

# Great Expectations for Lesbians to Provide Unpaid Care

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## Abstract

Lesbian unpaid caregivers face significant challenges in their caregiving because a seeming lack of additional family responsibilities constructs them as model caregivers, while they and their partners continue to experience homophobia and heterosexism. The intersection of female gender, lesbian sexual orientation and heteronormative public policies disadvantages lesbians financially, socially and in health related contexts.

## Résumé

Les lesbiennes qui ne sont pas payées qui donnent des soins à de proches dépendants font face à un défi significatif dans leur rôle de pourvoyeuse de soins, à cause du manque apparent de responsabilités familiale additionnelles les définissent comme un modèle de personnes qui donnent des soins à un proche dépendant, tandis que leur partenaires continuent à faire face à l'homophobie et à l'hétérosexisme. Le croisement du sexe féminin, de l'orientation sexuelle lesbienne et les politique publiques hétéro-normatives défavorisent les lesbiennes financièrement, socialement et dans les contextes liés à la santé.

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Women provide the majority of unpaid care to children, youth, adults and seniors who are affected by disability, onset illness, or health limitation in Nova Scotia and across Canada. Lesbians occupy a particular space within the caregiving dynamic wherein expectations of care, negative health and financial implications of unpaid caregiving are likely to be intensified by gender inappropriate and heteronormative public policy.

In this paper I seek to illustrate how the unpaid caregiving experience holds important differences for lesbians. Three key issues emerge from the research: first, the intersection of female gender and lesbian sexual orientation creates greater financial insecurity; second, heteronormative policies unfairly disadvantage lesbians financially, socially and in health related contexts; and third, lesbians are seen as model caregivers yet experience homophobia and a lack of partner relationship recognition by families as well as healthcare and social service providers.

This paper is based on an analysis of a detailed research report by Beagan *et al.* of The Healthy Balance Research Program, *Caregiver Portraits: Narratives of 14 Women Caregivers in Nova Scotia* (2005a). The three portraits (micro-ethnographies) of lesbian unpaid caregivers from *Caregiver Portraits* provide the main sources for my analysis. The theoretical framework used to analyze the micro-ethnographies of lesbian unpaid caregivers incorporates queer theory as a means to understand the impact of heteronormativity on the lives of lesbian caregivers. The term "heteronormativity" describes a set of interconnected

institutional structures, social practices, legislation and policies which reinforce heterosexuality as a social, political, economic, medical and family norm (Berlant and Warner 1998). In the context of unpaid caregiving, for example, a hospital policy which admits only "next of kin" as visitors unfairly excludes lesbian partners. Despite the adoption of *Bill C-23* enacting same sex marriage legislation in Canada in 2001, heterosexual partnerships remain a deeply instituted norm.

The assumption of heterosexuality in language, policy and visual surroundings, particularly in health care settings, leads to silencing and substandard care (Goldberg 2006). Heteronormative environments create stress for lesbians who are considering disclosing their sexual orientation in a situation which may not feel welcoming or safe. Failure to disclose sexual orientation may result in not asking for or being offered the help and support which is given to heterosexuals whose family responsibilities are assumed. Lesbian-identified women as a cultural group share characteristics, cultural experiences, social events and types of family units that constitute a community. Yet these experiences often fail to be recognized as legitimate and familial.

The research of Beagan *et al.* (2005b) is unique in the literature as it focuses on Canadian women, explores the impact of gender within the caregiving dynamic, and highlights some important differences for heterosexual female and lesbian caregivers. Other caregiving studies relevant to the gay community, including those by Cohen and Murray (2006), Fredriksen (1999) and Hash (2001; 2006), emphasize both the gay male and lesbian experience in the context of the United States, and these studies have been groundbreaking in recognizing the barriers to resources and support for lesbian and gay caregivers. Fredriksen reveals unnecessarily high rates of harassment, burden, strain and employment loss for gay male and lesbian caregivers (1999). Hash

(2001) describes the discrimination resulting from "next of kin" policies and the prevalence of a model "gay" caregiver attitude in families due to ignorance about same sex families and the perceived lack of childcare or other familial responsibilities. This literature exposes the differences in the caregiving experience due to sexual orientation yet gender remains a relatively unexamined category. The importance of female gender intersecting with lesbian sexual orientation in mediating the resources available to individual caregivers, the income earning potential of lesbian caregivers, and female family role expectations of lesbians are clearly evidenced by the *Caregiver Portraits of Beagan et al.* (2005a)

The research methods used in the *Snapshots* study by Beagan *et al.* (2005b) also depart from traditional forms. This study consists of micro-ethnographies of 14 primary caregivers from 7 different sociocultural groups using 24 hours of participant observation and semi-structured interviews. The researchers spent several hours with the participants over the course of many weeks at various times of day totaling 24 hours. The participants chose the best times for the contact and observation to occur. Researchers kept detailed field notes and shared in conversation with the participants. One hour was dedicated to a semi-structured in-depth interview which was recorded and later transcribed and analyzed. The interviewer asked about the positive and negative aspects of caregiving related to the emotional and physical demands of this work, encountering moral and/or ethical dilemmas and finally the services, policies and programs available. Narrative accounts have been composed from the field notes and interviews to present a holistic picture of each woman's experience. The analysis incorporates sociologist W.I. Thomas's (1929) theory that everything is real in its effect. Therefore, women who are unaware of resources available to them are effectively denied these resources, the consequences of

which are apparent in their struggles. Individual women in this context are seen as able to flourish to the degree that each has knowledge of and access to the necessary resources.

In 2005, the Caregiver Portraits team led by Dr. Brenda Beagan published *Caregiver Portraits* and a condensed report Entitled *Snapshots of the Lives of Caregivers: "I Do it Because I Love Her and I Care."* This team was part of the overall research of the Healthy Balance Research Program (HBRP).<sup>1</sup> Three other research teams included: a Survey team led by Dr. Janice Keefe, who contributed a population-based survey of unpaid caregivers in Nova Scotia; a Secondary Analysis team headed by Dr. Shelly Phipps, who performed secondary analysis of Statistics Canada General Social Survey data, 2002, and a National Longitudinal Survey of Children and Youth, 1994-2000; and a Qualitative Research team led by Dr. Jacqueline Gahagan, who conducted 19 focus groups in diverse communities of Nova Scotia.

From the research we know that policy can exacerbate the challenges faced by lesbians as situations of unpaid caregiving arise. Unpaid caregiving is one area where lesbians are more likely to experience barriers and challenges to achieving positive health, employment and financial supports because of policy that fails to recognize and validate lesbians and lesbian partnerships. This article conducts a feminist and queer theory exploration of the nuances of the unpaid caregiving dynamic in order to respond to gender differentiated expectations and perceived obligations for lesbians to perform unpaid care.

### **Gender and Caregiving**

Gender role stereotyping has been identified as a key factor influencing a dominant social expectation for women to provide unpaid care as needed (Armstrong and Armstrong 2001). It is often assumed that women across identities and communities have similar resources and

common experiences of caregiving. This is not the case for lesbians who tend to experience an intensified gender role expectation within families due to a perception that they lack a partner or have other family obligations, since they are less likely to be married or to have dependent children. This intensified gender role expectation has important implications for lesbian health and well-being.

HBRP findings from the Qualitative Research team make clear that unpaid caregiving affects women's employment, health and well-being. In addition, survey data describing the prevalence of women doing unpaid care has exposed gender differences for consideration. These quantitative findings suggest nearly one-third of Nova Scotian women provided unpaid care in 2005 (Keefe *et al.* 2006, 2). Prevailing social attitudes and institutional policy constructs women as natural carers. On the one hand, not only are women more likely to be doing unpaid caregiving, but they are also likely to provide different types of care than do men. Women tend to be more involved in providing intense personal, hygienic and daily caregiving (Keefe *et al.* 2006, 6). Some of these activities include bathing, administering medications, catheterization, blood sugar checks, colostomy care and feeding tube administration (Gahagan *et al.* 2004). On the other hand, men are more likely to provide assistance with transportation, shopping, house maintenance and outdoor work, which tend to be less frequent and less intensive caregiving activities (Keefe *et al.* 2006, 6). The type and frequency of caregiving activity has a negative impact on the health of the caregiver. Caregivers report health impacts including, but not limited to, a decline in mental health such as negative stress, depression, helplessness and loneliness (Gahagan *et al.* 2004, 33).

As women are more often taking on intense caregiving with very few support mechanisms in place, women are also found to suffer from poverty, isolation and illness associated with being a primary and

often solo caregiver. The health impact of caregiving is particularly obvious in cases where lone mothers are caring for a child with a disability (Burton *et al.* 2008).

Gender roles driven by community expectations tend to influence the activities that women take on. Caregiving has been assigned to women through socialization experiences and education as an activity specific to the female gender. Cutbacks in health care spending, which result in patients needing care outside of the hospital more often and for longer periods of time, as well as the inadequacy of home care supports and lack of appropriate policy to support dependent care, reinforces a social expectation of family caregiving (Armstrong and Armstrong 2001). The person in the family or community who takes on this care is more often than not a woman. Research also illustrates that families have become smaller, more spread out geographically and less able to provide the intensive care needed by vulnerable members (Shillington 2004). Family policy, on the other hand, has remained static, influenced by a pervasive perception that caregiving is primarily a family responsibility. By "family responsibility" it is clear that caregiving for children and dependent family members is commonly viewed as the private responsibility of women. Research has illustrated that "Families are likely to be characterized by inequality among members and by a sexual division of labour that leaves women doing most of the domestic work" (Armstrong and Armstrong 2001, 28). Public policy governing child care, respite and elder care remains underdeveloped, allowing responsibility for caring for dependent family members to be re-privatized as a result of cuts to social programs, therefore shouldering women with this responsibility (Freiler *et al.* 2001).

Evidence from three case studies of lesbian unpaid caregivers named Maggie, Melissa and Chris from the HBRP micro-ethnography report, *Caregiver Portraits*, illustrates how public policy reinforces an expectation that lesbians are

to provide unpaid care and creates particular challenges to providing such care. The highlighted challenges result from heteronormative policy development and create disadvantages that reinforce inequality among women and between women and men.

### **Maggie's Portrait**

Maggie is a woman in her fifties who identifies as a lesbian and a woman with disabilities. Maggie was designated within her family as the logical caregiver for her mother. Maggie's sister is a heterosexual and has a husband and children, and her brother, while not considered an adequate caregiver, does the finances. Maggie is an unpaid caregiver to her mother, who suffers from Alzheimer disease and arthritis that requires her to use a walker. Maggie's caregiving began when her mother was living independently; at that time, Maggie was bringing her mother groceries, taking her to appointments, assisting her with her finances and checking in with her. As required by her mother's health, Maggie has provided her with intense live-in care for months at a time. Maggie's caregiving continues in a supervisory and coordinating role now that her mother lives in a nursing home.

Much of Maggie's caregiving time has been spent coordinating medical care and advocating for pension benefits and long-term care access on her mother's behalf. During this time, Maggie's experience with resources in Nova Scotia such as home care and physiotherapy service were particularly frustrating. While providing live-in care for her mother, Maggie spent several weeks in severe stress; she was suffering from ill health yet she was unable to be relieved by provincial home care workers because of rules about waiting times. Accessible and affordable travel to care appointments in the hospital, such as physiotherapy, created additional challenges for Maggie and her mother, particularly after Maggie's mother had a total knee replacement.

Maggie's leisure time, personal relationships, professional opportunities and financial well-being have all been impacted by her caregiving. Maggie has experienced negative health effects from time-stress, such as depression and fatigue, when attempting to coordinate medical appointments, her mother's pension and long-term care access. This impact has been intensified by the social marginalization Maggie experiences because she is unemployed and lacks access to lesbian community events because of her poor health and her caregiving. Maggie is unmarried, does not have a partner, and reveals that her caregiving caused significant stress on a previous partner relationship. Maggie also has a low income, as she has had to access Employment Support and Income Assistance in order to support her health and caregiving. It is evident that caregiving has meant that at times Maggie has lived in poverty. Maggie has spent a significant amount of time caregiving that has not been balanced with time spent on a career, personal leisure, health or well-being. Maggie has been able to complete an education program and find a job, now that her mother is in long-term care.

Maggie herself voices how being a lesbian, in addition to being a woman, has put substantial pressure on her to be the caregiver and has caused a negative impact on the health of her partner relationships:

Many lesbians who have never been married and never had children, etc.,...I think [caregiving] can fall to them because they are "single" and a woman. I think that lesbians, because they're women, end up being caregivers. If there is a couple, like what happened with me and my ex, you know, you both end up being caregivers rather than just one, just the daughter.

(Beagan *et al.* 2005a, 263)

In the end, the strain on this lesbian

partner relationship caused it to break down. Homophobia also exists in Maggie's life as her mother refuses to accept and support her lesbian identity.

### **Melissa's Portrait**

Melissa is a woman in her forties who identifies as a lesbian and caregiver for her mother. Melissa provides full-time unpaid care to her mother who lives with her and her partner Susan. Melissa is a university student who finances her education with student loans while her partner Susan receives a modest disability pension. Melissa's mother is 72 years old and suffers from Parkinson's disease and diabetes; she has also had health interventions including knee replacements.

Melissa has had lengthy experience in the role of caregiver, to the point that it has become a main part of her identity. At the age of twelve, under her grandmother's tutelage, Melissa took on the role of maintaining the household. Melissa's two older brothers, on the other hand, were never expected to take on any caregiving responsibilities. Melissa's expected role within the family and community has meant that she is primarily responsible for her mother's daily care.

Melissa finds that time-stress is an issue she struggles with on a daily basis. In her own words, "There is no 'off you go' for me, it's 'Okay, how much time do I have to do this? How much time do I have to do that? Okay, do I have fifteen minutes to sit down and read a newspaper?' Every minute of my day is accounted for" (Beagan *et al.* 2005a, 213).

The provincial home care program that Melissa uses is delivered in a way that increases rather than reduces her stress. The main concerns with delivery are privacy issues and potential circumstances that entail dealing with homophobia when unfamiliar home care workers visit. The inconsistency of this system means that Melissa is forced to "come out" to a new home care worker weekly. Melissa's discomfort with the delivery mechanism of

this system comes from experiences of facing homophobia and heterosexism with health care providers when attempting to access services as a caregiver for her mother. For example, Melissa is asked, "Well, how does your mother feel about you having your alternative lifestyle going on with your female partner in the household? I've had people ask me that question - professionals. Why is my sexuality relevant? Would the sexuality of straight people be as relevant?" (Beagan *et al.* 2005a, 211). Melissa succinctly describes these experiences of homophobia and heterosexism as challenges to her caregiving.

Melissa has encountered particularly troublesome situations of heterosexism. Melissa's mother was admitted to the intensive care unit at one point and the hospital policy was to allow only immediate family members to visit. This created stress for Melissa and her partner in negotiating with the hospital to make an "exception" to allow Melissa's obvious partner Susan to be considered family according to the hospital's definition. Melissa's negative experiences of homophobia and heterosexism with health care providers have influenced her opinion of this sector.

Melissa also documents experiencing struggles with verifying her power of attorney status for her mother's financial affairs. Without the status of a male to assert authority, Melissa is forced continuously to produce paperwork to prove her power of attorney status. Melissa's own financial situation is precarious as she is basically living on a loan which will have to be paid back within six months of completing her education.

### **Chris's Portrait**

Chris identifies both as a lesbian in her forties and a woman living with a disability who is providing unpaid care to her mother who has been diagnosed with multiple sclerosis. She previously provided palliative care to her father who suffered

from terminal cancer. Chris has been intermittently employed and has attended university, completing a Master's degree around her caregiving activities. The researcher interviewing Chris noted that, "Chris said it is the way of her family that they take care of parents when they get old. She also thinks it is her role as the daughter to be the caregiver: 'So that's the modeling that I had growing up, that's what, and it's always the daughter. So I thought that was my role'" (Beagan *et al.* 2005b, 21). Chris faces a struggle with social exclusion as well, being unable to spend time with her mother when she wants to, as her sexually abusive brother lives in her mother's home.

Chris also struggles financially. As she explains, "I had no money, you know. I lived off my Visa for probably three months. I'm still recovering from that, hopefully this summer will put me out of all my debts, I'm hoping. But I'm still recovering from my Dad's death a year and a half ago. Trying to, you know, get back on track financially" (Beagan *et al.* 2005b, 20).

The experiences of Chris, Melissa and Maggie (Beagan *et al.* 2005b) illustrate that lesbian caregivers struggle with greater barriers in this role due to homophobia while experiencing greater financial and health stress because of the intersection of gender and sexual orientation. Lesbian families tend to be disadvantaged by taxation policy that leaves them with fewer financial resources (Lahey 2001). Women earn less income in general, and when lesbian partner incomes are combined, they remain a lower income couple.

Challenges faced by women unpaid caregivers include struggles with financial security, gendered expectations to provide unpaid care, health implications and time-stress illness resulting from attempts to balance multiple family responsibilities, paid and unpaid work. In addition to challenges of caregiving related to being of the female gender, lesbians experience burdens and barriers to support in their unpaid caregiving role related to their sexual orientation, requiring a deeper analysis and

understanding of the gender- and equity-differentiated impact of public policy.

When it comes to unpaid caregiving, federal jurisdiction over public policy relevant to sexual orientation shapes the legal definition of marriage/spouse/family for the purpose of all legislation and policy that requires a familial relationship in order to be eligible for a benefit. Several patchwork federal government-sponsored options exist for unpaid caregivers meeting a definition of family, marriage and/or spousal unit in Canada. These include: Medical Expense Tax Credit; Caregiver Tax Credit and other similar income-dependent, limited, non-refundable tax credits; Compassionate Care Benefit/Employment Insurance; Canada Pension Plan; Old Age Security/Guaranteed Income Supplement (OAS/GIS); and Veteran Affairs programs. Some of these programs reflect the adoption of *Bill C-23* recognizing same sex spouses in Canada; however, some, such as those with Veteran Affairs, have been slow to change and are not yet distributing retroactive benefits.

Under Nova Scotia's provincial jurisdiction, measures for home care and financial support for unpaid caregivers often depend on recognition of a family unit, based on heteronormative assumptions of a male breadwinner and/or income dependency as opposed to needs-based framework. These include programs and services accessible through the Nova Scotia Department of Community Services, the Victorian Order of Nurses (VON), Home Care, Social Assistance, Employee Assistance policies and Labour Standards legislation and housing maintenance and renovation subsidies (property legislation).

As illustrated by the example of survivor pension benefits, which until 1998 were denied to same-sex spouses, the formal definition of family driving various federal and provincial legislative policies has not been extended to same-sex spouses in an equitable and universal manner. Lesbian unpaid caregivers experience a penalty

because of the lack of formal recognition of a same-sex partner or spouse. This penalty plays out in tangible ways that are often exacerbated by identifying as both lesbian and female. Yet, provided recognition of a same sex spouse or partner is granted within a particular policy or legislation, the model of measurement for income is gendered to favour male income-earners.

Melissa's experience highlights this financial inequality as she and her partner are ineligible for Compassionate Care leave benefits. The Compassionate Care Benefit is a federal initiative providing 26 weeks of caregiving leave to a person with 600 hours of employment in the last 52 weeks to care for a dying relative. Recent changes to this benefit extend access to same-sex partners and their families. However, gender barriers to accessing this benefit have not been removed. Despite the fact that same-sex couples may access this benefit, women are much less likely to qualify on the basis that women who are caregivers are more likely to work part time and to be in Melissa's situation (that is, in an education program where they do not qualify for such provisions), or, in her partner Susan's situation, receiving a disability pension that disqualifies her from Compassionate Care eligibility.

Provincial initiatives including housing renovation and maintenance subsidies to alter accommodations to support wheelchairs, lifts and so forth are minimal in compensation and require less than \$11,000 in annual family income to receive a maximum benefit of \$3,000. Medical Expense tax credits and Caregiver tax credits, on the other hand, are more useful to those who have a higher single earner family income. These financial mechanisms are not designed to maximize benefit to lesbian partners nor single lesbians living with an elderly care recipient, as their combined incomes would likely be lower than average incomes but high enough to disqualify them from benefit.

The heteronormative structure of federally legislated financial policies and tax

and transfer system benefits creates differential access to resources that have an impact on the lives of lesbians and families providing unpaid care (Lahey 2001).

Gender differences in employment patterns and opportunity have an impact on lesbians who are either single or partnered. Women are more likely to work part time and to be working in lower income sectors. The socio-economic reality is that women's incomes are much lower than men's incomes. Sexuality further affects women's incomes. Women who are racially identified and/or living with disabilities are additionally disadvantaged. Because lesbian women do not have access to the male economy in their conjugal relationships, they are disadvantaged by their sex and sexuality in income-earning potential (Lahey 2001, 7).

The unpaid caregiving that Maggie, Melissa and Chris have taken on is not at all unusual for women in Canada. Yet their lesbian identity and family partnerships may be considered outside of the social and policy norm. Despite the fact that sociologists recognize there is a range of family forms continuing to emerge in Canada, from same-sex couples to friends in surrogate family roles to relatives living together (Janz 2000), there is a reluctance to abandon the traditional nuclear family policy concept. Nevertheless, we know that unpaid caregiving in Canada is undertaken by persons who are related in various ways by blood, marriage, commitment, friendship or community, while within these classifications gay and lesbian relationships in particular may not be recognized as formal relationships which are eligible for program/policy support (Shillington 2004).

The experiences of women who identify as lesbian reveal an intensification of expectations to take on the unpaid caregiving role typically assigned to the female gender. If there are female heterosexual and lesbian siblings in the family where elderly parent(s) require care, there is a greater likelihood that lesbian siblings will take on this caregiving (Hash 2001). Lesbians may find themselves in a

predicament in terms of family dynamics as heteronormative policy and gender role stereotypes converge to idealize lesbians as "model" unpaid caregivers. The experiences of Melissa, Maggie and Chris illustrate that lesbians are perceived as unattached, available and natural individuals to fulfill the caregiver role. The challenges faced by lesbian unpaid caregivers in these case study examples reveal the double burden of gender and sexuality at the point where homophobia and heteronormativity intersect in policy and program delivery.

Maggie's experience highlights how lesbians are seen as model caregivers; she and her partner were each involved in unpaid caregiving for family members, which contributed to the breakdown of their relationship. Relationship recognition is an issue in Maggie's life both on an interpersonal level with her mother and in the way policy impacts Maggie's life. As it is, Maggie is perceived as "single" and an available caregiver; when she has a partner in her life, her partner is seen as an additional hand to help in the caregiving. Maggie and her lesbian partner were not treated as a legitimate family unit. A lack of recognition of lesbian partners as a family unit in federal legislation prior to *Bill C-23* has entrenched heterosexual families as the norm in public policy, institutions and government programs. This entrenchment has made it seem okay for individuals to discriminate against women who are lesbian. Maggie's narrative illustrates how homophobia can come from within one's own family, as well as from health care providers and relatively insignificant others.

Melissa encounters homophobic attitudes in her unpaid caregiving which inhibit her from seeking provincial home care support. Melissa's partner Susan also experiences homophobia due to the "next of kin" hospital policy. This makes it very difficult for Melissa to have the necessary help and support as a caregiver.

The experiences of Maggie, Melissa and Chris highlight the relationship between unpaid caregiving and social determinants



of health including poverty and social exclusion. Unpaid caregiving increases both the likelihood of financial strain as well as social isolation where caregivers have few opportunities for respite. Lesbian caregivers may be isolated from the gay community as Maggie was, being ill, lacking a partner and having significant caregiving responsibilities. This may be compounded with social exclusion when lesbian caregivers such as Melissa are unwilling to access available home care for fear of homophobia and discrimination.

The Public Health Agency of Canada guidelines for health recognize social exclusion as determinant of health, stating that,

Social exclusion is exacerbated by gender, age, ability, sexual orientation, race, ethnicity and religion. Social exclusion describes the structures and dynamic processes of inequality among groups in society. In the Canadian context, social exclusion refers to the inability of certain groups or individuals to participate fully in Canadian life due to structural inequalities in access to social, economic, political and cultural resources. These inequalities arise out of oppression related to race, class, gender, disability, sexual orientation, immigrant status and religion. (2004)

The most significant impact, however, creating the highest probability of health-related stress is an increase in the number of elder care hours (MacDonald *et al.* 2005). Maggie, Melissa and Chris all provided care for their elderly parents.

The health impact of performing unpaid care has also been measured in terms of the relationship between women's longer combined paid and unpaid work hours and the intensification of the experience of stress due to time constraints, overwork, and struggling with a disjointed

system (MacDonald *et al.* 2005). Caregivers report significant health effects related to unpaid caregiving that include feelings of negative stress, depression, helplessness, isolation, physical injury, high blood pressure, poor nutrition, and disturbed sleep (Gahagan *et al.* 2004, xv). In addition to these health concerns, lesbian caregivers face heterosexism and homophobia that decrease the likelihood of disclosing sexual orientation to a health provider, making it less likely for lesbians to seek regular preventative advice, testing and medical care (Steele *et al.* 2006). There is also evidence to suggest that lesbians may be at a greater risk for certain illnesses, including breast and gynaecological cancers, coupled with being less likely to receive preventative health care such as regular breast exams and pap smears (Steele *et al.* 2006).

From the HBRP research, we know that lesbian caregivers have experienced homophobia, heterosexism and discrimination in the health care system that create additional challenges for individual health and well-being. These challenges intensify with the added responsibility of unpaid caregiving.

There have been recent attempts to redress systemic discrimination experienced by lesbian, gay, transgendered, transsexual, two-spirited and bisexual persons. This initiative has come mainly from the Canadian Rainbow Health Coalition, advocating such awareness-raising projects as the Halifax Rainbow Health Project. This coalition creates networks for research and activism to promote greater inclusion and knowledge to improve the health of Lesbian Gay Transvestite Transgendered Transsexual Bisexual (LGTTTTB) persons. Queer communities face some of the greatest health challenges of any minority group in Canada yet the health experiences of and gaps in health care for LGTTTB persons remains an under-developed health policy research area.

## **Conclusion**

Institutionalized policy has the

power to reinforce or dismantle expectations for lesbians to be seen as model unpaid caregivers within and beyond the family. Public policy development and program and service agreements will continue to influence the way in which gendered expectations of caring are taken up, perpetuated and/or shifted in the next 10 to 20 years. This is a decisive era to consider these issues: it is expected that more and more unpaid caregivers will be needed to care for the frail elderly as over 1/4 of the Canadian population will be over 65 in the next two decades (Lilley *et al.* 1999, 9).

The legal, social and economic ramifications of maintaining the status quo by continuing to frame policy using heteronormative guidelines is particularly devastating for lesbian caregivers. It is evident from the micro-ethnographic study conducted as part of the HBRP that lesbian caregivers experience significant barriers in their caregiving due to homophobia, challenges related to self care and a lack of financial and overall support.

There are various means through which a more positive policy environment could maximize the health and well-being of unpaid caregivers. One recommendation is to achieve formal relationship recognition for lesbian partners as spouses by changing the definition of family to reflect *Bill C-23* in all institutional contexts and across all legislation. Another option is to identify unpaid work as a skilled responsibility to be shared, depending on capacity, between individuals and government systems. The negative financial implications of unpaid caregiving can be buffered by readjustment of the tax/transfer system mechanisms to be tied to the individual rather than partners or families. As it currently stands, many low-income partners or individuals living with their elderly care recipients have combined low incomes which, taken as a family income, disqualifies them from dependent tax credits and housing subsidies. The final recommendation is to continue to advocate and support research and programs such as "rainbow health"

initiatives aimed at advocating for queer-positive, equitable policy and health care, which will benefit both caregivers and care recipients.

#### **Endnote**

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1. HBRP researchers looked at unpaid caregiving for frail elderly persons, children or adults with a disability, onset illness or other health-related limitation. The HBRP is a five-year program funded by the Canadian Institutes of Health Research investigating the interrelationship between unpaid caregiving and women's health, employment and well-being. The HBRP has been coordinated by the Atlantic Centre of Excellence for Women's Health, the Nova Scotia Advisory Council on the Status of Women and the Institute of Population Health at the University of Ottawa, and supported by Dalhousie University, the Isaac Walton Killam (IWK) Health Centre and the Bureau of Women's Health and Gender Analysis.

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