stairs I had to cancel the day. (P10)

Such mobility issues and the lack of accessible spaces within their communities further

restricted participants' ability to participate in society and increased their social isolation.

Restrictions on mobility also increased the burden of care on participants' partners and

families, who had to take on the responsibility for transportation and related activities of daily

living such as grocery shopping.

Several individuals described a gradual process of outfitting and re-modelling their

homes to make them more accessible and "safe" to move around in as their support needs

increased. The bathroom and bedroom were rooms that particularly represented challenges to

accomplishing everyday self-care tasks safely and were often tackled first.

The bathroom was the one that took the most renovations. I have a bath seat

now. I have the bars on the walls for getting in and out of the tub. Going out the back

door, there's a grip on the back door so that I can get in and out easier. And this house,

we bought it because it has an elevator. It was already here for a woman who had

terrible arthritis so we went, "Hey, we can live in this house for a very long time." So

the elevator gets me up and down the stairs and out of here when I need to. So we now

have the stuff in the house to take care of me. We now have a grab bar on my bed, you

know, the kind you see at the hospital. Immensely helpful for getting out of bed when

I'm alone. (P6)

Similarly, describing the help that she received through CCAC, P5 explained:

They put in grab bars for me… And this is something which was excellent in terms of the

care that I got there. They made sure once I left and came into my home I had all the

supports that I needed in terms of not only care giving but grab bars or if you noticed I

have a grab bar outside. I had to pay for the stair lift myself. So balance is a huge thing

for me in the bathroom. So, you know, I have a seat, I have a chair in the tub. (P5)

Given that "safety" in the form of home renovations and/or assistive devices has been a

recent focus of health care policy and provincial funding (Aging at Home Strategy, 2007;

Healthy Homes Renovation Tax Credit, 2012), as well as targeted by best practice initiatives by

several health professional colleges, the participants' focus on home renovations is not a

surprising finding.[19] Inexpensive one-time home renovations such as installing grab bars and

bath seats in the bathroom are a common focus of safety assessments and CCAC's

determination of whether one needs help with self-care tasks. While these types of

renovations were helpful in terms of managing tasks, the focus on such items further shifted

the responsibility for self-care onto individuals and families and away from the state.

Additionally, the focus on home renovations, rather than on increasing their community

integration and helping them to access services outside the home, further contributed to

restricting participants to their homes and isolating them.

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[19] For examples, see Prevention of Falls and Fall Injuries in the Older Adult. RNAO Best Practices Guideline
Available at http://rnao.ca/bpg/guidelines/prevention-falls-and-fall-injuries-older-adult;

Furthermore, not all individuals who wanted such modifications were able to arrange for them as a result of the cost and/or restrictions on renovations within rental spaces. As P4 explained, although she was told she needed to install a new shower head to accommodate the use of a bath chair after she broke her ankle she was not able to do so:

I developed a bit of a fear of falling, you know, because I know that would hurt something else. So maybe there was a little paranoia in there, maybe there wasn't. I thought no, you know, I'm a Canadian citizen, I've contributed for at that time 68 years. What? You know. And, you know, I was concerned about bathing. She said, "Well all you need to do is phone Shopper's Drug Mart assistive devices and you can rent them for X number of dollars a day." O.K. And so finally I phoned them finally. I thought I was making some progress. I wanted a chair to sit in in the tub. So a guy showed up with that. The filthiest thing I've ever seen. It's like it hadn't even been cleaned. Anyway, I thought, oh well. I can clean it up. And he said, "Well I'll have to change the shower head," so he brought another shower head. I guess it was for aim because the chair had a high back... And he fiddled around in there and he said, "I can't get the shower head off which means I can't put the new one on." The new one was the one that detaches. He said, "I can't put it on." I said "O.K. What do I do?" He said, "Well you can give me permission but if I break anything I'm not liable and you'll have to sign for that." If that's your need then maybe you've broken things before. [laughs] I wasn't hearing what I wanted to hear. So I said, "Just leave it." And I said, "Take the bath chair. It's no good to me without that. I'll manage." (P4)

For P4 and other women who lived alone, getting around their home required daily problem solving to manage doing their necessary activities. One participant decided to look for a smaller apartment that was accessible after they began to use a wheelchair. They were able to access community-supportive housing that was recently renovated to be fully accessible:

I had a two bedroom apartment and this came up and it's very small but I decided I didn't need a two bedroom because I can't move anyway. So I decided to take this because…it's for senior people so everything is here, wheelchair accessible... If I want to go out I go down to the elevator and press a certain button and can reach it. (P12)

Participants also expressed worry about how they would manage in the future in their current homes if their ability to get around became more restricted:

I mean I could use moving somewhere where there are not so many stairs [laughs] because everything has to be hauled up, right? The groceries… you never know what happens... I mean there might be a day where I might not be able to do these stairs. It's going to be maybe more difficult so I'm looking for a place where I either don't have so many stairs or maybe only half the stairs. (P2)

In terms of transportation outside the home, the majority of participants didn't own a car or drive and they primarily relied on friends and family members to help them get to appointments, go shopping, etc. This created limits on their ability to engage in social activities and confined them to their homes when their partners and families were at work. While some were able to at least get out and move around their immediate environments if they lived where they had elevators and flat paved roads, others were not:

Yeah, X [my spouse] has to drive because I have no license now. She has to take me everywhere I go actually. But I can walk around the block by myself with the walker. (P8)

Actually I can't walk very far and I can't take the subway. What I have is a brand new immune system and I can't have vaccinations yet, so I have a brand new immune system like a baby. I could get mumps or measles or chicken pox or whooping cough or smallpox if it still existed--My immune system is virginal so I can't travel the subway at active times. My energy is low--I don't have a car. We have one car and X has it when she works. So when she's not working I can use the car. But yeah, I do rely on friends and X [my spouse] for transportation. (P13)

Another participant who was used to driving in the past indicated that she was worried about not being able to drive in the future because her vision was deteriorating. As she had limited mobility in her hands and tired easily, she worried about how she would get around without her partner, who worked full time:

X [my spouse] is very concerned about driving because (a) I have vision only in one eye unrelated to anything, but I have vision only in one eye. And now with the neck surgery I have limited mobility. So I mean I would never drive the X or the Y [major highways]. And I'm actually a bit concerned that X is sort of holding me back from driving because more than anybody I need it because I get fatigued so easily and everything and if I lose my confidence to drive I think I would be sort of in a-- But X always accommodates me. She'll pick me up. But mainly TTC. That's why we live so close to the subway. And I can

use Wheel Trans, I mean like you know If I wanted to, which probably wouldn't be a bad idea if I needed to because it's very exhausting using TTC. [20] (P3).

Across the interviews, individuals reported that accessing public transportation was often difficult and complicated and as a result, while they sometimes used it, many preferred not to rely on it. As one participant described, while she preferred not to rely on her partner, she found it tiring and confusing to arrange for Wheel Trans as a result of the bureaucratic processes involved. Eventually she opted to use a private transit company as long as she was able to pay for it:

And then I had an eye specialist appointment and a couple of other appointments that I didn't want to miss, so, um, and I didn't have Wheel Trans organized because I had-- I had Wheel Trans but then wasn't using it for a while and then I still couldn't get clarification on whether I needed to be re-assessed or what happened. I mean it's just so crazy that you have to work so hard at this. So I just I couldn't face trying to get through that. So we called Y [transportation company] because that's another accessible transit but we couldn't figure out who was in our catchment area and when we finally did it took a little while to negotiate to get the rides organized. But once we did they were terrific. But you pay more. It's not like Wheel Trans. With Wheel Trans you just use your pass or your token. With Y it costs a certain amount. I think it was about eleven dollars or something for return. I think it depends on where you have to go with them. So they were able to take me to my eye doctor and take me home. But it's just a lot. Like I mean if you've got someone who is not as educated as we are and not at able to

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[20] A wheelchair accessible transportation service provided to individuals in some urban centres in Ontario if they qualify for it. Cost of the service is the same as regular public transportation but pickup is arranged ahead of time.

demand things and advocate, I don't know what the hell you'd do. If you don't have

maybe good English or you're not very well, which obviously you wouldn't be if you're

needing these services, I don't know. But it was a real struggle--Now I'm better

organized because I know who I can call because I can get Y if I need too. (P3)

Other participants were even more critical of relying on public transportation to get around:

Transportation? I use the TTC and I hate it. What can I say? Scraping the barrel. I don't

have money for a car. If I would have I would definitely get rid of my TTC pass and use.

The TTC is terrible. (P2)

Similarly, another participant who used a wheelchair and lived in an urban area where there

were paved roads and nearby access to groceries and other services explained:

Well I try to avoid Wheel Trans because it's a hassle... [You] spend way too much time

trying to book a ride at seven in the morning and then you don't really know if you're

going to get the ride or not or if they say you're going to get the ride often time you

don't find out until eleven o'clock at night and then you don't really know if they're

going to show up on time or not… It's a hassle so I try to avoid it. Fortunately I can spin

the wheels of my life within a few miles and get there on my own. So that's

transportation. (P16)

As a result of limitations placed on home care workers' permitted tasks and limited

time, several participants also relied on private cleaning services for which they paid out of

their own pockets. Paying for these services was the only way they were able to live in a clean

home, as they typically were unable to do it themselves as a result of fatigue and mobility

limitations and did not have other means of housekeeping support:

And we do have a cleaner who comes once every two weeks and then I can putter and maintain the rest of it. She does the baseboards and makes sure that everything is done. And I tend to tidy when she comes [laughs] so it helps keep the house nice… I get tired so sometimes I have a nap. (P2)

Well there's two ladies who come and they are here for about two hours or so and they do basic cleaning around the house, vacuum, wash the floors, wipe down the cupboards, do some dusting, that kind of thing. The PSW would help us with, for instance, changing the bed sheets. (P7)

We also got somebody to come in and clean the house. Over the years I have become less of a perfectionist around here. Do I care? Not much. Does my partner? A lot. So we have less dog hair than we had before. We have more things done with this person coming in because then my partner doesn't have to do all of it. The laundry. Because I'm disabled and I'm taking medications, the bed needs to be changed every two days. My night clothes twice a night. It's like having a child in the house in terms of laundry work. So that person coming, with the cleaning she could put stuff in and so could the personal services worker. And then my partner could do some in the evening. So that's how we kept up on that stuff. They didn't do any shopping, but they certainly helped do the preparation. (P6)

However, not all participants could afford to pay for such services and as a result they tried to manage by relying on temporary and informal help whenever they could.

I have a walk-in shower and so on, so I mean I can do my own showering and everything, but I really need somebody to change the beds, to do the cleaning, and

apparently you can't get that service unless you pay, do it privately, but my income is going to be quite low and so it's a concern about how you get the kind of care you need and the cost of that. (P3)

I was able to dust. I had difficulty vacuuming, but my neighbour three doors down has a very strong son, by the name of X [name]-- So I said, "T, can you come and help me vacuum?" "Sure. No problem." And he would come once every two weeks or three weeks and just help me vacuum. (P2)

Thus, participants' home and geographic environment, as well as their ability to access supports and care aside from publically funded home care, affected their need for home care, as well as their ability to manage while receiving home care. In particular, participants found it necessary to pay for housekeeping services and transportation services privately as public services were typically unreliable or unavailable. Furthermore, while receiving some formal home care services, many also depended on informal help that they received from their partners, friends and neighbours in order to manage everyday personal care activities and household tasks.

Conclusion

In this chapter I presented an analysis of factors that affect participants' need for care and the conditions under which the care happens. These factors include participants' health, social location, the type of care they needed and their access to social supports other than home care. All of these factors reflect and produce important differences and similarities between participants and mediate their experiences of accessing and receiving home care services, which is the focus of the next chapter.

Chapter 6: Access and Receipt of Home Care

She [my friend] was turned down [for home care] and she just didn't have the strength

to keep asking for it. So that's one thing that I will probably keep close to me is that it's

going to take some work to get it. (P15, short term user receiving one hour of home

care per week)

In this chapter I present an analysis of the project participants' experiences of accessing

and receiving home care services. As mentioned in chapter four, participants accessed home

care to address a variety of health issues, for differing periods of time and in a variety of ways.

Nine participants were short term users, or individuals who accessed home care once for an

acute health condition and discontinued the service voluntarily after a few weeks or months

because they had recovered. Seven participants were long term users and have been accessing

services for years, with some receiving home care for over five years at the time of the

interview. Many attempted to access home care services multiple times over a period of ten

years or more and have experienced different levels of access during each attempt. That is,

some participants reported that while at one point they were able to request and receive home

care, at other times they were not as a result of either being denied services or because of

delays and other structural complications.

The diversity of experiences captured in this study is important for our understanding of

how individual circumstances and experiences influence the process of accessing home care in

Ontario. These differences affect participants' expectations with respect to home care access

and services and the types of strategies and mechanisms they use to arrange for their care.

Across all of the narratives, however, there were several factors that mediated both access to

and the experience of receiving home care services. These included the initial point of access

(through a health care facility or physician versus at home on one's own), the type of care

sought (supportive versus nursing care), and previous knowledge of the social services system

and access to other social and environmental supports (partners and family, friends,

community housing and private care). In this chapter I present an analysis of participants'

experiences of accessing and receiving home care and illustrate how the identified factors

affect these experiences. During the analysis, it became clear that receiving home care was a

process-based experience. Furthermore, I identified three themes in participants' experiences

of receiving care that corresponded to three key stages in this process: (1) Access to Care, (2)

Receipt of Care (or Denial), and (3) Exit from Care (or Renewal).

The analysis presented in this chapter demonstrates that participants experience

multiple barriers to accessing needed care. As a result, participants have unmet care needs

that force them to engage in constant care provisioning strategies that negatively affect their

overall well-being and quality of life. These strategies include relying extensively on informal

caregivers such as partners, friends and neighbours, purchasing care services or going without

needed care.

The analysis of these experiences demonstrates that participants' unmet care needs are

the result of structural, environmental and ideological barriers within the home care services

system and heteronormative and heterosexist assumptions. More specifically, the analysis

demonstrates that the home care system is under-funded, ineffectively administered and

privileges the biomedical model of health. Finally, this chapter suggests that gendered

assumptions around responsibility for care exist in the current home care system. In particular,

structural barriers to personal home care services suggest that it is assumed that individuals would be able to draw on informal supports, such as female partners and family members to meet their everyday supportive care needs. Together, these interlocking barriers contribute to the downloading of the responsibility and cost of care on to individuals and families, rather than the state.

Access to Care

As mentioned in the previous chapter, many of the participants had chronic health conditions and have struggled with doing basic care activities for months to years prior to deciding to access formal public home care services. Many of the participants described delaying, or waiting to access home care, and explained that they decided to do so only after experiencing increasing difficulties in being able to cope as a result of worsening health. Many of the participants also valued their ability to manage without seeking outside (or formal) help and were not used to needing care. This was especially so for coupled participants, who primarily relied on their partner for emotional support and instrumental help with personal care activities. For example, when asked about her health before accessing home care, one participant responded:

> [My health was] perfect. I'd had thyroid cancer, two surgeries and it was removed. It was malignant. That was in I think 2000, I think. So I haven't-- There was nothing that slowed me down. I could get a dump truck full of mulch and move it in four hours. That's a lot of mulch, probably eight cubic yards. I did all my own gardening. We have two ponds in the back yard. We put those in. We built the decks ourselves. All of the home improvement stuff we've done ourselves. We put in our own bathroom, toilet,

tub, all the fixtures we've done ourselves. All of our own painting we've done ourselves.

(P15, age 55)

Similar to Aronson's (1998) research, participants in this study were unused to needing

care or accessing formal supports in general and some were explicitly wary of accessing formal

services for fear of experiencing homophobic discrimination. As a result, participants typically

delayed seeking help and accessed home care services after a period of time when they tried to

manage on their own or with only the help of their partners and families. Reflecting on the

events that led her to seek home care, P6 explains that this delay happened because accessing

formal services was seen as risky in terms of potentially experiencing homophobia:

So I'm getting less able to care for myself. I have a partner who is trying to go to work

leaving somebody who is crawling down the hall. She said, "We can't do this anymore.

Would you be willing to let someone come into our home and take care of you?" And I

thought to myself, well I'm not really fussy about that but I also love and care about my

family so I have to do that. I have to honour this relationship and just take it and do it

and risk it because my partner is going to die trying. (P6)

All of the participants accessed home care services in one of two ways: through a health

care professional (for example, their physician, surgeon or social worker) who referred them for

assessment to the CCAC or by direct contact with the CCAC or home care company. About half

of the participants accessed home care after being hospitalized and reported that their home

care (nursing or personal care) was arranged by a social worker who worked at the hospital and

that this was done before they were released from the hospital. Their primary physician at the

hospital was responsible for initiating the contact with the social worker and requesting an

assessment. The social workers were typically employees of the CCAC and were stationed in hospitals to assist with hospital patients' discharge planning. They were responsible for interviewing the potential home care client at the hospital, contacting the CCAC in their catchment area (within their local health integration area), providing the CCAC with preliminary details about the kind of care that the client would need at home (nursing, personal care or both) and requesting that the CCAC provide this care. Reflecting on this process, P5, who was in a rehabilitation hospital before she was discharged after her brain injury, stated:

> When I was leaving X [a rehabilitation facility], the social worker there, they set you up with services on the outside depending on what your needs are. So I came home in July of '07, the first week of July, and by August, the first week of August-- No, actually the end of July I had my first caregiver from R [a home care company]. (P5, long term user)

Similarly, when asked how she began to receive home care, P7, who was hospitalized after her toes were amputated as a result of complications with diabetes, said:

> Through the hospital. They told me that I needed, um, to have my dressings changed so they started coming in and that was it... The time that I was off I ended up in the hospital and home care was arranged while I was in the hospital. It was ordered by the doctor and somebody from home care came to tell me what would be happening. (P7, long term user)

 Other participants initiated access to home care by calling their CCAC and/or home care company from home and requesting an assessment. Typically these were people who underwent a day surgery (such as joint replacement) and were not hospitalized over-night

afterwards, or saw a physician in the community who recommended that they get home care.[21]

However, as P9 explained, going directly to CCAC was often complicated and took longer to arrange for care than going through a hospital, as a hospital-based physician typically was able to expedite the process. Reflecting on her and her spouse's experiences with home care, P9 explained that while she tried to initiate this process before her day-surgery, she was not successful:

> I found out by talking to a supervisor who came to see about X [my spouse] that, um, because I had day surgery I wasn't in the hospital, that that's why there's sort of, there's more of a delay for CCAC to get involved. If my surgeon had requested CCAC to interview me while I was in the hospital, it would have been arranged, but I didn't know to ask that of her and she didn't volunteer to do it for me. So we did try to contact CCAC. The nurse on duty when I was in day surgery, we tried to contact CCAC and get them on board, but it didn't work. Now I had my surgery done in Collingwood so that's a different area for CCAC than here. And like I said, I had contacted, you know, this group in advance but without-- I'm not the doctor requesting it so they couldn't do anything. (P9, short term user)

Across the interviews there was a difference in the ease and speed of access to home care services between individuals who needed personal care only and individuals who needed nursing care. Individuals who needed nursing care reported that a nurse came to their home right away, starting from their first day at home, and that a formal assessment with a CCAC case manager typically followed this. Indeed, individuals for whom a physician determined that they

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[21] I am using the term hospitalized to differentiate individuals who are admitted to the hospital for a few hours to undergo same day-surgery and are discharged the same day from those that are admitted for an overnight or longer stay at a hospital.

would need nursing services, reported that they were not discharged from the hospital until nursing home care was arranged. As P1 explains, although she was ready to leave the hospital and was discharged by her physician, she had to stay an extra twenty-four hours in the hospital because she was not able to see a CCAC social worker for a home care assessment. Reading from her notes about the experience, she said:

> Anyway, just to end all this, finally what happened was I called the nursing station, the nursing provider, and had a big kind of rumble with them by phone. Oh, here's a note. "Just found out that CCAC, who I've been waiting for all afternoon as they insist they must see me in person, will not be coming." This was in the hospital. 'They will come tomorrow around noon, they say. Arrrgh." So I couldn't leave the hospital because they didn't come. (P1, short term user)

Only one participant who needed nursing care, P13, did not receive it, even though she had it arranged prior to being discharged from the hospital. However, unlike other participants, who needed wound care or medication administration, she was supposed to receive intravenous hydration at home after she was determined to be palliative and discharged. Furthermore, she explained that she didn't pursue nursing home care, as she had to go back to the hospital shortly after coming home as a bone marrow donor was found for her:

> The hospital arranged it all. And I believe somebody from CCAC came in. Before I left the hospital they came in to just talk to me about-- but it never happened. Maybe I was going to get home care in the beginning but I didn't and then, when I was in there, because I was still seeing the oncologist because I hadn't had the bone marrow transplant, the oncologist arranged for CCAC-- I think they phoned to say they were

going to send me this equipment. It was going to come in the next two days and then a

nurse would come, so I think everything was done over the telephone. (P13, short term

user)

Regardless of whether participants accessed home care through a hospital or through

the community, unlike participants who needed nursing care, those who needed personal care

were told that they could have home care services only after an official assessment was done at

their home with a CCAC case manager. This extra step in the process significantly delayed

access to needed care and caused unnecessary hardship for participants and families. This delay

did not seem to be based on the level of care need that individuals had; in other words, based

on individuals' functional abilities and their access to other means of support such as an

informal or privately paid caregiver who could care for them in the meantime. In fact,

participants were not asked about how they would manage while they waited for an

assessment at home after they reported that they needed care and/or were released home

from a health care facility after undergoing a procedure that limited their mobility and their

ability to do self-care tasks. Again, this suggests that it was assumed that individuals would

draw on (or continue to draw on) the informal support of friends and family members during

this time. Additionally, it is possible that it was also assumed that women would be able to

manage without this type of care as a result of gendered assumptions about women's

responsibility and aptitude for care work and household activities.

Typically, participants who needed personal care were given a referral to CCAC and

were told by their physician or social worker to contact CCAC directly once they were at home.

For example, P2 was told to call the CCAC in her area after she came home from her knee

surgery. As she explains, despite having limited mobility and living at home alone in an apartment on the second floor of a building without an elevator, she was expected to manage without home care. Furthermore, she noted that she, rather than her health provider, had to initiate the request for care:

> Well of course I know you have to get your family physician for a referral, so when I got my cast I asked the surgeon and I said, "How would I go about getting home care?" With a broken kneecap you cannot bend your knee, so obviously you're in a cast like this and you cannot move. You cannot even sit properly on the toilet. And you cannot obviously go in the shower either, so I needed somebody to help me wash myself. My feet, I couldn't bend down, bend the knee, to wash my feet so I needed somebody to help with my feet. And on the days that the personal support worker didn't come, my neighbour below, the couple, they helped me a lot because the wife would come and help me wash my feet. I would wear the same socks all the time because I couldn't take them off and I needed to buy one of those mechanisms. It just looks like a shield, like a face shield, but then obviously for your feet, and there's a string on it and then you can sort of put the sock on it and pull it on and then your sock comes on. You know, but so they helped-- Sorry, where was I now? Yeah, so that really helped. So I had to ask the doctor. I said, "How would I go about this?" He said, "Check at the front," so I checked with the lady in the front and then CCAC obviously was contacted and then I told them which company I wanted because I work for this particular company, right? So I said, "O.K., I want my company," so somebody came and they came twice a week. (P2, short term user)

This added structural barrier to accessing personal care suggests that access to

biomedical care is privileged within the current home care system and that it is assumed that all

individuals have familial and other informal resources to draw on for personal or supportive

care. As a result, individuals who need personal or supportive care are forced to arrange for

care through informal means, such as relying on friends and family members, pay privately for

home care, or go without needed care. As I have discussed in the previous chapter this may be

especially problematic for lesbian and bisexual women who may have limited access to typical

informal caregivers such as spouses or children, and lack the financial ability to pay privately for

care.

Regardless of whether individuals had a scheduled non-emergency day surgery like P2,

or if they went to the hospital after an emergency, participants who needed personal care

could not request home care before being discharged. For example, unlike P1, who was not

allowed to leave the hospital until nursing care was arranged, P4, who needed personal care

after having an emergency surgery to fix a broken ankle, was discharged from the hospital

without personal home care arranged. This was despite the fact that P4 was injured in a

different city, lived alone and was on an opioid pain medication after her surgery. Recounting

this experience, P4 said[22]:

> So they let me out. They phoned my friends that I had been golfing with and said, "O.K.,
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> she's ready to go." I have no relatives here in town. So they phoned [them] and they
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> came over, so they took me downstairs about four o'clock. I woke up downstairs and
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> the woman says, "O.K., you need to leave now." "What do you mean leave?" I said, "I

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[22] This is a type of pain medication similar to morphine that can cause drowsiness, dizziness and nausea.

live alone, blah, blah, blah." And she said, "You have to leave the hospital. If you don't,

we'll call the police and have you escorted out." Well who shit in your cornflakes? You

know? It was just horrendous. Anyway. So one of the gals lives downtown and said,

"You can come and stay at my place as long as you want." Like she's in a condo so

[there is] an elevator. I was so woozy when I stood up to go to the car I just about

passed out. And here they shoved me out. So I stayed there a week and I thought, I've

got to go home. So I know I made some phone calls to try and set things up and get

them organized. And the social worker at the hospital came and saw me before the

surgery and I never ever saw her again, you know. And then, you know, somebody gave

me a card with home care's number on it and that sort of thing and so I just phoned. I

said, "I need to set up an appointment. I'm being released. This is my situation and I

need some help." I said, "I'm supposed to be, you know, bed rest, non-weight bearing,"

which meant I could use crutches and that was all. "I've got to cook, I've got to shop, so

I need something set up." She came and she said, "You look pretty strong and healthy.

You should be able to get around." (P4)

Like P4, many of the participants who received personal care reported that they

expected their home care to be available immediately after they left the hospital. However

actual receipt of home care services was delayed until after a CCAC case manager did a home

assessment and confirmed that they needed care. The CCAC case managers were also

responsible for deciding how much care was allotted to each individual. This meant that even if

individuals were pre-approved by a physician to receive the care and were discharged from

hospital after their scheduled surgery with the expectation that they would have care at home, they sometimes had to wait weeks to actually receive care.

As a result of this delay in process, participants who needed personal care reported that they had to figure out ways to manage at home without necessary help. Typically this meant relying heavily on their spouses and friends and neighbours, or managing by themselves at the risk of re-injuring themselves during a particularly vulnerable time. As P3 explained, although her surgeon assured her that she would have home care right away after she had a neck operation and had limited use of her hands as a result of rheumatoid arthritis, she could not get home care for a week after her discharge from the hospital:

> I mean except that it seems that this surgeon I guess is so important and he's like this guy has got all sorts of clout and it seems like he makes sure that the people that provide this care, because she [the social worker] worked on his floor. So I don't know how that got arranged and so on. I know I thought that the person from the CCAC, they were going to discharge me and she still hadn't shown up because you can't leave until they see you because they have to arrange it. And she finally arrived breathless at about one o'clock. The poor woman was just beside herself trying to cover so many patients and it turned out that they were sending me home that day and she couldn't arrange home care for a week… So luckily X [my spouse] was (a) available, well she made herself available, and (b) was physically able to do it and could handle that. I mean I don't know what I would have done if it was reversed and I had to care for her. But anyway, it took a week to get it in place, which is really kind of surprising. (P3, short term user)

Even when participants knew in advance that they would need personal home care after a planned surgery and tried to speed the process by arranging for an assessment in advance, they were not able to do so. For example, P9, who is a primary caregiver to her spouse, who also receives home care as a result of a degenerative spinal disease, reported that she could not arrange for an assessment with a CCAC case manager for two weeks after her shoulder surgery, despite her attempts to organize this before going in for her surgery:

So then I was scrambling to get set into place things that I knew needed to be set into place. X [my spouse] had been in the hospital for three weeks, from the end of September through the beginning of October, and she was quite ill and not strong and not able to do much, so I was really her primary caregiver.   And she had CCAC on board at that point and I thought that-- I knew I would be pretty incapacitated for at least a week after surgery because, um, not only was my shoulder going to be involved but my hip as well because they were going to take a chunk out of my hip to put in my shoulder. So I contacted CCAC as soon as I heard that I had the date from the surgeon to try and line up, you know, to get people to come after the surgery and I was told that I couldn't do anything, arrange anything ahead of time, that someone would come to see me, you know, after the surgery. I mean there's no point in them interviewing me now because they don't know what my needs are. I mean I'm healthy now, but after surgery my needs are going to be different. So it turns out that it took two weeks for them to come and interview me after surgery before starting on getting a PSW [personal support worker]. So the system let me down because, you know, you need the help the first week after surgery. That's pretty critical and after that, well it's nice. [laughs] So

fortunately I had friends who stepped in and you know, came and helped, and were,

um-- I had prepared food as much as I could, but they did the cooking and thawing out

of things and so forth and X's PSW did help me even though she wasn't really supposed

to, but she did help me. (P9, short term user)

As a result of experiencing difficulties in arranging for home care, some participants

decided not to pursue home care and instead to continue to manage on their own with the

help of their families and/or friends. However, reliance on informal supports may be

problematic in the long-term as many participants had chronic health conditions. Thus, while

they may temporarily meet their care needs by relying on friends and family, over time this may

become impossible as a result of increased need and caregiver burnout.   For example,

recounting her recent experience with accessing personal home care, P3 said:

I was hoping to get some home care when I had my right hand surgery, but we called

the CCAC, who referred us to the local whoever it is that does it. Turned out it was the

wrong one. They didn't even know which one to send me to, so that was very helpful.

And then we finally got the right one and she was supposed to come for an interview,

but they never showed up and then six months later she called to ask if I still needed it.

It was pretty pathetic. So we just gave up. So what I did was we got Meals on Wheels,

because that was my main concern was having somebody to come in and prepare meals

and do some of that. (P3, short term user)[23]

Another participant, P13, reported a similar experience with home care access to nursing care

after she was discharged home from the hospital. She was told that she would receive nursing

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[23] A service provided by various home care and community service organizations in Ontario whereby a prepared meal is delivered to homes for a fee.

home care services who would administer intravenous hydration to her. However, she reported

that she did not end up receiving home care services in time and as a result decided to go back

to the hospital to receive the necessary care:

I think before that they [CCAC] were going to give it to me again and it never

materialized and I was just as happy. It never materialized and by the time they were

going to come I needed to go to the hospital to get whatever it was I needed because

now it was too late. I couldn't wait longer than a week and they were supposed to have

arranged home care and they didn't, so I said, "You know what? Forget it, because I

have to go to the hospital today, because I have to have it today. Because I'm totally

dehydrated and I have to." So I never had home care again. That was it. (P13)

Once individuals who needed personal and supportive care were able to make an

appointment with the CCAC for the required home assessment, they were assigned a case

manager who came to their home and interviewed the participants (and their families) about

their care needs. Typically this assessment session involved questions about what daily care

activities the individual could and could not do on their own such as toileting, washing, bathing,

preparing meals, etc. Although none of the participants described being asked about their

informal means of support such as family members and partners, it is possible that it was

assumed that their primary support source would be their female partner and/or other female

family members as had been suggested in previous research (Morris, 2001; 2004). Three of the

participants described these assessments as follows:

It was short kind of questions and answers kind of thing. And the other thing

they're doing is checking your home out as well, how safe it is for their workers to come

in. And of course they saw all the animals and said, "One of the things you have to do is put away all the dogs." (P10, long term user)

Well she wanted to know what I needed done or what I could do, what I couldn't do. Like I couldn't bend over. I had to sit on a cushion about this high. I couldn't bend down to pick up anything. Had one of those little picker upper things. It took quite a while even to cook a meal, so I used to have a friend come over. First the ladies [neighbours in the building] helped, too. They used to set up a meal for me. Everybody looks after each other, you know. If you're sick or something, they'll help you out. (P11, long term user)

She came in and she said, "Well let me see you stand up," and you know, she walked through and she said, "You've got lots of room and room in the bathroom. That's good. And the kitchen is handy, so that's good." And I'm not feeling anything is good at that time. (P4, denied care, living in small basement apartment)

Case managers' emphasis on establishing participants' maximal functional "ability" or functional independence further suggests that the home care system is biomedical based as need for care is determined on a biomedical model of health. Within a biomedical framework, health is considered to be the absence of physical or mental impairment and acuity is determined based on a rating of an individual's self-care abilities rather than on their subjective experiences of health, their participation restrictions or their access to social support. That the majority of the participants received only a few hours a week of care, regardless of functional ability, further suggest that the standard against which independence is measured against is

relatively low. As P2 explained, this low standard is also formally supported by home care policy that supports access only to the bare minimum of personal care:

> I was eligible for services twice a week. Because the Ministry of Long-term Care and Health [sic] says we need-- twice a week for sure that you need to have access to a shower or sponge bath or whatever, but a wash anyway. It's to keep your body clean. (P2, short term user)

The focus on maximal functional independence in home care is problematic for several reasons. First, this focus assumes that functional independence is the most important aspect of support and of individuals' ability to participate in society. This is problematic given that the policy goals of home care are broader than that and include the goal of "help[ing] people maintain or improve their health status and quality of life" (Health Canada, 1999). Working within such a model, it is difficult to get home care that would enable individuals' quality of life as it only supports access to limited amounts of basic personal care, rather than the kind of assistance that would allow individuals to participate fully in society and enable them to participate in meaningful activities and social interactions outside their home.

Second, the emphasis on individuals' functional independence excludes consideration of how other aspects of an individual's social location, such as access to informal supports and geographic location, can affect needs for support. As a result, it is assumed that individuals who need care will be able to draw on informal supports, such as family members' help, to supplement home care and help with other daily tasks such as cooking, grocery shopping and cleaning. This is especially problematic for lesbian and bisexual women who may not be able to access such supports as a result of social and financial barriers. For example, most participants

in this study did not have natal family members to draw on for support as result of lack of children and strained relationships with natal families. Additionally, coupled participants reported that their partners typically worked full time and were also responsible for the majority of household responsibilities. Finally, the emphasis on maximal ability does not consider how variability in symptoms such as pain and fatigue may affect self-care abilities from hour to hour and from day to day. This, however, is a valid concern as many of the participants had chronic conditions which are known to vary in severity over time.

The emphasis on independence in home care also contributes to the individualization of responsibility for health and stigmatizes those who need care. This may then cause some people to delay seeking help or minimize their need for support, which can have potentially negative long term health consequences and unnecessarily burden informal caregivers and families.   Given that there is evidence that lesbian and bisexual women delay seeking formal health and care services as a result of fear of homophobia (Aronson, 1998; Solarz, 1999) this stigma may further negatively affect their health. For example, P9, who was unable to get home care for two weeks after her shoulder surgery and then only qualified for two hours a week despite being a primary caregiver to her spouse, stated that although she wanted more help she did not feel that her need was "acute" enough to deserve it:

> I really would say that I thought about it more since then, because at the time all I was thinking about was how I was feeling and just coping. I wasn't worrying about it or anxious about it, I mean, because there was somebody here… The CCAC service and the people that they send and so on I think are excellent, but the constrictions they're under for money is what is limiting how much they can do. And I can certainly understand;

you know, I was not super acute. I mean I could talk, I could walk, you know, I could

function, but slowly and with difficulty, as opposed to someone else with greater need.

I could understand that I would receive less time because of that. (P9, short term user)

Several of the participants stated that they felt frustrated with their CCAC case manager

and the CCAC interview process in general. In particular, they reported that they were

frustrated because they felt that they had to *prove* to their case manager that they needed and

deserved care, even if they were referred to CCAC by their physician. Participants understood

that case managers were gatekeepers to care and felt frustrated and helpless while trying to

impress on them they needed help:

I was left with the feeling that she, before she got here, came in convinced that I wasn't

going to get approved. And my approval was in her hands. I just wasn't in any shape to

fight it. (P4)

Um, okay in that our job over here was to show them that yes there was a need for care

in this family unit at that time. And it's like trying to prove that you're sick and you're

already sick and you have to prove it to somebody. It doesn't feel good. It's like, "Do

you think I'm lying? Do you think everybody phones up to have this?" No we don't. We

don't want it, but if it's available and it helps, and it did-- that's the good part about it.

(P6, long term user)

I mean they pay somebody who knows how much money. You get interviewed to death

about totally stupid stuff. I mean it should be enough-- There used to be a time in this

country when a doctor's note meant something. Now a doctor's note means nothing. It

just means more profit for the company because, "Oh, we've got to send somebody out

to interview you." "Oh we better get an occupational therapist to come in and interview you, too." All this nonsense… Because you have to remember, these middle management people, how they earn brownie points is the less hours they give people, the better. Don't give as many hours as people need and don't ever bring any problem forward to higher management. (P16, long term user)

Some participants reported that they also didn't realize the purpose of the interview or that case managers were responsible for determining whether they in fact needed care and how many care hours they would get as a result. As P15 explains, this lack of understanding meant that she was not able to appropriately communicate her level of need:

I didn't realize while she was interviewing me what she was interviewing me for exactly, but when she was asking the questions, and I think it was about an hour interview with her. And she would ask me questions: if I could do this, if I could do this, if I could do this, and I would answer it thinking, "I'm kind of normal but not being able to do the things still." They probably would have assigned me an extra hour or whatever because I'm not able to do those things. But in my head I'm still able to do them, like the bending forward and picking something up. It's not working. (P15, short term user)

Several participants further stated that in order to be able to get home care, they required a particular knowledge of the system and an awareness of the appropriate language and policies. Additionally, knowledge of the home care system helped participants to have faith that they were entitled to receive care and were able to advocate for themselves. This knowledge was gained through past occupational experiences working in social services, through hearing about friends' experiences with accessing home care and through conversations with their home care

caregivers. For example, P15 explained that she knew how to access home care as a result of getting information from a friend who has been receiving home care for several years:

> Through our mutual friend, she tells me the things that I need to be able to do and what I'm able to ask for and who I should be able to ask for it. She kind of guides me through everything because she's been there. She doesn't receive any medical, like CPP or retirement stuff... And she gives me a little extra strength and a little extra boost that, you know, "You can do this. This is what you need to do and how you need to do it."
> (P15, short term user)

Similarly, P5 was able to use knowledge of the system that she obtained from her caregivers to ask for more care hours after she was hospitalized for the second time:

> The hospital was ready to discharge me before I saw a social worker and I said, "No, I'm not leaving if I have to go and lie down in the hallway. If you take me out of the bed I'm not leaving until I see a social worker." Because that's what I was told to do by my two [caregivers]. So it was the social worker there who then said, "Do you need extra hours to help now that you're recovering from brain surgery?" And I said, "Yes." So when I came out, I got my caregiver again and I got an extra hour. (P5, long term user)
>
> However, "knowing how to," and being able to use this knowledge, were often tied to

having the privilege of being able to speak and understand English and having sufficient resources (such as time, effort, and mental and physical health) to follow through and get care. One participant, who was a PSW herself, explained that going through the process of accessing home care for herself made her realize how much access to home care was tied to knowledge of the system:

Like I know about CCAC, but before I started this kind of work I had no clue what CCAC was. So then we started going to school and we were learning all this about who does the funding and how the umbrella works. The Ministry of Long-Term Health [sic] and they give funding to CCAC and then organizations like mine get funding from CCAC, right? Because I know that. But if you have no clue and if you speak very little English or if English is not your first language or you speak it only a little bit, thank you, please, yes, good bye, so you're not going to know how to access it unless you are able to ask somebody in your own language. So I knew about CCAC so therefore I was able to be on the ball with it. But I think if I would not have known and if I wouldn't have-- I don't think I would have known how to go about it. I would have just been home and I would just have depended on my neighbours to, you know, to help me out. So I think, you know, some of those people don't know how to access it or they ask and if they maybe get a "Well ask me later" or "Phone this number" and if they're not really confident about doing all this kind of thing and they're not really confident about pushing for their own services they might not get it and might fall through the cracks. So in my view that happens also with straight people. You don't necessarily have to be a lesbian. But anyway, yeah, so accessing it properly, nobody out there stands there with a flag. "If you get hurt call your family physician." Like a lot of people don't know, right? (P2, short term user).

Some participants suggested that the experience of going through a home care in-home assessment was a learning process in and of itself. Being assessed made them realize that to get care was not as easy as they had thought previously. For example, P4, who was denied care

after her CCAC assessment, said that the experience made her more aware of the process and as a result that she would do things differently in the future if she needed care again:

> I would know now things that I needed that I didn't know then. I didn't know what my life was going to be like. Was I going to do six weeks and the cast comes off and I go ballroom dancing or what? You know. And I think I've already decided I'm going to be more assertive about my rights. I have a right to access these things just like anyone else, you know, and I don't need you to tell me I can dig into my savings to pay for it and things like that. (P4)

Similarly, P9 experienced difficulties in arranging for home care, and stated that the experience has made her aware of how little information was available how to arrange for home care:

> You know, like my GP didn't really know the extent of the services and what was offered. He just knew it was there and said, "O.K., I'll refer you and they'll call you and set it up." So, you know, information is not-- like there weren't brochures available in the doctor's office for instance. I mean where else would you get information about this, you know. I suppose if you approach a government office somewhere in X [another city], there's probably a brochure that tells you about it, but how do you access it? So when you go through these experiences, then you gain the information and of course now we can pass it on to other people. (P9, short term user)

"Knowing how to" get access to care, however, was not always enough, as individuals still had to use this knowledge and fight for their rights. As these narratives illustrate, the CCAC, rather than acting as facilitators for potential home care users, often acted as gatekeepers who were seen by participants as trying to restrict use of home care services. As a result of this

rationing and gatekeeping, participants had to engage in multiple provisioning strategies to

ensure that they had the care that they need such as relying heavily on their spouses for

support and attempting to increase their home care hours. However, this provisioning also

demanded a lot of effort and strength and negatively affected their quality of life. P1 explained

when reflecting on her experiences with the CCAC that in the current system the process of

getting care (and dealing with problems in access to care) requires continual 'strength' and

perseverance on the part of the users:

> Well I guess the first time wasn't so bad, you know. The CCAC person comes to see you.
>
> You've never seen them before probably the whole time you were in the hospital. They
>
> don't know you from Adam necessarily and all of a sudden there's sort of all this
>
> paperwork and this and that. So you know, in a sense that's a barrier in that, you know,
>
> in my case there had been a lot going on. But anyway they're just supposed to facilitate
>
> it, so that's fine. Another barrier was I know they're supposed to come in-- not the
>
> hospital person but the coordinator on the outside end is supposed to come and see
>
> you and mine never did and it might have been very helpful to have had a personal
>
> relationship when I was going through all this stuff, if indeed the person had been
>
> competent. I talked to her on the phone twice, I believe, and neither time was I
>
> particularly impressed. And I did deal with them that one other time, where they
>
> basically told me they couldn't guarantee I would get any better service from any other
>
> nursing agency which is, you know, horrifying when you think about it. And, you know, I
>
> speak English, I'm well educated and articulate, I'm not a push over, I'm assertive, all of
>
> that stuff and I went through all of this crap. I mean I could have died with some of this

stuff. You know, think about people who are timid, not English speaking, you know,

don't have any socioeconomic power to exercise. You know, it must be horrible for

people like that to get this kind of crap care. (P1, short term user)

These narratives thus suggest that access to home care services is not guaranteed in the

current system and that it often depends on an individuals' ability to demand care. Specifically,

to get necessary care, participants had to be able to advocate for themselves and have the

necessary knowledge of the system and processes, as well as the mental and physical strength

to do so. Given that participants were also dealing with major health issues while engaging in

this process, this further depleted their energy and negatively affected their overall well-being.

Furthermore, it is possible that many individuals will not be able to sustain this process over

time as a result of their chronic health conditions.

Receipt of Care

All but one of the participants reported that they were able to receive some home care

services after at least one access attempt; several participants however reported that although

they were able to receive home care services in the past, they were not successful in more

recent attempts. Most of the participants received either personal care or nursing care and

none of the participants received both personal care and nursing care at the same time.[24] In

terms of the amount of care, on average participants who needed personal care received a few

hours of care per week, regardless of how long they accessed home care or how severe their

functional limitations were. While the specific number of hours of personal care that

---

[24] One of the participants was assessed for home care by CCAC in their home (P4) but was subsequently denied after the interview. All other participants were able to obtain home care at least one of the times that they attempted to access it.

individuals received was determined by their CCAC case manager, most participants were somewhat able to negotiate how these hours were distributed over the week with their PSW.

Given that many of the participants had chronic health issues that necessitated daily and ongoing assistance with basic personal care activities, the limited amount of care that they received suggests that it was assumed that they would be able to manage by relying on their female partners and friends and family. And as mentioned in an earlier chapter, this assumption is also present in home care policy that defines home care services as services that supplement informal care provision (OHCA, 2010). However, this is an especially problematic assumption to make for older lesbian and bisexual women who are less likely to have access to typical sources of informal support such as natal family members or spouses. Additionally, as coupled participants in this study had partners who also worked full time, this assumption that female family members provide the bulk of necessary care placed additional burden and stress on their partners.

Participants who received nursing care typically received from twenty minutes to an hour of care per day, typically several days a week. Participants reported that the frequency of nursing care was determined by the physician and/or the nurse who delivered the care, rather than through an assessment with a CCAC case manager, as was the case for personal support services. However, it is likely that participants received an initial needs' assessment prior to receiving care through the hospital CCAC caseworker and that the amount of care was later adjusted by their home care nurse or their physician. For example, when asked who decided how often she received nursing care, one participant explained:

The doctors usually and she [nurse] also has input. You know, when she sees that it's doing better and if I'm between doctor's visits, then she'll say, "I'm putting you down to three times a week or twice a week' or whatever." But she asks me also about that or I suggest to her. So it's mostly the doctor. (P7, long term user)

The nursing care was primarily delivered by registered practical nurses and involved wound dressing and/or administering intravenous medication. Nurses did not do any other kind of care and left as soon as they finished the procedure.

I had a nurse coming from CCAC to give me an injection every morning. (P14, long term user)

The nurses come and change my dressing every day. (P7, long term user)

I had a life threatening infection for which I was hospitalized and as part of leaving the hospital they connected me with home care services because I had to have nursing care. I was taking-- I had to have two IV medications for several months and so I had to get nursing care at home to maintain all those and to do all the stuff related to that… I had to wear a pump and I also had to have a separate infusion and they came to do the separate infusion and to change the pump, you know, the one that I had to wear all the time, and you know, clean the lines and do all the maintenance associated with this medication. (P1, short term user)

However, the scheduling of nursing visits was typically not as easily negotiated as personal care visits and depended more on the schedule and availability of the nurse. For example, when one participant was asked whether she was able to negotiate when the nurse came, she responded:

Hell no. That's what some of that stuff was about. No. They scheduled it. I mean when

I needed it seemed to be the lowest priority. It was, you know, when they were

available and how much mileage they had to put on their cars and all this kind of crap.

So I mean maybe that's a little too harsh because I think there was some notion of doing

it at a time that was relevant to me, but believe me it was down towards the bottom of

the criteria. (P1, short term user)

As a result, some participants had to rely on their partners' help for nursing care when

their nurse was not able to come. For example, when asked how she managed between nursing

visits with her wound dressings, P7 explained:

It depends whether it's critical, like if I've just had surgery on my toe or if it's close to

healing. It just depends on where it's at. [My partner] can pretty much do anything that

the nurses have done except for IV. Most of the dressings she can do and she has done

and she will be in fact. They're crazy busy on Monday because it's a long holiday, so

she's going to be doing the dressing. (P7, long term user)

While such informal help was welcomed and seen as necessary to fill in the gap between formal

care visits, it can have negative consequences for participants' and their partners' health if a

medical complication or an accident occurs. Moreover, this placed additional burden on

participants' partners who also typically provided help with personal care activities and

household tasks, while maintaining paid work responsibilities.

Help with personal care activities was delivered by PSWs and typically involved helping

participants with bathing and dressing and doing some light housework such as laundry:

I get one hour a week, which barely seems enough, but it's enough to get a little dusting done, a little sweeping done, my sheets changed. The lady takes care of my legs from my knees to my feet, puts lotion on them, washes them, makes me feel better. (P15, short term)

If I want to take a bath I need someone to follow me up the stairs, just not to catch me [laughs]. I don't need to fall on top of anybody, but to know that somebody is there, sometimes steadying me so that I have a bath upstairs. Now we've put some hand holds and so forth in upstairs that make it easier to get in and out of the bath. But usually I plan those days for like Monday, Wednesday, Friday, when the PSW is here and then she comes in and gives me a hand and scrubs my back and washes my hair. It just makes life a lot easier… They make light meals for me… So it took some of the workload off [my spouse] because I can't run up and down stairs, you know, because I just heard the buzzer go off that the washing machine is finished. (P8, long term user)

For some participants, the PSWs also helped with other activities outside of personal care. For instance, P6 reported that one of her PSWs helped her think about how to conserve energy and carry out everyday activities so that she could manage being on her own. She also reminded her to take her medications:

I had a worker called a personal service worker and she helped me bathe. She helped me put my clothes on. She taught me how to put my clothes on without hurting myself, which was invaluable. I mean my mom just told me to pull my socks up. This lady said to sit down. But it's stuff that you don't think of, unless you are disabled and you're trying to preserve energy and you're trying not to fall over and you're trying to pull up

your pants and your hands are gnarled. And she was smart enough to say, "This is how

you do it. This is when you stand up." I didn't know that. So that was immensely

helpful. She also showed me how to get in and out of that bathtub without creating a

great amount of risk. I didn't know that… That was the personal service. She also cut up

food for me. Because of the arthritis, I have trouble manipulating with my hands a lot of

the time. So even just to cut up pieces of cheese or carrot sticks. And what we did we

planned ahead, so that I could open the fridge door if I were alone and I had food in

small containers for me so that I could just take them, walk three feet, sit down, eat it,

and go back to bed or sit in my easy chair. (P6, long term user)

Several participants reported that their PSWs also did "friendly visiting," by engaging

them in social interactions such as conversation after doing their assigned care work. This type

of social interaction was seen as particularly valuable by individuals who lived alone and/or

were not able to leave their house on their own.

Part of what they're supposed to do is to do some friendly visiting. In the friendly

visiting phase of this, this is after you've had your bath. Your little lunch is done. If they

have time, they will do a friendly visit and that's like, "How are you doing? How are

your kids? How are the grandchildren?" And making nice because that's what you

need. You need that kind of personal contact that says you're still a valuable human

being. (P6, long term user)

I got a caregiver who would come and if she'd finished her work before the hour was up

she would always chat. Or if I didn't want to chat we would just sit and watch [TV

shows]-- Luckily she liked that, too, so we would banter back and forth. And I really

liked the company. And then I learned that that was the norm. (P12, long term user)

This type of emotional support was especially valuable for relieving participants' social isolation

that they experienced as a result of being housebound. For example, reflecting on the impact

of being housebound and not being able to work as a result of her health, one participant

explained:

> I miss work. I miss being with people. It's difficult to be alone all the time… I should
>
> have been in hospital for a month and I was in the hospital for two and a half months
>
> and I nearly died. And that's a long time to be in--You spend a lot of time alone. And
>
> then I come home and I'm alone. And I mean I like some alone time but. (P13, cancer)

For some participants PSWs also provided encouragement and were seen as being a source of

potential professional medical support:

> She [PSW] lightens my mood and gets me laughing. What I tried to do especially with
>
> getting the walker was to increase the amount that I could walk, be on my feet, and
>
> therefore walk on our driveway and some days actually make the circle all the way
>
> around. Doesn't seem like much of a goal, but it was for me. And she'd encourage me.
>
> She walked with me. And she'd go get a ball and throw it for my dogs and get a stick
>
> and throw that for X [the dog] because that's what he likes. So it was great to see them
>
> out playing. (P10, long term user)
>
> Aside from the physical help that we need, it's nice to have-- mentally to know that you
>
> have someone coming on a regular basis to help out and to oversee. In X's [my
>
> spouse's] case, because her condition is much more severe and chronic whereas mine

was, you know, I was getting better. I knew that. So it's nice to have that other person

with some medical training to look and make sure that we're on the right track. So

there's sort of peace of mind, if you will, with having people come in. And, you know,

we end up being friendly and chatty and so it's just pleasant to have someone come in

and chitchat as well as do what needs to be done. (P9, short term user)

In terms of assigned care tasks, PSWs' assistance with showering and bathing was a

particularly important activity for many of the participants, who as a result of mobility and

balance issues typically were unable to do this task themselves. As P13 described, aside from

hygienic reasons, "being clean" was important to participants as it allowed them to maintain a

sense of normalcy:

Even in the hospital the nurses used to get a little annoyed with me because I insisted

every morning on having a shower and getting dressed. And if I couldn't do it myself,

they had to wheel me to the shower, hose me down, and dress me, because that's what

I do. I don't sit around in pyjamas and I don't lie in bed. I want to be clean and dressed.

And so I like to normalize the house as much as possible, too. (P13, short term user)

Similarly, P6 noted that being clean helped her "feel better":

And I can joke about it, but it was really helpful to know that if I wanted to leave here to

go to a doctor's appointment in the morning that she was here to help me get ready so

that I looked decent and that I was presentable. And people always think your

cleanliness is an indication of how well you're feeling. Probably it's true. I didn't know

that before. I learned that. Because when you're fluffed up and you look half decent,

you're still in pain but you look better, you feel better. And they helped me get that.

And that was one of the things that I wanted. I wanted to feel safe. I wanted to feel

clean. (P6, long term user)

Consequently, while access to home care services provided practical help with meeting

participants' self-care needs, it also fulfilled an important social need by allowing participants to

maintain a connection to their communities. This connection, in turn, reduced isolation and

played a valuable supportive function. Echoing this, the same participant noted, "So I know it's

just supposed to be about cleaning the house, but it's not. It's about having someone in your

space who picks up on your positive energy and gives that back" (P13).

This finding is supported by other research (Daly, 2007; Aronson & Neysmith, 1998)

indicating that while the focus of home care policy and funding is on acute technical support,

most home care users actually have chronic health issues and need long-term supportive care

with everyday activities (such as bathing, dressing, housekeeping) more than acute medical

care. Furthermore, for participants who experienced multiple health and mobility issues, formal

home care services respond to a small component of their everyday care needs and while they

provide a welcome relief, they represent only a fraction of the care and support that these

people need.

While home care through CCAC is publicly paid for and is not means-tested, several

participants reported that they were encouraged by CCAC to also pay for care privately by

contacting a home care company directly to supplement the public care that they were

provided. However, aside from one individual who was able to temporarily pay for a live-in

caregiver (P14), none of the participants identified this as a financially viable option. As an

example, one participant described being given this information by a CCAC case manager when

she was discharged from the hospital without knowing when she would have home care in place:

> And she gave me a card of a nurse who was doing it as a private business so if we couldn't get CCAC I might be able to arrange doing this on a private basis. But money is tight for us so that was not really going to be much of an option. (P9)

Another participant was denied home care after her ankle surgery and reported that she was explicitly told to seek private care instead. She said that she was told that she did not "qualify" for home care as she was able to stand up on her crutches and move around her apartment:

> She said, you know, "Well there is always private but you'll have to pay for that." And, you know, the way it was said, you know, it's like you're not deciding whether my eligibility is there based on health. (P4)

> Not knowing how to access additional needed support services and arrange for assistance beyond what was organized and publicly covered through the CCAC was a also a common concern for many participants. Several also referred to unmet care and housekeeping needs as a result of the fact that home care services were narrowly restricted to nursing and immediate personal care tasks such as bathing, dressing and minimal housework such as doing the laundry and making the bed:

> For instance, if you're here for two hours, you're not supposed to do any shopping so she doesn't do shopping. I discovered they're not supposed to cut toenails. Because my vision is gone, I need my toenails cut. They don't cut toenails, which I understand because I guess if someone cuts someone, who knows? (P14)

You get told by the CCAC when we first started with them, 'These are the regulations.

They can't do this. They can't reach for anything that's any higher than their shoulders.

They can't climb on anything.' You know, they can't climb on a chair to get stuff. Of

course any organization is going to lay down rules. And L [my caregiver] would just say,

"Tell me what you need done. If I can't do it then I'll tell you." They also tell you to put

your dogs and cats if you have them or any pets in a separate room so that they don't

offend or in case they're allergic to them. (P10)

Another participant who lived alone and wasn't able to move around when recovering from

knee surgery was more explicit about her need for housekeeping help:

I was worse and I was glad somebody was coming and I'm glad somebody wasn't scared

of the stairs, so that was a positive. But the PSW was not allowed to do some home

making, was allowed to do the dishes but that's it and clean up the bathroom a little bit,

but I really needed it because, as I said, I had some help from my neighbor but he wasn't

always available and when the heat is on there's always a lot more dust. I tried to sort

of keep it-- if I leave it too long I sort of get my own allergies so I try to keep it sort of

dust free. So it would have been-- because I do home care. I do some home making

with some of my clients. Not every client. It depends what you're allowed to do. (P2)

While some participants were able to meet some of these needs by paying for some

cleaning services out of pocket, as I discussed in the previous chapter most of the participants

were worried about being able to continue to pay for these services long term and about

needing more care in the future.

Despite their everyday need for help with personal care activities, the fact that they

were only able to get a few hours a week of home care meant that the rest of the time they had

to rely heavily on their partners, friends and neighbours for help, or go without care. As I have

discussed in the previous chapter, while women who had partners were able to meet some of

their care needs by relying on their partners' help, women who were single did not have this

ability and typically had to either manage without needed care or enlist the occasional help of

friends and neighbours. The need to continually supplement home care, however, caused many

participants stress as they were not able to rely on always having the needed help. In fact,

several participants explicitly identified having unmet care needs and worried about being cut-

off from the home care that they received in the future as a result of government cutbacks or

personal reassessments:

> I am certain once my case manager and this new guy who is her superior come here and
>
> realize that I am doing well I'm going to lose that extra hour. (P5, long term user)
>
> So I really could have used some home care and I think CCAC seen that I have a cast on
>
> my leg and seen that I cannot move, I think they could have given me an extra hour a
>
> week at least, you know, just a quick vacuum or something. Nothing major. Whatever
>
> they are allowed to do, within the boundaries of what they're allowed to do. I think the
>
> two hours for the shower, for the wash, that was good. I think I could have used an
>
> extra hour. (P2, short term user)

Similarly, P6, who was planning a trip, was worried that she would not be able to get care when

she returned home:

I'm concerned about whether we're going to get another worker when we get back

from Arizona next spring. I can see some supervisor sitting somewhere and saying, "She

managed in Arizona for six months. What's so difficult about her managing here in her

own home?" So we'll see. (P6, long term user)

Two of the participants were told explicitly by their case manager that the CCACs and

the ministry did not have enough money for their care and to expect to not receive home care

in the future:

In terms of management, they're open to listening. They have been very up front with

me when I asked for more hours where they said, "Well with the cutbacks—" I used to

have to deal with government agencies, so I know what happens when you work in a

non-profit and the funding bodies say, "Sorry, no more money for you." Where do you

cut back? So when they told me I might have to go to one hour a week, I said, "Well if

you can keep me at two I'll be happy, but if we have to do one it's better than nothing."

So now that I have three I am not saying a word. (P5, long term user)

She came and she said, "You look pretty strong and healthy. You should be able to get

around." I said, "I don't want this for life. I just want it to get over the hump." And

then she went into this song and dance about how all the organizations had been

grouped together and nobody knew where anybody was going and they don't have any

staff and I said, "Well you're staff." "Yeah, but we don't have people to send out to your

home." I said, "Okay, so they put a bunch together. You know, there's strength in

numbers. Why don't you have people?" "We didn't get any more money." The

government was the story, I was told. The old diss the government thing. (P4, denied

care)

Once participants began receiving home care services, they primarily dealt with

individual home care companies and only interacted with their CCAC case manager when they

did a reassessment. Although case managers are supposed to do a yearly assessment, several

participants reported that they saw case managers more rarely than that. Furthermore, case

managers changed often during the time that they received home care services, which

negatively affected participants' ability to establish a relationship with their case manager and

maintain a continuity of care.

> Mostly I dealt directly with the providers. The CCAC had told me that the coordinator,
>
> my coordinator, would call me and would come and see me within X number of days. I
>
> never laid eyes on the woman ever. She never came to see me. She was away on
>
> holidays or something. At some point I talked to somebody else. I'm sure I'll find it in
>
> here. But she eventually did call me at one point, but I never actually ever laid eyes on
>
> her and I know she was supposed to come and see me. (P1, short term user)
>
> I only see the case managers. In 12 years I've seen the case manager maybe seven
>
> times, so not very often. They change quite frequently. (P7, long term user)
>
> Well the immediate supervisor at R [a home care company] has remained the same
>
> since 2007. There have been four different-- no, now number five through CCAC. The
>
> fifth supervisor now is in place. I haven't met him yet and that's been since July of 2007.
>
> So the caregiver came first, then the area supervisor came after that, and then the R

supervisor came. So somewhere along the way there's a lack of communication. (P5, long term user)

In terms of the experience of undergoing a reassessment, participants noted that case managers did a similar assessment as they had done initially to determine their level of need. As with the original assessment, some participants stated that they did not really understand the purpose of the reassessment, nor find that it had any effect on their care:

> Well last year they came in… asked me if I was happy with it. I said "Sure" …Well it was such a surprise. She would come in and ask me all these questions and they were looking around, you know (P11, long term user)

When asked how many times she had been visited by a case manager during her four years of receiving care, P11 said that it was "only this once."

P5 recounted a similar experience:

> She asks me the same questions every time. I don't know if she remembers, but I know she does remember me now because this is unusual. When she comes in here, she says, "Oh yes, I can never forget you because I always remember your house and what it looks like inside." But she asks me the same questions every time and give her the same answers every time. (P5, long term user)

Likewise, when asked what happens during these reassessments, P16 stated:

> One thing they always have to check is your bathroom. I don't know why. I mean my bathroom was checked seven times by the same person, the same bathroom, and nothing had changed but, "We have to make sure it's safe" and this is the way they singsong talk to you. You know, you talk like this [using a high pitch voice]. "We have to

make sure the bathroom is safe." And so they go and see it. "It's safe." You know, the bars are still in the same place. The toilet is in the same place. The sink is in the same place and the bathtub is in the same place. (P16, long term user)

As case managers typically changed frequently, some of them were more thorough than others in their assessment and some were more willing to respond to feedback about their practices and language:

They went and looked in the kitchen to see-- so that was the initial one. She was more thorough than the others. She went to see, you know, did I do cooking, did I have to reach up, reach down. She went down to the basement to check the laundry facilities and walked around the house. She went upstairs with me, looked to see if I had grab bars and everything. And then she left. And then another woman came who hardly even-- I think I met her once because I'm supposed to see them twice a year, like the upper ones. The immediate supervisor I'm supposed to see four times a year. But subsequently, from the first CCAC persons, the others have all come and sat there and said, "So how are you doing? How do you like your caregiver?" Well the second one said, "How do you like your girl?" And I said, "Excuse me? Who is my girl?" "Oh, you know, your girl, R, your girl." I said "R is a woman. She's not a girl and she's not my servant." I said, "We're not back in slavery days." So she wasn't too happy with that. But she was gone shortly thereafter. So I am now waiting to see the fifth CCAC supervisor. He just started two weeks ago. He called and said who he was and he's going to call me back to set up a meeting. So basically they come and they sit there and they say, "Do you like your PSW and how are things working out?" (P5, long term user)

Several participants described being frustrated not only with the practice of doing reassessments but also with the role of the CCAC (and their case manager) in general in coordinating their home care. In particular, they were frustrated that despite the fact that case managers were responsible for determining their need and assigning them to a particular home care company, they did not continue to manage the care provision after an initial visit and were not readily available to mediate and/or respond to problems that participants had with their caregivers. P1, who reported several negative experiences with some nurses, stated:

> CCAC did almost nothing. At one point I called them. The woman who was supposed to be looking-- that's the time-- I probably called them more than once but this call I remember I was telling them I was really fed up with the nonsense with all these nurses and they basically-- well basically what they said is I wouldn't get any better from anyplace else was one thing they said. Or they couldn't guarantee that I would get anything any better from anyplace else and I don't remember if it was because of my wanting to question, but I know they gave me a bunch of names and I was supposed to call these nursing places and find out if they would offer what I needed. I mean the CCAC was useless. Useless. Totally. (P1, short term user)

Although the majority of participants accessed only personal care or nursing care, some stated that in the past they were also able to access other types of professional services such as occupational therapy, which they found helpful. For example, P3, who received home care after a neck surgery, stated that having an occupational therapist was helpful as she was able to suggest several assistive devices that helped her manage on her own:

I had an occupational therapist that came. Well actually no. Who was it? Was it a

nurse? Because there was a real problem with trying-- No, she was an occupational

therapist-- trying to figure out how to sleep because when I first came home, I mean

you've got all these stitches. You've got this huge collar. It was like really a juggling act

to try to figure out how to sleep, so she brought like a big body pillow and helped me

with positioning. And she taught X [my spouse] how to-- because you had to sort of--

the bed wasn't against a wall. That probably would have been a lot easier but you had

to put the body pillow so you sort of-- it's like with a newborn baby and you don't want

them to move so it was, yeah, she was an OT that came. And I think she came from X

[an organization] or something. Is that what they're called? The occupational therapy

people that were in because we were in X [a region] then. And I've had occupational

therapists come. Actually prior to that surgery, the Arthritis Society occupational

therapist came to set up the bathroom with bars and look at all the equipment I needed

because we needed a bath seat. We needed a hand held shower. So she did all that

preparatory stuff, but I mean I'm lucky because she came through the Arthritis Society.

And the same with before I had hand surgery, I met with the occupational therapist and

that's when we looked at the bidet. I'll show it to you actually. It's quite amazing, the

toilet seat… I don't know how people function without it. (P3, short term user)

However, access to such professional services varied across geographic areas and,

although participants in major urban areas, such as P3, were able to access these services in the

past, several individuals who wanted these services at the time of the interview stated that

were not able to do so unless they decided to pay for it privately:

And you know, if we needed things like physiotherapy or so on we'd have to be put on a list, our name on a list because there's quite a long waiting time to get those services in your house. We're still waiting for X [my spouse] to get a physiotherapist to come. A year [laughs]. Still nobody coming yet. (P9, referring to her spouse who is a long term user)

These narratives indicate that participants experienced multiple barriers to care as a result of structural, systemic and ideological barriers and the lack of financial and informal supports to supplement public care. As a result of these barriers, participants experienced stress and worry, which negatively affected their overall health and well-being.

Exit from Care (or Renewal of Care)

In exiting from home care, participants who had used home care for a brief period of time, such as during their recovery from a surgery or an infection, reported that they discontinued home care services either by calling CCAC and stopping it or having it end when their nurse determined that there was no more need for care. For these participants, discontinuing home care was a relief and represented their ability to return to their usual lives. As they explained:

So I had a personal support worker coming twice a week and then sometimes they'd come a little bit early, sometimes a little bit later, but I was home so it didn't really matter too much. And so I had home care for a while. And then-- which was fine, always came twice a week. And then I started to feel better and my cast came off, so then I cancelled it because I was able to do it myself again. Or at least I was pushing myself to do it myself again. (P2, short term user)

The reason I stopped was because I finished the medication and then eventually they

took the PICC line out. So I think it was about in January... So I got my PICC out and this

says that R's [my nurse] last day is January 3rd. [Reading from her journal] "I got my

PICC out. As predicted it took two minutes and I barely felt it. I'm a free woman again."

(P1, short term user).[25]

Although none of the participants stated that home care services were discontinued

without their consent, two who lived alone reported that they discontinued home care

prematurely as a result of their negative experiences with their home care workers or CCAC

case managers. One of these (P16) described a series of incidents with her home care workers,

her partners' home care workers, and her CCAC manager over a 15 year period. These involved

theft and demeaning comments with respect to her sexuality and gender presentation that

eventually caused her to discontinue home care. For example, she recounted several instances

when she was frustrated with her case manager's communication about her intentions and

practices, such as the timing of home inspections. When asked what prompted her to

discontinue home care, she recounted the following experience:

My home care worker was late one day and these were-- Remember I had finally gotten

home care workers that were really good. She was half an hour late and I'm thinking,

well I've got to leave in half an hour to get to a medical. I guess she's not coming.

Something must have come up on her plate. And then there's this bang, bang, bang on

my door. I'm kind of like, "What's this? G-20 police?" And the door was opened up by

the stupid case manager and there was my home care worker. And she said to my

---

[25] PICC stands for peripherally inserted central catheter which is inserted to deliver intravenous medication.

home care worker, "Hold the door and don't let it close." I'm serious. This is an idiot.

And then she starts talking to me about how I need to make an appointment to get

things done and I said, "I already told you on the phone I have no problems with making

an appointment with you." She was so aggressive that she terrified my home care

worker because that was my home care worker's response. My home care worker had

showed up on time, but a phone call had come in to her from this person saying, "Don't

go in there until I come." So basically I was ambushed. I was literally on my way to the

bathroom. The door is held right open and it's really cold. It happened one of the few

cold days. I had just gotten back from the hospital. There was vomit all over my bed

and she's doing this nonsense, this G-20 police stuff on me. And I just thought, you

know what? This is so insane that I'm out of this game because I'm so tired of being

abused by home care. You know, it was so upsetting to me. I just thought, I would

rather die, and I mean that, than to be demeaned on a constant basis by these people.

(P16, long term user)

Although P5 discontinued home care as well, her decision to do so was the result of

being switched from one home care company to another and losing her caregiver of five years

with whom she was comfortable. Like P16, she stated that she was frustrated with the lack of

communication from CCAC with respect to its practices as well as the behaviours of her new

home care workers. After trying out three different new caregivers in the span of a few weeks

and having several negative experiences with them, including one where a caregiver suggested

that they pray together, she decided to discontinue home care and attempt to manage on her

own instead:

So it just became more and more-- it was a pain. It became a pain for me because they never showed up at eleven o'clock like they were supposed to and they were always in a hurry to get out of the door. And the first one, the second time she came she threw my towels on the floor when we were finished me getting dry. I said, "Why are you putting them on the floor?" "Oh because the lady I just came from puts her towels in the wash after every shower." I said, "Well I don't have that many towels and I'm not about to go up and down the stairs." So I said, "You could have asked if I wanted laundry done, but you know you just did laundry last week." So I don't know, and I asked them, I said, "How many clients do each of you have? Do you have a lot?" Because I'm thinking how many must they have that they can't keep it straight what they do for whom. And then she was out the door again. I asked her if she could sweep because this was another Monday and she said to me, "Oh, I have a doctor's appointment. I'll sweep the following Monday." So I said, "Well I can't have the place"-- because I mean it's summertime, the cat was there, we're in and out. So the Thursday lady came early again and it's the same thing again. "Is this the shampoo? Is this the--?" And that's a little thing, but you know. So I asked her to sweep and it was like I was holding a gun to her head to ask her to sweep. She did not do it willingly. So after it ended up with one of them came four times, one came three times because it was a holiday Monday in between. So I just called up at the end of May and said to the supervisor, "They are both very nice women, but the service isn't going to work for me because it's summertime and I need to shower every day"… So that was it… I terminated the service. (P5, long term user)

However, when asked how she would manage without home care, she stated that she was already worried about the potential for re-injury:

Well it's already been a little tricky, because part of having somebody here for the shower is mostly having somebody here because I'm a little scared about going in and out of the tub, even though I have grab bars. I still have to reach for the towel and there's no way to get a towel any closer to me without it getting wet. I can't have it in the shower enclosure. So that's tricky. Now I have to do the laundry myself, so that's going to be tricky because I'm not supposed to go up and down the basement stairs when there's nobody in the house, because the risers on the basement steps are a lot narrower than regular stairs. I'm more at risk going up and down those stairs. But in terms of my peace of mind, vastly [laughs], a vast increase in terms of my peace of mind. (P5)

The rest of the participants who accessed home care were still receiving home care at the time of the interview. All had permanent physical limitations and did not expect to ever not need home care services. However, when asked if they expected the service to continue in the future, several stated that they didn't in fact know what would happen, nor did they have an alternate plan if it was discontinued:

They do re-assessments yearly… And they haven't said anything about not coming. (P8)

CCAC has rules and they go by points and if it doesn't fit then da-da-da-da. Like for instance, I have no idea if, you know, because of my abdominal lesion, because of my eyes, the woman who comes, B, thinks that they'll let me have it forever. True or false? I have no idea. (P14, long term user)

My concern is longer. I guess I worry if I think about it about the amount of care that will be available to me because everybody is cutting back. So I think if I were to want or need, yeah need-- want is different-- if I were to need more care, I wonder if I would get it-- So I don't think I can depend long term on it. And that has nothing to do with being gay. (P12, long term user)

Conclusion

In this chapter I presented an analysis of the experiences of the participants of this study in accessing and receiving home care services. As I have shown, participants' access to care and their experience of receiving care was mediated by several factors, including social location, the type of care needed, their access to informal supports, and the ways in which they accessed home care. In particular, my analysis suggests that the current home system privileges access to acute biomedical care over long term supportive care and assumes that that all home care users will be able to supplement home care by relying on the help of informal familial caregivers. Evidence to support this includes the fact that access to such care was arranged in a timelier manner than access to personal care and all participants who wanted medical care were able to access it. This has implications for older lesbian and bisexual women's health as they may experience worse health outcomes in this system as a result of not having access to assumed familial supports and/or financial resources to pay privately for care.

Furthermore, my analysis shows that there are multiple barriers to care and that home care is rationed. As a result, many participants routinely had unmet care needs and were forced to continually advocate and demand needed care. As my analysis in the previous chapter illustrated, participants also had to engage in additional provisioning strategies to access

necessary supportive care by relying on friends, partners and neighbours or paying for

additional services out of pocket. These findings are also supported by research on home care

with other populations that have found similar barriers to access and care (Aronson &

Neysmith, 1997; Daly, 2007). These findings thus provide further evidence of the negative

consequences of the neoliberal reframing of care as an individual and family responsibility,

rather than a basic human right.

Chapter 7: Queering Home Care - Connecting sexualities, attitudes and practices

There's certain things that are private. I've never been, I've never been very active in the "lesbian community." Do I have lesbian friends? Yes. Do I go to gay pride? Yes. But then I never go to the dyke march (P14)

In this chapter I focus on sexuality, and present an analysis of the ways in which participants' sexualities and sexual identities affect their home care experiences. As I had discussed in chapter four, participants in this study identified in a variety of ways in addition to lesbian or bisexual, and these labels had varying meaning for participants. As a result, to understand how and why sexuality mattered in the context of home care services, it is first necessary to understand how sexuality mattered in participants' everyday worlds. Therefore, in the first part of this chapter I explore the role that sexualities and attitudes towards sexualities played in participants' understanding of themselves, their relationships with their families and communities and their experiences with individuals outside of home care.

I then focus specifically on the context of home care services and analyze the impact of sexualities, attitudes towards sexualities, and sexual practices. In this chapter I argue that attitudes and reactions towards sexualities and sexual identities negatively affect participants' relationships with home care caregivers, their home care outcomes and overall well-being. These negative effects are not only the result of individual caregivers' actions, but are also due to the structural and institutional conditions of home care. In particular, home care is primarily provided by home care workers within an organizational and policy environment that does not explicitly recognize the existence of non-heterosexual sexualities, nor the negative effects of homophobia and heteronormativity. The combination of these structural conditions and home

care workers' explicitly homophobic and heterosexist behaviours result in participants experiencing ongoing anxiety and stress, as well instances of inappropriate and poor care.

As I have mentioned in chapter four, the majority participants in this study identified in a variety of ways other than simply "lesbian" or "bisexual" at the time of the study and had different romantic and intimate relationship histories and experiences. As has been found in previous research (Diamond 2008; Barker, 2004), many lesbian-identified study participants mentioned having had past relationships with men, living for extended periods of time with men and/or being married to men. Several of the women in the study also noted that they 'came out' as lesbian relatively late in life. For example P2 stated:

> I came out at an older age. Like I was already mature when I came out. I never was out when I was young. I always looked upon women as allies with, you know, anti-violence and ban the bomb and equality for women. I never sort of-- I never sort of related to women like in a lesbian manner. And then one year I came out. I was actually taking a course at George Brown College and one of the women in my, uh, she said, "I'm gay." So and then I thought maybe I'm gay, too. So and then I had certain questions and there were certain experiences that happened, so I thought maybe I'm gay. (P2)

While all of the participants verbally identified as lesbian or bisexual for the purposes of this study, their comments with respect to the importance of their sexuality and disclosure suggest that many also had internalized negative social attitudes about sexuality and homosexuality. As a result, it is likely that many of the women who downplayed the importance of their sexuality likely did so as a result of this negative internalization. For example, many participants reported having difficult or ambivalent relationships with their natal families as a

result of past and ongoing homophobia. They recounted instances of being shunned as a result of their sexuality and their romantic relationships and reported being restricted from seeing family members as a result. Although I didn't explicitly ask in the interviews about how the participants first came out to their families, it is likely that, as P6 described, many of them learned about homophobia early on within their families:

> So I'm feeling somewhat left out of the picture because here's sexism and women can't do it and women have only one thing in life to provide and that's children. Wrong for me. And I was learning that I was a lesbian. And my mother at the age of 12 looks at me and she says, "Do you know the worst thing in life that you could be?" And me in my wisdom and knowledge at the time thought, well probably a killer. Wrong. It was a lesbian. And I thought, hmm. Best not ask her about that. [laughs] So for the rest of my life until she died in her 80s, we never talked about it. We called her 'Our Mother The Pope Miss Homophobia' and the bigot and the racist. And do you know she swore she wasn't. She didn't get it. So when you don't get it, you can't change it. (P6)

As a result, it is probable that despite their participation in this study, many of the participants retained some shame or stigma with respect to their sexualities and that this stigma was also cohort-based. The women in this study lived the majority of their lives in an environment where homosexuality was criminalized, pathologized and overtly discriminated against. As a result of this experience, many were used to not openly discussing, or disclosing, their sexuality. This stigma can be seen in an excerpt from my interview with P7, which illustrates the tension or ambivalence that several of the participants expressed about their

sexualities and highlights the effects of institutionalised and familial heteronormativity on their

behaviours and interactions:

> Well I was pretty old when I came out. I was 35, I think, um, 36. It doesn't matter.
>
> Somewhere there. When my son left home, didn't have any idea I had any yen for
>
> women, but within three months I was involved with a woman and it was right. And so
>
> for six months. I was living in Sault Ste. Marie at the time. Not a great place to live. And
>
> I worked for Big Sisters. And I know how it could be perceived that I would be trying to
>
> convert and who knows what, so I didn't tell anybody, including my best friend. I made
>
> up this guy. And there is a point to this story. So for six months I didn't tell anybody and
>
> I was really, really happy and it was horrible not to be able to talk to my friends about it,
>
> but I didn't feel safe. So I thought that I couldn't do it living like that and so I asked my
>
> partner for some time apart. We were living together by then. I asked her for some
>
> time apart and, um, thought about what I was doing and decided I could not live in the
>
> closet and if I was going to be a lesbian I'd be a lesbian and that was it. And so that's
>
> why everybody knows, because I don't think they can provide good health care if they
>
> don't know who I am. Also [my partner] has to intercede at times and come on visits
>
> with me sometimes and my GP is X's [my partner's] GP because I wanted a family
>
> doctor. So I cannot conceive not being out and nobody that comes to our house, um, I
>
> don't want them to be in my space and not know. And I just introduce [my partner] as
>
> my partner. When we bought the house, I told the woman who was 72 that we were
>
> buying it--She said, "Who is that woman that comes with you?" And I said, "Well she's
>
> my partner." "Oh. Oh, your partner. Okay, I get it." Well I think she thought tenant, or

not tenant obviously, but, um, some other kind of partnership. She did not have a clue…

I don't really see the need to push it in somebody's face. If somebody like X [the home

seller] who had lived here for 52 years and wanted to know that the people who were

living in her house liked the house, I didn't want to upset her necessarily. But there's not

very many people that don't know. (P7)

Although P7 acknowledged experiencing homophobia in the past and noted that it is

important for her to be out to her health care providers, in the same excerpt she notes that she

didn't want to "push" her sexuality on the seller of her house by refuting her assumptions

about her partner. Consequently, while she acknowledged that she has experienced overt

homophobia in the past, she does not make the connection to internalized homophobia, which

resulted in her avoiding coming out in a recent encounter so as to not 'upset' a heterosexual

person. The accusation of pushing homosexuality on heterosexual people by coming out has

historically been a common homophobic criticism levelled at LGBTQ people who live open lives.

Similarly, several other participants reported that they felt that their sexualities and

sexual identities didn't "matter" and that they didn't feel that it influenced how they lived their

lives or interacted with others. However, as I illustrate below, participants recounted multiple

instances in which they modified their behaviour and/or disclosure of their sexuality based on

individual and situational cues and they reported on strategies that they employed to judge

potential reactions to future disclosures. Many participants also described surrounding

themselves with supportive (primarily LGBTQ-identified) people in their social circles and in the

health providers that they were able to choose, such as their family doctors. All of these

behaviours can be seen as strategies that participants used to both avoid and resist

heterosexism and homophobia in their everyday lives. These narratives support the argument that their sexualities did in fact matter in their everyday lives and in their interactions with different care providers.

Participants' narratives also suggest that many were engaged in an identity monitoring process while interacting with health care providers and accessing home care. A similar concept, called visibility management, is discussed by Lasser and Tharinger (2003) to explain the process by which LGB youth "actively monitor and modify the degree to which their sexual orientation is known by other" (237). The authors argue that unlike "coming out," which implies a one-time, verbal instance of disclosing one's sexual identity, visibility management is an ongoing process that is both "strategic and continuous" and encompasses verbal and non-verbal types of communication and strategies. While the authors developed this concept to explain how LGB youth interact with others, I would argue that it can be extended to understand how lesbian and bisexual older women (and potentially other GBTQ people) make decisions around disclosure. In particular, the inclusion of non-verbal modes of communication makes this concept particularly well-suited to capturing how older lesbian and bisexual individuals engage in this process while allowing care providers access into their homes. The analysis of participants' decisions with respect to disclosure and identity management demonstrates that participants' sexuality negatively affected their everyday interactions, as well as their interactions with caregivers who provided them with home care.

Be(Com)ing out

While many of the participants reported that they were "out" as lesbian or bisexual in their everyday lives, for most the level of verbal disclosure varied and was often situation-

specific. There was also a difference observed in the amount of disclosure and in decision-making between coupled and single participants. The majority of the coupled individuals reported that they were out by default as a result of being in a relationship with a woman. Coupled participants therefore did not come out explicitly as lesbian but rather communicated it through comments about their relationship status and/or by introducing a female partner as their spouse. This type of coming out was considered particularly important in the context of accessing health care and was motivated by their desire to have their partner recognized as a legal decision-maker. For example, P1 and P13 explained that they were out because they had introduced their partners to their health providers:

> Yeah, yeah, sure. X [my spouse] was here in the house and I'm out to everybody. Well-- I'm going to reframe that. I'm certainly out to most of them because I talk about X or whatever. With people at the hospital, like the surgeons who did my knee and this and that, I never specifically said to them, "I'm a lesbian," but X was there all the time and I listed her on forms as my partner and all that stuff so, you know, it doesn't concern me what they think. But she certainly plays a spousal role. (P1)

> Because my wife comes with me to all my appointments and I was really sick and we were really scared. And it was important that we both get--my wife was not so out at school because she was worried about how the students would respond or the other professors. But once I got sick, um, she was very concerned that if anything would happen and they would not know what kind of stuff she was going through, so she just sort of came out. My spouse, my wife. So she came out quickly and I've always been out, so it was easier for me. (P13)

Similarly, P10 explained that she "came out" publicly when she got legally married:

> I'm out, um, and of course once we got married quite out [laughs], as a surprise to some
>
> of them, although I have been living with another woman since I was 20 so I don't think
>
> it was really a surprise to anybody. [laughs] If so, they're stupid. It doesn't matter
>
> anyway. (P10)

Marriage or being in a relationship with another woman was therefore central to many participants' decisions with respect to disclosure of their sexuality and the significance that they attributed to it in their lives. This finding is in line with other research on lesbian and bisexual identity that suggests that many women identify their sexuality based on their current partner rather than based on the history of their emotional and romantic attachments (Nichols, 2004; Diamond, 2005).

In contrast, most of the single participants reported that they were not out in their everyday lives and that they choose to not be out because of their single status. In particular, many of the single women thought that sexual identity and sexuality was a "private matter" and did not affect their everyday lives and experiences. For example, P2 explained that she wasn't out to her general practitioner:

> Well I'm not in a relationship, so I don't have to notify-- Like if I would have a partner
>
> and if there's something majorly wrong with me, I would have to notify my partner. You
>
> know, obviously then it's a different story, but right now I'm not in any relationship at
>
> all. I mean I think if I have a sore foot or if I feel, I don't know, pain in my chest, would it
>
> matter if I'm a lesbian or not? I mean I would still have to be treated for my chest pain
>
> or my pain in the foot, right? I mean I don't--but I think for, uh, for, you know, being

diagnosed with something and if you have a partner, obviously the partner would have to be notified and it would be, you know. Or if your partner is on your-- what do you call it?--on your, uh--on your piece of paper saying that the primary spouse or whatever, yeah, so then it would be different. (P2)

Similarly, P16 and P12 explained,[26]

Well generally my opinion is if I'm not having sex with you, it's none of your business. I don't talk about it. I mean whatever they assume. I mean most of them know because they met my partner and presumably because I had a woman partner--I mean I see no point in it. This whole ridiculous thing of people having to out themselves, I just--I'm not into being in or out of the closet. I'm into, you know, what is appropriate. (P16)

I don't know. I was to the first one. I think with this doctor it's just never come up. I don't really find it necessary to come out to people who probably couldn't care less anyway. I do know a woman who makes a point of being out and there's no difference at all to their life. So why bother? If my doctor needed to know, I would tell him. Maybe he does know. (P12)

The ambivalence with respect to the political implications of lesbian or bisexual sexuality and the significance of disclosure in a heteronormative society were particularly evident in the narrative of P14, who reported that she did not feel that it was necessary to disclose her sexuality given that she was single at the time of receiving home care. As she explains, in part this decision was also made based on the fact that historically she had hidden her sexuality professionally and has never considered herself a "political" lesbian:

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[26] P16 was recently widowed and was living alone at the time of the interview.

You know, I lived with someone when I lived in New York and that's when I actually had-- when I was diagnosed with my cancer and she was a little butchy. And that's just what it was. So I guess on many levels I've always felt that way, but I didn't take her to my company parties. If I were working now and I was living with someone or had a partner, um, I would feel differently-- Now I wasn't always out the way I am, okay? I lived in New York when I first changed lifestyles and, um, I remember there was a company Christmas party and I took a male friend, but then this guy that I'm close with, the same thing happened with him in Toronto and he's been living with a man for 30 years. He had a holiday party and he called and he said, "Come with me." I said "Sure." So I don't think-- there's certain things that are private. I've never been-- I've never been very active in the "lesbian community." Do I have lesbian friends? Yes. Do I go to gay pride? Yes. But then I never go to the dyke march because far more than being--well I was going to say far more than being a lesbian politically, I'm very much an egalitarian and a feminist and so I will fight for equality and everyone knows my position on that. For instance, in the dyke march people said, "Well they didn't treat the women as equals" and my answer was, "Well that's what you fight for. You don't separate yourself and have your own march." I don't do that. So I'm very much of a feminist. I am not-- politically I'm not a lesbian. (P14)

However, P14's narrative also suggests that her decision-making with respect to disclosure in home care was in part also affected by her normatively feminine gender presentation, which has allowed her the ability to pass as heterosexual and hide her sexuality.

For many participants in this study, their sexuality and sexual identity was not a political

or social category, but was instead relationship-based. Furthermore, many participants, like P14

likely had hidden their sexuality for most of their lives in order to avoid homophobic

discrimination and violence. The connection that many participants made between the *need* for

disclosure and their relationship status is thus not surprising. Given that in our culture all

women are assumed to be heterosexual until they are found out to be otherwise, being

recognized by others as a lesbian or bisexual requires verbal disclosure, masculine self-

presentation or the presence of a female partner. Thus participants were aware that being in a

relationship with a woman meant that it was harder to keep their sexuality private and that it

explicitly necessitated disclosure.

Despite the ambivalence many participants expressed with politically identifying as a

lesbian or bisexual (or identifying as a lesbian or bisexual while being single), many noted that

explicit verbal disclosure was important in the context of accessing primary health care

services. In particular, several participants reported that they were out to their family

physicians and that they did so to be able to get appropriate and competent health care:

He [the family physician] knows. I'm very up front with him. (P11)

I've always been out to all my doctors. (P13)

As P14 and P5 further explain, they felt that their doctors needed to "know" them in order to

be able to competently treat them:

I mean my vision therapist doesn't have to know I'm lesbian, but she certainly does

know. And I think it's important that she know. I mean I know about her family and

what's going on and she knows about my life. So when I started seeing this other

woman, I told her. She got all excited [laughs], you know. My family doctor I feel like I

could ask anything of her and I would also give anything to them as a result, you know.

I'm not-- of course she knows I'm lesbian. Any doctor I work with immediately knows

I'm lesbian. I think they have to know what my practice is. (P14)

I feel it's important because they're treating me and me being a lesbian it's me. So they

can't treat me unless they know I'm a lesbian and they're willing to deal with the whole

person, not just me-- well they have to deal with me as a woman of colour, but they

have to deal with me as a queer lesbian, I mean a queer woman. (P5)

Likewise, when asked about why she felt that her physician needed to know about her

sexuality, P15 explained that she felt that it was necessary so that she could explain to her

some of the emotional and psychological stress that she experienced on a daily basis:

Um, because if they don't understand some of the stressors that you go through-- like

we'll go down here to the local pub and the people will be like, "Oh yeah, yeah, here

comes the lesbians," or they have the nickname for us: "soup dykes." And it's just

belittling. (P15)

Many of the participants viewed their sexuality as "private" and typically did not reveal

this to individuals in their everyday lives unless they were forced to do so, such as in the case of

accessing health care. Participants' narratives also suggest that they may have minimized the

importance of their sexuality as result of internalized stigma and the desire to avoid potentially

negative homophobic reactions.

LGBTQ-identified Health Care Providers

Despite participants' insistence that their sexuality was a private matter, it was important for them that their health care providers were not explicitly homophobic. While most of the participants indicated that they did not necessarily *prefer* to be treated by LGBTQ-identified providers, participants' narratives reflect a spectrum of opinion with respect to their desire for providers with LGBTQ competence. While some participants only wanted their providers to be non-homophobic, others indicated that it was important that their providers are explicitly LGBTQ-inclusive and affirming. For example, when asked whether she preferred an LGBTQ health provider, P12 explained:

Well I don't see what advantage. If I had a care provider who was certainly anti-gay, I would get rid of them. But as long as they're neutral about the issue, I'm fine (P12)

Similarly P16 called this having "compatibility" with a health provider:

I have no clue what my doctors are or are not. Does it matter? No. All I care about is a certain level of proficiency and after that obviously compatibility.

When then asked to explain what she meant by compatibility, she replied:

You know whether or not you're compatible with somebody. You know if somebody hates you or not. You know what I mean? You can tell. You're either compatible or you're not. I'm interested in are they good at what they do and then are we compatible, like is it just easy, easy, easy. (P16)

However, other participants wanted health care providers who were respectful of their lives and understood the kind of stressors that might affect LGBTQ people, such as systemic

homophobia and social isolation. For example, when asked if she preferred to have an LGBTQ health provider, P13 said no. However she clarified her response saying:

> But it's important to have providers who are respectful and know a little bit about what it's like to be lesbian or gay. (P13)

Another participant, P15, who also answered that she did not prefer an LGBTQ- provider was even more explicit and explained that it was important to have a provider who understood and was empathetic to experiences of homophobia and heterosexism:

> I don't care what they are. I just expect them to accept me as to who I am and there's special things that you have to overcome being gay that I don't think straight people have to go through. I spent 40 years living as a straight woman and, you know, I have three children. I had two marriages to men and it was difficult to come out to my family and the health care providers. I mean they were like red necks so it's made a big difference coming here to Canada. (P15)

It is also possible that participants did not indicate that they preferred LGBTQ-providers so as not to seem anti-straight. In line with this, some participants noted that while they "didn't care" about the sexuality of their health providers, they did try to pick individuals who were LGBTQ-identified when they were able to. According to P2:

> Well I have these benefits and I know, just the same with our community, uh, small businesses are always looking for other businesses, so I know this person through an organization called X [social activity group for LGBTQ people]. And so and then at that time, when I met this person, um, you sort of recognize. "Oh hello. How are you doing?" And we got talking and so I found out he was doing his career change and doing

this type of work, massage therapy, and was a massage therapist and I said, "Oh well the day—"Because when I first started with the company, you have to accumulate so many hours before you get benefits, so I didn't get benefits, you know, at first, so I thought, well if I ever get benefits and I get to that point, then I'm going to try him out and see. It's mostly to support your own community, right? I don't know about my dentist if she's gay or not [laughs], but you try. I would try to support the community and, you know, choosing, you know, because I know a lot of people might not want to go to a doctor if they find out they're gay or not. I mean, you know. But I think it's possible. I think for me, if I can choose it, then I will try it. Yeah. So that was one of the reasons. Yeah. (P2)

Although some narrators downplayed the importance of disclosure, most emphasized the importance of having LGBTQ-sensitive providers. In particular, participants believed that it was important for their health care providers to know about their sexuality so that they could provide appropriate care. Participants' decision-making with respect to disclosure of sexuality in their every-day lives also has implications for their ability to get competent and respectful care in the context of home care. Although passing as heterosexual may offer some protection in the short-term, it can increase vulnerability to oppression in the future and may be isolating if this prevents an individual from reaching out to and connecting with others. It may also cause individuals to experience added stress and worry with respect to being found out and subjected to homophobic discrimination. For example, as I discuss later on in the chapter, several participants worried about encountering homophobia in future encounters with home care providers.

Finally, individuals may overestimate their ability to be able to address or deflect

homophobia in their home, based on their encounters with health care providers outside the

home. Many individuals expressed that LGBTQ sensitivity was important in a health care

provider, but they did not say they had searched for a provider who was LGBTQ positive, and

suggested they had encountered individuals who were not. In the home care context

individuals are not able to choose their provider, and may be more vulnerable to discrimination

as they cannot easily leave and choose another provider. As a result, it is possible that

individuals who have successfully avoided homophobia in their interactions with primary care

providers in the past may overestimate their ability to deal with homophobia in the context of

home care. This analysis of participants' decision-making with respect to disclosure and health

care providers provides further support for the argument that sexuality matters in the context

of home care.

Connection to (formal) LGBTQ communities

When asked directly about whether they are "connected" to LGBTQ communities, many

participants answered that they were not. However, they explained that they answered this

way because they were not at present actively involved in political activities and did not attend

LGBTQ-events organized by formal LGBTQ organizations. For example, although P10 initially

said that she was not connected to any LGBTQ communities, she then added:

Um, well you know what? I shouldn't just say no right off the top, because especially

where we go in Arizona is a lesbian community and we chose that place because of the

lesbian community. It is supportive. If X [my spouse] wants to go off kayaking for the

day with whoever, um, there's always, um, a friend, sometimes not necessarily

someone I know that well who drops by and says, "I hear X is off kayaking. Do you need anything? Can I make you a sandwich?" Whatever, you know, keep you company for a while. Or offers to take the dogs down to the dog run if I'm not doing well that day. So we're definitely involved down there. (P10)

Similarly when asked if she was connected to LGBTQ communities, P16 said:

I don't know what that question means. I mean we're all in principle connected. I mean this is X [city]. How can we not be connected? You can't walk past a street corner without an *Xtra* box [location where a local gay and lesbian free newspaper is distributed].

When I then explained that I meant, for example, attending LGBTQ events, she added:

No. I've never done that stuff. I can understand the need of, you know, some really young people in their identity formation trying to explore what that is all about and I'm glad that now, you know, young people have that in place, but no. I mean no. Again I don't see, um, much a need for it. I understand, too, you know, some of the older ones they like to get together. And for people who like to do that, I think it's wonderful that those things are there for them. I used to be a pastor at one time in my life and a pastor friend of mine, you know, did stuff for the older people at X [an urban LGBT community center] and that's wonderful. But, you know, you couldn't catch me there. You couldn't pay me to go to one of those things. I mean how boring. I'd get bored to death. God almighty, spare me, you know. But some people, they like that. (P16)

Several participants explained that while they didn't consider themselves presently "connected" politically to an LGBTQ community, they did have social connections to LGBTQ

communities through their friends and family networks. For example, P3 explained that while she didn't feel that she was connected to an LGBTQ community, she preferred to primarily interact with LGBTQ people, and in particular with other women:

> I think the bottom line is--I mean whether you value a friend it has nothing to do with who they sleep with. However, I certainly don't like women who sleep with men, so I'm very particular. I have no interest in heterosexual couples. I mean it's rather pathetic, I guess, because I've been there and I know what their relationships are like and I know what men are like. They don't come highly recommended in my view. Once again it's a generational thing, it's a cultural thing. I mean we have a friend who is Greek and when she thinks of the Greek men, it's the same way I think about Jewish men. I mean they're often very-- it's a cultural thing--they're very chauvinist. They're very--I don't know. I prefer to be with women. And so I mean if they happen to be a couple and we can get along--actually we met a really nice couple. Um, she's a librarian with X [my spouse]. We met her at a bat mitzvah for a Jewish woman who was having a bat mitzvah at 60 or whatever and her partner is an environmental scientist. (P3)

Similarly, P1 explained that while she wasn't at present politically involved, her social circle primarily consisted of LGBTQ people:

> Depends on what you mean by community. I certainly, we have gay and lesbian friends and, you know, kind of links to the broader community in that both of us have been at various times active in various ways in various political things and so on. But neither of us are in any kind of direct, uh, activities at the moment. Like I was on a community advisory board supporting our youth project for a number of years. X has done a million

things back in history. But neither of us is doing anything active at the moment. But

you know, we have a lot of connections in the community. (P1)

Like P1, several other participants reported that although they weren't presently

politically involved in the LGBTQ community, they were in the past. Participants recounted a

number of reasons, including lack of access and poor health, for their lack of current

involvement in formally-organized LGBTQ communities:

No, not really, I mean aside from our circle of friends, which is a lesbian community. We

see each other on a regular basis and, you know, go to each other's cottages or have,

uh, various people have gatherings, you know, once a year, where we all get together

and see each other. And other than that, on an individual basis I mean you'll go and visit

somebody, just like normal friends, right? And our friends in X [city nearby], they have a

community centre there where they have dances quite often, so we'll be invited and go

down and partake of that. There's not so much up here that we've found. (P9)

For others, like P11 and P13, not being as involved with organized LGBTQ events and activities

occurred gradually as they got older, more ill and less able to travel:

Well a lot of our friends, most of our friends are proudly gay because we're involved in

the church. X [my wife] is a member. I'm not. But we go every Sunday and have for

about-- X has for about 20 years and I've gone for about 10. The cancer group is

gay/lesbian and, uh, most of our friends are lesbian. Not all of them, but most of them--

I don't get involved in the political stuff. I'm done with that. Like we go to the church

service at pride. We look at the floats and then we come home. I don't watch the--,

mind you, last year we watched the parade on television. I used to march in the parade.

I don't do that anymore. And like we used to go to the dyke march and I don't do that anymore. I feel that's up to you guys now. [laughs]-- We have a circle of friends. We do potlucks every now and then. We're all gay and if there are dances, if we could find dances, we would go. [laughs] It's harder and harder now to since the dances stopped-- We used to have a group of friends and we just would add to it. We would have a potluck here and just anybody who wanted to invite anybody who was going to the dance would come on the Saturday to the potluck and then--so it was kind of a community but it was based on love of dance more than us getting together or eating more than anything. That's basically my involvement now. (P13)

I just couldn't get out. Like I've been home for almost--I've been stuck in here now for almost four years. I just couldn't go anywhere. (P11)

Only three of the participants reported being currently involved in a formally organized LGBTQ community (through an LGBTQ centre, social group, etc.) and actively engaged in formally organized social activities with other LGBTQ people. All of these participants were single, were relatively healthy, and thus were able to leave their house and attend community events. These participants considered this involvement an important component of their everyday lives and a source of companionship. For example, P2 explained that she was connected to LGBTQ community through her membership in two activity groups:

Well I always renew my membership every year [referring to two social activity groups for LGBTQ people in Ontario] so obviously it's giving me something. [laughs] And I do activities with them. Yeah. (P2)

Similarly, P5 helped organize and attended events in her local LGBTQ community:

> Um, well what does it look like now? Okay. In the past I was very connected. I started off with X [Ontario lesbian organization]. I was one of the founding members of X. And I started doing care counselling there primarily with, um, lesbians of colour … And now I volunteer for [LGBTQ festival]… So that's my connection right now officially. (P5)[27]

Thus, participants' responses reveal that the majority had many social connections to LGBTQ people in their local (and national) communities. This finding is not surprising, as most participants' social lives and support networks consisted mostly of LGBTQ people and the majority of their lives revolved around interactions with LGBTQ people in the context of travel, business and socializing. The finding that many of the participants did not feel that they had a formal connection to an organized LGBTQ community is also not surprising given that many participants had ongoing health issues and difficulties performing activities of daily living and were housebound. As a result, they were likely not well enough to attend community organized activities and may have had difficulty arranging for transportation and/or travelling to activities. Consequently, many participants relied on informal connections for LGBTQ-related information and social activities through their LGBTQ friends and families. This finding has implications for home care services and for the implementation of future interventions to support older lesbian and bisexual women. In particular, it suggests that interventions and information targeting this population may be better implemented if it is disseminated through social circles, rather than through formal LGBTQ organizations.

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[27] Information deleted from quote because it could identify participant

Experiences of Homophobia in Everyday Life

Despite several participants' insistence that their sexuality was a private matter and

didn't affect their everyday lives, many described having experienced overtly homophobic

violence and oppression in the past. Specifically, several recounted experiences of violence and

discrimination in their interactions with primary health care providers and employers. Reports

of these types of experiences are supported by the research evidence presented in chapter 3

about the oppression and discrimination experienced by lesbian and bisexual women in North

American society:

> For instance, before the GP I have now, I had a white man, straight, and I told him that
>
> in terms of a Pap smear, it is very, very difficult for me. I asked him to get the smallest
>
> speculum possible. "What do you know about small speculums?" I said, "Because I've
>
> been having Pap smears for years, so I know what I need for my body." So he didn't get
>
> the smallest speculum. I said, "This is going to be a problem." So he was about to start
>
> and I said, "I would like a nurse in the room." "Why?" I said, "Because I'm a female
>
> patient and you're a male doctor and you're about to do this procedure on me. I'm
>
> entitled to have a—"How do you know that?" So he started it and I said, "I'm in pain. I
>
> need you to stop." And he yelled at me, "Shut up. I have patients in the waiting room."
>
> I said, "Well the pain is too much. You have to stop." "Well you're just going to have to
>
> put up with it." And I said, "No, this is it. I do not want to see you anymore." (P5)
>
> Well in terms of the gynaecologist, I once had a gynaecologist tell me that my cervix had
>
> no feeling. I said, "No, your cervix has no feeling." [laughs] And I had to impress upon
>
> him the fact that I haven't had anything larger than a digit inserted into my person and

that speculum hurts and I'm nervous. He kept saying, "Relax." I said, "It's very difficult

to relax because this is a whole new experience for me and I don't like it." And I was

being treated for pre-cancerous, um, polyps, so I had to go a lot. So after that I decided

it was very important that my doctors all know and nurses and everybody who is going

to give me a needle know up front that I'm gay. This is where I'm coming from and I

want at least to be respected for it and if you don't want to respect me then let me

know right away. (P13)

When I was in the hospital in X [city in northern Ontario] in traction and had to stay in

the hospital because there was nobody at home to take care of me and, um, I was in for

five weeks or something, which is ridiculous when I think of it now. Um, and a woman,

a gay woman who I knew in the community, um, was dying of lung cancer. You have to

know this was in '86 or '87 and they put a yellow sticker on the door, which they put on

the people who had AIDS. I was a professional and the nurses treated me that way and

came and sat and had coffee with me and stuff and treated me really well. And when I

asked them about the sticker on the door, they said, "Well she's gay and she's dying of

cancer." And I said, "But that's not contagious." Well they just did not know I was gay

and I'm ashamed to say I did not come out to them because I thought I was going to

spend the rest of my life in X, which is not a big city and these people would be

providing me with health care the rest of my life and I did not want to give them an

opportunity to put a yellow sticker on my door so I did not come out to them. In the X

[city], at work I was everywhere within the hospital, but I did not have a regular GP. The

first time I saw a doctor with any regularity was when we moved here. So that was not

a good experience, because they limited the visitors she could have because of this freaking yellow sticker on the door. So, yeah, it shut me up. (P7)

Participants were also aware of the impact of institutionalized homophobia and heterosexism in society in general and the potential "risks" of living as an openly LGBTQ person in society. Furthermore, they noted that at times the negative impact of disclosure might be hidden, such as in the case of discrimination in the context of employment or housing. For example, P6's, P1's and P12's narratives illustrate this awareness of institutionalized and systemic homophobia:

Like say, for instance, if I had somebody who went off, it's me here dealing with it. So that's the risk for me as a gay person. I mean they're still shooting us. They're still killing us. They're still beating us. They're still harming us at work, not hiring us. Not promoting us. Putting us in isolation pay areas in the armed forces. That has not stopped. And I'm one of those that got kicked out of the armed forces because I was a lesbian at the age of 18. 'We don't want your type here.' I thought he meant I couldn't type. [laughs] No. He said, "No, you won't be sleeping with any of my girls again." And I am such a smart ass. I wanted to say to him, "Sir, they did not mention your name." And I thought, shut up, because at that time it was illegal, was a criminal offense and certainly a military no-no. So I could have gone to the klink in the military or to the jail for this foolishness. I was so young and naive. What did I know? I just knew I found women. I was happy. I was dating them. Apparently they didn't like it. (P6)

I think more for us, for lesbians and gays, I think it's more, you know, I think it's more

about maybe finding affordable housing, because like sometimes people are being

discriminated against because they have a dog or they have an animal or there might be

if they go for an interview for an apartment, uh, just the unspoken discrimination. "The

unit has already been filled." "It's been taken." In the meantime, there's two lesbians

or two gays sitting in the chair and wanting to know what the price is of the apartment

and if they can see it and rent. Some landlords don't want that. (P12)

Some participants also reported experiencing overt homophobia more recently as a

result of verbal disclosure. For example, P7 experienced homophobia in an online community

and P5 lost a valued social relationship after she disclosed her sexuality:

I was maintaining a site on the internet for people with fibro [fibromyalgia] and then,

when I told them that [my partner] and I were getting married, I was called an

abomination and many other things and so it just broke my spirit. And even the

population there was transitory and I just never could care like that again. (P7)

For instance when I was going to Curves [a gym] at X [a city neighbourhood] and I met a

woman there from India and we became friends and I let her know sort of by the way

that I was a lesbian and since that happened all of a sudden she stopped talking to me.

And every now and then I call her up and say, "How are things going?" So she has a

part-time job at Loblaws, so what she tells me is, "I'm at Loblaws all the time after my

regular job so I really don't have the time to socialize with you anymore." But when I

was going in to the hospital for my surgery, this was before I let her know that I was a

lesbian, she was there. The surgery was at eight o'clock. She was there for six when I

went in for my pre-op and she was there after the surgery and then when I came out

and I spoke with her and she came over to visit me and I just in a roundabout way she

stopped talking to me. (P5)

Additionally, P13 reported a recent stay in a metropolitan teaching hospital where she

encountered a nurse who communicated her homophobia through avoidance, negative posture

and denial of care:

So the nurse came in to tell me that the tech was going to come and X [my spouse] and I

were reading the newspaper. I was dressed. I dressed every morning, showered every

morning and I dressed and the bed was made because I make the bed and we were both

lying on my bed reading the newspaper and the nurse came in and was horrified. And I

had a roommate actually and the nurse came in and was horrified and sort of [makes a

nasal hmmphing sound] and then walked away and then came back and said the tech

was coming, but I had time to go for a walk if I wanted. I could go out. The tech will be

here in a few hours. And so we went out. We were gone for an hour and a half and

when we came back I said, "When do we expect the tech?" The nurse said, "She's been

and gone. You weren't here, so she's gone." Well I said, "Well now you have to call her

back." And she was just really-- she wouldn't look at me. She wouldn't discuss things

with me. She was very nasty-- So I went to the nursing station and talked to the head

nurse and apparently the tech comes every two hours so they just-- she would be back

in another two hours. But this nurse was being very nasty and any time X was around

after that, for the next day or so she was quite rude or wouldn't talk to me at all. And

even my roommate commented, "She really has a problem whenever X [your spouse]'s

around. I think she's homophobic." She was very homophobic and nasty. She had done

it the time I was in before, too. She'd done the same thing, but it was briefer. I only had

her briefly. This time I had her a lot. So I actually complained to the head nurse, who

said that she wouldn't get in trouble. She would get education and that she'd had it

before, but I wasn't the first person to complain about her. But if I didn't complain

about her nothing would happen and if I did she would at least have to go through the

same kind of retraining and, you know, if you hit a nail on the head so many times it'll

eventually click to the hole, I guess. I don't know. So I did file a complaint and I don't

know what happened… I was there for a week. And it made the week hellish because

there were lots of things she [nurse] wouldn't do or she wasn't there for-- Like even my

meds and when I was sick she was not very responsive especially if X [my spouse] was

around. She was a little bit better when I was on my own, but if X was there she just

and we weren't touching, we weren't kissing, we weren't necking up a storm, we

weren't-- (P13)

Given that P13's experience happened in a major hospital in an urban downtown area that is

known to have an explicit diversity policy and training for staff that encompasses sexual and

gender diversity competence, this experience is particularly shocking. Furthermore, it

illustrates the persistent and systemic nature of homophobia and heterosexism within our

health care system.

Several participants also described experiences of heterosexism where their relationship

was not recognised as valid or important. These examples again reveal the entrenched nature

of heteronormativity and heterosexism in everyday life. For instance, P8 described a recent

hospital visit with her spouse where she had to prove that she was legally married; although she identified herself as "spouse," she was called instead "partner," thus invalidating her legal relationship:

> Yeah, well the neurologist asked because I wanted to make sure when she went into the hospital that I had access to the information, because she wasn't cognizant enough to know what was going on and, um, and that's when we were signing her in. That's why I said partner. At X [a large hospital in southern Ontario], they said to me, "Well who are you?" And I said, "I'm her spouse." They looked at me and she said, "Well I'll just put down partner." And I looked at her and I said, "I don't care what you put down as long as I have all of the information of a spouse because we are legally married and if you need to see the certificate I can bring it in." So, you know, and the doctor was fine. He asked me what the relationship was and I said, "She's my spouse." I could have been married to anybody. It didn't make any difference to him. And the nurses were all great with it. You know, they were fine, the nurses. Because they would ask. I didn't flaunt it, okay? If somebody asked me if she was my sister, I would just say, "No, she's my spouse. Okay?" And just leave it at that. And you either accept it or you don't and I move on with my day. Our family doctor, I don't know that we've actually said anything particular to him. I go into all the appointments with her just because her memory isn't always there. So I bring the list. So all the appointments we do together. So they'd have to be blind not to know. [laughter] The physio guy is well aware that we're an item and, you know, I go to Curves while she goes to physio. I come back because it's an hour and so for the last like say 15 minutes and if he wants to talk to me about anything

I'm there. But I kind of leave her just on her time with him. And X [a Christian home care company] well-- they seem to be okay. They know we sleep in the same bed. (P8)

P15 and P7 recounted similar recent experiences:

Um, I would like to think that Canada is more open than the U.S. as far as gayness, but it's very difficult. People want to judge you quickly. You have to decide if it's important for them to find out that you're gay or not. Like I go to this nice little laundromat and they're like, "Oh, who is this? Is this your sister?" And it's like, "Yeah, she's my sister." It's not important to them what she is or who she is. "She's my sister. It's just from a different mother in a different kind of way." (P15)

You know, our hairdresser, for instance, when we first went to them, it was a couple, and X [my partner] went to the husband and I went to the wife and, um, I told the wife that we were partners, so she told her husband and he was totally against gays and lesbians and he was very uncomfortable. And that's good, because X is reserved and I'm not reserved and so Z [the hairdresser wife] and I would babble away and carry on talking and, um, one time she said, "Well you know, Y [the husband] was never comfortable until we got to know you and X. Is that right, Y?" she hollers across the room. "You weren't comfortable talking to lesbians before M [the participant] and X, right?" And there's other hairdressers like that probably that X had. I didn't have a problem with it. X did. She would go pink, pink. I probably went pink, pink too, but um- -oh sometimes I don't want to educate the fucking world about how they have to be decent to people. I get tired of it. And sometimes I do. X doesn't make me-- I know that everybody has their own story and their own experience and they have to do

what's good for them and sometimes being out isn't good for them, but if we're not out

then we make it harder for everybody, I think. (P7)

These types of experiences reveal the heteronormativity and heterosexism in health

care and other areas of everyday life and provide additional evidence of the embedded-ness of

societal prejudice towards LGBTQ people. Furthermore, participants' narratives reveal that they

expected and were aware of the potential for discrimination in their everyday lives, and in

particular in their interactions with health care providers and institutions. The above

experiences were isolating and draining and made participants feel upset that they had to

continually educate individuals in their environment in order to be recognized and treated well,

while going about their daily lives. It is likely that these experiences caused them to experience

ongoing stress and worry, which had negative effects on their overall health and well-being. It is

therefore not surprising that they were hesitant about disclosure and downplayed the impact

of their sexuality in their everyday lives and in their interactions with health care providers.

This downplaying can be seen as an active strategy that they employed as a way of managing

their stress and limiting the negative effect of their vigilance on their mental well-being.

These negative experiences of everyday homophobia also have important implications

for home care services and for older lesbian and bisexual women's health. It is likely that these

types of experiences contributed to participants' mistrust of formal health care services and

health care providers. As a result of these experiences, they may be less likely to seek

preventative health care, which may increase their risk of experiencing poor health in the

future. This mistrust of formal health care services and providers may also cause them to rely

more heavily on their friends and family for support and delay seeking necessary home care in

the future. These, these types of experiences likely also caused them to experience ongoing stress and anxiety, which can negatively affect their long term mental health and increase their risk of poor physical health and chronic illnesses.

Sexuality in the Context of Home Care

In this section I focus specifically on experiences of home care and discuss how participants' sexualities affected their experiences with home care providers. As was the case with participants' beliefs about disclosure in their everyday lives, when questioned directly, many participants reported that they did not feel that that sexuality significantly affected their experiences with home care:

No. Not overtly, you know. It didn't even cross my mind when I was trying to get home care set up. You know, I'm just-- because I don't discriminate, so I just assume until I'm proven wrong that you don't either, you know. [laughs] (P4)

I don't really think that it has. Some of my friends have had problems, but I don't know whether it's giving them [home care workers] a compliment or not, but it doesn't seem to matter to them one way or the other. (P8)

I don't hide who I am, you know. I don't hide who I am, you know. And how would I know [if the provider is homophobic]? You know fast enough if someone is prejudiced, okay? I'm Jewish. That comes in terms of prejudice that's certainly on a par with the lifestyle. Lifestyle is often more accepted than religion. I think as you age or as you get older--I don't know how old you are, but I'm sure you can feel it now--you know if someone doesn't accept who you are. Could be for any number of reasons. If I feel that, I probably overreact and my back goes up. And how would I respond if it was a

home care worker? With time I probably would ask for a change. I probably would. I would just say, "There's a personality conflict. It's just not really working." Because I think it has to work with a home care worker, because she's coming because you need something. You know, they're not coming as your friend. They're coming because you need their assistance and if you're feeling that they're prejudiced against you for whatever reason, I think the whole atmosphere would be dreadful. I don't know how you'd be able to work with someone like that. And so my advice would be to say, "I'm not saying she's prejudiced, but I just am not comfortable with her and could I please have someone else?" I would call. (P14)

Like P14, the majority of the single participants reported that they did not typically come out to their home care workers and did not feel that it was important in the context of home care. However, they were aware that living alone and having the assumption made that they were heterosexual may have accorded them the privilege of not having to disclose their sexuality, thus protecting them from potential homophobia. For example, P11 noted that she hasn't told her caregivers about her bisexuality:

Uh, I haven't really told them. They don't know anything about my past.

When asked why she chose to do this, she explained that it was because she wasn't presently sexually "active":

Well because I'm not active anymore. I didn't need a worker until the past four years-- I think I did mention it once to them, but they weren't really interested. (P11)

Along the same lines, P2, who was also a home care worker herself (PSW) explained this in more detail:

I don't know. I don't know. How would that help if somebody says--Just for me it was

never applicable because I'm single. I live by myself, so there was never any, like there

was no partner at home so there was no exposure to a gay couple or a lesbian couple,

right?   There was just no exposure. (P2)

P2 was also a home care worker herself and reflecting on her experiences with providing home

care, she added:

 I mean I have experienced having gay clients but I haven't had experience in gay

couples and obviously for me it wouldn't matter anyway because I'm lesbian myself.

But I think for, um, I think for couples that are gay [and] that need [home care] service,

uh, obviously sensitivity training, you know, that people are not getting upset about

when they see two men or two women, you know, or even when they see them kissing

good-bye or I'll see you later, that they're not freaking out, you know. (P2

Some participants reported that although they didn't feel that it was *necessary* to

disclose their sexuality because they were single, this would become necessary if they lived

with another woman. Their sexuality would then be more "obvious" as a result of the presence

of a female partner or clues in the home environment, such a shared bedroom space and

clothing items:

Well yes, that would be more obvious. I did have one partner of whom I was quite fond,

but that broke up before I had any of this. Had she still been around, they would have

figured that out eventually. We had a very large apartment, but only one bedroom

where there was only one bed. Anyone with half a brain would have noticed that. So

again, I don't think I would have specifically said, "This is X, my partner." It just wouldn't

have occurred to me, but if they had said, "Oh, you two live here," or, "Are you two

lovers?" I would have said "Yeah." (P12)

Well obviously you're living with another woman. You have a certain relationship, you

know. Also, you know, I mean I'm not everyone's cup of tea in terms of femininity. You

know, people suss things out. You know, no husband on the scene, that sort of stuff.

(P16)

Previous research has also suggested that the LGBTQ individuals often create affirming

home environments through the display of LGBTQ and sexuality-themed items and decorations

(Gorman- Murray, 2006; Johnston & Valentine, 1995). As a result, it is possible that individuals

who access home care may be wary of being found out through items in their home

environment such as gendered clothing items, photographs of family members and LGBTQ

themed items (e.g. rainbow flags, pride items, LGBTQ books and music, nude photographs).

Although, I did not explicitly ask about this during the interviews, I observed that only a few of

the participants had LGBTQ items on display in the public areas of the home (e.g. living room,

kitchen, front of the house) such as rainbow flags or sexuality-themed imagery and books.

Furthermore, most of these were small items that were not necessarily easily identifiable as

LGBTQ-themed as they were also common household items such as a mug or a garden

decoration.

Although several of the coupled individuals stated that caregivers could potentially find

out about their sexuality through sleeping arrangements or family photographs, none reported

being worried about being found out without their consent. Only two of the single participants,

P14 and P5, explicitly discussed their material environment in connection to their identity, and

both lived alone. Responding to my question about whether she is out to her caregivers, P14

recounted an experience with a delivery person who thought that she was a decorator:

> Well I mean I certainly don't hide who I am, you know. I remember when I moved here
>
> and I hadn't decorated because I couldn't see colours or anything and someone
>
> delivered something to me and he was gay... He said, "Oh, is your client lesbian?" And I
>
> said, "Why do you ask that?" And he said, "Well because she has all these women
>
> paintings all around." I hadn't even thought about that. And I thought, 'Oh, that's a
>
> riot. I guess I do.' Never ever thought about it. (P14)

> P5, unlike the other study participants, was worried about being found out as a lesbian

by her caregivers as a result of the items in her environment. Explaining why she thought that

she would be found out by her caregivers, she stated:

> If you need to use the bathroom and you go upstairs, you'll see dyke and queer and
>
> everything--Well you can see from my windsock [referring to a rainbow coloured
>
> decoration hanging on her porch] and everything out there [referring to her pride
>
> souvenirs, pictures and rainbow-coloured items inside and outside her home]. (P5)

Given that out of all of the study participants she had the most items in her environment that

were LGBTQ-themed, it is possible that she was also more aware of this possibility than other

single participants who were able to pass as straight when accessing care.

> Despite the importance that participants ascribed to their sexuality in their everyday

lives, several participants noted that coming out to a caregiver was not immediate and involved

decision-making. For example, P5 explained that coming out to her previous caregiver was a

gradual process during which she gauged her caregiver's potential reaction to her disclosure:

I was waiting. I gauge the situation to see how I come out, because this woman is taking

care of me on a really intimate basis. So I didn't, uh, I think it was in 2008 that I finally

said to her, um, "Do you realize that I'm a lesbian?" And she said, "Hmm, well not

really." Just like that. "Not really." And I said, "So how do you feel about it?" She says,

"No big deal." So that was it. So now I talk about all my lesbian activities and she talks

and asks me questions… I'm not out to any of the fill-ins. (P5)

When asked to explain her decision to not come out to temporary fill-ins, she explained:

I have an established relationship with my ongoing caregiver. With the others I don't

want to jeopardize--When I say I'm out to everybody, you know, where I see it's

necessary, I am out. Where it's not necessary because I don't want to have somebody

who is filling in for my regular caregiver be homophobic with me and then I am stuck

with that person. So I just have not said anything to the others. (P5)

Later, in a second interview, she explained that she had recently lost her long- time caregiver as

a result of CCAC changing contracts with home care providers and she was worried about

coming out to a new long-term caregiver.[28] She described a recent experience that made her

uncertain about whether she would be safe coming out to this caregiver after the caregiver

attempted to engage her in Christian prayer:

So they sent somebody and I was told eleven o'clock and then at ten o'clock my

doorbell is ringing. Luckily I had gotten home from the gym and it's a woman from B [a

home care company]. I said, "But you're supposed to be here at eleven." She says, "Oh,

well I was in the neighbourhood and I thought I would just try to see if you were here."

---

[28] I interviewed P5 twice; between the first and the second interview she lost her long-time caregiver.

So a little warning bell went off, because you tell me a certain time, I told him [CCAC

case manager] I have a schedule that I follow and it was still cold and luckily she had a

car so she was waiting in the car. So she came in and we did a shower--We do the

shower and I have the Serenity prayer on my bathroom mirror. Right away she tells me

that she's a Jehovah's Witness and can she bring some prayers and would I like to pray

with her. So I thought, this is not going to work, you know. And at that point I didn't

have all my queer stuff because I had just had the place painted. I don't know if you can

tell. [laughs] So I spoke to at that point my [previous] regular caregiver. I'd spoken to

her and she said, "That's a big no-no. They're not supposed to be talking about prayer

and let's pray together." (P5)

Disclosure and gauging who would be 'okay with it' were also important considerations

for participants who lived with other women. Unlike women who lived alone, coupled women

were not as easily able to pass as heterosexual or avoid the conversation and thus planned

accordingly. This was particularly a concern if they received care from the same caregiver for an

extended period of time. For example, P13 reported:

And the first young woman who came was really good. She was lovely. She was

efficient. She was friendly, not overly friendly, but friendly. I don't blurt out, "I'm gay,"

but I say, "X is my wife." I just sort of kind of ease in "my wife" and she'll hopefully get it

and she was just fine with that and she set up everything and did everything. (P13)

Similarly, P6 explains that she gauged from caregiver to caregiver who would be "okay with it":

In the friendly visiting phase of this--this is after you've had your bath. Your little lunch

is done. If they have time, they will do a friendly visit and that's like, "How are you

doing? How are your kids? How are the grandchildren?" And making nice because

that's what you need. You need that kind of personal contact that says you're still a

valuable human being. And for my lifestyle, the children aren't here anymore. He's

raised. He's married. We have two grandchildren. But I was in a lesbian relationship.

So do I say to that worker, "Yeah, he's not my biological child. I co-parented for 40 years

and he's now 47." Do I give out that personal information to somebody I don't know?

And how is it going over? The other thing, being a Unitarian we welcome all faiths. We

had one gal here last year who was from the Roman Catholic faith. That was interesting.

We didn't talk about lesbian there. But I'll tell you, she was one of the best workers.

And it's kind of like you know who is okay with it. There were a couple didn't even clue

in. (P6)

P15 even more explicitly explains the importance of disclosure as a result of having a female

partner:

I don't want someone to come here that's going to be belittling me or not accepting

that I'm gay and that I have a wife. I have pictures of the two of us on the wall and I

have the two of us--I talk about her constantly. So I want someone that's going to be

accepting to who I am. (P15)

When asked to explain why it was important for her to be out to her caregivers, she adds:

Um, because I don't want them to go away from me and be like blah, blah, blah, you

know, and talk about that she's working at a lesbian house or "I think they're gay" or "I

think they're this." It's like no, I'm totally out. If you're going to be a part of my life and

a part of my close life, I don't want to be judged by you. This is who I am. Take it or

leave it. And if you don't like it, you better be asking your boss for somebody else. (P15)

The continual need to monitor and know when it was all right to disclose was at times

emotionally draining and several participants explained that sometimes they avoided the issue.

Such vigilance can negatively affect their stress level and well-being. For example, P6 explained

that sometimes she chose not to disclose because:

I just kind of went, "That's way over her head." And that was exceptionally rude on my

part, making an assessment of another human being and part of it is that you get tired.

It's like you're sick. Do you want that day to go through the bigotry? Maybe not. And

other days, if you feel well enough, yeah, you want to put it out there. So I almost think

that I should have made my spouse stay home from work and tell everyone. (P6)

Similarly, P3 stated:

I don't think we ever discussed it and I don't know if she knew about X. Well I think I did

say "my partner," you know, "helped out" because I mean she didn't come on board for

a week or so. I may have. I may have mentioned X. But I mean I would have been okay

with her. With the other lady that came, I mean I wouldn't even want to get into it. You

know, and the assumption would be probably that I had a husband. My eyes would

glaze over and that would be fine. I just wouldn't want to get into it. But it's so much

nicer when you don't have to wonder what sort of judgements are happening. (P3)

In line with this, P7, who has had one lesbian home care worker, explained that this experience

made her realize how much easier and more comfortable it felt to be around someone when

she didn't have to continually monitor their potential reactions:

Doesn't matter how out I am or how open I am or how comfortable I am, I still know

that I'm probably the only lesbian that the other nurses know and so there's a sort of

just--I don't know. It's just a bit different. (P7)

Overall, many participants expected to be treated well and did not expect that there

would be a negative reaction to their disclosure from caregivers. Participants also explained

that they felt "safer" receiving care in their home, rather than within an institution, such as a

hospital or a long term care residence. Participants also reported that being in their own home

made them feel safer because they could control the outcome of disclosure. Feeling safer in

their homes can also reflect having experienced homophobia previously within health care

institutions after they identified as lesbian or bisexual, and they thus mistrusted institutional

health care environments and health care providers. Coupled participants in particular reported

that they felt safe and that they could manage the potential repercussions of disclosure in

home care, as they could rely on their partners to intervene if necessary and address any

potential issues:

No, because I've reached a point in my life where if I had a problem with them, I would

just ask them tactfully to leave. (P10)

When asked whether this has happened, however, she added:

No. But I feel completely comfortable with having to do it and believe me, if I didn't, X

[my spouse] would be three steps ahead of me holding the door open. [laughs] (P10)

Similarly, P6 recounted a conversation with a lesbian friend who intervened to protect her

partner after experiencing homophobia from a home care worker. She provided this example to

illustrate why she felt safer to receive care at home with her partner:

So this morning I was talking to my friend in X [a nearby town], the one who is caring for

the brain tumour woman. I said, 'So what do you do when you have a worker that's

giving you a problem?' She said, 'I phone up the agency and say they're not welcome

here anymore. And I tell them it's my home. It's our life. If they have a problem,

they're not coming back.' I said, 'You said that?' She says, "Yes, of course. It's our

home." I said "Oh, okay." And this is a woman who wouldn't say dyke if she had one in

her hands. And I said, "Where did you get the gumption to say that?" She said, "My

partner almost died. I spent six months by her side. I'm not taking shit off anybody."

Okey dokey. Here I am walking in parades, wearing my little red ribbons, doing this for

30 years, all it takes is six months of her sitting with her partner and now she's like a

born again feminist. But she just said it. She said, "This is our home." (P6)

Coupled participants, however, were worried about what would happen to them if their

partner was no longer present and could not advocate for them or if they had to enter an

institution. They anticipated that if they were living in a long term care residence, they would

be less able to control and respond to homophobia and poor treatment as then they would

have to deal not only with caregivers but with the organization of the institution and other

residents. Additionally, participants may have worried about whether their partners would be

recognized within such institutions as family members. In particular, participants reported that

were worried about experiencing religious-based homophobia in institutional care. In line with

this, P6 explains:

I'm not so much worried about the workers right now. They're cool. Some of the

managers may not be yet. It's the people that are going to be sitting in the room next to

me and across the table at dinner or sitting playing cards with me in the afternoon that I don't want to hear about their bigotry or their hatred. I've had enough, thank you very much. I had enough of that when I was 11. I don't need it anymore. And I want to actively say ahead of time, I have to be here because I have no other way to take care of myself, to honour my relationship, so move over. I'm not going to have you join the lesbian nation. You can if you want, but you don't have to. You just need to respect me as a human, as I intend to respect you. I may wear a few rainbow things on my bed, but, you know, pretty colours are good. So that's what I want to do currently, as I'm able and I have an extremely politically active partner who is working on other things like water and conservation of the planet and let's support our women in the NDP caucus and all of those other things which are extremely important. And I said, "But this one is for me because what happens if you die? Who is going to advocate for me? Who is going to do the paperwork? Who is going to help me count my pills? Who is there that's not a bigot who is doing a really good job with me?" And I want those people to realize that we've been here all along and we've been very accommodating to them, but it's time to move over and stop it and to stop it through organized religions in particular. Paying money to learn how to hate people really bothers me. Yeah. So that's where I'm coming from and that's why I agreed to do this with you. It's totally selfish. I wish every other senior disabled lesbian could talk with you, but a lot of them are at my age and you didn't come out. You lived in the closet. They still live in the closet and they're afraid to say anything because they know what comes of saying who you really are. And now it's so personal. Like you people are coming into my home and I don't know if

you're gay. I don't know if you're straight. I have no idea what your belief or your value

system is. (P6)

 Likewise, P3 was worried that she would be subjected to religious-based homophobia if she

were alone and had to enter an institution. However, unlike P6, P3 attributed the potential for

homophobia specifically to racialized home care workers, who she associated with homophobic

religious values:

> You know, I mean if X [my spouse] was not in the picture because she had predeceased
>
> me or something, I guess it wouldn't be an issue because I mean she wouldn't be here.
>
> But, um, yeah, I would sort of-- I think I would only because I mean I don't care if she's
>
> not comfortable with it. I mean that's her issue. But if she starts making inquiries or
>
> wondering why or giving me any sort of bible stuff about it, I certainly wouldn't want
>
> that. And I mean it could happen, because I know, too, that I mean because I'm at X [a
>
> Jewish institution where she volunteers]. I know the nature of a lot of the caregivers
>
> that are there and a lot of them are Filipino and a lot of them are black. I mean they're
>
> in a Jewish institution and I was walking by the elevator and this black woman was
>
> getting into the elevator singing loudly 'Jesus loves me' or something, you know, which
>
> is fine, I mean if she wants to, but I mean it's kind of an inappropriate thing. I mean she
>
> was all by herself and you don't have to be singing. I don't think I'd particularly want
>
> that. I mean that's her personal belief system. It's fine, but I wouldn't particularly feel
>
> comfortable with having a rendition of Jesus loves me as she was walking around my
>
> house doing things. But I don't know how I would say that, because you don't want to,
>
> you know, because often attached to that are some concerns, too, about people who

are gay. So I think I would be a little uncomfortable wondering, because I certainly

wouldn't want to get into any discussions around that. But that may be my own bias.

Maybe I'm projecting something onto them that doesn't exist. But I certainly wouldn't

want to be-- I think I'd have a bit of a concern, a bit paranoid. (P3)

Given that homophobia is often justified on the basis of religion in our society, the

association P6 and P3 make between religion and homophobia is not surprising. However, this

reveals bias not only towards religious people, but also potentially towards racialized home

care workers specifically. While P3 acknowledges that she may be biased, she doesn't

necessarily take responsibility for it, which is problematic. P3 also does not consider how other

factors may have shaped her experiences with racialized individuals and thus influenced her

association of homophobia with racialized communities. Consequently, P3's narrative raises

complicated questions with respect to the rights of clients and home care workers and the

potential for conflict between clients' rights and home care workers' rights.

It is also important to note another structural element that may have influenced why

some participants assumed that they would be less likely to encounter homophobia in the

context of home care: the gender of their care worker. Given that home care workers were all

female as it the typical practice in home care services in assigning female workers to female

clients, it is likely that participants assumed a shared "female experience" and that they felt

more comfortable being cared for by other women. Additionally, given that many had

especially negative homophobic experiences with male health care providers, they may have

assumed that they would be less likely to encounter homophobia from women. Evidence from

primary health care research also suggests that lesbian women, like heterosexual women

typically do prefer female health care providers as a result of assumptions about conversational style, relational competence and the likelihood of experiencing violence (Stevens, 1996; Roter & Hall, 1998; Solarz, 1999). However, as I discuss below, the assumption of a shared gendered experience, or affinity, may also be problematic in the context of home care if it intersects with workers' heteronormativity, as it may result in care workers reacting negatively to participants' disclosure of sexual identity, sexual practices and self-presentation as a result of workers' own gendered assumptions.

Experiences of Homophobia in Home Care

As was the case with their experiences with primary health care, most of the participants did not report experiencing any physical or verbal homophobia or abuse in the context of home care. Of those who did, only one participant, P16, reported being denied care and described experiencing continual harassment from homophobic care workers and case managers. Given that P16 had described herself during the interview as "not everyone's cup of tea in terms of femininity," her gender presentation may have played a role. Indeed, she suggests that it did with her reference to "men's clothes" in the quote below. However, like P3, she attributed the homophobia (and transphobia) that she experienced to home care workers' racialized identities and cultural backgrounds:

> I had home care workers come in who said stuff like, 'I'm not washing your clothes.'
> This is one woman. The first day she comes in, she's Ms. Rasta Queen. You know. She's
> like going like this, you know, and singing Bob Marley songs and I'm thinking, "Wow!
> She's way out, but okay." The next day she comes in, she's got a bible and she's telling
> me she's not washing my clothes and I said, "Oh. Did I hear you correctly? You're not

washing my clothes?" "Yes." I said, "Can you tell me why?" "Because I don't wash

men's clothes." And I said, "Oh, so you think that my clothes belong to a man?" "I don't

wash men's clothes." I said, "Well there's no men living here. None of the clothes here

are worn by a man." "I am not washing men's clothes. That's not what I get paid for."

This is the kind of nonsense you get that you put up with. (P16)

While P16's experience was stressful and negative, her narrative is problematic as it suggests an

anti-religious and racist bias. Furthermore, unlike P3, she doesn't acknowledge her bias, nor

consider any other factors that may have influenced her experiences with racialized home care

workers. Given that home care workers in Canada are more likely to be racialized and

immigrant women (Armstrong, Armstrong & Dixon, 2008) and that recent research has shown

that they can experience racial and cultural-based discrimination from clients and families,

evidence of this type of bias is especially concerning (Bourgeault, Atanackovic, Ahmed, Parpia,

2011). This and other similar narratives thus reveal the complex tensions between racial,

cultural, religious and sexual rights and the potential for discrimination for both workers and

clients in the context of home care.

Several participants whose caregivers knew of their sexuality described other instances

of homophobia in home care, such as their caregivers avoiding social interactions with them

and questioning the validity of their sexualities and relationships. While these types of

behaviours were not as explicitly derogatory as their past homophobic experiences, they were

nonetheless stressful and negatively affected their health and well-being. For example, P7

recounted negative experiences with a home care nurse:

Well interestingly enough, one of the home care nurses, her nose would wrinkle every

time she was here. And I didn't know if it was because we were messy or because she

didn't like me or because I was a lesbian. I figure it couldn't be because she didn't like

me. I mean everybody likes me--so I assume she was homophobic and I just told the

company that provided her that I didn't want her again and I never saw her again. (P7)

P13 had a similarly negative experience:

And the second nurse was homophobic. She was very, uh, she asked me if I was

married and I said, "Yeah, that's my wife." "Your wife?" I said, "Yes, we're gay." "Oh,

well." She was just weird. She was very weird and talked a lot about herself and her

friends and her trips and I didn't really care and not a lot about my nursing care or my

whatever. And she never wanted to come back and see how I was. She would hook me

up, but I think she actually thought I should be able to hook myself up, but I wasn't

going to do that. She had to start the pump. I don't want to know how to and X [my

spouse] didn't want to learn how to do the pump. That wasn't our job. That's her job.

And she was a bit of a knob. She came for almost two weeks. She was snobby and

homophobic in a very droll over class kind of way. I found it very irritating. She talked

about posh things, about travelling with friends, and all her friends were teachers or

doctors or professors or PhDs and they'd all gone to wherever they'd gone for their--, I

can't even remember because I didn't care. I wanted her to take my blood pressure. I

didn't want to know where she went last summer. I don't care. [laughs] And she looked

gay to me. She looked closety gay to me and I thought, "You're just irritating me and

you're pissing me off and you have this shocked thing about the fact that I have a wife

and that we're actually married." She got really, "Oh I don't know if I agree with that."

You know what? It's not for you to agree with. It's the law, lady. So she irritated me.

(P13)

P13 narrative illustrates the damaging effects that these types of experiences could have on

participants' overall well-being. Furthermore, her narrative is interesting in that it illustrates

that LGBTQ people may also use assumptions about homosexuality as a weapon against other

people.

Participants who received personal care had similarly negative experiences. For

example, P6 stated that some caregivers withdrew or avoided social interactions with her as a

result of homophobia. However, unlike other participants' experience, she did not experience

derogatory comments or the questioning of her sexuality. Instead, she experienced

heterosexism through indifference and lack of engagement. When asked what happened after

she came out to her caregivers, she explained that for the most part this was ignored and/or

caregivers avoided talking to her or inquiring about her life and her family:

Oh they just kept chopping the cheese. [laughs]. Oh yeah, and there was never an in

depth conversation about the relationship. That was different. Nor did I get, 'Well what

does your husband do?' Never asked. "What did your husband do if he were retired?"

"Where are your children?" Lesbians have children. We have had them in so many

different ways. You just never know what we'll come up with next. There was the

turkey baster craze. There was "have you got a kid?" "Good." "Do you want to get

married? "Yes." "Do you have children?" "Good." We're not going out. That wasn't

there so I didn't get the chance to brag about my granddaughters as heterosexual

people do. You know that thing where they haul out the pictures and show you the

kids? Well nobody asked to see that. When I was a worker, if the person had

photographs on the wall, I would acknowledge, "What lovely children. You must be so

happy." Nothing. Oh yeah, there aren't any pictures, but nobody even, "I don't see any

pictures of your grandchildren. Do you have any?" As a friendly way over any cultural

thing. I don't care who you are. You're happy about your grandchildren or your dog or

your cat. So it was missing. It's what was not said to me. I didn't get that rosy feeling,

"Oh my god, I'm really sorry you're sick and how is your family?" (P6)

Another participant who received personal care, P15, had a different experience and noted that

some of her caregivers explicitly questioned her about her sexuality. While the types of

comments that she recounted were not necessarily hostile, they were potentially burdensome

and speak to the invisibility of lesbian and bisexual women in home care:

They've questioned as to, "Oh, I didn't know you were able to get married now." Or

"How do you like it now that you're able to get married?" "Do you have problems with

your wife, at work, or whatever?" Asking how hard it is to be gay or straight. (P15)

Often, however, homophobia and heterosexism were difficult to recognize if individuals

were unfamiliar with receiving home care and the potential scope of the social support that

home care workers *could* provide. Furthermore, even if participants recognized it, it was

sometimes too discouraging or energy-draining for them to actively resist it. As P6 explains,

although she knew that there was something "missing" in how home care workers interacted

with her, she was not able to identify her experiences as homophobic until after she interacted

with a home care worker who was more accepting:

Well I kept thinking, you know, they're not saying anything derogatory, but just by their

not asking, for me there was something missing. If I-- as a social worker frequently if I

went into the home and I saw there was a spouse person, I would normally as a

courtesy ask how they were. I didn't get that. I never got, "How is your spouse?" Not

until I got one who came on a regular basis and met her and sometimes she would meet

her in the hallway here as she was leaving to go to work. Always very cheerful, always

very polite to her, but didn't really say like, "How is your relationship? Is everything

great here?" None of that personal stuff that you would expect in a heterosexual

relationship. And I know that because when I go to group for disability stuff or

whatever, we're always talking about those friggin husbands. They all hate them, but

they all talk about them. So there wasn't that happening. That's the big thing that I

noticed-- It's so subtle. Like I really like bigotry when they slap you right in the face and

they go, "Listen you friggin queer." You know that you're being done in. [laughs] It's

the subtle stuff that's left out that is so horrendous and sometimes we miss it ourselves

and the other people don't even know they're doing it and how offensive it can be if

we're smart enough to get it. And if we want to take issue with it. I mean the global

economy is falling apart and we're doing this. Which one do I want to fight about? This

one. For today. (P6)

Similarly, P16 spoke about the negative environment that could be created as result of this

masked form of discrimination:

You know, people know if they're being respected or not. People know. You don't even

have to say, "I respect you." No. People know. And it's, um-- it comes from deep

within. It's an attitudinal thing and people know whether or not they're being

respected. And then of course things can get very overt where it's obvious you're not

being respected, you know, where abuse can take all kinds of forms. But there are also

the subtler and more subtle forms that just come out as you can feel it, sense it, the

nuances are there. (P16)

Although it is encouraging that many participants did not report overtly homophobic

discrimination in the context of receiving home care, it is likely that they may have had similar

experiences to those of P6 that they did not identify as homophobic. It is possible that they may

not have been as attuned to this possibility as a result of their gendered assumptions about

their caregivers and their likelihood of being homophobic. These narratives also reveal that the

burden of disclosure, and its consequences, continues to lie with lesbian and bisexual women,

who must decide whether to come out. This adds a layer of stress or the "persistent alertness

to the possibility of exclusion and potential harm" to their encounters with care providers

(Sinding et al., 2010, 91). This additional anxiety and stress may negatively affect their long

term health and well-being as well as contribute to their avoidance and mistrust of home care

and other formal care services and providers.

Given that many of the participants had experienced more explicit and violent

homophobia in the past, more subtle experiences of homophobia or heterosexism may be

invisible in comparison. Furthermore, poor care may be rationalized as being the result of

other factors, such as professional incompetence, rather than homophobia. In line with this,

several researchers (Blaxter, 1997; Bolam, Murphy, & Gleeson, 2004; Lee, Taylor, Raitt, 2011)

have proposed that marginalized individuals may be resistant to explicitly acknowledging the

effects of an oppressive system, such as heteronormativity, on their behaviour and may avoid

attributing negative experiences to oppression in everyday encounters because this may be

self-protective in the short term. This distancing or avoidance may occur despite individuals'

acknowledgement of the existence of oppression on a more general social level or when talking

about the experiences of other people.

Finally, participants' experiences of homophobia reveal another interesting aspect with

respect to gender and sexuality in home care. As mentioned earlier, given that all of the home

care workers were female, it is possible that assumptions of gender affinity, or a shared gender

experience were made not only by the participants, but also by the home care workers. That is,

it is possible that workers had not only heteronormative expectations of participants, but also

had gendered and sexualized expectations about the proper roles of women; these

expectations may have contributed to their negative reactions to participants' disclosure of

lesbian sexuality and intimacy. Given that home care workers assisted participants with

intimate and personal care tasks it is also possible that workers felt threatened by the potential

homoerotic nature of the work. These examples of potential gender affinity and expectations

have implications for home care policy and the training of home care workers.

Looking to the Future

Several participants expressed worry about the potential for experiencing homophobic

discrimination in home care if they had to access home care again. This was a particularly

significant worry for those who had recently experienced homophobia in other areas of health

care within institutional contexts. For example, P13, who recently experienced homophobia

while being hospitalized, stated that she worried about what would happen if she became

sicker and had to access home care again:

> I'd be afraid I'd get that kind of--a lot of nurses do that--but I'd get that kind of a person.
>
> That would be awful. At least I was able to move around. If I wasn't able to, I would not
>
> want to be at the physical mercy of someone who didn't respect me. That would be
>
> awful. And I felt that way at X hospital with that nurse, although I was, I was pretty sick
>
> though. I was a lot sicker than I realized at the time. I just pushed myself. I didn't
>
> realize how much I pushed myself. But to be weak around that kind of person would be
>
> just devastating. It would be physically vulnerable and not safe, is what I think. It would
>
> not be safe to have. So yeah, I would do everything in the world not to have to have
>
> personal care. (P13)

As mentioned earlier, two participants associated homophobia with religiosity and

expressed anti-religious views with respect to the potential for experiencing religious-based

homophobia from racialized home care workers:

> I could sit here for a whole week and give you examples, but I mean of course it does
>
> because generally when you're dealing with people, as I've said, who come from a
>
> hetero patriarchal background where-- and you know certain faith backgrounds are very
>
> negative, I mean someone who will come out and tell you that you should be killed, you
>
> know, that sort of stuff, you get the continental drift that they find it quite objectionable
>
> even though I'm not sitting there in any way coming on to them, let alone even just
>
> letting them know who and what the heck I am. It is really nobody's business. Of
>
> course it does. Even in people who, uh-- you would think are enlightened. Oftentimes

you'd be surprised at the latent prejudice that's there. I mean even with some gay guys.

I mean you look at any human rights legislation and you'll see these different pockets of

hatred and these are things that are so-called things that are protected by legislation.

Well really all they are is pockets for hatred and hatred is part of humankind's

development. And homosexuality is a big one. And I don't think it's going to change in

my life. (P16)

Similarly, P3 added:

I had a cleaning person once who came in and she came equipped with all these

Christian, um, pamphlets and I remember my ex-husband called me because I mean I

knew I couldn't do the housework and it's sort of like why would I want-- I mean my

partner is my partner, not my housekeeper, you know. So I got a cleaning lady, but I

remember he called me and he said, "Did you know that Jesus was in the room with

us?" I said, "No, I didn't." He said, "Yes. He's here right now." And I thought, "This is

creepy." Like that's what she was saying to him, you know, Jesus lives in the home. I

thought I don't want that, you know. So I mean like I would want to be very certain that

the person wasn't there with another agenda and that they felt comfortable providing

the care and that they were willing to sort of follow with some directions for how you

wanted things to be done. And now that I've had this experience, I know that doesn't

always happen. So I think that would be a concern is sort of, you know, how to ensure

that the person is someone that I'm comfortable having in my home, because I've had

some very strange people, like when I've had cleaning people or someone and, um, you

would hope that they weren't in the home care business, but many of them are because

they're minimally trained and they're minimally educated and they work for a very low

wage. So I think that's a concern. I don't think it's culture as much as along with the

culture, because I know that the people at X [a Jewish institution where she

volunteered], the Filipino and black women are very religious and not always

appropriately so, because we'll find in the waiting room religious pamphlets and so on,

which mysteriously arrive in the waiting rooms and so on and I make sure they get

disposed of in the recycling because it's not appropriate. It's a public institution, it's a

hospital. So, um, I think that would be my only concern. It wouldn't be the colour or

the racial origin. It's more the religious aspect. We know they don't like us. (P3)

In both of these narratives, participants make a direct connection between caregivers'

racialized identities and the potential for experiencing religious-based homophobia from them.

P16 also expresses anti-immigrant bias. As mentioned earlier, these narratives are problematic

as they reveal bias and illustrate participants' rationalization of this bias. These narratives also

highlight the potential tension between supporting workers' and clients' rights and have

implications for ensuring the well-being of both workers and clients in the home care system.

Desire for Diversity Training and Education

Across the interviews, several participants voiced a desire for mandatory diversity

training and education for home care services organizations and home care workers. As P5

explains, this type of training was seen as particularly important for home care workers given

the intimate nature of the care and the fact that it occurs in isolation:

Because it's so intimate and you depend upon that person and that person can be mean

to you, especially if you're an older person and you're still out. So if you're 85 and

you're a lesbian, you don't have to be practicing to be a lesbian, you are a lesbian.

Because I have friends, straight friends say to me, "Well you haven't had a relationship

in how many years. Are you still a lesbian?" [laughs] So to me it's a matter of who has

the power and they can always use that against you. (P5)

Others stated that creating this type of training also made sense given that other public service

agencies that interact with vulnerable populations already have this policy in place:

Well the police have it. They have racial consciousness. They have sexuality

consciousness. I think home care would benefit from having sessions on race, gender,

sexuality, any other issues, not just gays. But I think gay people probably don't expect

anything particularly different in the way of treatment. (P12)

When asked why this type of training was necessary, participants explained that knowing that

their caregivers and home care agencies had had that type of training would make them worry

less about the potential for experiencing homophobia:

I think they need to have workshops generally on anti-homophobia, anti-oppression,

anti-racism as a beginning and then look at the individual needs in terms of a person of

colour, a lesbian. I don't think somebody has to be out for you to treat them differently.

You should be treating people with respect and understanding and caring across the

board and that doesn't happen. Somebody walking--as I said, two caregivers walking

through my front door, like wandering around and, "Look at the big house you have."

Those are not things that you should be saying… If I knew they were getting sensitivity

training and anti-oppression training, then to me that's a whole different way of me

approaching--them approaching me. It's them approaching me because I'm the one

needing the care. So I'm literally at their mercy. (P5)

Similarly, P4 noted that had she known of a home care company that had this sort of training

she "probably would have gone there first."

The desire for LGBTQ competence training again reveals that participants were worried

about that potential for homophobia while receiving care. As a result, despite some

participants' downplaying of the significance of their sexuality, attitudes about sexuality

negatively affected their experiences with home care and their overall well-being.

Consequently, this type of training has the potential for supporting older lesbian and bisexual

women's health by reducing their anxiety and fear of experiencing homophobia.

Conclusion

In this chapter I presented an analysis of how sexuality affects older lesbian and bisexual

women's experiences of receiving home care in particular and health care in general. The

analysis in this chapter illustrates that sexuality negatively affects participants' interactions with

caregivers and contributes to their overall stress and anxiety. Despite the fact that some

participants downplayed the importance of their sexuality, across the interviews it was clear

that their sexuality did in fact matter in their decision-making and in their interactions with

home care providers. For example, many participants engaged in an identity monitoring

processes while accessing home care. This monitoring of disclosure and the potential for

homophobia added a layer of emotional and psychological stress for participants and negatively

affected their quality of life. While most part participants did not encounter overt homophobic

discrimination, many reported subtle and insidious heterosexist behaviour that affected the

quality of the care and made them feel invisible and silenced. Furthermore, participants

worried about potentially encountering homophobia in their future interactions with home

care workers.

Chapter 8: Quality in Home Care

Quality is such a nebulous word. It's what's good.   (P12)

In the previous chapters, I presented an analysis of participants' experiences with

accessing and receiving home care and explored how sexuality (and disclosure of sexuality)

affected the care that they received. In this chapter, I focus on the issue of quality and analyze

participants' definitions of quality home care and the factors that they identify as enabling (or

hindering) quality in home care. As noted in chapter 2, the issue of quality is interesting to

examine given that many of the recent reforms that have been implemented in Canadian

health care have been done with the rationale of improving the quality of care.

The analysis in this chapter is informed by feminist political economy (FPE) critiques of

neoliberal approaches to measurement and evidence in health care (Armstrong & Armstrong

2001; Mykhalovskiy, Armstrong, Armstrong, Bourgeault, Choiniere, Lexchin et al., 2008). These

critiques have demonstrated that the primary emphasis of neoliberal quality reforms has been

on standardization and improvement of adverse biomedical outcomes, as well as on market

strategies. The assumption is that a low number of these types of outcomes necessarily

indicates that existing services and care are of good quality. However, this assumption may not

be accurate.

Quality in home care (as in other areas of health care) has primarily been quantitatively

evaluated using biomedical outcomes such as the number of readmissions to a hospital, the

number of falls, the appearance of ulcers or other health care complications, the lengths of stay

in home care, the number of individuals waiting on the wait list, etc.[29] In fact, a recent report

on quality in the Canadian health care system (Health Quality Ontario, 2012) did not include any

non-quantitative outcomes in the section on home care, nor any discussion of how the report's

principles of quality, such as accessibility, equity or patient-centeredness, could be measured in

order to assess quality in home care.

While quantitative outcomes can provide us with some information about current home

care services, they cannot measure whether home care recipients perceive the care that they

receive as quality care. Furthermore, while this type of evidence can be useful for assessing

some elements of health care system's quality and performance, there is indication from

qualitative studies of primary care that there are other important aspects of quality such as

accessibility and equity that are not currently being captured (Armstrong & Armstrong, 2010;

Armstrong, Boscoe, Clow, Grant, Guberman, Haworth-Brockman et al., 2009; Dubé, Ferland,

Moskowitz, 2003; Sinding & Wiernikowski, 2008).

Additionally, measuring quality in home care solely in terms of quantitative biomedical

outcomes is problematic due to the nature of the job of providing care. Providing care, or

caregiving, is composed of task-based and relational elements that can affect the quality of the

care provided. Unlike other types of jobs that are more task-based and primarily involve non-

sentient beings (e.g. making widgets, working with computers), providing health care involves

having both the professional competence to perform an activity (such as administering

medication or giving a bath) as well as the ability to establish a therapeutic or caring

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[29] See, for example, CCAC website. 2013. Outcome based pathways. Available at: http://www.ccac-ont.ca/Content.aspx?EnterpriseID=15&LanguageID=1&MenuID=1575; Health Quality Ontario website. 2013. Home care quality indicator definitions. Available at: http://www.hqontario.ca/public-reporting/home-care/information-about-quality-indicators/maple

relationship with the client. As Kitts and Armstrong (2001) further explain, "caregiving is not a simple act but rather a complex social relationship -- one embedded in personal histories and located within specific conditions" (11). Within a feminist political economy analysis of care in particular, care is conceptualized as something that is dynamic and relational, and quality is thus the result of successful interactions involving the caregiver, the care recipient and the environment in which the care is provided. Consequently, to assess quality in home care it is necessary to examine how these different factors can affect the quality of care. Using an FPE framework to examine quality has encouraged me to look for these dynamic, relational and interactional aspects of quality and my analysis of the participants' narratives demonstrates that the meanings that participants assign to quality consist of these types of aspects.

More specifically, in this chapter I demonstrate that participants identified quality as encompassing three key dimensions: client-centeredness, competence, and comfort. These dimensions demonstrate that quality is ensured through both interpersonal and technical competencies. Additionally, participants identified several specific individual, relational and environmental factors that enabled or supported the quality of care in home care. Based on this analysis, the chapter is divided into four sections: (1) participants' conceptions of quality; (2) factors that they identified as enabling (or hindering) quality in home care, (3) participants' evaluation of the quality of the home care that they have received and (4) participants' expressions of gratitude.

My analysis in this chapter shows that while many aspects of quality are generalizable to other home care contexts and populations, there are aspects of quality that are unique to the specific experiences of older lesbian and bisexual women. These result from the presence of

heteronormativity and heterosexism in home care, which negatively affect the quality of the care and participants' ability to complain.

The Conceptualization of Quality

From the analysis of the interviews, three key conceptual dimensions of quality were identified: client-centeredness, competence and comfort. These were seen as separate dimensions that together comprised quality home care and were found across participants' experiences of different types of care (supportive versus medical) and different caregivers.

Client-centeredness. The majority of participants emphasized that quality home care was home care that was client-centred: that is, home care that was delivered in a manner that was focused on the home care recipient and their wishes in terms of how they wanted the care provided. The desire for client-centred care was expressed by participants who received very technical medical care such as administration of IV medication as well as by those who received help with self-care and housekeeping activities. Participants explained that client-centeredness was created when their caregivers understood and strove to deliver care in a manner that respected individuals' surroundings, life patterns and expertise.

Although participants understood that care provision was work and involved technical and professional expertise and skills, they felt that care was different from other types of work in that it involved assistance with intimate activities that made them feel vulnerable. As a result, they wanted to feel cared for and respected. Quality care was therefore care that was provided in a manner that enabled their participation and ability to direct the care. Reflecting on the meaning of quality home care, P1 explained that it was important that caregivers took the time to listen to her and made her feel as though they cared about her:

Well it means client centered. It means the appropriate service for the needs of the

client. Everything is part of client centered, really. And, um, it means, uh, being a

partner in care with the person who is receiving the care, not just doing things to

somebody, but actually seeing them as an integral, active part of their own care. Well

client-centered means that the needs of the client are the primary ones that are being

dealt with, not the needs of the caregiver. And of course the needs of the caregiver

have to be taken into consideration. That isn't to say that person isn't allowed to have

any needs or, you know, whatever, but it's the client's needs that are primary, so

nobody is giving you grief because they think they've put too much mileage on their

bloody car. I mean really, that kind of nonsense. Or leaving and coming back or, you

know, being nasty to you because they don't like that you've called just before they go

home for the day or something. So yeah, and the whole service has to be set up that

way and I know, you know, I've worked a lot with small community-based agencies that

provide not home care service per se but lots of different kinds of services to people and

many of the ones I've worked with have been spectacular. You know, they really, really

provide that kind of care. And occasionally I come across it elsewhere. Like I felt

mostly, um, at X [a large downtown teaching hospital in an urban center] that mostly,

with a couple of exceptions, I got that kind of care from the respirology unit. But in lots

of other walks of life, other types of service, especially big ones, yeah, so you know

these big, and I don't think it's always or it's not necessarily a function of size, but

certainly big service providers tend to have a lot more problems, I think, delivering client

centered care. People get really caught up in: 'This is just my job. I go home at 4:30.'

And, you know, you can also see, I mean when people have Mc-jobs, you can see that they get hung up on that kind of stuff.   (P1, received nursing care)

Many participants explained that client-centeredness was important since home care was provided in individuals' private homes, where they felt safe. Participants wanted their caregivers to understand that because they were delivering care in these intimate environments, caregivers should strive to investigate and abide by the client's wishes as to how they wanted caregivers to do particular tasks. This was especially important for participants who received help with intimate and instrumental daily care activities, including bathing, dressing and housekeeping. Although participants understood that their caregivers were professionals, they felt that as care recipients, they had expertise that was key to ensuring the quality of care.

Participants explained that it was important for them that their caregivers listen to how they wanted the care provided because these clients had developed specific strategies and techniques for doing everyday activities in ways that allowed them to manage their particular difficulties, such as issues with balance, mobility and sensory issues. For example, P14, who was blind, explained that client-centeredness was an important element of quality because it enabled the delivery of care in a manner that was responsive to, and respectful of, individuals' expertise and desires:

Quality home care for me is doing, responding to the needs of the client rather than, like being sensitive to the needs of the client rather than just, "This is what I'm here to do." A client's needs will change. A person's needs will change and the same way I believe in customer service meaning inclusion rather than accommodation, I bring that into home

care as well. I think you have to think of the client as opposed to of yourself. "This is

how I cook." I'm making this up. "This is how I cook this." No, no, no. Doesn't matter

how you cook it. What's important is how the client wants it. You know, you must, I

don't know, "brush your teeth before you take a shower." I don't know, if the client, I

mean I'm a perfect example of that. I brush my teeth, I use an electric toothbrush. I

brush my teeth in the shower because then if it sprays a little I don't care. And I came

up with that. If that's how I do it, I don't want someone telling me to do it differently.

Little things like that, because like it or not, it's the little things that will determine

satisfaction or dissatisfaction in most aspects of life. Equally true with home care. (P14,

received housekeeping and personal care)

Similarly P2 explained that client-centeredness was established not only through listening to

care recipients and being aware of their feelings, but also through how caregivers behaved and

interacted with them while providing care. In particular, client-centeredness was demonstrated

if caregivers were respectful in how they interacted with clients. Respect for the client was

demonstrated in caregivers' speech patterns, tone of voice, mannerisms and body language. P2

explains:

Quality is if we tell the personal support worker, uh, and that the personal support

worker listens to us. For example if I, you know, I don't know, if I want, um, for washing,

for example, if I want the laundry done a particular way, like if I say to the personal

support worker, "This is wool. Please don't put it on hot," that they have the

understanding that I need to wash it on cold. Uh, when I say, um, "This is the detergent

that you use for the dishes. Please use that," that they're not looking in the cupboard

for some sort of friggin' chemical and clean the dishes with that, right? And that they

obviously respect you, that they don't talk down to you, that they don't talk to you like

you're retarded and that they don't, I hate to use the word, but that they don't talk to

you like you're feeble, right? You're not. Well even if you are feeble, that they talk to

you with respect. I mean the same way we're being taught all the time. You know, to

keep the client as independent and dignified as possible. Um, you know, look for little

things. If you're sort of going to give the client a shower and you know the client is a

little bit chilly, you know, maybe you should close the bathroom door so it's a little bit

warmer, you know. Or, you know, if you're in the middle of showering a client and, you

know, the phone rings, just let the phone ring. Don't pick it up and leave the client

alone, you know. [laughs] It's amazing. It's amazing. Yeah, so little things like that. So

quality care. And obviously affordable and available, accessible. Yeah. (P2)

Thus while current quality reforms typically focus on the standardization of care tasks

and improving medical safety, participants' narratives demonstrate that quality care did not

mean having access to the same kind of care and care tasks that were performed in a routine

and standardized manner. In fact, an important element of quality care was care that was

tailored to the specific needs and practices of individual clients. As a result, quality care was

identified as care that was responsive, individualized and relational, and that recognized their

sexuality and their family life, rather than care that was standardized.

Competence. Across the interviews, participants explained that quality home care was

competent care. This meant that participants wanted their caregivers to have the necessary

skills and knowledge to do the required tasks and duties, but did not necessarily mean that they

wanted them to do these in a standardized manner. Competence was typically seen to be

demonstrated when caregivers did their job correctly, completed all of the required tasks and

duties in the appropriate order, and had the necessary equipment with them. The lack of this

type of competence was seen as not only indicating poor quality, but also a lack of respect for

the care and for the client. This can be seen in P13's discussion of her experience with receiving

poor quality care from one nurse. P13 thought that this care was of poor quality because it was

both incompetent and disrespectful:

> Quality care? She should have had her own stethoscope. [laughs] She would have to
>
> come prepared to do the things, the medical things that are written on that sheet.
>
> Don't tell me that you do these things and then, "Oh no, they're written but I don't have
>
> to do them." And she'd have to respond to what I was saying and that's I guess about
>
> treating me with respect and treating people with respect. Like she wasn't responding
>
> to what I was asking. She was responding to her own little world of whatever. (P13)

In contrast, P1 explained that her experience with a particular nurse was quality home care

because her nurse demonstrated competence and did of all of the required tasks:

> She [my nurse] was a big positive. She was wonderful. As I said, she was reliable. She
>
> stayed with me the whole time. She really looked after me. She paid attention to
>
> things, took my blood pressure, and did all the things that they should have been doing
>
> all the way along. And, you know, stayed with me, which was very helpful. (P1)
>
> Professional competence was also important for participants who received

housekeeping and personal care. As P14 explained, competence in this type of care was

demonstrated when caregivers completed all of the aspects of the cleaning tasks and in the

appropriate order, that is, in a manner that was accessible, useful, and enabled participants' independence.

> Because it meets the needs that I have, you know. The needs that I have are little ones. My bathroom. I have to think about tidy and clean. Tidy for obvious reasons, because if it's not, you might as well throw it out. And clean because I've become a little obsessed with that after I lost my vision because before I knew if it wasn't. Well for me that means little things. I put all the toilet paper in a stack. I can't do that because I find it very difficult to put them one on top of the other equally because of my vision. Quality is they don't say, "Oh, that's silly. You can do that." They do it. I'm thinking of the bathroom. They make sure it's clean, that the toilet seat is clean, that the sink is clean, the counter, the mat. If it's dirty, they'll put it in the wash and run a wash. That to me is quality. The same as in the kitchen. (P14)

Consistency and correct order in how caregivers did tasks was especially crucial as many participants had their homes arranged in a manner that was accessible given their specific needs. This meant that it was important that caregivers placed items where participants remembered them, placed items where participants could easily reach them, and ensured that furniture was arranged in a manner that enabled participants to move around easily. This enabled participants to manage independently and feel comfortable being on their own. Given that many participants had multiple mobility and functional limitations and spent long periods of time on their own, this consistency was also important for ensuring participants' safety at home.

P16, who received personal care, was even more explicit about linking quality to professional competence, explaining that while demonstrating respect for the care recipient was important, proficiency in task was equally as important. Asked to talk about what defined quality home care, she responded:

Just your rights respected, who you are as a human respected and the person actually doing their job. Somebody actually doing their job with proficiency. Yeah. That's about it. It's not like I'm looking for a friend, I'm so lonely I need a friend, or I'm so lonely I need somebody to have a cup of tea with me. Nonsense. No. Someone who does their job properly. It's that simple. (P16)

Similarly, P8 explained that quality home care occurred when the caregiver "is professional and knowledgeable about medical matters and is able to perform the duties that we need of them." (P8) Thus while participants valued client-centeredness, it was important that this was combined with competence. This ensured that the care was not only respectful but also useful and appropriate to their needs.

Comfort. Finally, participants also expressed the view that quality home care was home care that was delivered in a manner that made them feel comfortable. This meant that they felt comfortable accepting professional help with tasks that they normally did on their own as well as felt comfortable with sharing their home with someone who was unknown to them. As a result, comfort for participants' had both general and specific meanings. That is, participants expressed a desire for care that made them feel comfortable in general in terms of needing intimate types of care that involved touching their bodies. Enabling comfort was especially important given that they were receiving this intimate care from someone who was unfamiliar

to them. Additionally, they explained that comfort related to their experiences as older lesbian and bisexual women; they specifically expressed concern about receiving care from caregivers who might be homophobic.

Participants explained that comfort mattered in general because they did not want caregivers who made them feel worse for needing the care in the first place. Many participants explained that they were not used to relying on other people for self-care and wanted their caregiver to be sensitive to this and not make them feel like a burden. Comfort was established when caregivers did not express a negative attitude, listened to their wishes and in general demonstrated a willingness to do the work required. For example, P13 explained the significance of this comfort:

> In the hospital I got quality care. It comes across by the nurses taking care of your needs without, uh, a judgment or negativity. Like sometimes you mess yourself, and I have to be clean, and I guess with home care I would too. You just want to be clean. You don't want to talk about it. You don't want to be left there either in your own mess. You want to be respectfully, quietly cleaned. And that's, I guess, yeah, "Oh poor dear. You made a mess." I know that and I'm not six. (P13)

She further explained that it was especially important for the caregiver to not express negative judgments because this could work at odds with the clients' emotional needs:

> Quality home care means taking, where the home care person actually takes care of the person's physical and, I'd call it emotional, yes, emotional needs. That's what makes you feel good. And that's quality care. And I don't know if they can always do that.

Maybe they can't. But I think that's quality care. You don't have to make me feel

wonderful, but you have to not make me feel bad. (P13)

Similarly, P15 noted that quality home care was care that was "well-rounded":

It's good for you mentally. It's good for your spirituality. You're not being judged.

You're receiving everything that you need, that that person is able to give to you. And

it's without complaint. (P15)

Comfort was especially important as participants explained that accessing care at home

could be a vulnerable experience and as a result they wanted to feel reassured and safe. This

was especially concerning as participants were worried not only about being exposed to

violence but also to homophobia from their caregivers in the context of receiving care. As P6

observed, accessing home care meant taking a risk in terms of their personal safety, as the care

was provided one-on-one in private homes without oversight; this context made her worry

about being abused. As a result, she explained that it was important that caregivers be aware of

this vulnerability and fear and took the time to establish a comfortable and safe environment.

In this excerpt, P6 also bring up the issues of potential cultural differences between workers

and clients that may further complicate workers' and clients' sense of comfort with intimate

care tasks:

Risk it in terms of who is coming into my home. Will they personally harm me? Will

they insult me? Like if they throw me on the floor or trip me, I'm there for the day. If

they insult me because I'm a woman, or if I tell them that I'm a lesbian, or whatever it is

that bothers them, then I'm hurt. I'm upset. Then I'm left with what do I do about that

person? Do I tell my partner? Do we lose the service that we now have decided we

need? Is it my word against his or her word? That whole gamut of the things starts to

take place. And I'm home alone. She's not here. That's why they're here. Occasionally

they would see each other in the morning and say hello. The other thing is the home

care system. They are so overburdened that they are running around every day trying to

fill positions so that everybody gets taken care of. The number of times that she would

get called at the last moment and say, "Can you do X or can you do somebody else? Can

you fit it in because so-and-so is ill?" Constantly. So that system of the workers is

pushed beyond. So they manage five people, they think they're done for the day.

Wrong. They're now being asked to see someone else. The other thing, they are not on

the higher level of the pay scale, which is kind of like what you do to children. You hire

day care workers and you give them pittance and you say, "Have a nice day." So the

two most vulnerable sets of people in society, the people that care for them are not

getting compensated enough money for the kinds of things that they're doing. I look at

the worker and I think, "Can she really count those pills? Does she want to take those

pills home? They're worth a fortune." People have been known to take medication

away from clients. So here is what I'm risking. And I don't want to give the picture that

all workers are like that, because they're not. But if you have 10 people, you may have

one person out of that who is in a bad position and they do things. So being home

alone. If I said to you this afternoon, "Come into the bathroom. I'm going to give you a

bath," how would you feel? I don't know. You're not rushing in there. You're, in every

culture people have a feeling of personal space and what they would permit someone

else to see or to touch, right? The big one being genitalia. Get your hands off of that.

But even in some cultures, just to be naked in front of somebody, or that worker is of

the other culture, which also took place. (P6)

Similarly, P12 explained that establishing comfort was important because it enabled her to trust

her caregiver and feel safe.

Well as I said, doing what needs to be done without me nagging and having it done by a

sympathetic or empathetic person. One of the qualities that I liked about the

homemaker I had for a long time was I always felt that she had total integrity and it

obviously had nothing to do with her ability to wash a saucer. You just felt that as a

person, you could totally rely on her and you felt that she was really concerned about

you, that you weren't just a number on her route for today, that she actually cared how

you were. So [that] you are more than a number… that I would call quality. (P12)

Comfort was also seen as important because participants noted that home care had

both task-based (physical) and caring-based (interpersonal/emotional) elements that were both

important for ensuring quality. As P5 explained,

Well to me, there's two kinds of home care. There's the physical care that you get when

you get the help in the shower, the laundry is done for you, the housecleaning. And

then the other type of care is how the caregiver relates to you as a human being, as a

person and how caring they are of you. Quality home care is somebody I can get along

with, who treats me as a "normal" human being, treats me with respect, treats me with

understanding and caring. To me, that's quality. (P5)

The ability of caregivers to demonstrate interpersonal/emotional competence was thus

crucial to their ability to establish comfort. Comfort was also viewed as important for the

quality of care because participants felt that home care fulfilled more than their basic personal care (or medical) needs. As discussed in chapter 5, receiving home care also provided participants with an important source of emotional support, for care recipients were typically isolated in their homes. As P3 explains, participants also struggled with their desire to remain independent while needing help with basic daily activities, and a caring and positive attitude from their caregivers helped them feel better about receiving care. Asked to discuss what constituted quality care, she responded:

> Somebody who is willing to meet my needs, and who doesn't feel put out and rushed, and someone who looks like they're enjoying what they're doing because for me, particularly, I find it really hard to take care from someone. I'm not, well that's it. I mean I'm not an easy person to get along with, and I'm very independent, so it's a matter of feeling like, um, it's difficult. I mean I don't want someone fussing over me either. I want someone that's going to expedite the process, you know. Come in, get the job done, leave. I mean you know? I don't know. (P3)

An additional element of comfort that was specific to older lesbian and bisexual women was the desire for caregivers who were comfortable with providing care to LGBTQ people. Comfort in this case referred to at least outward acceptance and tolerance of LGBTQ sexualities, intimacies and families. This was communicated when caregivers provided care without expressing complaint or judgement about LGBTQ families, identities or sexualities. For example, P13 stated that comfort with LGBTQ people was important so that caregivers wouldn't refuse to provide care based on homophobic fears with respect to contracting HIV/AIDS:

Um, that they don't want to do it because you're gay, and they may get AIDS, or

because you're gay, and they may get this or that, they don't like this because they're

religious and you're not religious and you shouldn't be gay kind of things. (P15)

Similarly, P13 explained that this type of comfort was necessary because of the potential for

homophobia and that home care companies need to ensure that they support this type of

comfort explicitly in their training and education polices:

They need to know that homophobia exists and they need to tell homophobics "shut

your mouth" and that "it isn't your job to or your right to comment on someone's

marriage or their relationship." Like she [the nurse] could have said nothing. She could

still be a homophobic if she wants to be. There are lots of people who are, but you

don't have to like me, but you have to treat me with respect. Treat me with respect and

shut your mouth. There are people don't believe that people of different races should

marry, but you don't walk into somebody's house and say anything about that. And

that's what she should have done. She should have just focused on her job. It's my life.

I guess it's the same thing if you go in a person whose house is messy. You don't say,

"Oh my god. Look how dirty this is." If you're there to do whatever, you just do

whatever and think, 'thank god I don't live there' and off you go. Or ask if you can help

but that's, you know, even that I wouldn't, unless that's what you're there to do. You

know, maybe they need it. But I wouldn't comment. (P13)

Comfort with being around LGBTQ people and touching LGBTQ people's bodies was

seen as an important aspect of quality care because participants noted that accessing home

care entailed an element of risk for them in terms of the possibility of experiencing homophobic

discrimination or violence. As P6 explained, receiving home care was riskier than receiving care from friends because she couldn't 'pre-screen' her caregiver for homophobia:

> Having to have them [my friends] help me was difficult, but not as hard as that stranger because I didn't have the piece about the homophobia. I knew I wasn't getting a bigot because otherwise they wouldn't be in my circle of friends. So I had already pre-screened who is coming to help me. When you get home care, you don't have the opportunity to pre-screen the worker. They just arrive. (P6)

P3 added that quality care, however, was more than care that wasn't provided by an outwardly homophobic person; quality care was also care that was provided by someone who felt at ease with providing care to a lesbian woman and interacting with her family members:

> I mean I want someone that I'm comfortable with, and therefore I want someone that's going to be comfortable in my home, um, because I live in a lesbian household. I want someone that's going to be comfortable with [me]... I think that the agencies need to be prepared because I think we're a different population that's coming up now, too. I mean we know this in health care. I mean I was just doing a presentation on health literacy, and the fact that probably for financial reasons, but more and more we're being asked to be partners in our health care, to self-manage and so on. So if people are more like doctors can't just burst out of the room and say they're not going to listen because you're bringing stuff from the internet, well similarly if I'm calling an agency and I need some home care, I don't think it's, it should be in my rights to say, "I want someone who is comfortable working in a household where I'm living with another

woman and we're lesbian." I mean not that it's a sexual issue, but I mean it's just this is

who my household is and this is who my support person is. (P3)

Overall, comfort, client-centeredness and competence were identified as key dimensions of

quality home care. Although in some respects these were distinct dimensions of quality, they

were mutually reinforcing and supported the overall experience of quality. As mentioned in the

previous chapter, it is likely that assumed gender affinity influenced both participants'

expectations of caregivers and caregivers' responses to participants. As a result, it is possible

that participants' emphasized the relational aspects of quality in their conceptualization of

quality, and factors that influenced quality, as a result of their assumptions about female care

workers' abilities and aptitude to provide this type of care.

Factors that Influence the Quality of Care

In addition to the three dimensions of quality in home care, participants identified a

number of factors that they felt contributed to enabling (or hindering) quality in home care.

Participants identified these factors while recounting their positive and negative experiences

with their caregivers and reflecting on the characteristics that influenced whether they

identified the care that they received as quality home care. These factors were personal

(located in the caregivers' abilities and characteristics), relational (the result of the care

interaction), or structural (located externally to the caregiver or the relationship). In total

participants identified four key factors: time, autonomy, attitude, and communication.

Time. Time was identified as an important factor for enabling quality in home care. Time

had both individual and structural elements. In terms of individual elements, time meant

caregivers who came on time, took the time to do all of the aspects of the required task, and

stayed the entire time that they were supposed to. Many participants described having

received poor quality care from caregivers who came late (or hours early), did not want to stay

the whole hour or were unreliable with scheduling and attendance. However, participants also

noted that time was a structural issue. That is, that it was also the result of home care workers

being over-booked and home care companies not allotting enough time for caregivers to attend

to multiple clients across the city. Participants explained that they were aware that their

caregivers were very busy and had multiple clients, but that they felt disrespected and upset

when caregivers did not respect the client's time as well and that this influenced the quality of

the care. This was especially upsetting as the organization and planning of the care was time-

consuming and exhausting for clients. P1 identified the care that she received from one nurse

as quality care because this nurse (unlike the rest) was reliable and took her time to do all of

the necessary activities:

> She was client centered. She was reliable. She did everything she was supposed to do.
>
> She took all the time she needed. You know, I know she had other clients she had to go
>
> to so, you know, but her bookings seemed to be paced out at an appropriate, um, in an
>
> appropriate way. She wasn't racing off. She wasn't trying to maximize her income by
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> racing off from my place to another. I guess that's another thing I would say, that high
>
> quality care is not-for-profit care. For profit care by its very nature has problems being
>
> high quality because, you know, the bottom line is money-- As I say, I had other people
>
> on weekends sometimes, or the odd time she took an extra day off, but no, she was my
>
> main person and she was, you know, totally reliable. I could call her; she always called
>
> me back. (P1)

Similarly, P11 explained that the care she received was quality home care because it was on time and reliable and that this reliability made her feel cared for:

Very efficient, and they're on time, and if they can't make it, they phone and, you know, send somebody else if the girl can't make it in. So they care, you know, which is nice. If they didn't care, they'd say, 'oh she can do it herself.' You know. But they know I can't do things by myself. Some things I can do. (P11)

Likewise, for P5 quality care occurred when her caregivers came on time, stayed the whole time and demonstrated a general willingness to provide care. When asked to comment about what factors were important to enabling quality in home care, she explained:

Coming on time. Being attentive to my needs. Not making remarks about my size. Not wanting me to pray. Not bringing other matters into the picture that don't relate to what they're here to do. And also just like a sense of willingness to be here. I didn't feel that at all with both of them. It was like, okay, so this is my job. And I asked both of them. I said, "How long have you been doing this job?" And one of them said "seven years." The other one said I think "four." And I said, "Do you enjoy doing this because you get to meet all these different people. You work with people who have different needs." And one said, "It's a job." And the other one said, "Yes, I like to meet different people." But I didn't get the sense from either one of them in their desire to be out of here that they really, well one truly meant that, you know, she wanted to be here for an hour. Neither of them wanted to be here for an hour. (P5)

Receiving care from caregivers who were not reliable or punctual was particularly frustrating for participants who needed assistance with basic self-care activities, as they felt

trapped waiting for a caregiver to come and give them a bath or help them get dressed. For

example, P3 explained that she was frustrated with one caregiver who was unreliable:

> That was the other problem with that other woman [a caregiver]. She never showed up
>
> on time. And basically when X [my spouse] left in the morning, I'd sort of be sitting in
>
> my pyjamas, and then until somebody came I couldn't get washed, or dressed, or
>
> anything. I think those are the key factors: reliability, comfort level. I mean if they're
>
> comfortable with what they're doing, because if they're not, it's really, it's so awkward
>
> because it's really intrusive in a way, you know, if somebody is doing bathing and
>
> showering and stuff like that. So as long as they're comfortable, and they're reliable,
>
> and they come when they say and, um, they look like they enjoy what they're doing.
>
> You know, I feel really it's hard to take care and help from someone, so if they look like
>
> this is sort of the last straw on their day, it's not very nice. (P3)

Similarly, P1 said that the care she received was quality care because her caregivers were

punctual and reliable, which allowed her the freedom to organize her day:

> Came at the hours that I needed it. There were two days established, and so I was
>
> asked the two different days if they were fine with me, and I said yes, so that things
>
> weren't changed and that we had agreed to do it in the morning. I wasn't particularly
>
> fussy about which time, as long as it sort of was the morning. So and then the PSW
>
> came in the morning, instead of in the afternoon. So as I said, the person came
>
> sometimes a little bit late, a little bit early, but it was always the morning. So that was
>
> good. Yeah. So I was able to use my afternoons, you know, to ask my neighbour if they

could go shopping for me, and stuff like that, but at least my bodily wash was done.

Yeah. My personal care was done. Yeah. (P2)

Thus, delivering care services in a timely and consistent manner supported quality as it ensured that care was client-centred and respectful of clients' time and lives.

Several participants explained that time was also an important external factor for promoting quality in that having enough time with a particular caregiver allowed for the development of a relationship between the caregiver and the client/recipient. This meant both caregivers staying the entire time that they were supposed to as well as remaining as their caregiver for long periods of time. Several participants explained that they felt that the quality of the care they received was negatively affected when their regular caregivers were taken away because CCAC changed home care companies or assigned them a new caregiver. These changes typically occurred without explanation to the care recipient and without their consent. This type of change was particularly upsetting if participants received care for a long period of time from a caregiver that they liked and trusted. As P14 explained, receiving care from the same caregiver over time allowed both her and the caregiver to learn about each other and negotiate care provision in ways that was satisfying to both of them, thus creating quality home care. This consistency was expressly necessary for P14, who was blind and needed to make sure that her caregivers understood how to put things away so that she knew where to find them when she was on her own,

Well quality developed by getting to know each other. So when I've had someone only once, it was a problem. Couldn't wait until they left. Or that woman that sat and looked at me. You know, I thought if I was a millionaire I'd rather die than have that

woman there. [laughs] Because it wasn't meeting my needs. And that's the difference

for me in quality, and you develop that over time. You also as a client have to have a

little bit of patience. You have to be willing to be nice to the person. You have to be

willing to be flexible with them as well. You know, I've had the one who comes regularly

when she's had a night job call me and say, "Is it okay if I come an hour later?" She

hasn't done it often and if it's okay I say "absolutely." So she feels that, you know, it's

always a two-way street. You treat them like an equal, and they treat you honestly,

something special, and you end up with what you need. [The PSW] keeps asking, "Any

time you need to, call me." I won't, but that's irrelevant. She would do it, you know.

Now she'll run washes and stuff, right? I do also, but she'll run washes. They all have to

learn where I've put things. If you put something in the wrong place for me, you might

as well take it home. That's what I'm talking about. (P14, blind)

Similarly, P12 explained that it was very frustrating for her that her caregiver was removed

without notice or consent after 9 years together:

The only thing I would add on this subject of care is that CCAC, I don't expect them to

change the way the day is spent. Allocated their worker's time. So I had the same

caregiver for 9 years, I just said that. We knew each other really well, and she would

come in, and she would do stuff I believe nobody would do. And then suddenly CCAC

said, "Enough. No more." And we were separated. Now for me, it's okay. But what

offended me was that I had a friend who was 105, kind of old, and her caregiver was

taken away. "Sorry, you have someone else now." I think at 105 that's tough to

swallow. And I happen to know that my caregiver has been kind of put through the

ringer in terms of changing her routine and the people with whom she had a good

working relationship she's now separated from. (P12)

Time was therefore an important enabler of quality as it supported client-centeredness and

establishment of comfort. Furthermore, consistency with respect to time reduced participants'

overall stress and worry and enabled their trust.

Autonomy. Another relational factor that affected the quality of the care was whether

the care was delivered in a manner that involved the care recipient and promoted their

autonomy. This factor was identified as being particularly important for supporting client-

centeredness and comfort. Participants explained that quality in home care was made possible

when they felt that they were able to participate in decisions with respect to how home care

was provided as well as to constructively express complaints or dissatisfaction with care. As P6

explained, her experience with one PSW was quality care:

She just treats you as an equal, like I'm part of my, um, regardless of ability, I'm part of

the team. (P6)

According to, P3, having the autonomy to address poor quality care was important to the

overall experience of quality in home care:

To make sure that people can meet your needs, but also allow you some autonomy. I

mean that's a big issue, too, is what happens if you don't like the person who is

providing the care? And what element of choice is there? Like I mean do you have any

choice? And how can you, um, speak up if you're not comfortable?-- I think that is

important. But I think, too, like people who are not well, or who are very dependent on

other people, often don't want to say anything because they're afraid they'll lose the

care, or they'll lose the goodwill of the person who is there, because what happens if there's absolutely nobody else, and this person gets a sense that you complained, or something, then you would worry about how well they're going to provide the care. I mean it's pretty scary and you're pretty vulnerable. (P3)

Furthermore, she noted that autonomy affected her comfort with receiving care. Having the ability to express and address her complaints with respect to care provision was important for enabling her comfort and therefore affected the overall quality of care:

If a person is uncomfortable with you because you're a lesbian, and you can tell that they're uncomfortable with you, it's kind of hard to maybe call up and say that. I don't know. And I mean like how do you, I think a lot of people don't even feel they have a right. I mean they're so appreciative that somebody showed up at their door. But I mean if that person doesn't look comfortable with you, and you're not feeling comfortable with them, um, I think you should be able to say so, but I mean that would be important and it's not only if you're a lesbian, but it could be any number of reasons. I mean if you're just not, because this is, it's a very personal thing, and it's a very invasive thing. So I don't know how you, I mean if they started trying to please everybody, I guess it would be phenomenally difficult. But I think there should be some opportunity to express, you know, to get some assessment of whether you're comfortable, and it's not a big issue, and you can just find someone else. Because I think a lot of people, it could be lesbian, but it's not only that. It could be. I mean if you have, like for example, if they come into a family where you have separate sets of dishes, they need to be aware of that, and they need to be aware of how to manage in

the kitchen and so on. So if you're not comfortable, I mean the whole thing is that you

need to have, I mean somebody can't say to you. 'Well listen, just be damn happy

you've got somebody and too bad,' because it's not, I mean there has to be some ability

to be able to speak up for what you want that's going to make you comfortable. (P3)[30]

Therefore, quality care was care that was delivered in a way that promoted participants'

autonomy and thus supported their feeling of comfort and respect. Given that many individuals

also indicated that they felt helpless and vulnerable as a result of needing home care, the

presence of this factor likely enabled their sense of being in control and positively affected their

overall well-being. Furthermore, as participants worried about experiencing homophobia and

not being able to resist it, feeling respected by their caregivers reduced their anxiety.

Attitude. A factor related to autonomy is the type of attitude that caregivers expressed

while providing care. Attitude was an individual-based factor that affected the quality of the

care. Specifically, participants explained that quality in care was promoted when their

caregivers had an optimistic attitude and in general were encouraging and genial when

providing care. This was viewed as a significant factor because participants wanted to receive

care from individuals who were outwardly willing to provide care and who appeared happy.

This type of attitude made them feel less like a burden and promoted their level of comfort.

When caregivers had this type of attitude, participants described feeling cared for and uplifted

in terms of mood, which was important for their overall emotional health and coping:

I mean, I may not be that old yet, but when you're in pain, when you're dependent on

someone else, which never makes anyone happy, because I mean I want someone who

---

[30] Referring to the Jewish kosher custom of keeping separate sets of dishes for meat and dairy.

is not going to look put out by me, who is going to be willing to work cooperatively with

me, so that if I, for example, um, like when they're doing the bathing, and so on, um, if I

feel that I would like to have some control over it, so that, you know, maybe they could

be present so that I don't injure myself, let's say getting in and out, but I would prefer to

wash myself, and maybe they could help with my hair or something. I'd like it to be

something where once again you can work out a partnership, so the person puts you at

ease. And that is a difficult road because it's not, I mean it's a tough job because I think

when people aren't well, they're not at their best. So I mean I really, I was sensitive to

that. That woman who came up, and she was gasping for breath, I mean you don't feel

very good. (P3)

A positive attitude was identified as an important factor for quality regardless of how

long caregivers stayed in the home, whether they remained as their caregiver or what was the

type of task that they provided to participants (medical or personal/supportive). For example,

P1 explained why her nurse's attitude was important:

She did what a nurse should do in my view, and what many of them don't, or at least

the ones I had, didn't necessarily. I mean some of them were better than others, for

sure, but, you know, she was very client centered. And she was also a very nice woman.

You know, really quite positive and pleasant. (P1)

Similarly, P3 and P8, who received personal and supportive care from PSWs, explained that

while competence was an important factor for quality, caregivers' attitude was equally

important:

Um, that they are, um, well in home care [it] matters certainly, you know, [that they are] compassionate, you know, a warm-hearted person, who, uh, listens to your story and, you know, is able to tell you what the scope of their duties, what they're allowed to perform, and what they're not allowed to perform, so tell you what the ground rules are. And then to basically carry through to do the activities that you need to do, within the timeframe. (P8)

Someone who enjoys their job. I don't know how you'd put it but, you know, I don't want to look like I'm putting someone out. (P3)

P4 and P15 added that a positive attitude could be expressed when caregivers showed an interest in care recipients' opinions and engaged them in conversation while providing care:

So if somebody that's going to come in has got a smile, somebody that's going to brighten my day, somebody that can talk about things other than the weather and the strike, you know, interesting people, you know. I just want them to be open, and honest, and a happy person, that's all. (P4)

Um, that I feel good, when that person is leaving my house. I feel good when they're entering my house. That they've made me feel good about the two of us interacting with each other. "Have a nice week." "You have a great week, too." "How is your kids this week?" "How are your kids?" "My husband gave me this." "Oh, that's so fantastic." You know. Just really a good relationship and an uplifting relationship between the two of you. (P15)

Caregivers' positive attitude thus supported quality in home care because it made participants feel comfortable with receiving care and buoyed their emotional well-being.

Some participants attributed a positive attitude to specific individuals and felt that

certain individuals were just "naturally" better suited to provide this type of personal care

based on their character and personality. They emphasised that providing care was different

from other types of jobs and that having an empathic and a caring character was crucial to

being able to provide quality home care. As P5 explained:

> Um, well I've learned a lot from this experience, that it takes a certain kind of individual
>
> to do that kind of job... Um, it's not, it's not a job. I shouldn't say it's a job to provide
>
> that kind of care giving. It takes a certain kind of personality and a huge amount of
>
> commitment and a lot of giving of yourself. And I don't think that anybody, male or
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> female, because I know there are male caregivers also, could do this job effectively and
>
> efficiently, if they don't have compassion as their bottom line. And I did not feel
>
> compassion from the two women who came. But when I got my first replacement,
>
> when my regular caregiver went away, I felt that compassion. And there were others,
>
> replacements, no compassion. So I stuck with the one that I felt the compassion with.
>
> Yeah. (P5)

As P3 put it:

> I think it's, well I know because X [my spouse] did home care work. I mean that's
>
> because she was interested in it. But when she wasn't working in the library, she did
>
> personal care work as a PSW and someone like X would be a joy to have, because she's
>
> not doing it because, you know, it beats working at McDonald's, if you know what I
>
> mean. I mean she does it because it's choice, and she loves what she does, and she
>
> relates positively to people and she, um, so I think that's what I felt with this young

woman that was coming. I mean it was sort of something she personally enjoyed doing.

She made you feel like it wasn't an effort, and it wasn't putting her out, you know, and I

think that's what I mean by comfort, you know, someone who looks, it'd be the

difference between me doing it and X, you know. It's very hard not to have a curled lip

and a sort of look, whereas Z [the PSW] would, and she always did. She'd come in, and

sometimes she'd pick up a little something, because she knew the person wanted it, you

know, or they'd enjoy it. And I mean that's how this woman was. I mean like she

brought me this magazine, I mean just loaned it to me, but she thought that I'd be

interested because, you know, we talked and she knew I was interested in things, in

certain things, so she brought this magazine that she'd read this interesting article so I

read it, and then we could talk about it the next time. So I think that's what I mean by

comfort. It's sort of somebody that looks like they're enjoying what they're doing and

spending time with you. Because otherwise it's pretty personal and it can be awkward.

(P3)

Having a positive attitude and expressing interest and care in participants' well-being

was thus significant for supporting quality, as it enabled participants' comfort with receiving

care. At the same time, although participants' desire for pleasant and engaged caregivers is

understandable, it also raises a potential conflict between home clients' needs and caregivers'

abilities and scope of practice. Given that caregiving involves emotional work that is typically

unpaid and unrecognized (Armstrong, Armstrong & Scott-Dixon, 2008; Aronson & Neysmith,

1996; Stacey), participants' desire for their caregivers to engage in this kind of care may be

potentially problematic. While participants have the right to quality home care, home care

workers have rights as well; the latter includes the right to not experience workplace

discrimination on prohibited grounds. These narratives thus reveal complex tensions with

respect to the rights of clients and workers in home care.

Communication. Many of the participants noted that another factor that can affect the

quality of the care is caregivers' ability to communicate with them and understand their

instructions. Specifically, participants said that it was important for caregivers to be able to

speak and understand English. This was identified as a common concern with their caregivers as

participants explained that many of their caregivers were recent immigrants from non-English

speaking countries. Participants described experiencing difficulties in communication with

caregivers in the past and were worried about the potential to be misunderstood in the future.

For example, P3 was worried about receiving intimate care such as bathing from someone who

could not understand her and not being able to express discomfort or direct the care:

> If I want someone with a really good command of English, because I'm not comfortable
>
> around someone that I can't understand or that I'm afraid may not be able to
>
> understand instructions or something, I think that's legitimate. And I think that more
>
> and more, I mean that's a whole issue with the people who pay, you know, the
>
> government pays you to pay an aide, like for attendant care. That's becoming more and
>
> more of an issue, too, because I mean if you have someone that's helping you with your
>
> toileting, and somebody that's helping you with your showers, I mean this is pretty
>
> intimate and if you don't feel comfortable with that person, if you feel at all ill-at-ease,
>
> because maybe the person isn't someone you can understand, and you're worried that

they're not getting the instruction carefully or, you know, I think that you have a right to be able to say that, and I don't think it's, um, it's a discriminatory thing. (P3)

The ability to communicate with their caregiver was identified as a particularly important factor for participants who had no other help aside from home care, as the ability to communicate with their caregivers increased the amount of time caregivers took to complete a task. P5 added that difficulties with communication also affected caregivers' ability to be self-directed and added to her discomfort with receiving help in the shower as it prolonged the task:

> The little things that bug me, one of the little things was they know how to read. You get to this level, you must know how to read. So I'm being washed. "Is this the body wash? Is this the shampoo?" Well it's written, yes. I'm trying not to be sarcastic with her. I said, "Yes, it's right here." And this happens every time. (P5)

Similarly, P16 described the care that she received from two caregivers as quality care not only because of their positive attitude but also because she was able to communicate with them, unlike with her other caregivers. She explained that the care she received was quality care for several reasons:

> Well the fact that (a) you could communicate, meaning that they spoke a proficiency of English, (b) that they actually genuinely had some interest in helping me, and they seemed to have positive feelings toward me. It was a pleasure seeing them. And when they came in, I didn't have to start babysitting them. You know, I'm getting an unpaid job? I don't need an unpaid job. And, you know, that was it. They did their job really well. They were very decent people. Yeah. (P16)

However, other participants such as P14 were able to successfully manage even when communication was an issue:

Um, the woman that works with me is from Uganda. She's here alone trying to save some money to bring her kids. Right now she's back visiting her kids in Uganda, and it's interesting because they've sent in other people and one of them is really very good. But it's very interesting because they all have certain things in common. They all have a story. Just about most of them come from somewhere else in the world. Most of them are here alone, trying to bring their children or their husbands. A lot come from different parts of Africa and they mean well, and most of them have difficulty with the English language. And so you have to adjust and make sure they understand, you know… But they're very good. All the ones I've had have been excellent... My regular person from Uganda, I decided I'd buy her cookbooks. What I didn't realize is she doesn't read English, and so she didn't know how to tell me that, and so I got the book and I gave it to her and I said, "Take it home and see which ones make sense and then we'll go through them." And I noticed she didn't take it. I said it a second time, and she didn't take it, and I thought, "I'm so stupid. She's not leaving it here because she wants to. She doesn't know how to tell me." So I returned the cookbook and totally just switched gears and go through a recipe with her. (P14)

The ability to communicate their needs was thus an important factor for supporting quality as it enabled comfort and supported participants' ability to voice expectations with respect to their care. However, it is important to consider that the issue of language may not only represent the desire to be understood, but may also indicate potential biases on the basis of race, ethnicity,

and nationality. Participants may have felt more comfortable expressing concerns about language than they did about race, ethnicity, and nationality. In this context, these narratives may thus indicate another potential area of conflict between workers' and clients' rights in home care.

Quality in Home Care

Across the interviews, the majority of participants explained that the quality of care that they received was variable and they often defined the meaning of quality home care by discussing differences between different caregivers and caregivers' differing attitudes with respect to homosexuality. As noted in previous chapters, most participants received care from multiple caregivers, regardless of how long they received home care or the type of home care they received. Overall, the majority of participants said that they have received quality care from at least one caregiver and that they were grateful for the support that home care provided. As P6 explained:

It's like going backwards. But I'm starting to look at it [that] if I need the care, that it would be a forward thing, because then it allows me to do other things that improve the quality of my life. That's the biggie thing about the home care. Improves the quality of my family's life, and for me personally, and that comes out in bathing, talking to me, helping me with food. Those are pretty basic, right? And some of them even said, "Do you need me to walk the dog?" I thought, "Oh my god. A dog walker." But over and above, they were all good, okay? (P6)

P1 and P3 had similar experiences:

Yeah, certainly, when I had that person that was working with Dr. X, I mean she was

amazing. She was efficient. She was pleasant. She was reliable, like you knew when

she was coming and she would, yeah, she was excellent. I mean it was a godsend. (P3)

They [PSWs] do exactly what I ask, as far as the shower goes. They do exactly what I

ask, as far as changing the bed sheets. The mattresses are so damn big I can't even lift

it, let alone change the bed, eh? And they stay and chat for a while, and it brings a new

point of view. So no, I guess quality home care is what I'm getting. (P8)

Recalling her experience with one nurse, P1 further explained how important the experience of

good quality care was for decreasing her overall stress:

Then the next day R [a nurse] came, and after that life was much better, not that it was

without, she made a few mistakes, too, but she was very good about dealing with them.

She came every day. She came when she said she was going to come. She called me if

she was going to be late. She stayed for the full hour. She took my blood pressure and

checked all my vitals, did all the stuff she should do. If she had any concerns, she called

and talked to my nurse at the hospital. She was so great. It just, like my stress level and

X's [my spouse], too, just went from like total 250 percent down to kind of something

normal, under the circumstances, because it felt at last I'm dealing with somebody who

is actually focusing on me and isn't thinking about how much mileage and how many

people they can see in between starting me and ending me, and all this kind of stuff,

who actually was like a real nurse. (P1)

Thus, although many participants were glad to have received at least some quality care, many

were also frustrated with the variability and inconsistency in quality. Negative experiences with

quality were also particularly upsetting as they added to participants' discomfort with receiving

care and negatively affected their ability to cope with the symptoms of their illness or injury

such as pain, fatigue and depression. Participants also expressed frustration with the lack of

ability to control quality or modify the factors that they felt could have improved the quality of

their care. As P13 explained:

> The second nurse made me, well she didn't make me, she pissed me off. But if I were
>
> not a stronger person, she could have made me feel bad. Yes. And that's not quality
>
> home care. Whereas the first person was, she wasn't going out of her way to chitter-
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> chatter, but she was just efficient and friendly. She wasn't overly friendly, but she was
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> friendly, and I felt the positive air about her. And I think that's quality care. Right?
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> That's quality care. You know hopefully, with home care that some, maybe a lot of
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> people that you're dealing with are dying, and they know they're dying. People who are
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> dying know they're dying. They might be afraid, they might be trying to, but we know,
>
> we know we're dying. And so you want to be treated with respect, and you don't want
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> to dwell on that, but you don't want to fluff it off and you don't want to be in a "poor
>
> dear, poor dear." You want to just be treated respectfully. Yeah. (P13)

The variability in quality caused participants to experience unnecessary stress and

worry. Furthermore, several participants who no longer received care stated that even though

they had had some positive experiences, based on the variability in quality of the care that the

received, they did not expect to receive quality care in the future if they were to access home

care again.

For example, P1 expressed uncertainty with respect to receiving quality care in the future as a result of her and her friend's variable experiences with the quality of home care:

Well I would not feel, I mean I guess it sort of depends on what kind of care but, you know, my friend, the one I help out, the one who is moving, he gets some home care services and, you know, he doesn't get nursing care. He gets other kinds of like home making and all that kind of stuff and the stories he tells me are, you know, it's kind of the sort of absurdity of, um, non-client centered, non-care centered services. And so he seems to be reasonably happy now with the person he has. Well I think he is quite happy. But again, I probably shouldn't be saying this, but one of the things is that she [the PSW] does stuff she's not supposed to do, because that's what's useful to him, you know. And the stuff that she's kind of assigned to do isn't all that useful to him. You know, it was quite an interesting kind of thing to sort out. So, you know, depending on the services I would need, based on my experience, and hearing about his experience, I don't have any confidence that the CCAC is really taking, you know, has my interest at heart. I don't have any confidence that I'm going to get a competent caregiver, whatever their type of care is, but certainly not nursing care. I mean in the end I had somebody who was really competent, but I went through a lot of people before that. And I don't have any confidence that any of this care will be set up to meet my needs, like in terms of scheduling and all of that kind of stuff. So there's not much else. [laughs] (P1)

Thus, while participants reported that they did receive some quality care, they typically did not have consistency in terms of good quality across their caregivers. As a result, participants had

low expectations of receiving good quality home care in the future. However, many participants also did not have an alternate plan for care and simply hoped that they would not need home care in the future. These narratives suggest that individuals may choose to avoid or delay accessing needed home care in the future in order to avoid experiencing similarly poor care. This avoidance of formal services in the future, however, may have negative implications for individuals' and families' long-term health and quality of life.

Gratitude and Homophobia

Although many of the participants expressed being grateful for having received home care, several also specifically voiced being grateful for not experiencing homophobic discrimination from home care workers after they came out as lesbian or bisexual. These expressions of gratitude revealed another important dimension to quality for older lesbian and bisexual women. In particular, participants' narratives illustrated the negative impact of structural heterosexism and heteronormativity on participants' expectations of quality care. For example, P10 said she was thankful for her caregiver's lack of a homophobic reaction to her disclosure of sexuality:

> I think right up front, I said, "This is my wife," and she said, "Oh, good." And that was
>
> about it. Just went on from there. But there was never any-- like she didn't hold back.
>
> If X [my spouse] and I were sitting together talking or anything, it didn't bother her
>
> whatsoever. She'd come in and sit down. She was good that way. She was an
>
> accepting type of person. (P10)

Similarly, P13 and P6 expressed similar sentiments:

And she's [my caregiver's] great. She's very good. And she has no problem at all that

we're gay. In fact she sees X [my spouse] as well, so she's great. (P13)

She [my caregiver] was quite open. She said, "I'm getting used to this." She was young,

laughing, having a great time. Oh she says, "You're really a lesbian." I thought, "No, I'm

faking it lady." [laughs]. (P6)

Later, talking about the same caregiver, P6 added she was grateful for this caregiver's attitude

despite concerns about her technical professional competence:

The young woman who dropped me in the bathtub, I forgave her because we had a

good laugh. It really broke the ice, almost broke me. But afterwards she said, "How do

you manage on your own?" And I said, "I can't. This is what my fear is that I will fall

here, not have enough strength because of the fibro and the polio to pull myself out of

it. If I crack my head, I'm unconscious, I'm in trouble." And she said, "You know, before

I came here"--and I have to give her tons of credit for this--she said, "I read your case

file." I said, "You what?" She said, "I did." I said, "Oh." She said, "Yes. Then I looked

up fibromyalgia so that I would know ahead of time how to help you." I don't care if she

dropped me. Twenty points for that one. Twenty points for wanting to know what a

lesbian is, how do we live. And she did it in such a way that it wasn't offensive. Very

open, very caring. Wanted to increase her knowledge about the fibro or whatever else

was going on. (P6)

Sinding, Barnoff, McGillicuddy, Grassau and Odette (2010) have suggested that the

expression of gratitude for receiving ordinary care is another example of the ways in which

institutionalised heterosexism and homophobia works to maintain lesbian (and bisexual)

women's oppression and exclusion in health care services. Although these types of narratives are positive in that they indicate that lesbian and bisexual women today may be less likely to encounter overtly homophobic reactions, they indicate that lesbian and bisexual women continue to be invisible and marginalized. Furthermore, these narratives suggest that lesbian and bisexual women may also be less likely to complain about receiving poor or incompetent home care given their low expectations of being treated well. As a result, older lesbian and bisexual women may be vulnerable to experiencing poor quality care in home care.

For example, as P6 explained above, despite being dropped by her caregiver when she was helping her in the bath, she didn't complain because her caregiver did not mind that she was gay and had a positive attitude. Similarly, when asked about her negative experiences with care, P11 said that she was grateful for receiving (any) care:

> No. I don't complain about them [my caregivers]. They [the home care company] can be really rotten over there and fire them and stuff like that. Actually good girls get fired for nothing--If it wasn't for them, I'd be sitting in fur balls. [laughs] I'd be starving to death. [laughs] So they do help a lot. And the girls are friendly. (P11)

These types of narratives have implications for enabling quality in home care for older lesbian and bisexual women as they suggest that older lesbian and bisexual women may be less likely to complain about poor quality care.

Conclusion

In sum, participants defined quality home care as care that was client-centred, competent and comfortable. They identified four factors that influenced the quality of the care: time, autonomy, attitude, and communication, all of which were also linked to caregivers'

attitudes around sexuality and lesbian intimacy. Furthermore, the analysis revealed that there

are unique issues with respect to quality for older lesbian and bisexual women that result from

systemic heteronormativity and heterosexism. In particular, my analysis shows that quality care

for older lesbian and bisexual women is care that is sensitive and inclusive of LGBTQ sexualities,

intimacies and families. In terms of rating the quality of the care that they have received,

participants noted that while they experienced quality care from some caregivers, quality was

typically variable across caregivers. Furthermore, they noted that the quality of care was

typically difficult to modify as the factors that affected it were not under their control. This

analysis suggests that quality has individual, relational and structural elements that need to be

incorporated into future evaluations in order to support consistency and improvement in the

quality of care for older lesbian and bisexual women.

Chapter 9: Conclusion

In undertaking this study, my primary purpose was to learn about the lived experiences of older (> 55 years old) lesbian and bisexual women who accessed and received home care service in Ontario. Specifically, I had three interrelated objectives in this study: (1) to learn about the current experiences of older lesbian and bisexual women who have accessed home care services in Ontario in the last five years (2008-2012), (2) to gain an understanding of the impact of sexuality on women's home care experiences, and (3) to explore older lesbian and bisexual women's conceptions of quality home care and the factors that enable (or hinder) quality care in order to provide recommendations that can be used in health care policy, planning and delivery. The research is shaped by a feminist political economy approach and LGBTQ and queer studies that place those homecare services and the treatment of lesbian and bisexual women with an historical, political and economic context.

Neoliberal reforms in Ontario (and Canada) have increasingly shifted the bulk of care of individuals to private homes from health care institutions. Often these types of reforms have done so under the assumption that individuals who need care prefer to be cared for by familial, rather than formal caregivers and assumed a heterosexual and heteronormative family in which a female child or partner is available to provide care. Although the result of these reforms is problematic for all women, it is especially so for older lesbian and bisexual women who often face additional, specific barriers to accessing quality care. Older lesbian and bisexual women are more likely to live alone and have less access to familial caregivers as result of familial homophobia and fewer children, than heterosexual women and men. Older lesbian and bisexual women are also more likely to be poor and to have less access to pension supports

than heterosexual women. Additionally, older lesbian and bisexual women experience homophobic discrimination in social and health care institutions, have lower rates of health seeking behaviours and delay seeking access to formal services for fear of potential discrimination.

The findings of this thesis provide evidence that access to home care is influenced by historical, social and political contexts and reveal the negative effects of neoliberal reforms for older lesbian and bisexual women in Ontario. More specifically, there are two main findings from this thesis. The first finding is that older lesbian and bisexual women in my study have reduced and restricted access to care. In particular, this thesis suggests that access to home care services is increasingly restricted and that there exists rationing of public home care services that reflects systematic and structural barriers. This study also suggests that while there is a bias towards providing medical acute care in the home care system, older lesbian and bisexual home care recipients may actually need long-term social and supportive care more than medical care. Finally, structural limitations on home care workers' time and scheduling can limit their opportunities to form relationships with older lesbian and bisexual women and establish the necessary environment that would support their ability to provide quality care. Additionally, managed competition and changes in home care contracts from year to year can mean that home care workers and clients cannot easily maintain continuity of care, which may also negatively impact quality. As a result of these barriers, the bulk of the care that older lesbian and bisexual women in this study need is continually downloaded unto them and their families.

However, while it is assumed that all public home care users would be able to supplement care informally and/or privately, this study shows that the older lesbian and bisexual women interviewed need more care than they are provided and that they have limited resources with which to supplement publically funded home care. These older lesbian and bisexual women are also reticent about relying on the help of natal family members and friends. Instead they rely heavily on their female partners for ongoing instrumental and emotional support, manage on their own at increased risk to their health, or go without needed care. All of these findings suggest there are negative implications of current practices for older lesbian and bisexual women and for their long term health and well-being.

The second main finding of this thesis is that attitudes and discourses around gender and sexualities can negatively affect older lesbian and bisexual women's need for home care, their access to care, as well as the quality of the home care that they receive. The results of this study suggest that there are important life circumstances that affect lesbian and bisexual women's need for home care and their ability to access care. Older lesbians may be more likely to live alone and lack access to typical informal caregivers such as adult children and natal family members. Additionally, the interview material also suggests that older lesbian and bisexual women may delay accessing home care services as a result of both their desire to maintain their independence and their distrust and fear of formal health and care services (and providers), as well as their negative experiences in formal care contexts.

Attitudes and discourses around sexuality and sexual practices affected these older lesbian and bisexual women's home care outcomes and their expectations with respect to care. More specifically, these attitudes and discourses can negatively affect home care outcomes as

result of implicit and explicit homophobia and heterosexism in home care, which result in

instances of negative, inappropriate or poor quality care. In part, these negative outcomes

result from the structural conditions of the care, whereby care is primarily provided within an

organizational and policy environment that does not explicitly recognize the existence of non-

heterosexual sexualities or the negative effects of homophobia and heteronormativity.

Additionally, this care is provided by workers who do not often have access to appropriate

sensitivity and training and other educational practices around sexuality and gender diversity.

Finally, the experiences of the participants also suggest that older lesbian and bisexual women

are invisible and silenced within the home care system and its policies and practices.

In sum, the findings of this thesis suggest that both context and identity matter in how

older lesbian and bisexual women are able to access care, how care is delivered and whether

the care that they receive is competent, appropriate and compassionate. Furthermore, the

findings illustrate that older lesbian and bisexual women in Ontario may have limited access to

needed care and that too often the home care that they do receive may not adequate,

appropriate, or of good quality.

Limitations

This study has several limitations that need to be taken into consideration. First, despite

the lengthy and extensive recruitment strategies and time period, I was only able to gain access

to 16 participants and they are relatively homogenous in terms of socio-demographics. Most of

the participants of this study are relatively young, have high levels of education and live in

urban geographic locations with access to social support services such as public transportation,

health care and LGBTQ social networks and community organizations. Participants' access to

these types of supports may have buffered somewhat their experiences of accessing home care and they may not be representative of the experiences of individuals in Ontario living in different environments.

Additionally, despite targeted recruitment efforts within the bisexual community in Ontario, I was able to recruit only one participant who identified as bisexual at the time of the interview. As a result, the results of this study may not have captured the experiences of other bisexual women living in Ontario who access home care. However, while only one participant explicitly identified as bisexual, several women in this study identified with sexual identities other than lesbian, such as "queer," that may have increased the applicability of this study to the experiences of women who do not exclusively identify with a homosexual identity. Also, for many people, including some of my participants, a bisexual life history is compatible with a lesbian self-identity. In any case, this study sought to examine how sexuality and sexual identity can affect access and experience as opposed to capturing the experiences of all LGBTQ-identified individuals.

At the same time, my participants' similarity to each other also allowed me to deepen my analysis and explore how their relative privilege mitigated and influenced the quality and equity of care that they received in the public home care system. I was also able to capture important differences between women in terms of relationship status, income and experiences of oppression, all of which enriched my understanding of the ways in which these factors can influence care outcomes and needs. Finally, despite having relative economic and social capital, my participants had difficulties accessing and securing needed care. This has important implications for understanding access to quality care in general, and the equity of our home

care system for less privileged individuals. Consequently, the results of this study provide rich

and detailed information with respect to the home care experiences of older lesbian women in

Ontario. Moreover, these results fill an important gap in current knowledge and have

implications for theory and policy.

Theoretical Significance of the Study

The results of this study add to and build upon existing knowledge with respect to home

care services and the effects of neoliberal restructuring of health care and home care. More

specifically, the findings of this thesis extend existing feminist political economy research

(Armstrong, Armstrong & Coburn, 2001; Armstrong et al., 2011; Grant et al., 2004; Daly, 2007)

that has found that neoliberal restructuring of home care in Ontario has had negative effects on

individuals and families and has restricted their access to publicly funded care. For example, the

findings of this thesis demonstrate that current home care services do not adequately support

these older lesbian and bisexual women. Furthermore, their access to care within the current

system is continually restricted through the rationing of care and the downloading of

responsibility for care on individuals and families. As a result of these barriers, these older

lesbian and bisexual women cope by relying heavily on their partners or go without needed

support. However, as many of the partners in this study also had paid work responsibilities, this

has implications for the long term health of individuals and families. Given that the majority of

individuals had chronic health conditions, this added burden of providing the bulk of needed

care may lead to caregiver burnout and may negatively affect older lesbian and bisexual women

and their families.

The findings of this thesis also extend existing research on home care services in Ontario (Aronson & Neysmith, 1997; 2001; Daly, 2007; Williams, 1996; 2002) that has shown that while the current system privileges access to acute, short term medical care, the kind of care that many home care users (and especially women) need is long term supportive care. As a result of this disconnect between needs and policies, existing home care services frequently fail women and families who must either privately supplement public care or go without. This thesis therefore also adds to other feminist research that has documented the increasing downloading of responsibility and cost of care onto individual women and families, instead of the state (Armstrong et al., 2011; Aronson & Neysmith 1997; 2001; Sinding et al., 2010). This thesis contributes to this work by highlighting the particularly negative consequences of the devaluation of social and supportive care for older lesbian and bisexual women who may have less access to social supports. As a result, this thesis further illustrates the need to incorporate intersectional and gender-based analysis in home care research and policy.

By privileging the voices of home care users, rather than managers or policy makers, this thesis also adds to research that has critiqued the evidence base supporting neoliberal health care reforms and assumptions (Armstrong et al., 2001; Mykhalovskiy, 2008; Choiniere, 2011). More specifically, this thesis furthers the argument that practices of measurement do must attend to context and difference and in doing so reveal the material costs of neoliberal reforms. In foregrounding the perspectives of users and by attending to differences between them, this thesis adds to this body of research by illustrating the multiple ways in which these differences can affect the access and receipt of care. In doing so, this thesis indicates that current home care policies and practices are not 'neutral,' but rather implicitly and explicitly may erase the

experiences of lesbian and bisexual women. The thesis therefore deepens our understanding of the barriers to equity within the home care system and has important implications for future research, policy and practice.

Finally, this research also extends previous research on LGBTQ health care practices and experiences (Aronson, 1998; Fredriksen -Goldsen et al., 2011; IOM, 2011; Solarz, 1999) by illustrating the ways in which sexualities and genders matter in the context of home care contexts. In particular, this study provides additional evidence for older lesbian and bisexual reduced health seeking behaviours and their impact on health and well-being. This study also expands existing research on heteronormativity by providing further evidence for the existence of heteronormativity and heterosexism in the Canadian health care system and illustrates the negative effects of these institutionalized biases for LGBTQ people and families.

This thesis builds on previous work on LGBTQ kinship and caregiving (Aronson, 1998; Fredriksen, 1999; MetLife, 2006; Weston, 1997) by bringing forth the experiences of older lesbian and bisexual women, a group that is often invisible in LGBTQ communities, as well as mainstream communities, as a result of ageism, sexism and ableism. Finally, this thesis adds to LGBTQ research by demonstrating the ways in which LGBTQ communities are resilient and actively resist heteronormativity and heterosexism through the strategic use of direct and indirect strategies, such as active resistance to homophobia, identity management processes and the creation of informal support networks.

Implications for Future Research

As I have shown in the literature review, research on older lesbian and bisexual women in health care policy and long term care is limited. More research is needed on the experiences

of older lesbian and bisexual women and their health and social support needs. This thesis has

made some important contributions, but there are several issues that emerged from the

analysis that call for further exploration. For example, the findings of this research indicate that

differences between lesbian and bisexual women had significance for how they understood

their sexuality and its role in home care. Furthermore, this study has illustrates how access to

home care was a learning process and that individuals employed a variety of strategies to

secure care. Finally, this research identified several barriers and facilitators to the

establishment and maintenance of quality in home care. All of these are areas for potential

future research and could lead to increased understanding of lesbian and bisexual women's

lives and experiences. This in turn, could be used to better support their health and their access

to needed care and supports.

Given that this study focused on a small subset of the population, future research in this

area could also address in more depth the experiences of lesbian and bisexual women who are

racialized, live in more rural environments and/or are older. For example, this study suggests

that that bias and fear may exist around home care workers' potential religious and cultural

beliefs with respect to sexualities and sexual practices. This raises important tensions around

workers' and clients' rights and responsibilities in home care that could be explored further.

However, given that it was difficult to gain access to these participants, and that many of them

were isolated from the formal LGBTQ communities, it is important that future researchers

consider the use of additional and novel or non-traditional means of gaining access to diverse

LGBTQ participants. For example, this could mean using a longer recruitment period, involving

home care and health care providers who may be able to facilitate access, and using

community-based liaisons that may be able to use informal social networking.

The findings of this study also have implications for future feminist research on care and

caregiving. This thesis demonstrated that a consideration of sexuality alongside gender can

reveal important dimensions with respect to the equity and quality of care services. It is

important for future feminist research to consider not only the significance of gender in

mediating access to care, but also the significance of sexualities and sexual identities.

Additionally, the findings of this study demonstrate that attitudes around sexualities and sexual

practices can affect the care relationship and quality of the care that individuals receive. Future

research on care should consider the significance of sexualities and gender in mediating the

experience of receiving and providing care within families, health care services and institutions.

Implications for Policy

The findings of this study have several implications for home care services policy,

planning, and delivery. First, given that this thesis showed that attitudes around sexualities and

sexual practices can affect access, receipt and the quality of home care, it is important to

incorporate a consideration of sexual diversity into existing home care policies and practices.

This could be done through the creation of specific policies that target LGBTQ communities and

better support their access to home care services. For example, policy can be created that

would support LGBTQ inclusive practice and environment within the Community Care Access

Centres, individual home care agencies and other social services. Specifically, this could mean

mandatory training on LGBTQ issues that could be incorporated into educational and

professional curriculum and training.

The findings that suggest that there are structural barriers to quality within the current home care system, indicate other areas for future policy change and research. For example, this study suggests that while home care is provided is individuals' private homes, existing home care policies do not often allow home care workers and home care users sufficient ability to negotiate how care is provided and delivered with in these spaces. Additionally, case managers in the current system have limited ability to support and facilitate individuals' access to home care services. Therefore, policies could be created that would facilitate not only access to needed care, but that would also give home care users and workers greater autonomy in deciding how and when care is provided.

Policy changes that improve the conditions for care workers such as access to better pay and benefits and additional educational requirements could also support the quality of home care in Ontario. Finally, although time and caregiver consistency were important to supporting access to quality home care for those interviewed, these factors are not supported by current home care policies and practices that are based on market efficiency principles. The creation of home care policy that would allow workers and clients to maintain consistency and to gain access to more time with caregivers could support better access to quality care.

Lastly, the results of this thesis also have potential economic implications for public investment in social care and long term care. The findings of this thesis demonstrate that existing services do not adequately support these older lesbian and bisexual women and that they experience multiple barriers to care that supports their long term health and quality of life. Given that this thesis showed that these lesbian and bisexual women delayed or avoided using home care services as a result of poor quality of care, this may result in them being more likely

to use more expensive health care services such as hospital based emergency care. Therefore, a greater investment in home care services and policy may be economically more prudent in the long-term.

However, if we are truly committed to supporting individuals' health and well-being, the findings of this thesis also reinforce the argument that instead of focusing on cost-cutting, we instead need to increase public investment in home care and long term care. To ensure equity and access to quality care, additional federal and provincial money may need to be invested into ensuring that services are able to meet home care users' needs and that they are equitable. This type of investment in home care would ensure that "the right to care is a fundamental human right" (Charlottetown Declaration, 2002) within Canada.

References

Abelove, H. (2003). Freud, male homosexuality, and the Americans. In *Deep Gossip*

    (pp.1-20).Minneapolis: University of Minnesota Press.

Aging at Home Strategy. (2007). Ontario Ministry of Health and Long Term Care.

    Retrieved January 1, 2011 from the Queen's Printer for Ontario, 2008 website

    http://www.health.gov.on.ca/en/public/programs/ltc/33_ontario_strategy.aspx

Albeda, R., Lee Badgett, M. V., Schneebaum, A., & Gates, G. J. (2009). *Poverty in the*

    lesbian, gay, and bisexual community. Retrieved from the Williams Institute

    Website http://williamsinstitute.law.ucla.edu/research/census-lgbt-

    demographics-studies/poverty-in-the-lesbian-gay-and-bisexual-community/

Altman, D. (2001). *Global Sex*. Chicago: University of Chicago Press.

Anderson, L., Healy, T., Herringer, B., Isaac, B., & Perry, T. (2001). *Out in the Cold: The*

    Context of Lesbian Health in Northeastern British Columbia. Vancouver: British

    Columbia Centre of Excellence for Women's Health.

Arber, S. (1998). Health, at risk: Poverty and national health strategies. In L. Doyal

    (Ed.) *Women and health services* (pp. 54-68). Great Britain: Open University

    Press.

Armstrong, P. (2001). Evidence-based health care reform: Women's issues. In

    Armstrong, P., Armstrong, H., & Coburn*, D. Unhealthy times: The political*

    economy of health *and care in Canada (pp.* . Toronto: Oxford University Press.

Armstrong, P. (2007). Relocating care: Home care in Ontario. In M. Morrow, O.

    Hankivsky & C. Varcoe (Eds.)*, Women's health in Canada: Critical perspectives on*

theory and policy (pp. 528-553). Toronto: University of Toronto Press.

Armstrong, P., Amaratunga, C., Bernier, J., Grant, K., Pederson, A., & Willson, K. The

Context of Health Care Reform in Canada. (Eds.) (2001). *Exposing privatization:*

Women and health care reform in Canada. Aurora: Garamond Press.

Armstrong, P. & Armstrong, H. (2003). *Wasting away: The undermining of Canadian*

health care. Second Edition. Toronto: Oxford University Press.

Armstrong, P. & Armstrong, H. (2005). "Public and private: Implications for care work."

Sociological Review, 53(2), 167-187.

Armstrong, P. & Armstrong, H. (2010). *Wasting away: The Undermining of Canadian*

health care (Wynford Project Edition, with new Introduction). Toronto: Oxford

University Press.

Armstrong, P., & Banerjee, A. (2009). Challenging questions: Designing long-term facility

care with women in mind. In P. Armstrong, C. Amaratunga, J. Bernier, K. Grant,

A. Pederson, & K. Wilson (Eds.), *A Place to call home: Long-term care in Canada*

(pp. 10-28). Nova Scotia: Fernwood Publishing.

Armstrong, P., & Kitts, O. (2004). One hundred years of caregiving. In K. Grant, C.

Amaratunga, & P. Armstrong (Eds.), *Caring for/caring about: Women, home*

care and unpaid caregiving (pp. 45-73). Aurora: Garamond Press.

Armstrong, P., Armstrong, H., Bourgeault, I., Choiniere, J., Mykhalovskiy, E., & White, J.

(2000). *"Heal thyself": Managing health care reform*. Toronto: Garamond Press.

Armstrong, P., Clow, B., Grant, K., Haworth-Brockman, M., Jackson, B., & Pederson, A.

(2012). *Thinking women and health care reform in Canada*. Toronto: Women's

Press.

Armstrong, P., Boscoe, M., Clow, B., Grant, K., Guberman, N., Jackson, B., Pederson, A.,

Seely, M., & Willson, K. (2011). *How women define the quality of health care: A*

Canadian study, Occasional Paper #6. Women and Health Care Reform.

Retrieved January 1, 2013 from

www.womenandhealthcarereform.ca/publications/qualityOfHealthCare.pdf

Armstrong, P., Armstrong, H., & Coburn*, D.* (2001). *Unhealthy times: The political*

economy of health *and care in Canada* . Toronto: Oxford University Press.

Armstrong, H., Armstrong, P., & Connelly, M. P. (1997). Introduction: The many forms of

privatization. *Studies in Political Economy*, (53), 3-9.

Armstrong, P., Armstrong, H., & Scott-Dixon, K. (2008). *Critical to care: The Invisible*

women in health services. Toronto: University of Toronto Press.

Armstrong, P., & Connelly, M. P, (1989). Feminist political economy: An introduction.

Studies in Political Economy, 30, 5-12.

Aronson, J. (1991). Dutiful daughters and undemanding mothers: Contrasting images of

giving and receiving care in middle and later life. In C. Baines, P. Evans, & S.

Neysmith (Eds.), *Women's caring: Feminist perspectives on social welfare* (pp.

138-168). Toronto: McClelland & Stewart Inc.

Aronson, J. (1998). Lesbians giving and receiving care: Stretching conceptualizations of

caring and community. *Women's Studies International Forum,* 21 (5), 505-519.

Aronson, J. (2004). "'Just fed and watered': Women's experiences of the gutting of

home care in Ontario." In K. Grant et al. (Eds.). *Caring possibilities: Women's*

work, women's care. Aurora: Garamond.

Aronson, J. (2000). Restructuring older women's needs: Care receiving as a site of

struggle and resistance. In S. M. Neysmith (Ed.), *Restructuring caring labour:*

discourse, state practice and everyday life (pp.52-72). Toronto: Oxford

University Press.

Aronson, J. (2006). Silenced complaints, suppressed expectations: The cumulative

impacts of home care rationing. *International Journal of Health Services,* 36 (3),

535-556.

Aronson, A. & and Neysmith, S. M. (1996). 'You're not just in there to do the work':

Depersonalizing policies and the exploitation of home care workers' labor.

Gender and Society, 10, 59-77.

Aronson, J., & Neysmith, S. M. (1997). The Retreat of the state and long-term care

provision: Implications for frail elderly people, unpaid family carers and paid

home care workers. *Studies in Political Economy*, 53, 37-66.

Aronson, J. & Neysmith, S. M. (2001). "Manufacturing social exclusion in the home care

market." *Canadian Public Policy*, XXVII (2), 151-165.

Balsam, K. F., & D'Augelli, A. R. (2006). The victimization of older LGBT adults: Patterns,

impact, and implications for intervention. In Kimmel, D., Rose, & David, S. (Eds.),

Lesbian, gay, bisexual, and transgender aging (pp. 122-142)*.* New York, NY:

Columbia University Press.

Banerjee, A. (2009). An Overview of long-term care in Canada and selected provinces

and territories*.* In P. Armstrong, C. Amaratunga, J. Bernier, K. Grant, A. Pederson,

& K. Wilson (Eds.), *A Place to call home: Long-term care in Canada* (pp. 29-57).

Nova Scotia: Fernwood Publishing.

Barbara, A. M., Quandt, S. A., & Anderson, R.T. (2001). Experiences of lesbians in the

health care environment. *Women & Health*, 34(1), 45-62.

Barker. J. (2004). Lesbian aging: An agenda for future research. In Herdt, G., & De

Vries, B. (Eds.). *Gay and lesbian aging: Research and future directions* (pp. 29-

72). New York: Springer Publishing Company.

Bauer, G.R., & Jairam, J.A. (2008). Are lesbians really women who have sex with women

(WSW)? Methodological concerns in measuring sexual orientation in health

research. *Women &Health*, 48(4),383-408.

Belgrave, L. L. (1993). Discrimination against older women in health care. *Journal of

Women & Aging*, 5 (3/4), 181-199.

Bezanson, K., & Luxton, M. (2006). *Social reproduction: Feminist political economy

challenges neo-liberalism.* Canada: McGill University Press.

Bergeron, S., & Senn, C. Y. (2003). Health care utilization in a sample of Canadian

lesbian women: predictors of risk and resilience. *Women & Health*, 37(3), 19-

35.

Berlant, L. & Warner, M. (1998). Sex in public. *Critical Inquiry,* 24 (2), 547-566.

Bierman, A. (2007). Sex matters: gender disparities in quality and outcomes of care.

CMAJ: Canadian Medical Association Journal, 177 (12), 1520-21.

Bierman, A., Ahmad, F., Angus, J, Glazier, R., Vahabi, M., et al. (2009). *Burden of illness,

Ontario women's health evidence-based report.* Institute for Clinical Evaluative

Sciences (ICES). Retrieved from the Power Study website http://powerstudy.ca/

Blaxter, M. (1997). Whose fault is it? People's own conceptions of the reasons for health inequalities. *Social Science &Medicine*, 44(6), 747–756

Boehmer, U. (2002). Twenty years of public health research: inclusion of lesbian, gay, bisexual, and transgender populations. *American Journal of Public Health*, 92(7), 1125-30.

Boehmer, U., & Case, P. (2003). Physicians don't ask, sometimes patients tell: disclosure of sexual orientation among women with breast carcinoma. *Cancer*, 15;101(8), 1882-9.

Boehmer, U., & Miao, X., & Ozonoff, A. (2011). Cancer survivorship and sexual orientation. *Cancer*, 117(16), 3796-804.

Bolam, B., Murphy, S., & Gleeson, K. (2004). Individualization and inequalities in health: a qualitative study of class identity and health. *Social Science & Medicine,* 59(7), 1355-65.

Bourgeault, I. (2006). Sociological perspectives on health and health care. In Raphael, D., Bryant, T., & Rioux, M. *Staying alive: Critical perspectives on health, illness, and health care* (pp. 35-58). Toronto: Canadian Scholars Press. .

Bourgeault, I. L. & Atanackovic, J. & Rashid, A. & Parpia, R.(2010). Relations between immigrant care workers and older persons in home and long-term care. *Canadian Journal on Aging / La Revue canadienne du vieillissement* 29(1), 109-118.

Bradley, E.H., Curry, L.A., & Devers, K. (2007). Qualitative data analysis for health

services research: Developing taxonomy, themes and theory. *Health Services*

Research, 42, 1758-

1772.

Braun, V. , & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative*

Research in Psychology, 3: 77-101.

Brodie, J., & Bakker, I. (2007). 'Canada's social policy regime and women: An

assessment of the last decade.' Ottawa: Status of Women Canada. Retrieved

January 1, 2012 from

http://www.swc.cfc.gc.ca/pubs/pubspr/0662450870/200703_9780662450870_1

_e.html

Brotman, S., & Ryan, B. (2008). *Healthy aging for gay and lesbian seniors in Canada: An*

environmental scan. Retrieved April 1, 2012 from the Rainbow Health Ontario

website http://www.rainbowhealthontario.ca/resources/searchResults.

cfm?mode=3&resourceID=182eeb51-3048-8bc6-e8cc-1c95ec6d5795

Brotman, S., Ryan, B., Meyer, L. (2006). *The health and social service needs of gay and*

lesbian elders: Final report. McGill School of Social Work. Montreal, QC.

Brotman, S., Ryan, B. Collins, S., Chamberland, L., Cormier, R., Julien, D., Meyer, E.,

Peterkin, A., Richard, B. (2007) Coming out to care: Caregivers of gay and lesbian

seniors in Canada. *The Gerontologist,* 47(4), 490-503.

Brotman, S., Ryan, B., Jalbert, Y., & Rowe, B. (2002). The impact of coming out on health

and health care access: the experiences of gay, lesbian, bisexual and two-spirit

people*. Journal of Health and Social Policy*, 15(1), 1-29.

Brotman, S., Ryan, B., Jalbert, Y., & Rowe, B. (2008). The impact of coming out on health

and health care access: the experiences of gay, lesbian, bisexual and two-spirit

people. *Journal of Health and Social Policy*, 15(1),1-29.

Cahill, S., & South, K. (2002). Policy Issues affecting lesbian, gay, bisexual, and

transgender people in retirement. *Generations*, 26(2), 49-54.

Calasanti, T.M. & Slevin, K.F. (2006). Introduction: Age matters. In (Eds.) *Age matters:*

Realigning feminist thinking (pp. 1-18). New York: Taylor & Francis Group.

Canadian Healthcare Association (CHCA)*. 2009. *Home care in Canada: From the margins*

to the mainstream. Ottawa, Ontario: Canadian Healthcare Association.

Canadian Home Care Association. (2008). *Portraits of home care.* Retrieved January 1,

2012 from http://www.cdnhomecare.ca/index.php

Canadian Home Care Association. (2008). *Home care in 2010 – Essential for an aging*

population. Retrieved January 1, 2011 from

http://www.cdnhomecare.ca/index.php

Canadian Home Care Association. (2011). *Submission to Drummond Commission.*

Retrieved January 1, 2012 from

http://www.homecareontario.ca/public/about/publications-position-papers.cfm

Canadian Institute for Health Information (CIHI). (2003). *Health care in Canada.* Ottawa,

ON: Author. Canadian Institute for Health Information. (CIHI). (2012). *Home Care*

Reporting System, 2011–2012. Retrieved January 1, 2013 from

http://www.cihi.ca/CIHI-ext-portal/internet/en/

document/types+of+care/community+care/home+care/hcrs_metadata

Carabine, J. (1992). 'Constructing women': Women's sexuality and social policy. *Critical Social Policy, 12*, 23-37.

Carabine, J. (2004). *Sexualities: Personal lives and social policy*. United Kingdom: The Policy Press.

Chamberland, L. (2003). Elderly women, invisible lesbians. *Canadian Journal of Community Mental Health*, 22(2), 85-103.

Chapman, R., Watkins, R., Zappia, T., Nicol, P., & Shields, L. (2012). Nursing and medical students' attitude, knowledge and beliefs regarding lesbian, gay, bisexual and transgender parents seeking health care for their children. *Journal of Clinical Nursing*, 21(7-8), 938-45.

Charlottetown Declaration on the right to care. (2002). the National Coordinating Group on Health Care Reform and Women and the Maritime (now Atlantic) Centre for Excellence in Women=s Health Retrieved from the Women and Health Care Reform website http://www.womenandhealthcarereform.ca/publications.html

Coalition for Lesbian and Gay Rights in Ontario (CLGRO). (1997). *Systems failure: A report on the experiences of sexual minorities in Ontario's health-care and social-services systems*. Toronto: CLGRO.

Coburn, D. (*2001*)*. Health, health care, and neo-liberalism*. Armstrong, P., Armstrong, H., & *Coburn, D.* (Eds.), *Unhealthy times: The political economy of health and care in Canada* (pp. 45-65). Toronto: Oxford University Press.

The Community Care Access Corporations Act. (2001). Retrieved January 1, 2013 from the Queen's Printer for Ontario, 2013 website http://www.e

-laws.gov.on.ca/html/source/ statutes/english/2001/elaws_src_s01033_e.htm

Community Care Access Centers [website]. 2011. Accessed June 1, 2011.

http://www.ccac-ont.ca/Home.aspx?LanguageID=1

Cook-Daniels, L. (1997). Lesbian, gay male, bisexual and transgender elders: Elder abuse

and neglect issues*. Journal of Elder Abuse & Neglect*, 9(2), 35-49.

Cook- Daniels, L. (2008). Living memory LGBT history timeline: Current elders would

have been this old when these events happened. *Journal of GLBT Family Studies,*

4(4), 485-497.

Coyte, P.C. (2000). *Home care in Canada: Passing the buck.* Paper prepared for the

Dialogue on Health Reform. University of Toronto, Toronto, Ontario. Retrieved

from: www.utoronto .ca /hpme/dhr/pdf/Coyte2.pdf

Coyte, P.C., & McKeever, P.(2001). Home care in Canada: passing the buck. *Canadian*

Journal of Nursing Research, 33(2),11-25.

Cruikshank, M. (2009). *Learning to be old: Gender, culture, and aging*. Maryland:

Rowman & Littlefield Publishers Inc.

Daley, A. (1998). Lesbians in health care: heterosexual hegemony and strategies for

change. *Canadian Social Work Review*, 15(1), 57-71.

Daley, A. (2003). Lesbian health and the assumption of heterosexuality: an

organizational perspective. *The Canadian Journal of Community Mental Health*,

22(2), 105-121.

Daley, A. (2006). Lesbian and gay health issues: OUTside of Canada's health policy.

Critical Social Policy, 26(4), 794-816.

Daley, A. (2010). Being recognized, accepted and affirmed: Self-disclosure of

lesbian/queer sexuality within psychiatric and mental health service settings.

Social Work in Mental Health, 8(4), 1-20.

Daly, T. (2007). "Out of place: Mediating health and social care at Ontario's state –

voluntary sector Divide." *Canadian Journal on Aging,* (Suppl.1), 63-75.

D'Augelli, A. R., Hershberger, S. L., & Pilkington, N.W. (1998). Lesbian, gay, and bisexual

youths and their families: disclosure of sexual orientation and its consequences.

American Journal of Orthopsychiatry, 68, 361–371.

D'Augelli, A. R., & Grossman, A. H. (2001). Disclosure of sexual orientation, victimization,

and mental health among lesbian, gay, and bisexual older adults. *Journal of

Interpersonal Violence, 16*, 1008-1027.

Davies, M., Addis, S., MacBride-Stewart, S., and Shepherd, M. (2006). *The Health, social

care and housing needs of lesbian, gay, bisexual and transgender older people:

Literature review*. Cardiff: Cardiff Institute of Society, Health and Ethics.

Davis, C., & Wright, A. (2001). *How well are we doing? A Survey of the GLBT population

of Ottawa*. Ottawa: Pink Triangle Services.

Denenberg, R. (1995). Report on lesbian health. *Women's Health International*, 5(2),

81-91.

Department of Justice. (1985). *Canada Health Act*. Government of Canada: Department

of Justice. Retrieved January 1, 2008 from http://laws-

lois.justice.gc.ca/eng/acts/c-6/

Denzin, N. K., & Lincoln, Y. S. (2000). Introduction: The discipline and practice of

qualitative research. In N. K. Denzin & Y. S. Lincoln (eds.), *Handbook of qualitative research* (2nd ed.). Thousand Oaks, CA: Sage, 1–28.

De Vries, B., & Blando, J. A. (2004). The Study of gay and lesbian aging: Lessons for social gerontology. In G. Herdt & B. De Vries (Eds.) *Gay and lesbian aging: Research and future directions* (pp. 3-28). New York: Springer Publishing Company.

De Vries, B. (Winter 2005/2006). Home at the end of the rainbow. *Generations*, 29(4), 64-69.

Diamond, L. M. (2003). Was it a phase? Young women's relinquishment of lesbian/ bisexual identities over a 5-year period. *Journal of Personality and Social Psychology, 84,* 352–364.

Diamond, L.M. (2005). A New view of lesbian subtypes: Stable versus fluid identity trajectories over an 8-year period. *Psychology of Women Quarterly*, 29 (2), 119–128.

Diamond L.M. (2008). Female bisexuality from adolescence to adulthood: results from a 10-year longitudinal study. *Developmental Psychology*, 44(1), 5-14.

Diamond, L. M. (2008). *Sexual fluidity: Understanding women's love and desire*. Cambridge, MA: Harvard University Press.

Diamond, L. M. & Savin-Williams, R. C. (2003). The intimate relationships of sexual-minority youths. in G.R. Adams & M. Berzonsky (Eds.), *The Blackwell handbook of adolescence* (pp. 393-412). Malden, MA: Blackwell.

Diaz-Granados, N., Ross, L., Azar, R., Cheng, C., Coulombe, L., DesMeules, M., Fear, J.M., Grace, S.L., Gucciardi E, McDermott, S., Munce, S., Poynter, B., Steele, L., Strohm,

S. ,Wang, S., Wathen, C.N., Webster, F., Whitney, D., & Stewart, D.E. (2006). *A Literature Review on Depression Among Women: Focusing on Ontario*. Report for the Ontario Women's Health Council, Toronto, Canada. Retrieved March 10, 2012 from *girlsactionfoundation.ca/files/Depression_Review_Eng_Printing.pdf*

Dibble, S.L., Eliason, M.J., & Christiansen, M.A. (2007). Chronic illness care for lesbian, gay, & bisexual individuals. *The Nursing Clinics of North America*, 42(4), 655-74.

Dobinson C., with MacDonnell. J., Hampson. E., Clipsham, J., & Chow, K. (2005). Improving the access and quality of public health services for bisexuals. *Journal of Bisexuality*, 5 (1), 39-78.

Dolan, K. A. (2005). *Lesbian women and sexual health: the social construction of risk and susceptibility*. New York: Haworth Press.

Doyal, L. (1995). *What makes women sick: Gender and the political economy of health*. New Jersey, New Brunswick: Rutgers University Press.

Doyal L. (2001). Sex, gender, and health: The need for a new approach. *BMJ*, 323(7320), 1061-3.

Dubé, L., Ferland, G., & Moskowitz, D.S. (2003). *Emotional and interpersonal dimensions of health services: Enriching the art of Care with the science of care*. Quebec City: McGill University Press.

Eliason, M.J. (1996). *Who cares? Institutional barriers to health care for lesbian, gay, & bisexual persons*. New York: NLN Press.

Eliason, M.J., & Schope, R. (2001). Does "Don't ask, don't tell" apply to health care? Lesbian, gay, and bisexual people's disclosure to health care providers. *Journal of*

the Gay and Lesbian Medical Association, 5(4):125-134.

Eliason, M.J., & Raheim, S. (2000). Experiences and comfort with culturally diverse groups in undergraduate pre-nursing students. *Journal of Nursing Education*, 39(4),161-5.

Emerson, R., Fretz, R., & Shaw, L. (1995). *Writing ethnographic field notes*. Chicago: The University of Chicago Press.

England, K. (2010) "Home, paid care work and geographies of responsibilities." *Ethics, Place and Environment, 13(2): 131-150.*

England, K*.,* Eakin, J*.,* Gastaldo, D. *and* McKeever, P. *(*2007*)* Neoliberalizing home care: managed competition and restructuring home care in Ontario. In England, K. and Ward, K. (Eds.), *Neoliberalization: Networks, states, peoples* (pp. 169-194) Oxford: Blackwell.

Farmanova-Haynes, E., Bose, A. & Vissandjée, B. (2006). Impact of immigration and settlement on women's mental health, mental Illness, substance use and addiction. Appendix in *Women, mental health and mental illness and addiction in Canada: An Overview.* Retrieved from the Canadian Women's Health Network website January 1 2008 http://*www.cwhn.ca*

Fish, J. (2008). Navigating queer street: Researching the intersections of LGBT health. *Sociological Research Online*, 13, 1.

Fredriksen, K. (1999). Family caregiving responsibilities among lesbians and gay men. *Social Work,* 44, 144-55.

Fredriksen-Goldsen, K., & Hooyman, N. R. (2007). Caregiving research, services, and

policies in historically marginalized communities: Where do we go from here? *Journal of Lesbian and Gay Social Services*, 18(3/4), 129-145.

Fredriksen-Goldsen K. I., & Muraco A. (2010). Aging and sexual orientation: A 25-year review of the literature. *Research on Aging,* 32, 372–413.

Fredriksen-Goldsen, K. I., Kim, H. J., Barkan, S. E., Balsam, K. F., & Mincer, S. L. (2010). Disparities in health-related quality of life: a comparison of lesbians and bisexual women. *American Journal of Public Health*, 100(11), 2255-61.

Fredriksen-Goldsen, K. I., Kim, H. J., Emlet, C. A., Muraco, A., Erosheva, E., Hoy-Ellis,C. P., Goldsen, J. & Petry, H. (2011). *The Aging and health report: Disparities and resilience among lesbian, gay, bisexual, and transgender older adults*. Retrieved from the Caring and Aging with Pride website http://www.*caringandaging.org*

Fuller, C. (1998). *Caring for profit: How corporations are taking over Canada's health care system*. Vancouver: New Star Books.

Fuller, C. (2001). The Information gap: The Impact of health care reform on British Columbia women. In Armstrong, P., Amarantunga, C., Bernier, J., Grant, K., Pederson, A. & Willson, K. (Eds.) *Exposing privatization: Women & health care reform in Canada* (pp. 287-306). Aurora: Garamond Press.

Fullmer, E., Shenk, D., & Eastland, E. (1999). Negating identity: A feminist analysis of the social invisibility of older lesbians. *Journal of Women & Aging*, 11(2/3), 131–148.

Gabrielson, M. L. (2009). *The long-term care decision making of older lesbians: a narrative analysis*. (Doctoral dissertation). Retrieved from the University of Iowa

website http://ir.uiowa.edu/etd/234.

Gabrielson, M. L. (2011). "I will not be discriminated against": older lesbians creating

new communities. *ANS Advances in Nursing Science*, 34(4), 357-73.

Garnets, L. D., & Peplau, L. A. (2001). A new paradigm for women's sexual orientation:

Implications for therapy. *Women and Therapy*, 24, 111-122.

Garnets, L., & Peplau, L. (2006). Sexuality in the lives of aging lesbian and bisexual

women. In D. Kimmel, T. Rose, & S. David (Eds.), *Lesbian, gay, bisexual and*

transgender aging: Research and clinical perspectives (pp. 70-90). New York:

Columbia University Press.

Gazso, Amber. 2009. "Reinvigorating the debate: Questioning the assumptions about

and models of the "Family" in social assistance policy." *Women's Studies*

International Forum 32 (2): 150-162.

Gee, E. M. (2002). Misconceptions and misapprehensions about population ageing.

International Journal of Epidemiology, 31(4), 750-3.

Glenn, E. N. (2010). *Forced to care: Coercion and caregiving in America.* Cambridge,

MA: *Harvard University Press.*

Goins, E.S., & Pye, D. (2012). Check the box that best describes you: reflexively

managing theory and praxis in LGBTQ health communication research. *Health*

Communication, 28(4), 397-407.

Golafshani, N. (2003). Understanding reliability and validity in qualitative research. *The*

Qualitative Report, 8 (4), 597-607.

Golden, C. (1996). What's in a name? Sexual self-identification among women. In R. C.

Savin-Williams & K. M. Cohen (Eds.), *The lives of lesbians, gays, and bisexuals: Children to adults* (pp. 229–249). Fort Worth, TX: Harcourt Brace.

Gorman-Murray, A. (2006). Gay lesbian couples at home: Identity work in domestic space. *Home Cultures*, 3(2), 145–68.

Grant, K., Amaratunga, C., & Armstrong, P. (Eds.). (2004). *Caring for/ caring about: Women, home care and unpaid caregiving*. Aurora, Ontario: Garamond Press.

Grant, J. (2010). *Outing age 2010: Public policy issues affecting gay, lesbian, bisexual, transgender elders*. National Gay and Lesbian Task Force Policy Institute. Washington, D.C. Retrieved January 1, 2011 from http://www.thetaskforce.org/reports_and_research/outing_age_2010

Greene, B. (Ed.). (1997). *Ethnic and cultural diversity among lesbians and gay men.* London: Sage.

Grossman, A., D'Augelli, A., & O'Connell, T. (2001). Being lesbian, gay, bisexual, and 60 or older in North America. *Journal of Gay & Lesbian Social Services*, 13(4), 23–40.

Grossman, A., D'Augelli, A., & Dragowski, E. (2007). Caregiving and care receiving among older lesbian, gay, and bisexual adults. *Journal of Gay & Lesbian Social Services*, 18(3/4), 15–38.

Guberman, N. (2004). One hundred years of caregiving. In K. Grant, C. Amaratunga, & P. Armstrong (Eds.), *Caring for/caring about: Women, home care and unpaid caregiving* (pp. 75-90). Aurora: Garamond Press.

Guest, G., Bunce, A., & Johnson, L. (2006). How many interviews are enough? An experiment with data saturation and variability. *Field Methods*, 18(1), 59-82.

Halberstam, J. (1998) *Female Masculinity*. Durham, NC: Duke University Press.

Hankivsky, O., Morrow, M., Armstrong, P., Galvin, L., & Grinvalds, H. (2004). *Trade agreements, home care and women's health*. Status of Women in Canada. Retrieved January 1, 2010 from http://publications.gc.ca/site/archivee-archived.html?url=http://publications .gc.ca/ collections/Collection/SW21-109-2004E.pdf

Hankivsky, O. (2007). More than age and biology: Overhauling lifespan approaches to women's health. In M. Morrow, O. Hankivsky and C. Varcoe (eds.), *Women's health in Canada: Critical perspectives on theory and policy* (pp. 64-92). Toronto: University of Toronto Press.

Hanson, C., & Hanson, L., Adams, B. (2001). *Who benefits: Women, unpaid work and social policy*. Available on web-site of Canadian Research Institute for the Advancement of Women: www.criaw-icref.ca/hanson.htm

Harmer, J. (2000). *Older gay, lesbian, bisexual, transgender, transsexual persons: Community challenges and opportunities for the 519 community centre and the GLBT community 2000 Report*. Retrieved December, 12, 2007 from the 519 Church Street Community Centre's website http://www.the519.org/programs/older/report_2000.pdf

Hash, K. (2001). Preliminary study of caregiving and post-caregiving experiences of older gay men and lesbians. *Journal of Gay & Lesbian Social Services*, 13(4), 87-94.

Hash, K. 2006. Caregiving and post-caregiving experiences of midlife and older gay men and lesbians. *Journal of Gerontological Social Work* 47(3/4), 121-38.

Health Canada. (2010). *Healthy Canadians: A federal report on comparable health indicators 2010*. Government of Canada. Retrieved January 1, 2013 from http://www.hc-sc.gc.ca/hcs-sss/pubs/system-regime/2010-fed-comp-indicat/index-eng.php#t27

Healthy Homes Renovation Tax Credit. (2012). Ontario Ministry of Health and Long Term Care. Retrieved January 1, 2013 from the Queen's Printer for Ontario, 2012 website https://www.ontario.ca/taxes-and-benefits/healthy-homes-renovation-tax-credit

Heaphy, B. (2007). Sexualities, gender and ageing: Resources and social change. *Current Sociology*, 55(2), 193–210

Henderson, J. W. (1998). Issues in the medical treatment of elderly women. *Journal of Women and Aging*, 9(1/2), 107-115.

Herdt, G. & de Vries, B. (Eds.). (2003). *Gay and lesbian aging: Research and future directions*. New York, NY: Springer Publishing Company.

Herek, G. M., Chopp, R., & Strohl, D. (2007). Sexual stigma: Putting sexual minority health issues in context. In I. Meyer & M. Northridge (Eds.), *The health of sexual minorities: Public health perspectives on lesbian, gay, bisexual, and transgender populations* (pp. 171-208). New York: Springer.

Hiestand, K.R., Horne, S.G., & Levitt, H.M. (2007).Effects of gender identity on experiences of healthcare for sexual minority women. *Journal of LGBT Health Research*, 3(4),15-27.

Higgs P., & Jones, I. R. (2009). *Medical sociology and old age: Towards a sociology of*

health in later life. London: Routledge.

Hinrichs K. L., & Vacha-Haase, T. (2010). Staff perceptions of same gender sexual

contacts in long-term care facilities. *Journal of Homosexuality*, 57, 776–789.

Hodson, D., & Skeen, P. (1994). Sexuality and aging: The hammerlock of myths*. Journal*

of Applied Gerontology, 13(3), 219–235.

Hudak, J. & Giammattei, S. V. (2010). Doing family: Decentering heteronormativity in

'marriage' and 'family' therapy. *AFTA Monograph Series: Expanding Our Social*

Justice Practices: Advances in Theory and Training, (Winter). American Family

Therapy Academy, Washington, DC . Retrieved January 1, 2012 from

http://www.psychologytoday.com

Hyman, I. (2009). *Racism as a determinant of immigrant health*. Policy Brief. Metropolis

and Public Health Agency of Canada. Retrieved January 1, 2012 from

http://canada.metropolis.net/events/health/health_seminar.html

Institute of Medicine (IOM). (2011).*The health of lesbian, gay, bisexual, and*

transgender people: Building a foundation for better understanding. Washington,

DC: National Academies Press.

Jackson, B. E., Pederson, A., Armstrong, P., Boscoe, M., Clow, B., Grant, K.R., Guberman,

N.,& Willson, K. (2006). 'Quality care is like a carton of eggs': Using a gender-

based diversity analysis to assess quality of health care. *Canadian Woman*

Studies 24 (1): 15-22.

Jenkins, D., Walker, C., Cohen, H., & Curry, L. (2010). A lesbian older adult managing

identity disclosure: a case study. *Journal of Gerontological Social Work*,

53(5):402-20.

Johnston, L., & Valentine, G. (1995). Where ever I lay my girlfriend that's my home: The performance and surveillance of lesbian identities in domestic environments. In D. Bell & G. Valentine (Eds.), *Mapping desire: Geographies of sexualities* (pp. 88-103). London: Routledge.

Jorm, A. F., Korten, A. E., Rodgers, B., Jacomb, P. A., & Christensen, H. (2002). Sexual orientation and mental health: results from a community survey of young and middle-aged adults. *British Journal of Psychiatry*, 180, 423-7.

Jowett, A. & Peel, E. (2009) Chronic illness in non-heterosexual contexts: An online survey of experiences. *Feminism & Psychology*, 19(4), 454-474.

Kaestle, C. E., & Ivory, A. H. (2012). A forgotten sexuality: Content analysis of bisexuality in the medical literature over two decades. *Journal of Bisexuality, 12*, 35-48.

Kimmel, D., Rose, T., & David, S. (Eds.). (2006). *Lesbian, gay, bisexual, and transgender aging: Research and clinical perspectives*. New York: Columbia University Press.

Kim, H. J., & Fredriksen-Goldsen, K. I. (2012). Hispanic lesbians and bisexual women at heightened risk for [corrected] health disparities. *American Journal of Public Health,* 102(1), e9-15.

Kimmel, D., T. Rose, N. Orel, and B. Greene, 2006. "Historical context for research on lesbian, gay, bisexual, and transgender aging." In Kimmel, D., Rose, T., and David, S. (Eds.) *Lesbian, gay, bisexual, and transgender aging: Research and clinical perspectives* (pp. 1-19)*.* New York, NY: Columbia University Press.

Kitchen, P., Williams, A., Pong, R.W., & Wilson, D. (2011). Socio-spatial patterns of home

care use in Ontario, Canada: a case study. *Health & Place, 17*(1), 195-206.

Kaye, R. A. (1993). Sexuality in the later years. *Aging and Society*, 13, 415-426.

Kochman, A. (1997). Gay and lesbian elderly: Historical overview and implications

for social work practice. *Journal of Gay and Lesbian Social Services*, *6(1)*, 1-10.

Kohli, M. (2009). *Priority Setting in Community Care Access Centres* (Doctoral dissertation).

Retrieved from University of Toronto Research Repository T-space website

http://hdl.handle.net/1807/17787

Knauer, N. J. (2009). LGBT Elder Law: Toward Equity in Aging. *Harvard Journal of Law*

and Gender, 32; Temple University Legal Studies Research Paper No. 2009-9.

Available at SSRN: http://ssrn.com/abstract=1309182

Krehely, J. (2009). *How to close the LGBT health disparities gap*. Retrieved March 13,

2012 from the Center for American Progress website

http://www.americanprogress.org/issues/lgbt/report/2009/12/21/7048/how-

to-close-the-lgbt-health-disparities-gap/

Krieger, N. (2001). The ostrich, the albatross, and public health: an ecosocial

perspective--or why an explicit focus on health consequences of discrimination

and deprivation is vital for good science and public health practice. *Public Health*

Report, 116(5), 419-23.

Lancaster, R., & Di Leonardo, M. (1997). Introduction. In Lancaster, R. & Di Leonardo, M.

(Eds.) *The Gender & sexuality reader: Culture, history, political economy* (pp. 1-

12). New York and London: Routledge.

Lang, A., Macdonald, M., Stevenson, L., Storch, J., Elliot, K., LaCroix, H., & Donaldson, S.

(2009). *An Environmental scan of the state of the knowledge on safety in homecare*. The Canadian Patient Safety Institute. Alberta. Retrieved from http://www.patientsafetyinstitute.ca/english/research/commissionedresearch/safetyinhomecare/pages/default.aspx

Lapovsky-Kennedy, E. and Davis, M. (1993) *Boots of leather, slippers of gold: The History of a lesbian community.* New York: Routledge

Lasser, J., & Tharinger, D. (2003). Visibility management in school and beyond: a qualitative study of gay, lesbian, bisexual youth. *Journal of Adolescence*, 26(2), 233-44.

Lee, E., Taylor, .J, & Raitt, F. (2011). 'It's not me, it's them': How lesbian women make sense of negative experiences of maternity care: a hermeneutic study. *Journal of Advanced Nursing*, 67(5), 982-90.

The Lesbians and Breast Cancer Project. (2004). Research Report. Retrieved April 14, 2012 from DAWN website http://dawn.thot.net/lbcp/

Levitt, H., & Horne, S. (2002). Explorations of lesbian-queer genders: Butch, femme, Androgynous, or "other*." Journal of Lesbian Studies*, 6(2), 25-39.

The Local Health System Integration Act. (2006). Retrieved January 1, 2012 from the Queen's Printer for Ontario, 2013 website http://www.e-laws.gov.on.ca/html/statutes/english /elaws_statutes_06l04_e.htm

Masini, B. E., & Barrett, H. A. (2008). Social support as a predictor of psychological and physical well-being and lifestyle in lesbian, gay and bisexual adults aged 50 and over. *Journal of Gay and Lesbian Social Services,* 20(1/2), 91-110.

McDermott, E. (2004). Telling lesbian stories: Interviewing and the class dynamics of

'talk'. *Women's Studies International Forum*, 27(3), 177-187.

McDermott, E. (2006). Surviving in dangerous places: Lesbian identity performances in

the workplace, social class and psychological health. *Feminism and Psychology*,

16(2), 193-211.

Mathieson, C. (2007). Negotiating sexualities in women's health care. In M. Morrow, O.

Hankivsky, & C. Varcoe (Eds.), *Women's health in Canada: Critical perspectives

on theory and policy* (pp. 272-296). Toronto: University of Toronto Press.

Mathieson, C., Bailey, N., & Gurevich, M. (2002). Health care services for lesbian and

bisexual women: Some Canadian data. *Health Care for Women International*, 23,

185-196.

Mayer, K. H., Bradford, J. B., Makadon, H. J., Stall, R., Goldhammer, H., & Landers, S.

(2008). Sexual and gender minority health: what we know and what needs to be

done. *American Journal of Public Health*, 98(6), 989-95.

Mays, V. M., Yancey, A. K., Cochran, S. D., Weber, M., & Fielding, J. E. (2002).

Heterogeneity of health disparities among African American, Hispanic, and Asian

American women: Unrecognized influences of sexual orientation. *American

Journal of Public Health*, 92(4), 632-9.

McCandless, N. J., & Conner, F. (1999). Older women and the health care system: A time

for change. *Journal of Women & Aging*, 11(2/3), 13–27.

McDonald, C., McIntyre, M., & Anderson, B. (2003). The view from somewhere: Locating

lesbian experience in women's health. *Healthcare for Women International*, 24

(8), 697-711.

MacDonald, S. (2011) *Ontario's aging population: Challenges and opportunities*. Ontario

Trillium Foundation. Retrieved February 1, 2012 from

http://www.otf.ca/en/knowledgeSharingCentre/research.asp

Maxwell, J. (2005). *Qualitative research design: An interactive approach, second edition*.

Thousand Oaks CA: Sage Publications.

Maxwell, C. J., Leger, H., Hirdes, J., Ellis-Hale, K., Tjam, E. Y., Chi, I., Wu, T., Fletcher, P.C.

& Oakley, K. (1998). *Older women's health issues paper*. Health Canada.

Retrieved from the Canadian Association on Gerontology website

http://cagacg.ca/

McKee, V. (1999). Seniors survey identifies double discrimination for senior lesbians.

Herizons, 13(1), 9.

MetLife Mature Market Institute & the Lesbian and Gay Aging Issues Network of the

American Society on Aging. (2006). *Out and aging: The MetLife study of lesbian

and gay baby boomers*. New York: Metropolitan Life Insurance Company.

Retrieved January 10, 2010 from

https://www.metlife.com/mmi/research/index.html?WT.ac=GN_mmi_research

Meyer, I.H. (2003). Prejudice, social stress, and mental health in lesbian, gay, and

bisexual populations: conceptual issues and research evidence. *Psychological

Bulletin*, 129(5), 674-97.

Meyer, I. & Northridge, M. (Eds.). (2007). *The health of sexual minorities: Public health

perspectives on lesbian, gay, bisexual, and transgender populations*. New York:

Springer.

Meyer, I. H., Schwartz, S., & Frost, D. M. (2008). Social patterning of stress and coping:

does disadvantaged social statuses confer more stress and fewer coping

resources? *Social Science & Medicine*, 67(3):368-79.

Monette, M., & Hill, A. (2012). Arm-twisting medical schools for core geriatric training.

CMAJ: *Canadian Medical Association Journal*, 184(10), E515-6.

Moore, D. (2009). Designing long term care for lesbian, bisexual, transsexual and

transgender people. In P. Armstrong, M. Boscoe, B. Clow, K. Grant, M. Haworth

Brockman, & B. Jackson (Eds.), *A place to call home: Long-term care in Canada*

(pp. 104–110). Toronto, Canada: Fernwood Publishing.

Morris, M. (2001). *Gender-sensitive home and community care and caregiving*

research: A Synthesis paper. Ottawa: Women's Health Bureau, Health Canada.

Morris, M. (2004). What research reveals about gender, home care and caregiving:

Overview and the case for gender analysis. In K. Grant, C. Amaratunga, & P.

Armstrong (Eds.) *Caring for/ caring about: Women, home care and unpaid*

caregiving (pp. 91-113). Aurora, Ontario: Garamond Press.

Morris, M., Robinson, J., Simpson, J. (1999). *The Changing nature of home care and its*

impact on women's vulnerability to poverty. Ottawa: Status of Women in

Canada.

Morrison, S., & Dinkel, S. (2012). Heterosexism and health care: a concept analysis.

Nursing Forum, 47(2), 123-30.

Morrow, D. F. (2001). Older gays and lesbians: Surviving a generation of hate and

violence. *Journal of Gay & Lesbian Social Services*, 13 (1/2), 151-169.

Morrow, M. (2007). 'Our bodies, our selves' in context': Reflections on the women's

health movement in Canada. In M. Morrow, O. Hankivsky and C. Varcoe (eds.),

Women's health in Canada: Critical perspectives on theory and policy (pp. 33-

63). Toronto: University of Toronto Press.

Mravcak, S. A. (2006). Primary care for lesbians and bisexual women. *American Family*

Physician, 74(2), 279-86.

Mulé, N.J., Ross, L.E., Deeprose, B., Jackson, B.E., Daley, A., Travers, A., & Moore, D.

(2009).Promoting LGBT health and wellbeing through inclusive policy

development. *International Journal for Equity in Health*, 8 (18), n.p.

Murphy, B. (2005). Towards a feminist political economy. *InterPares*. Ottawa, ON.

Retrieved January 1, 2011 from the Canadian Women's Health Network

http://www.cwhn.ca/en/node/27162

Mykhalovskiy, E., Armstrong, P., H. Armstrong, I. Bourgeault, J. Choiniere, E. Lexchin, S.

Peters, & J.P. White. (2008). Qualitative research and the politics of knowledge in

an age of evidence: The Possibilities and perils of immanent critique. *Social*

Science and Medicine. 67(1): 195-203.

Nestel, S. (2012). *Colour coded health care: The impact of race and racism on Canadians'*

health. Toronto, ON: Wellesley Institute. Retrieved June 15, 2012 from Wellesley

Institute website http://www.wellesleyinstitute.com/health-care/colour-coded-

health-care-the-impact-of-race-and-racism-on-canadians-health/

Nichols, M. (2004). Lesbian sexuality/female sexuality: Rethinking 'lesbian bed death.'

Sexual and Relationship Therapy, 19 (4), 363-371.

Ochs, R. (1996). Biphobia: It goes more than two ways. In B. A. Firestein (Ed.),

    Bisexuality: The psychology and politics of an invisible minority (pp.217-239).

    Thousand Oaks: Sage.

Ross, E., Scott, M., & Wexler, E. (2003*). Environmental scan on the health and housing*

    needs of aging lesbians. Older Lesbians in Valued Environment (OLIVE) Report.

    Retrieved from the Rainbow Health Ontario website

    http://www.rainbowhealthontario.ca/resources/searchResults.cfm?mode=3&re

    sourceID=922b4faf-09bb-91a7-0866-8938b879a8af

Ontario Action Plan for Home Care. (2012). Ontario Ministry of Health and Long Term

    Care. Retrieved March 1, 2011 from the Queen's Printer for Ontario, 2008

    website http://www.health.gov.on.ca/en/ms/ecfa/healthy_change/

Ontario Auditor General*. 2010 Annual Report.* December 6, 2010: Chapter 3; Section

    3.04,113-131. Ottawa. Retrieved January 1, 2012 from

    www.auditor.on.ca/en/reports_en/en10/304en10.pdf

Ontario Health Coalition. (2008). *Home care: Change we need - Report on the Ontario*

    Health Coalition's home care hearings. Toronto. Retrieved January 1, 2010 from

    OHC website http://www.web.net/ohc/Homecare.htm

Ontario Health Coalition. (2011). *Still waiting: An Assessment of Ontario's home care*

    system after two decades of restructuring. Toronto. Retrieved January 1, 2011

    from http://www.web.net/~ohc/homecare2011finalreport.pdf

Ontario Ministry of Health and Long Term Care. (2006). Community Care Access

Centers: Client Services Policy Manual. Accessed Jan 1 2011.

http://health.gov.on.ca/english/providers/pub/manuals/ccac/ccac_mn.html

Ontario Ministry of Health and Long Term Care. (2012). Home, community and

residential services for seniors. Accessed Jan 1 2013.

http://www.health.gov.on.ca/en/public/programs/ltc/default.aspx

O'Shea, D. J. (2009). Navigating health systems. In S. Loue (Ed.), *Sexualities and

identities of minority women* (pp. 105-128). New York: Springer.

Peterson, K.J., & Bricker-Jenkins, M. (1996). Lesbians and the health care system. In

Petersen, K.J. (Ed.). *Health care for lesbians and gay men: Confronting

homophobia and heterosexism* (pp. 33-48). New York: Harrington Park Press.

Platzer, H., & James, T. (1997). Methodological issues conducting sensitive research on

lesbian and gay men's experience of nursing care." *Journal of Advanced Nursing*

25(3), 626-633.

Portacolone, E. (2011). The myth of independence for older Americans living alone in

the Bay Area of San Francisco: A critical reflection. *Ageing and Society*, 31, 803-

828.

Ramsay, H. (1994). Lesbians and the health care system. *Canadian Woman Studies/les

Cahiers de la Femme*, 14 (3), 22-27.

Ramsey, F., Hill, M., & Kellam, C. (2010). *Black lesbians matter: An examination of the

unique experiences, perspectives, and priorities of the Black Lesbian community*.

Retrieved April 2012 from the Zuna Institute website

http://zunainstitute.org/index.php?option=com_content&task=view&id=113&It

emid=148

Ramos, M.M., Téllez, C.M., Palley, T.B., Umland, B.E., & Skipper, B.J. (1998). Attitudes of

physicians practicing in New Mexico toward gay men and lesbians in the

profession. *Academic Medicine*, 73 (4), 436-8.

Rankow, E.J. (1995). Lesbian health issues for the primary care provider. *Journal of*

Family Practice, 40(5), 486-96.

Reid, J. D. (1995). Development in late life: Older lesbian and gay lives. In A. R. D'Augelli

& B. E. Patterson (Eds.), *Lesbian, gay, and bisexual identities over the lifespan*

(pp. 215-242). New York: Oxford University Press.

Richard, C. A., & Brown, A. H. (2006). Configurations of informal social support among

older lesbians. *Journal of Women and Aging* 18(4), 49-64.

Rioux. M. & Daly, T. (2006). "Constructing disability and illness". In D. Raphael, T. Bryant,

& M. Rioux (Eds.), *Staying alive: Critical perspectives on health, illness, and health*

care (pp.305-324). Toronto: Canadian Scholars Press.

Roter, D. L., & Hall, J. A. (1998). Why physician gender matters in shaping the physician-

patient relationship. *Journal of Women's Health*, 7(9), 1093-1097.

Rubin, G. (1992). Of Catamites and kings: Reflections on butch, gender and boundaries.

In J. Nestle (Ed) *The Persistent desire: A Femme-butch reader*. Boston, MA:

Alyson.

Rural Ontario Municipal Association (ROMA). (2011). *A Voice for rural and northern*

Ontario. Retrieved January 1, 2012 from

http://www.roma.on.ca/WCM/ROMA/ROMA_Content/Advocacy/A_Voice_for_Rural_a

nd_Northern_Ontario.aspx?WebsiteKey=3b16a877-3264-4044-acb4-3bac8528523d

Ryan, C., Huebner, D., Diaz, R.M., & Sanchez, J. (2009). Family rejection as a predictor of

negative health outcomes in white and Latino lesbian, gay, and bisexual young

adults. *Pediatrics*, 123(1), 346-52.

Saulnier, C.F. (2002). Deciding who to see: lesbians discuss their preferences in health

and mental health care providers. *Social Work*, 47(4), 355-65.

Seggewiss, K. Variations in home care programs across Canada demonstrate need

for national standards and pan-Canadian program. *Canadian Medical Association

Journal*, 180(12), E90-2.

Serano, J. (2007). Whipping girl: A Transsexual woman on sexism and the scapegoating

of femininity. Emeryville, California: Seal Press

Shankle, M., Maxwell, C., Katzman, E., & Landers, S. (2003). An invisible population:

Older lesbian, gay, bisexual, and transgender Individuals. *Clinical Research and

Regulatory Affairs*, 20(2), 159-182.

Sharpe, P. A. (1995). Older women and health services: Moving from ageism toward

empowerment. *Women & Health*, 22(3), 9-23.

Shippy, R. A. (2007). We cannot go it alone: The impact of informal support and

stressors in older gay, lesbian and bisexual caregivers. *Journal of Gay and Lesbian

Social Work*, 18, 39–51.

Sinding, C. (2003). Disarmed complaints: Unpacking satisfaction with end-of-life

care. *Social Science and Medicine 57 (8),* 1375-1385.

Sinding, C. (2010). Using institutional ethnography to understand the production of

health care disparities. *Qualitative Health Research 20* (12), 1656-1663.

Sinding, C., Barnoff, L., Grassau, P. (2004). Homophobia and heterosexism in cancer

care: the experiences of lesbians. *Canadian Journal of Nursing Research*, 36 (4),

170-88.

Sinding, C., Barnoff, L., McGillicuddy, P., Grassau, P., & Odette, F. (2010). Aiming for

better than "nobody flinched": Notes on oppression in cancer care. *Canadian

Woman Studies* 28(2,3), 89-94.

Sinding, C., Hudak, P., Wiernikowski, J., Aronson, J., Miller, P., Gould, J., & Fitzpatrick-

Lewis. D. (2010). I like to be an informed person but..." negotiating responsibility

for treatment decisions in cancer care. *Social Science & Medicine*, 71(6), 1094-

101.

Sinding, C., & Wiernikowski, J. (2008). Disruption foreclosed: older women's cancer

narratives. *Health (London), 12*(3), 389-411.

Skeggs, B. (2004). *Class, self, culture*. London: Routledge.

Smith, M. (2006). Queering public policy. In Orsini, M. & Smith, M, *Critical policy studies*

(pp.91-110). Vancouver: UBC Press.

Smith, D.M., & Mathews, W.C. (2007). Physicians' attitudes toward homosexuality and

HIV: survey of a California medical society- revisited (PATHH-II). *Journal of

Homosexuality*, 52 (3-4), 1-9.

Solarz, A. (1999). *Lesbian health: Current assessment and directions for the future*.

Washington D.C.: National Academies Press.

Srivastava, P., & Hopwood, N. (2009). A Practical iterative framework for qualitative

data analysis. *International Journal of Qualitative Methods*, 8(1), 75-84.

Stein, A. (1997). *Sex and sensibility: Stories of a lesbian generation.* Berkeley and Los

Angeles, California: University of California Press.

Stein, A. (1997b). Sisters and queers: The Decentering of lesbian feminism. In

Lancaster, R. N. & Di Leonardo, M. *The Gender & sexuality reader: Culture,*

history, and political economy (pp. 378-391). Great Britain: Routledge.

Stein, G. L., Beckerman, N. L., & Sherman, P. A. (2010). Lesbian and gay elders and long-

term care: identifying the unique psychosocial perspectives and challenges.

Journal of Gerontological Social Work, 53(5), 421-35.

Stein, M. (2012). *Rethinking the gay and lesbian movement*. New York: Routledge.

Stevens, P. E. (1993). Lesbian health care research: A Review of the literature from

1970 to 1990. In Stern, P. N. (Ed.) *Lesbian health: What are the Issues?* (pp. 1-30).

New York: Taylor & Francis Group.

Stevens, P. E. (1996). Lesbians and doctors: Experiences of solidarity and domination in

health care settings. *Gender & Society*, 10, 24-41.

Stevens, P. E. (1998). The Experiences of lesbians of color in health care encounters:

Narrative insights for improving access and quality. *Journal of Lesbian Studies*, 2

(1), 77-94.

Sutherland, K., Leatherman, S., Law, S., Verma, J., & Petersen, S. (2012). Chartbook:

Shining a light on the quality of healthcare in Canada. *HealthcarePapers, 12*(1),

10-24.

Steele, L. S., Ross, L. E., Dobinson, C., Veldhuizen, S., & Tinmouth, J. M. (2009). Women's sexual orientation and health: results from a Canadian population-based survey. *Women & Health*, 49(5):353-67.

Stuart, L. (2008). *L word: Insights on lesbian health*. Retrieved July, 21, 2008 from the Women's Health Matters website http://www.womenshealthmatters.ca/resources /show_res.cfm?ID=42708

Taylor, Y. (2005). Classed in a classless climate. *Feminism & Psychology*, 15(4), 491-500.

Taylor, Y. (2005b). The Gap and how to mind it: Intersections of class and sexuality. *Sociological Research Online*, 10 (3), n.p.

Tjepkema, M. (2008). Health care use among gay, lesbian and bisexual Canadians. *Health Reports/Statistics Canada,* 19(1),53-64.

Valverde, M. (1985). *Sex, power and pleasure.* Toronto: The Women's Press.

Vosko, L. F. (2003). The Pasts (and futures) of feminist political economy in Canada: Reviving the debate. In Andrew, C. (Ed.). *Studies in political economy: Developments in feminism* (pp.55-84). Toronto: Women's Press.

Wallace, S. P., Cochran, S. D., Durazo, E. M., & Ford, C. L. (2011). *The health of aging lesbian, gay and bisexual adults in California.* Policy Brief. UCLA Center for Health Policy Research, PB2011-2, 1-8.

Warner, Michael. (1991). Introduction: Far of a queer planet. *Social Text*, 9(4), 3–17

Weston, K. (1996). *Render me, gender me: Lesbians talk sex, class, color, nation, studmuffins*. New York: Columbia University Press.

Weston, K. (2009). The lady vanishes: On never knowing, quite, who is a lesbian.

Journal of Lesbian Studies, *13*, 136–148

Weitz, T., & Estes, C. L. (2001). Adding aging and gender to the women's health agenda. *Journal of Women & Aging*, 13(2), 3-20.

Wiktorowicz, M.E. (2006). Health care systems in evolution, chapter 11. In Raphael, D., Bryant, T., & Rioux, M. *Staying alive: Critical perspectives on health, illness, and health care*. Toronto: Canadian Scholars Press. 241-262.

Williams, A.M. (1996). "The Development of home care in Ontario: A Critical geographical analysis", *Social Science & Medicine*, 42(6):937-948.

Williams, A. M. (2002). Changing geographies of care: employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine*, 55(1), 141-54.

Williams, B. (1994). Patient satisfaction: A valid concept? *Social Science & Medicine*, 38 (4), 509-516.

Wilson, P. A., & Yoshikawa, H. (2007). Improving access to health care among African-American, Asian and Pacific Islander, and Latino lesbian, gay, and bisexual populations. In I. H. Meyer & M. E. Northridge (Eds.), *The health of sexual minorities: Public health perspectives on lesbian, gay, bisexual, and transgender populations* (pp. 607-637). New York: Springer.

Wilton, T. (1998). Gender, sexuality and healthcare: Improving services. In Doyal, L. (Ed.). *Women and health services* (pp. 147-162). Great Britain: Open University Press.

Wilton, T. (2000). *Sexuality in health and social Care: A Textbook*. Buckingham: Open

University Press.

Yin, R.K. (2003). *Case study research: Design and methods,* 3rd Ed. Thousand Oaks,

California: Sage Publications.

Appendices

Appendix A: Interview Dates and Sources of Referral

No.	Dates Interviewed	Source for Study Information
1	May 3 2011 May 9 2011	Heard about from a friend
2	May 15 2011	Met at an LGBTQ event
3	May 23 2011	Heard about from a friend
4	June 23 2011	Heard about from a friend in same LGBTQ social group
5	July 29 2011	Saw ad on an online LGBTQ health list-serve
6	Aug 19 2011	Saw flyer at an LGBTQ social organization
7	Sep 3 2011	Heard about from a friend
8	Sep 19 2011	Heard about from a friend
9	Oct 3 2011	Heard about from a friend
10	Oct 3 2011	Heard about from a friend
11	Nov 14 2011	Saw flyer at an LGBTQ social organization
12	Apr 3 2012	Heard about from a friend who saw flyer at an LGBTQ organization
13	Apr 30 2012	Saw flyer at an LGBTQ organization
14	May 15 2012	Saw flyer at an LGBTQ organization and online LGBTQ health list-serve
15	June 1 2012	Heard about from a friend
16	June 19 2012	Saw a flyer, couldn't remember where

Appendix B: Study Interview Guide

Part 1. Overall health and support needs
First I'd like to ask you a few questions about your health and social support needs

1) Tell me please about your overall health right now?

2) Tell me about your expectations for your health as you age?
   Probe: How do you expect/imagine that your health and care needs will be/ change in the next 5 years? 10 years

3) Can you tell me about your current health care providers?
   Probe: Can you tell me about how often you see them?
   Can you tell me about your relationship with them?
   Are you out to your care provider? Can you tell me what some of your reasons are for this? Can you tell me how you disclosed/came out to them?

4) Can you tell me in what ways (if any) has your sexuality affected your relationship with your health care providers in the past?
   (Probe) Is it important for you to have lesbian/gay identified care providers?
   Can you tell me about some of your reasons for this?

5) What types of supports do you need in your everyday?
   Probe: physical, emotional, mental, practical (housekeeping, transportation, finances, etc.)

6) Who can you turn to for support?
   Probe: who can you turn to for emotional support? Who can you turn to for practical support (such as transportation, money, etc.)?

7) Do you have children?
   Probe (If yes): Ages? In what ways are they able to help you when you need it?

8) Can you tell me about your family members?
   Probes: Who are your significant family members now? Can you tell me about your relationship with them?
   (Who were your significant family in the past?)

   Probe (if partner is mentioned): Can you tell me about them/ can you tell me about your relationship with them?
   (Probe about demographics, relationship, types of care if provided)

9) Are you connected to any lesbian and gay communities?
   Probe (If Yes): Can you tell me about that?
   How has your relationship/ involvement with that community changed as you have gotten older?
   Probe (If Not): What are some of the reasons that you decided not to be? Were you connected to any communities in the past? How has this changed?

10) Tell me about any other communities that you are connected to right now?
    Probe (If Yes): Can you tell me about that?
    How has your relationship/ involvement with that community changed as you have gotten older?

11) Do you currently act as a caregiver to anyone?
    Probe (If Yes): Can tell me about that? How does this impact your own health and care needs? How do you imagine this may impact your health in the future?
    Probe (If No): Have you acted as a caregiver to someone in the past? Can tell me about that? How did that impact your own health and care needs?
    Probe (If No): Do you imagine that you may become a caregiver to anyone in the future? Can you tell me about that? How do you imagine this may impact your health?

Part 2. Home Care Experiences:

Now I'd like to talk to you about your experiences receiving home care services

1) Are you receiving home care services from the CCAC right now?
   Probes (If Yes): Can tell me about that?
   What kind of care/services do you receive?
   How has this changed over time?
   Do you receive care from the public system/community/private care?
   Can you tell me how many hours of care you receive a week, and what tasks?
   Can you tell me about your caregiver(s)?
   Do you have regular personnel? Can you tell me about them (demographics)?
   Are you allowed any choices/flexibility in terms of caregivers and scheduling of care? Can you tell me about that?

2) How did you start using publicly funded (CCAC) home care services?
   Probe: Can you tell about why you decided to use these services? How has this changed over time?
   (If applies) Can you tell me why you stopped using these services?

3) Can you tell me about your experience of accessing home care services?
   Probe: Can you tell me how you accessed these services? What prompted you to seek these services? Can you tell me about thus process? How this has changed?

Probe: Can you tell me of any difficulties or barriers you experienced accessing these services? (If yes): How did you overcome these barriers?

4) (If Not receiving home care right now) Can you tell me about your experience(s) receiving/accessing home care services in the past?
What kind of care/services did you receive?
Did you receive care from the public system/community/ private care?
Can you tell me how many hours of care did you receive a week, and what tasks?
Can you tell me about your caregivers?
Did you have regular personnel?
Were you allowed any choices/flexibility in terms of caregivers and scheduling of care? Can you tell me about that?

5) Can you tell about your positive experiences with home care services?
Probe: What made those experiences positive for you?

6) Can you tell me about your negative experiences with home care services?
Probe: What made those experiences negative for you?

7) Based on your previous experiences, can you tell me if you have concerns about needing/using home care services in the future?
Probe: Do you have any concerns about using home care services in the future?

8) Are there other support services that you pay for out of your pocket?
Probe (If yes): Can you tell me about that? How does this experience compare to the home care services experiences? How has this changed over time?
Probe (If No) Do you think that you may need more care in the future? What do you think this would look like?

9) Are there any others supports that you use that are provided on an informal/volunteer basis (not through CCAC)? (friend-based circle of care?)
Probe (If yes): Can you tell me about that? How does this experience compare to the home care services experiences? How has this changed over time?

Probe (If No) Do you think that you may need more care in the future? What do you think this would look like?

10) Are you out to your caregivers? (or were you out to your caregivers?)
Probe (If yes): Can you tell me about some of your reasons for that? How did you come out to your caregivers or how did they find out? (Home, literature in house…) Can you tell me about any reservations you may have about disclosing to your future care providers?

Probe (If no): Can you tell me about some of the reasons that you have not come out to your caregivers? Do you have any reservations about your caregivers finding out? Can you tell me about that? How do you think they may find out?

11) Tell me in what way (if any) has your sexuality affected your home care experience? *(Probe): Do you have any concerns or reservations about home care workers or agencies knowing about your sexual orientation in the future? Tell me in what ways do you imagine that it can impact home care services…? Based on your experiences with other health care providers, how do imagine that this may impact home care service in the future?*

Part 3. Quality of Care:

Now I'd like to talk to you about your quality home care

1) Can you tell me what "quality home care" means to you?
Probe: What are some factors that determine quality of care (or positive/good care) for you?

2) Would you describe the home care you receive (have received in the past) right now as being "quality home care?"
Probe: How has this changed over time?
(If yes) What about it makes it quality care for you?
(If no) How would the home care service need to change for this to be true?
(If applies, differences between experiences/types of care/ providers?)

3) Is anything you think home care workers/agencies need to know to improve the quality of home care services for lesbian/bisexual older women in the future?

Wrap up: Is there anything else/ more that you would like to share with me about your experience with home care services?

Participant Demographics Sheet

Date: _____

Participant ID_____

1) What is your date of birth (Month/Year)? _____/_____

2) What country were you born in? _____

3) If born outside of Canada, what year did you immigrate to Canada? _____

4) What is your first language? _____

5) How do you identify in terms of your sexuality/sexual orientation?

   Lesbian/ Bisexual/ Queer/ Gay/ Other: _____

6) How do you identify in terms of your gender/gender expression? _____

7) What is your ethnicity/ ethnic background?

   _____

8) What is the highest level of education that you have achieved?

   Elementary School/ High School/ College/Undergraduate/ Graduate School

9) What is your annual income level? (please circle one)

   $ 0 - 9, 999/ $10, 000 - 19, 999 / $20,000 - 29, 000/
   $30, 000 - 39,000/ $40,000 - 49,000/ $50,000 -59,000/   60, 000+

10) What class background do you identify with? (e.g. working class, middle class, etc.)
    _____

11) What is your relationship status?

    Married/ Common-in-law/ Widowed/ Divorced/ Single/ Other: _____

12) What is your occupation? _____

13) If currently not working, what was your occupation? _____

Appendix C: Guiding Study Questions

1) What are older lesbian and bisexual women's experiences of accessing and receiving home

   care?

2) How do demographic, contextual and socio-economic differences across women influence

   how they are able to access home care and how they perceive this experience?

3) How do women's sexualities or sexual orientation affect their home care service

   experiences?

4) What do women identify as barriers to receiving quality home care services and what

   practices and policies facilitate access?

5) What do they identify as most important to them in terms of how and what kind of home

   care is needed and provided?

6) Do current home care services accommodate older lesbian and bisexual women who need

   to access and receive quality home care services?

7) How do older lesbian and bisexual women define quality home care?

Appendix D: Code Book

Demographics
- Location
- SES/ income/ insurance
- Family/ relationships
- Gender
- Age
- Occupation

Health
- Medical model
- Illnesses/health issues
- Gender & age (ideas about hardship/suffering)
- Dis/ability and sick-role
- Expectations

Access
- How
- When
- Why
- Process
- Changes over time

Care
- Type (PSW/ Nurse)
- By whom
- For how long
- Home care
- Other (community, volunteer, neighbours)

Support
- Everyday
- Mobility devices
- House modifications
- Financial aid/ access to services

Caregivers
- Description
- Type
- How many
- Relationship

Emotion
- Joy/ Love
- Stress/Conflict
- Anticipation of support
- Managing/ coping

Sexuality
- Sexual identity
- Relationships (past and present)
- Disclosure/ Monitoring
- Past experiences with health providers
- In relation to home care
- Relationship to community/ LGBTQ

Quality
- Skill
- Personality/ Mood
- Social support/ isolation
- Training
- Affirmation/ comfort
- Consistency/ reliability
- Task-specific

Scarcity
- Rationing
- Gatekeeping
- "Abusing the system"
- Definition of "need" & "want"
- Unmet need

Appendix E: Examples of Preliminary Study Themes

Theme	Description
Being "the only lesbian/gay client"	Participants indicated that they felt that they were the only lesbian or gay client and that this meant that they felt they had to educate their caregivers.
Resilience vs. Stress (continual monitoring of safety/coming out) – Identity Monitoring	Continual monitoring of their identity and disclosure occurred when participants accessed and/or received home care. Participants also reported feeling stress and worry about the potential consequences of their coming out in the context of receiving care.
Supplementing formal-care (importance of informal networks)	Participants typically relied on a combination of informal care giving arrangements and 'families of choice' to supplement formal caregiving.
Quality in home care = respect (the limits of 'client-centered' care)	Quality home care was seen as care in which home care workers were knowledgeable in terms of skill and practice, arrived on time and consistently, were personable and compassionate. Participants also reported a desire for 'comfort' to be included in how quality is determined; this desire meant a way of making sure that they had a caregiver that respected them.
Type of Care matters	Participants indicated that they had different expectations of how medical versus supportive care should be provided; efficiency and competency were identified as more important in the former and being personable and engaged more important in the latter.
Experience in Social Services	Participants who identified previous professional background in health/social services and/ or experience arranging this type of service for a friend/family member relied on this knowledge to 'navigate' the home care system; they also used their experiences to articulate expectations of quality of care.

Appendix F: Participants' Socio-demographic Characteristics

Measure	Frequency/ Range
Mean Age	63.9 years (Range: 55 - 72 years old)
Sexuality*	7 Lesbian 2 Lesbian/Queer [1] Lesbian/Queer/Dyke 1 Bisexual 4 Gay 1 Women-loving-woman/ *femme*[‡]
Ethnicity/ Race*	2 Jewish 1 Anglo-Irish 1 Dutch 1 English German 1 Chinese/South Asian/Caribbean/Caucasian 1 French Canadian 1 English Canadian 1 Hungarian/English 1 Welsh 1 British 1 Scottish/Irish 1 English Irish 1 French Acadian/ Aboriginal (Micmac) 1 Aboriginal 1 Aboriginal (Dene)
Education	1 Grade 10 4 High School 7 College or Undergraduate 4 Graduate degree
Employment Status	11 Retired 1 working 4 on disability leave
Household Income	20, 000 to 60,000+
Health Conditions	Hip replacement, Lymphoma, Blindness, Arthritis, Fibromyalgia, Knee Surgery, Ankle surgery, Colostomy, Spinal Fusion, Diabetes, Bipolar Disorder, Brain Injury, Depression, Respiratory Infection, Amputation, Chronic Pain, Sleep apnoea, Stroke, Psoriasis, Brain cancer, Heart Attack, Shoulder surgery, Liver Cirrhosis
Relationship Status	6 single, 1 widowed, 2 common-in law, 7 married
Living Situation	7 lived alone, 9 lived with partner
Children (Yes/ No)	9 No, 7 Yes
Time on Home Care	Ranged from 2 weeks to 15 years; 9 short term and 7 long term users
Type of Home Care	RN/RPN, PSW, Other: OT, SPT, Meals on Wheels, Wheel Trans†

* Self-identification, open-ended category

[‡]*Note:* This participant chose to identify as herself as *femme* (and explained that this is French for woman and that this is how some lesbians in Quebec identified themselves when and where she came out; did not refer to herself as 'femme' for the purpose of a claiming a lesbian gender identity)

†All participants, but 1, primarily accessed either personal care (PSW) and/or nursing (RN/RPN)

Appendix G: Informed Consent Form and Ethics Approval Certificate

Study Name: Queering Home Care: Older Lesbian and Bisexual Women's Experiences of Accessing and Receiving Home Care Services in Ontario.

Researchers: Alisa Grigorovich

Purpose of the Research: To gain information about older lesbian and bisexual women's experiences of accessing and receiving home care services in Ontario.

What You Will Be Asked to Do in the Research: If you agree to participate in the study, you will be asked to participate in an interview during which you will be asked a series of open-ended questions about your experiences with home care services. The interview will take approximately one to two hours and will be audio taped.

Risks and Discomforts: I do not foresee any risks or discomfort from your participation in the research.

Benefits of the Research and Benefits to You: While there are no direct benefits to you for participating, the information that you provide may help professionals working in the future with older lesbian and bisexual women. As a token of appreciation for participating in the study you will be offered a gift certificate in the amount of $20 to the grocery store, pharmacy or coffee shop of your choice.

Voluntary Participation/ Withdrawal from the Study: Participation in this study is entirely voluntary. You can stop participating in the study at any time, for any reason, if you so decide. If you decide to stop participating, you will still be eligible to receive the promised pay for agreeing to be in the project. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

Confidentiality: All information you supply during the research will be held in confidence and unless you specifically indicate your consent, your name will not appear in any report or publication of the research. The data collected in the research process will include digital audio recording and researcher handwritten notes. Your data will be safely stored in a locked facility and only research staff will have access to this information. The data will be stored for the period of seven years and will be archived after the period of the study in the Graduate Gender, Sexuality and Women's Study's office at Founders College, Room 206. Confidentiality will be provided to the fullest extent possible by law.

Questions About the Research? If you have questions about the research in general or about your role in the study, please feel free to contact me by email (xxxx@yorku.ca) or my Graduate Supervisor - Dr. Pat Armstrong at (xxx) xxx-xxxx, extension xxxx or by e-mail (xxxx@yorku.ca). You may also contact my department, the School of Women's Studies, 206 Founders, York University, 4700 Keele Street, M3J2 H8, (416) 650-8144. This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, please contact the Sr. Manager & Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University (telephone 416-736-5914 or e-mail ore@yorku.ca).

Legal Rights and Signatures:

I _____, consent to participate in "Queering Home Care: Older Lesbian and Bisexual Women's Experiences of Accessing and Receiving Home Care Services" conducted by graduate student Alisa Grigorovich. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

Signature_____   **Date**_____
Participant

Signature_____   **Date**_____
Principal Investigator

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UNIVERSITÉ
UNIVERSITY

Certificate #:	STU 2011 - 007
Approval Period:	02/07/11-02/07/12

Memo

To: Alisa Grigorovich, School of Women's Studies, xxxx@yorku.ca

From: Alison M. Collins-Mrakas, Sr. Manager and Policy Advisor, Research Ethics
(on behalf of Wade Cook, Chair, Human Participants Review Committee)

Date: **Monday 7th February, 2011**

Re: Ethics Review

Queering Home Care: Older Lesbian and Bisexual Women's Experiences of Accessing and Receiving Care Services in Toronto

I am writing to inform you that the Human Participants Review Sub-Committee has reviewed and approved the above project.

Should you have any questions, please feel free to contact me at: 416-736-5914 or via email at: acollins@yorku.ca.

Yours sincerely,

Alison M. Collins-Mrakas M.Sc., LLM
Sr. Manager and Policy Advisor,
Office of Research Ethics

Appendix H - List of Organizations, Groups and List-serves Where Study Information Was Distributed

2Spirits (Toronto)
Access Alliance (Toronto)
ACT (AIDS Committee of Toronto)
Alzheimer's Society of Ontario
Arthritis Society of Ontario
Baycrest Health Centre
Canadian Gay and Lesbian Archives (Toronto)
Care Watch (Ontario)
CARP (Canadian Association of Retired People)
CATIE
Central Neighborhood House (Toronto)
Centre for Addiction and Mental Health (Psychiatry)
Centretown Community Health Centre
Christie Gardens (Toronto)
DAWN (DisAbled Women's Network)
Dick Moore and Associates
East End Community Health Centre
Egale (National)
Family Services Toronto (FST)
Fifty Plus Toronto
Forty Plus Activity Group
Gay Okanagan Network
Gay York Region (York)
Gilda's Club Toronto
Gushing Grannies (Toronto)
Hanging Out List-serve
Heart & Stroke Foundation Support Groups (Ontario)
Hola
Holland Orthopedic and Arthritic Centre
Inside Out Lesbian & Gay Film Festival
LGBT caregiver list serve (primarily U.S. based but also has Canadian people on it)
LGBTQ Counseling Program @ David Kelley Services (Toronto)
Lyba Spring Sexual Health Education and Consulting Services
March of Dimes Support Groups (Ontario)
Miles Nadal Jewish Community Centre
MS Society of Ontario
Native Canadian Centre of Toronto

North York Women's Centre
Older Women's Network (Ontario)
Ontario Health Coalition (Ontario)
Ontario Lesbian Social Network
OPSEU (Ontario Public Service Employees Union)
Ottawa Senior Pride Network
Out in Kingston (Kingston)
Out on the Shelf (Guelph)
Parkdale Community Health Centre (Toronto)
Personal Support Network of Ontario
PFLAG (Ontario)
Pink Triangle Services (Ottawa)
Pride Organizations (Toronto, Durham, Tri-Pride, Hamilton, Peel, Windsor)
Queen Community Health Centre (Toronto)
Rainbow Health Network list-serve (Ontario)
Rainbow Health Ontario (Ontario)
Second Mile Club of Toronto
Senior Pride Network (Ontario)
Seniors for Seniors
Sherbourne Health Centre (Toronto)
Silver Foxes (Toronto)
Sistering
St. Anne's Place (Toronto)
Storefront Humber
Sunshine Centres for Seniors (Toronto)
The 519 Community Centre (Toronto)
The Good Companions
The Well (Hamilton)
Toronto Bisexual Network/ Toronto Women's Bisexual Network
Toronto LGBT Home care company
Toronto Metropolitan Community Church
University Women's Club of Toronto
Wellspring Cancer Support Centre (Toronto)
West Toronto Support Services for Toronto
Women's Health in Women's Hands Community Health Centre (Toronto)
Women's Support Network of York Region
Woodgreen Community Services (Toronto)
WRIB (Women for Recreation, Information and Business) (Ontario)