## OPENING THE CLOSET DOOR ON REPRODUCTIVE CANCER CARE FOR SEXUAL MINORITY WOMEN: INTERACTIONS WITH HEALTH PROVIDERS

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# A THESIS SUBMITTED TO THE FACULTY OF GRADUATE STUDIES IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF MASTER OF SCIENCE IN NURSING

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#### **ABSTRACT**

The aim of this critical feminist study was to illuminate aspects of interactions between sexual minority women with reproductive cancers and their health care providers (HCPs) that may perpetuate or challenge barriers to receiving equitable care. For this qualitative inquiry, one-on-one interviews were conducted with six reproductive cancer survivors who self-identified as lesbian or bisexual women, four of whom were also health or service providers, and one Registered Nurse who was not also a cancer survivor (n=7). Four themes emerged from these interviews: the reproductive cancer journey, the meaning of family, interactions with HCPs, and environmental barriers. The participants outlined areas they felt were most important to their cancer care and interactions with HCPs, as well as some of the barriers they encountered. Aspects related to gender, sexuality, reproduction, and their intersections were pervasive throughout the findings and shaped the meaning of reproductive cancers for sexual minority women.

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#### CHAPTER ONE:

#### INTRODUCTION

Interpersonal interactions between nurses and clients<sup>1</sup> play a critical role in the facilitation of equitable care within health care environments, while also contributing to the difference between positive and negative health care experiences for clients. Specifically, during care that is cancer-specific, the focus of interpersonal interactions between nurses and other health care providers<sup>2</sup> and clients is often on life-saving interventions or survival treatments (Boehmer & Case, 2004, 2006), which can contribute to even greater feelings of vulnerability for clients. Interactions during cancer care between clients and health care providers can potentially create or perpetuate barriers to quality care that reflect larger organizational or institutional structures and policies, which may contribute to lower levels of health and wellbeing for individuals (Boehmer & Case, 2004, 2006). These barriers to care have been described in the literature as exclusion from health care settings caused by a multitude of organization and individual level factors (e.g., Bjorkman & Maltrud, 2009; Dibble, Eliason, Dejoseph, & Chinn, 2008; Irwin, 2007; Platzer & James, 2000; Stevens, 1994, 1995).

Barriers to care perpetuated by interactions with health care providers (HCPs) can undeniably be a concern for any and all women receiving cancer care; however, it is well documented within the literature that negative interpersonal interactions with HCPs can have specific implications for members of bisexual and lesbian communities living with a cancer

<sup>&</sup>lt;sup>1</sup> The term client and patient are used interchangeably throughout this document, as some nursing curriculums vary on the words used to describe the individuals we care for in practice.

<sup>&</sup>lt;sup>2</sup> The term health care provider(s) is primarily used to denote nurses and physicians within this thesis, based on data that emerged from the findings.

diagnosis (e.g., Boehmer & Case, 2004; 2006; Lesbians and Breast Cancer Project Team, 2004; Sinding, Barnoff & Grassau, 2004). One category of cancer with particular implications for both heterosexual and lesbian or bisexual (LB) women are reproductive cancers, which can alter sexuality, body image, and intimate relationships (Akyuz, Guvenc, Ustunsoz, & Kaya, 2008; Ekwall, Ternestedt, & Sorbe, 2003; Howell, Fitch, & Deane, 2003; Lesbians and Breast Cancer Project Team, 2004). Reproductive cancers are defined as those that "start in the organs related to reproduction" (U.S. Department of Health and Human Services, 2013, p. 1) and include breast, cervical, uterine, ovarian, vaginal, and vulvar cancers. Specifically, sexual minority women are a portion of those experiencing reproductive cancers whom are often under researched, despite findings to suggest that they may be at an increased risk for development of these cancers when compared to heterosexual women (Brown & Tracy, 2008; Dibble, Roberts, Robertson, & Paul, 2002; Zaritsky & Dibble, 2010; Rankow, 1995). Findings that suggest LB women's increased risk of reproductive cancer development provide important rationale to illustrate the need for further research within this area to explore these issues.

From my own experiences as a Registered Nurse working on a gynecology/oncology unit, I was deeply humbled by women's emotional and physical experiences living with cancer. However, all of the interpersonal interactions I had with women during my work referred to themselves as married to a man or in a relationship with a male partner. As a self-identified lesbian woman, I began to wonder how nurses and other HCPs were challenging or perpetuating barriers to care during interactions with sexual minority women experiencing the same diagnoses, and what kind of barriers these women may confront in their interactions with HCPs. Heterosexual women's partners often were included in interactions regarding decision-making

processes, and I wondered if this was also the case for LB women. I also wondered if women were self-disclosing their sexual orientation or if their HCPs were assuming heterosexuality.

Furthermore, at the beginning of my graduate degree program, I also had the opportunity to work as a research assistant for a Canadian Institutes of Health Research (CIHR) funded study exploring the barriers related to home care access for lesbian, gay, bisexual, trans, two-spirited, queer, and intersex (LGBTTQI) communities, which allowed me to witness first hand the micro and macro-level barriers existent for these individuals within the health care system. The curiosity stemming from my nursing experience in both practice and research has influenced my personal interest in seeking to uncover potential barriers during interpersonal interactions between LB women living with reproductive cancers and the HCPs who work with them.

#### **Research Aim and Questions**

In order to capture an accurate picture of interpersonal interactions and the barriers that may exist within these relationships, both LB women with reproductive cancers and the individuals who work with these populations must be given a voice to reflect on their experiences. Therefore, the aim of this research study was to illuminate aspects of interpersonal interactions between sexual minority women with reproductive cancers and HCPs that may perpetuate or challenge barriers to receiving equitable care. The final sample for this thesis included six sexual minority women who had experienced a reproductive cancer, four of whom also identified as health or service providers, and one Registered Nurse who was not a sexual minority reproductive cancer survivor. Exploring these participants' insights allowed for the potential to answer the following research questions: 1) What is the meaning of health and reproductive cancer for sexual minority women? 2) What role does social support play

throughout the cancer journey for sexual minority women? 3) How do interactions with HCPs perpetuate or challenge inequalities in cancer care for sexual minority women? and 4) How do health care environments and the cancer care interactions that occur within them perpetuate or challenge system level barriers for sexual minority women?

A focus specifically on reproductive cancers allowed for the exploration into how sexual minority women described the meaning of a cancer that had implications for their female bodies and health as women. Furthermore, as the goal of this research is to ultimately assist in fostering emancipation and social change, a critical feminist lens was used as the methodological framework to guide this qualitative study. A critical feminist lens allows for the investigation into some of the intersections of both sexuality and gender and how it affects aspects of cancer care. It also takes into account some of the historical and larger political contexts that influence micro and macro-level system barriers.

The studies that have examined interactions between sexual minority women and HCPs have often focused on women's experiences using broad qualitative interview approaches (Boehmer & Case, 2004, 2006), feminist narratives, (Stevens, 1994, 1995) phenomenology (Williams-Barnard, Mendoza, & Shippee-Rice, 2001), or quantitative questionnaires (Cochran & Mays, 1988; Klitzman & Greenberg, 2002; Stein & Bonuck, 2001; White & Dull, 1998).

Applying a critical feminist framework to this study also allowed for the reflection on social dominance and unrecognized barriers that often exist for marginalized groups, while also allowing participants to be active members within the research process (Campbell & Bunting, 1991; Falk-Rafael, 2005; Fontana, 2004; Hall & Stevens, 1991; Longo & Dunphy, 2012). A critical feminist methodology delves into the historical and structural contexts which have

contributed to the current situation being researched, also permitting the researcher to critique and exposes forces that may be contributing to injustice (Fontana, 2004).

#### **Summary**

Little has been written on how HCPs can best provide cancer care to sexual minority women with reproductive cancers, and therefore is important to disseminate research findings of this nature so that nurses and other HCPs working in a variety of diverse health care settings can unite to improve care for these women. It is my hope that this research will assist in highlighting some of the possible barriers LB women may face during their cancer care interactions with HCPs, but also ways in which these barriers may have been challenged in practice. Staying aligned with my critical feminist methodology, I also sought to reveal any possible institutional and organizational structures that may have contributed to perpetuating barriers in cancer care interactions for these women (Fontana, 2004; Reinharz, 1992). The goal of knowledge created within this study is not only to help improve care provided by nurses and other providers, but also to act as a resource for sexual minority women experiencing reproductive cancers themselves. Ultimately, it is my hope that this study may promote further nursing research, awareness, and knowledge development into the unique needs and potential barriers to care that exist for sexual minority women living with reproductive cancers.

#### **CHAPTER TWO:**

#### LITERATURE REVIEW

In this chapter I review some of the existing literature on areas pertaining to sexual minority women's health needs, reproductive health, health care interactions, and cancer risks. I also highlight some of the Canadian studies that have a similar research focus and discuss the implications of the literature review's findings for my own study.

#### **Sexual Minority Women's Health Risks and Needs**

Sexual minority women's specific health care needs intersect many diverse sectors of health services, and range from issues of sexual health to mental health (Barnes, 2012; Dobinson, MacDonnell, Hampson, Clipsham, & Chow, 2005; Flemmer, Doutrich, Dekker, & Rondeau, 2012; Roberts, 2006; Spinks, Andrews, & Boyle, 2000). Yet, individuals in these communities are often subject to discrimination and marginalization in society, health systems, and from health care providers (Beagan, Fredericks, & Goldberg, 2012; Boehmer & Case, 2004; 2006; Bonvicini & Perlin, 2003; Bjorkman & Malterud, 2009; Dibble et al., 2008; Dobinson et al., 2005; Eliason, Dibble, & Dejoseph, 2010; Fish, 2010; Katz, 2009; Klitzman & Greenberg, 2002; Mathieson, 1998; Matthews, 1998; Pelletier & Tschurtz, 2012; Platzer & James, 2000; Rondahl, 2009; Rondahl, Innala, & Carlsson, 2006; Spinks et al., 2000; Sinding et al., 2004; Stein & Bonuck, 2001; Stevens, 1994, 1995; Williams-Barnard, Mendoza, & Shippee-Rice, 2001). This marginalization in society and the health care system often the leaves the health needs of sexual minority women unmet, which is especially concerning given research to suggest increased risk for certain illnesses for this population of women (Dibble et al., 2002; Roberts, 2006; Zaritsky & Dibble, 2010). The literature on the health risks and needs of sexual minority women must first

be analyzed in order to understand and address the organization and institutional contexts perpetuating barriers to care and unmet health needs.

LB women are a part of what we commonly refer to as members of LGBTQ communities, the acronym standing for lesbian, gay, bisexual, trans, and queer. There are many other unique groups that fall into the category of diversity in expression of sexuality and gender-identity, including two-spirited, questioning, and intersex. However, for the purpose of this research and to stay within a specific scope, I will be focusing only on lesbian and bisexual women, also referred to as sexual minority women, in order to gain a specific insight into their experiences. Women who identify as lesbian commonly define themselves as women who primarily engage in emotional and/or sexual relationships with other women. Bisexual women or men more commonly define their sexual orientation as "the potential for being sexually and/or romantically involved with members of any gender" (McInnis and Kong, 1998 as cited in Dobinson et al., 2005, p.6).

For women who identify as bisexual, there are specific health needs, risks, and barriers to care that are often perpetuated by oppressive forces in both heterosexual and gay and lesbian communities (Dobsinson et al., 2005), creating a need to examine these issues individually. A Canadian qualitative study by Dobinson et al. (2005) explored bisexual experiences, needs, and lived realities for 62 men and women who identify as bisexual. The responses from participants indicated that they often experienced biphobia (i.e., an aversion to people who identify as bisexual, manifested in negative attitudes towards these individuals) and often did not feel as though they had a place in heterosexual or gay and lesbian communities (Dobinson et al., 2005). Participants also discussed having less support from family and friends, lack of inclusive health

care services in both the heterosexual and LGBTQ sphere, and overall felt there was a lack of understanding to their unique needs (Dobinson et al., 2005). In terms of health needs, bisexual men and women also experience higher rates of mental health issues, which may be contributed to lack of inclusion from both heterosexual and LGBTQ communities (Dobinson et al., 2005).

Lesbian women also face specific health risks, needs, and barriers to care that can be both similar and dissimilar to those experienced by bisexual women. For example, some literature suggests that in comparison to their heterosexual counterparts, lesbian women may have increased risk of anxiety, depression, suicidal thoughts and self-harm (Barnes, 2012; Flemmer et al., 2012; Roberts, 2006). Eating-disorders and post traumatic stress disorder occurrences were also found to be higher in lesbian women than heterosexual women (Barnes, 2012; Roberts, 2006). These mental health issues can be largely due to a multitude of factors, which may include internalized homophobia, defined as "learned biases that all individuals incorporate [internalize] into their belief systems as they mature in a society biased against homosexuals" (O'Hanlan, 1995 as cited in Bergeron & Senn, 2003, p.21), and can contribute to feelings of inferiority and isolation (Bergeron & Senn, 2003). Also, stigma from society, family, and friends can also contribute to mental health issues and become a catalyst for further health risks such as smoking, alcohol abuse and drug use (Barnes, 2012; Roberts, 2006).

It is important to note that sexual identity does not always dictate sexual behavior. Many self-identified lesbian and bisexual women report having a history of male sexual partners (Barnes, 2012; Flemmer et al., 2012; Roberts, 2006; Weisz, 2009) that may put them at risk for certain sexually transmitted infections. Although lesbian women are generally found to have lower rates of HIV, herpes, syphilis or gonorrhea, women who have a history of male sexual

partners, IV drug use, or sex work may actually be at increased risk (Barnes, 2012; Roberts, 2006). According to literature by Barnes (2012), Marrazzo and Gorges (2012), and Roberts (2006), women who have sex with women exclusively are often at higher risk for bacterial vaginosis, and are still at a high risk of contracting Human Papillomavirus (HPV). HPV is also a risk factor for cervical cancer, and along with other factors, could contribute to increased rates of this cancer for lesbian and bisexual women (Barnes, 2012; Marrazzo & Gorges, 2012; Matthews, Brandenburg, Johnson, & Hughes, 2004; Roberts, 2006).

Cancer screening is also an important area to explore in terms of lesbian and bisexual health, as it is an essential part of early disease detection and decreasing mortality rates. Lesbians are frequently found less likely to report routine PAP smears and cervical cancer screenings when compared to heterosexual women (Barnes, 2012; Matthews et al., 2004; Roberts, 2006; Tracy et al., 2010). It is important to note that in two studies on gynecologic cancer screening in lesbian women, those less likely to report routine screening also reported greater bias and discrimination from health providers related to their sexual orientation (Matthews et al., 2004; Tracy et al., 2010). However, in a more recent study, there was no correlation found between everyday discrimination based on sexual orientation and lesbians' screening behavior, and lesbian women who were recommended to receive cancer screening by their health care provider were twice as likely to seek routine screening (Tracy, Schluterman, & Greenberg, 2013).

Expanding on this, some studies suggest that health care providers may not be providing sexual minority women with accurate or updated guidelines on how often PAP smears are required (Barnes, 2012; Flemmer et al., 2012; Roberts, 2006). Some studies found that providers were informing women who have sex with women that regular screens were not necessary, as

they were not having sexual intercourse with a male partner (Barnes, 2012; Flemmer et al., 2012; Roberts, 2006). The literature on mammography is less consistent, with some reports stating there is a higher frequency and others refuting these findings (Hart & Bowen, 2009; Roberts, 2006). However, more recent research suggests that guidelines for screening should be the same for all women, regardless of sexual history, and providers should provide accurate information on frequency to promote regular screening (Roberts, 2006).

In fact, most recently and relevant to the geographic location of my research, the province of Ontario changed its screening guidelines for cervical cancer in 2012, using language that is more inclusive to all women. The current guidelines read: "Cervical cancer screening is recommended every three years for all women starting at age 21 who are or ever have been sexually active. Sexual activity includes intercourse, as well as digital or oral sexual activity involving the genital area with a partner of either gender" (Cancer Care Ontario, 2013, p.1). Furthermore, although language related to sexual orientation is not used, the breast cancer screening guidelines for mammograms in Ontario state that all women between the ages of 50 and 74 should receive a mammogram generally every two years. They also stress that women who may be considered high risk and are between the ages of 30 and 69 should receive a mammogram and breast MRI annually (Cancer Care Ontario, 2014).

Specifically for trans women and trans men, who may also self-identify as either gay, lesbian, or bisexual, there are often even greater barriers to care when it comes to reproductive cancer screening. For trans people, the sense of real and/or perceived transphobia from health care providers while receiving these tests can create barriers to care and place trans people at risk for missing early cancer detection (Canadian Cancer Society, 2014). There may also be

inaccurate information given to trans men and women regarding their need to receive screening for cancers such as cervical and breast. In fact, trans women require mammograms every two years if they have been on gender-affirming hormones for greater than five years and are between the ages of 50 and 69, and must also receive regular PAP tests every three years starting at age 21 if they have undergone a vaginoplasty and are sexually active (Canadian Cancer Society, 2014). Trans men who have a cervix and are sexually active must also receive PAP tests every three years starting at age 21, and if they are between the ages of 50 and 69 they should also see their HCP about chest exams and/or mammograms every two years, even if they have undergone top surgery (Canadian Cancer Society, 2014).

To date, there are no statistics representing the proportion of women, either cisgender or trans, affected by reproductive cancers who identify as lesbian or bisexual, yet there are findings to suggest these women may be at increased risk for developing these cancers (Brown & Tracy, 2008; Dibble et al., 2002; Hart & Bowen, 2009; Zaritsky & Dibble, 2010). Risk for gynecologic cancer development specifically is linked to factors including, but not limited to: nulliparity (never having given birth), limited or no history of breastfeeding, and no history of oral contraceptive use (Dibble et al., 2002; Zaritsky & Dibble, 2010). A study on these factors found that lesbians had significantly fewer pregnancies and lower use of oral contraceptives, placing them at a potential risk for ovarian cancer development (Dibble et al., 2002). Another more recent study had similar findings and also found that lesbians had a greater trend toward obesity, another risk factor for ovarian cancer (Zaritsky & Dibble, 2010). Many of these risks, including obesity and fewer or no pregnancies, are also risk factors for breast cancer development, suggesting that lesbian and bisexual women may be at increased risk for development of these

cancers as well (Roberts, 2006).

Limitations to the literature reviewed on health risk factors for lesbian and bisexual women included the lack qualitative analyses used to explore reasons behind certain health risks or needs, such as lower rates of cancer screening. Furthermore, there is a lack of research exploring risk factors that were specific or inclusive to bisexual women, as well as reproductive cancer research focusing on lesbian or bisexual identified trans women or trans men. The lack of information on these groups makes it difficult to generalize research findings to trans and bisexual communities and therefore requires further investigation.

#### **Barriers to Care for Sexual Minority Women**

Prior to the 1970s, many lesbian and bisexual women lived in silence, condemned from society and their families and in some cases, even considered criminals or mentally ill (Irwin, 2007; Makarenko, 2007; Spinks et al., 2000). In 1973, a historical step was taken when the American Psychiatric Association removed homosexuality as an illness or disorder from their Diagnostic and Statistical Manual of Mental Disorders (Irwin, 2007). In Canada, gay marriage was legalized in 2005 and there has been increasing overall acceptance from a political standpoint in terms of providing equal rights and freedoms to all individuals, regardless of sexuality or gender-identity (Makarenko, 2007). Many LGBTQ individuals have also taken a stand in advocating for increased services and rights within their own provinces and communities.

Unfortunately, homophobia, biphobia, transphobia, and heterosexism are still issues that remain prevalent in general societal contexts, as well as on organizational and institutional levels (Irwin, 2007). Homophobia can be described as "an irrational fear and dislike of lesbian, gay,

bisexual and transgender people which may lead to hatred and result in physical or verbal abuse" (Douglas Scott, Pringle, & Lumsdaine, 2004 as cited in Irwin, 2007, p. 71); while heterosexism is defined as "a belief that heterosexuality is the only form of sexuality, the only acceptable form of sexuality, or a superior form of sexuality" (Sinding et al., 2004, p.176). Biphobia and transphobia is an aversion to or violence against bisexual individuals and trans people respectively, and can result in similar physical or verbal abuse. Homophobia, biphobia, transphobia, and heterosexism remain prevalent in health care institutions from both a policy level and individual providers attitudes, contributing to further discrimination and exclusion of sexual minority women (Bjorkman & Malterud, 2009; Dibble et al., 2008; Dobinson et al., 2005; Fish, 2010; Irwin, 2007; Matthews, 1998; Platzer & James, 2000; Sinding et al., 2004; Stevens, 1994, 1995). Homophobia, biphobia, transphobia, and heterosexism in health care can also create a barrier to accessing services that heterosexual individuals might receive, such as providers refusal to provide health care, exclusion or denial of a same-sex partner during interactions, and lack of accurate information related to specific health needs (Dobinson et al., 2005; Irwin, 2007; Roberts, 2006, Weisz, 2009).

Similar to society as a whole, institutional policies and individual providers can elicit heterosexist, biphobic, transphobic, or homophobic attitudes in practice, which may be detrimental to care and contribute to a lack of continuity in patient care. In fact, in a Canadian study by Mathieson (1998) in which 98 lesbian and bisexual women were interviewed, over two thirds of the sample stated that they were "always" aware of heterosexual assumptions in health care (p.1637). Even 12 years later, the same feelings of heterosexism in health care was reflected

by lesbian women in a qualitative Canadian study by McIntyre, Szewchuk, and Munro (2010), which explored lesbians experiences of PAP testing and health.

Furthermore, LB women face an intersection of both their sexual orientation and gender that can contribute to oppressive forces and further reinforce their marginalized position within society. Lesbian and bisexual women of diverse races, classes, abilities, and gender-identities may face even greater barriers to equitable care (Fish, 2010). Yet, health service access and equity literature often fails to address the diversity that exists within LGBTQ communities (Daley & MacDonnell, 2011). A Canadian study by Daley and MacDonnell (2011) found that in 24 health access and equity documents, the majority of documents reflected the dominant multicultural discourse, with a focus on language and racial/ethnic groups. Although these documents do not necessarily seek to directly exclude LGBTQ communities, they provide few to no references regarding how health access barriers and inequities affect diverse members of LGBTQ communities (Daley & MacDonnell, 2011).

In terms of organization and institutional barriers, in a study by Stevens (1995), lesbians reported the waiting rooms of their providers office lacked inclusion. "Nothing matches anything about your life" (Stevens, 1995, p. 27), one woman reported regarding lack of magazines, posters, or LB inclusive admission forms. More recent Canadian research explored the experiences of mid-life lesbian women related to PAP testing (McIntyre et al., 2010). The authors found that even 15 years after Stevens (1995) work, lesbian women were still absent from dominant sexual health scripts, little communication occurred between women and health care providers about sexuality influencing their sexual health, and that women felt conflicted by how their lesbian identity influenced their health needs (McIntyre et al., 2010).

The exclusion of lesbian women in health systems can create a perception that the health care space is unsafe, and a view of heteronormativity can become present (Beagan et al., 2012). Heteronormativity is "the pervasive assumption of heterosexuality, rendering other sexual orientations (and people) invisible or marginal in health care settings (Beagan et al., 2012, p.48). It is an "interlocking set of assumptions" that concludes heterosexuality as the preferred and normal sexual orientation (Beagan et al., 2012, p. 47) and often times is present from the moment the individual walks through the health care setting's doors. Heteronormativity can be elicited in a variety of ways either through verbal or non-verbal interactions and written or implied communication (Beagan et al., 2012; Bjorkman & Malterud, 2009; Rondahl et al., 2006). Examples of written exclusion can include medical pamphlets lacking information for sexual minority women and lack of hospital documentation regarding a woman's sexual orientation or sexual history.

Fortunately, there are current initiatives in place that are promoting inclusion of LGBTQ communities in health promotion and health services in Canada. One such Canadian initiative is The Canadian Cancer Society's (2014) Get Screened Campaign, which aims to "increase colon, breast and cervical cancer screening rates among LGBTQ communities in Hamilton, Ottawa, and Toronto" (p.1). Initiatives such as this attempt to raise awareness for LGBTQ cancer screening and also recruit volunteers within LGBTQ communities to act as advocates to further promote activism for inclusive cancer screening information and services.

#### Reproduction and Reproductive Health for Sexual Minority Women

Another significant area to review within the existing literature on sexual minority women's health is how issues of reproduction, conception, and family are taken up in health

systems during care. There are often specific implications for sexual minority women in regards to their reproductive health and the varied configurations of their family make-up. As my study is specifically addressing some of the issues that arise for sexual minority women who have cancers affecting their reproductive organs, reproduction and reproductive health become especially important to investigate within the literature.

As previously stated, it is important to note that sexual orientation does not necessarily dictate sexual behavior (Barnes, 2012; Flemmer et al., 2012; Roberts, 2006; Weisz, 2009) and many lesbian and bisexual women may have had past instances of pregnancies, abortions, and/or oral contraceptive use (Marrazzo & Stine, 2004; Moegelin, Nilsson, & Helstrom, 2010). A study conducted by Marrazzo and Stine (2004) looked at the reproductive health history of 392 lesbian and bisexual women within a large American city. They found that 25% of all participants had reported being pregnant at least once, with women who identified as bisexual more likely to report past pregnancies, and 206 participants reporting use of oral contraceptives (Marrazzo & Stine, 2004). However, the rate of reported lifetime male sex partners did not differ by whether a woman identified as bisexual or lesbian (Marrazzo & Stine, 2004).

A more recent study analyzed data from a health clinic that had specific services for women who have sex with women (WSW) and compared these findings to a predominantly heterosexual comparison group (Moegelin et al., 2010). The authors found similar results to those of Marrazzo and Stine (2004), as from their sample of 204 WSW group, 22.7% had been pregnant at least once, with one in every 10 women having reported an induced abortion at some point (Moegelin et al., 2010). Also, within the WSW group, 15.4% had never received a PAP test, while the predominantly heterosexual comparison group reported that only 8.6% of women

had never received this test (Moegelin et al., 2010). These findings become especially important for HCPs, as they indicate how providers' assumptions about a woman's sexual identity may not accurately capture and accommodate her reproductive health needs (Marrazzo & Stine, 2004; Moegelin et al., 2010).

Additionally, many sexual minority women who seek to become pregnant with their female partner, or independently, face other obstacles within health systems. A Canadian mixed-methods study conducted by Yager, Brennan, Steele, and Epstein (2010) looked at some of the challenges for lesbian and bisexual women trying to conceive (TTC). One of the themes that emerged from their qualitative interviews with women who were TTC was that although the women had positive experiences with their health care providers during this time, they often anticipated or expected negative interactions (Yager et al., 2010). Participants also spoke about a lack of social support from family, coworkers and others in their community during the time of TTC (Yager et al., 2010). Furthermore, an American content analysis found that of 402 fertility clinic websites, only 29.6% of those explicitly acknowledged alternative families, such as lesbian couples or single women, and only 10% of clinics displayed non-discriminatory language (Johnson, 2012).

Another issue specific to sexual minority women who wish to conceive children is the potential for exclusion of the non-birth mother. Several authors have noted some of the subtle privilege given to the birth mother within female same-sex relationships (Biblarz & Savci, 2010; Ehrensaft, 2008; Hayman, Wilkes, Halcomb, & Jackson, 2013). This ranged from exclusion of the non-birth mother during fertility treatments (Hayman et al., 2013), to the birth mother being given priority to legal rights over custody (Ehrensaft, 2008). Lesbian and bisexual women in

same-sex relationships with children also face issues surrounding the involvement of a sperm donor in the child's life or navigating parenting with the involvement of the child's biological father (Ehrensaft, 2008).

Indeed, sexual minority women's families are often those that "blend social and genetic parenting" (Ehrensaft, 2008, p. 177), but this is not to undermine the value and support within these family units. In a literature review of the scholarship on LGBT families in the past decade, Biblarz and Savci (2010) found that much of the recent research in family health suggests that children whom were raised by two mothers have the same psychological wellbeing, peer relations, and social/behavioral adjustment as those raised by heterosexual couples. When comparing adolescents whom were raised by two mothers and those raised by heterosexual couples, there were also no differences in depression scores, grade point average, self-esteem scores, tobacco and alcohol use, or number of sexual partners (Biblarz & Savci, 2010). Although some individuals and societies still tend to disagree with the notion of same-sex couples raising families, this increase in new research helps to contradict the negative assumptions surrounding two women raising children.

An important limitation to note from the research on sexual minority women's conception and reproduction was the lack of research on bisexual families. Although there was available research regarding reproductive health for bisexual women, one literature review noted a lack of scholarship on bisexual families within the last decade (Biblarz & Savci, 2010). This leaves many questions unanswered in terms of the make-up of these family units and what unique challenges face these women during conception and family planning. Furthermore, there was a lack of discussion within the existing research on how lesbian families navigate through

conception and family planning if they are of lower socio-economic status. In Canada and the United States, fertility treatments can incur their own financial costs, which may make this route difficult for some sexual minority families.

#### **Disclosure of Sexual Orientation During Health Care Interactions**

The concerns surrounding disclosing one's sexual identity to health care providers can also significantly affect the quality of care a sexual minority woman receives. A lack of information on an individual's sexual orientation within a health care setting can potentially prevent referrals to accurate information, lack of partner inclusion during health care interactions, and an overall increase in distress during health care experiences (Rondahl et al., 2006). A study first conducted over 25 years ago on black lesbian and bisexual women's health care experiences was the first of its kind, and found that only 33% of lesbians and 18% of bisexual women from a sample of 594 discussed sexual orientation in a health care context (Cochran & Mays, 1988). These results on the lack of open disclosure with providers could have been further heightened due to an intersection of gender, sexual orientation, and race contributing to further fear of stigma (Cochran & Mays, 1988). More recent research has suggested that disclosure rates have risen in the past 25 years for lesbians, but these rates may vary depending on geographic location, ethnicity, and other factors (Austin, 2013; McDonald, 2009; Stein & Bonuck, 2001).

An American study by Stein and Bonuck (2001) found that out of 575 gay, lesbian, and bisexual individuals, 70% disclosed their sexual orientation in a health care setting. However, it is important to note that of these 70%, only 29% were asked by their provider, the rest volunteered this information independently (Stein & Bonuck, 2001). Specifically and more

recently, in terms of lesbian women from both urban and non-urban areas within the southern United States, Austin (2013) found that out of 1141 self-identified lesbian women, 40% did not disclose their sexual orientation to health care providers, while 60% of women did self-disclose. Yet, 13% of women still reported facing discrimination from providers based on their sexual orientation (Austin, 2013). The study by Austin did not specify whether or not health care providers inquired about sexual orientation, but rather their study seemed to only measure the percentages of women who self-disclosed independently or not.

Sexual minority women sometimes also fear negative treatment before a therapeutic encounter even begins as a result of real and/or perceived heterosexism, homophobia, biphobia, or transphobia from their providers (Rondahl et al., 2006; Sprinks et al., 2000). Some women are initially hesitant to disclose their sexual orientation due to fear of a confidentiality breach, the information getting back to their family or others who may not know (Rondahl et al., 2006; Sprinks et al., 2000), or receiving negative treatment (Cochran & Mays, 1988; Dobinson et al., 2005; Klitzman & Greenberg, 2002; Platzer & James, 2000; Rondahl et al., 2006; Stein & Bonuck, 2001; Stevens, 1994, 1995; Williams-Barnard et al., 2001; White & Dull, 1998). In fact, half of the women interviewed in a qualitative study by Williams-Barnard et al. (2001) believed that they would be less cared for if their provider knew they identified as a lesbian.

Furthermore, a Canadian study by Dobinson et al. (2005) found that bisexual men and women specifically expressed similar concerns of receiving less than adequate care following disclosure of their bisexual identity to health care providers. Polek, Hardie, and Crowley (2008) also found that bisexual women in their American study were the least likely to disclose their sexual orientation to health care providers, even more so than self-identified lesbian women. Yet,

it is important to note that there are clear advantages to health care providers discussing sexual identity with lesbian and bisexual women. A Canadian study by Bergeron and Senn (2003), which used path models to explore health care utilization by lesbian women, found that disclosing sexual orientation to health care providers was significantly related to health care system utilization and seeking preventative health care.

Unfortunately, negative interactions with health care providers may occur as a result of disclosed sexual orientation. Negative interactions can include a range of described experiences, which have been cited in the literature as lack of partner acknowledgment, sexual comments or harassment, homophobic reactions, heterosexist reactions, and incorrect or insufficient information provided (Boehmer et al., 2005; Boehmer & Case, 2004; 2006; Brown & Tracy, 2008; Dibble et al., 2008; Lesbians and Breast Cancer Project Team, 2004; Matthews, 1998; Rankow, 1995; Sinding et al., 2004; Sinding et al., 2006; Stevens 1994, 1995.) However, it is also important to note that positive interactions have been shown to not only benefits clients (Hart & Bowen, 2009; Bergeron & Senn, 2003), but providers as well (Harris & Templeton, 2001). Bergeron and Senn (2003) found a significant relationship between lesbian women's comfort with health care providers and seeking preventative health care. More recently, Hart and Bowen (2009) had findings from their quantitative study examining sexual orientation and breast cancer screening to suggest that having trust in one's provider may influence lesbian women's intentions to receive breast cancer screening.

It is not always that health providers are homophobic or do not wish to provide equitable care, but rather sometimes they are inadequately prepared or educated on how to discuss issues of sexuality with sexual minority women (Beagan et al., 2012; Bonvicini & Perlin, 2003). In fact,

in a nursing literature review by Eliason et al. (2010), seven out of the top ten nursing journals had no articles focusing on LGBT-specific issues in a five-year period. The lack of representation of these issues in the literature translates into a lack of nursing education and curriculum development cognizant of key issues for these individuals. Similar gaps in LGBTO education can be found in the field of medicine, as seen in a Canadian study from Ontario examining obstetrician-gynecologists' knowledge of lesbian health (Abdessamad, Yudin, Tarasoff, Radford, & Ross, 2013). Abdessamad et al. (2013) found that 78% of the physicians surveyed had received no lesbian health education while in medical school and 81% had received no lesbian health training during residency. Additionally, a fear of conducting themselves incorrectly or stereotyping lesbian and bisexual women by focusing only on their sexual orientation has been shown to contribute specifically to nurses' insecurity in providing continuity in therapeutic communication (Beagan et al., 2012; Rondahl et al., 2006). A Canadian study by Beagan et al. (2012) found that the majority of 11 nurses interviewed in their qualitative critical feminist investigation did not want to reduce individuals to their sexual orientation, associating acknowledgement of difference as discrimination, instead of associating the lack of acknowledgement as creating further invisibility.

This finding from Beagan et al. (2012) regarding nurses' fear of discussing LGBTQ identity is reinforced by findings from a Canadian discourse analysis by Daley and MacDonnell (2011). Daley and MacDonnell used a gender-based diversity analysis to identify and understand dominant and counter discourses in health services access and equity documents. They found that some documents neglect the significance of LGBTQ identity, and suggest that providers provide cultural competence care by asking about sexual behavior only (Daley & MacDonnell,

2011). This finding suggests that although asking questions pertaining only to sexual behavior may prevent providers from making assumptions or stereotyping, it does not take into account the significance of an LGBTQ identity or portray an understanding of how this may be an integral part of individuals' health and wellbeing (Daley & MacDonnell, 2011).

#### **Sexual Minority Women's Interactions with HCPs During Cancer Care**

Interactions with providers during a life-threatening illness such as cancer can often be of greater importance for lesbian and bisexual women than interactions during routine examinations, but this area of cancer care for sexual minority women remains an area largely unexamined in nursing research. Women experiencing reproductive cancers may face treatments that involve radiation, chemotherapy, hormone therapy, or invasive surgeries to their breasts, uterus, or cervix (U.S. Department of Health and Human Services, 2013), contributing to an increase in feelings of vulnerability. Breast cancer experiences and women's interactions with health care providers during treatment is largely addressed in the literature on sexual minority women's health. Additional studies also often address all types of cancers experienced by sexual minority women, with few studies focusing on those with gynecologic cancers as well (Boehmer, et al., 2005; Boehmer & Case, 2004; 2006; Brown & Tracy, 2008; Dibble et al., 2008; Lesbians and Breast Cancer Project Team, 2004; Matthews, 1998; Rankow, 1995; Sinding et al., 2004; Sinding et al., 2006; Tracy et al., 2010).

Many individuals, regardless of sexual orientation or gender identity, agree on the importance of emotional support from a family member or loved one during their cancer care.

Lesbian and bisexual women may have a current female partner during their cancer care and it is important that she is acknowledged and included in discussions in order to facilitate dialogue on

best course of action for the individual's illness. However, some of the literature describes women's discontent with the exclusion of their female partners during cancer care interactions with health providers (Boehmer & Case, 2004, 2006; Matthews, 1998). An American study by Matthews (1998) found that many of the 24 lesbian women interviewed for a qualitative study agreed on the importance of having their current partner present during treatment planning and decision-making. Yet, a number of women still hide their relationships for fear of poor treatment or discrimination (Matthews, 1998). A more recent American study by Boehmer & Case (2006) found that some providers did not acknowledge women's partners as a family member or spouse, and would not discuss elements of cancer care with their partner in the room. This demonstrates some of the possible heterosexist assumptions that could be elicited from providers, which may contribute to exclusion of women's support system and could further marginalize sexual minority women.

Exclusion of same-sex partners during cancer care interactions with providers also has implications if the individual is estranged from their family. LB individuals may have a lack of social and family support as a result of stigma in society and contradicting beliefs in their family's values (Dobinson et al., 2005; Matthews, 1998). Therefore, a woman's partner may be her only form of social support, and there is additional imperative for health providers to remain inclusive to partners during interpersonal interactions (Matthews, 1998). Canadian research conducted by Sinding et al. (2004) found in their participatory qualitative study of 26 lesbian and bisexual women with cancer, that women expressed extreme gratitude when their partners were included in interpersonal cancer care interactions and decision-making with health providers. This suggests that a long-standing history of heterosexism and homophobia in cancer care may

contribute to women's gratitude for aspects of care that are often the norm for heterosexual women (Lesbians and Breast Cancer Project, 2004; Sinding et al., 2004).

In addition to inclusion of partners, open communication about women's sexual orientation in general and specifically during cancer care has shown to be an important aspect of interpersonal interactions with providers (Dehart, 2008; Matthews, 1998; McIntyre et al., 2010; Sinding et al., 2004). Open communication and avoidance of heterosexist assumptions is particularly important during cancer care interactions, as the health care relationships tend to be longer and can include conversations on life-altering decision making. An American quantitative study on breast health behaviors in 173 self-identified lesbian women found that over half of all participants believed that heterosexist assumptions from health care providers effected either their: quality of care received from providers, frequency of visitation to providers, amount of discussion they engaged in with providers, or actual health outcomes (Dehart, 2008). Heterosexist assumptions during cancer care interactions can also contribute to women's unwillingness to continue with care, which could ultimately jeopardize her health and wellness further (Lesbians and Breast Cancer Project, 2004; Sinding et al., 2004).

Overt heterosexist, homophobic, biphobic, or transphobic remarks from health care providers can also seriously affect LB women's access to quality cancer care, and combined with the aggressive medical treatment they may be receiving, women may feel even more vulnerable (Lesbians and Breast Cancer Project, 2004). However, many women in the Lesbian and Breast Cancer Project (2004), completed in Ontario, Canada, expressed open identification of their female partners to health care staff, and willingness to advocate for acceptance of themselves and their partners if it had not been provided. Although these findings may not be widely

generalizable due to the sample size of 26 women, most LB women in this project also reported that they had not encountered homophobia in their cancer care (Lesbian and Breast Cancer Project, 2004).

Despite sexual minority women's self-advocacy against their invisibility in health care systems, exclusive language used by providers may hinder continuity in care. For example, frequent questions of: Do you have a husband?; Are you on birth control?; and, Could you be pregnant?, are examples of heteronormative assumptions and demonstrate a lack of inclusive language (Lesbians and Breast Cancer Project, 2004). Boehmer & Case (2006) solidify the importance of inclusive language during health care interactions by reporting the increase in cancer related self-efficacy and adjustment when sexual orientation is openly discussed.

#### **Canadian Research Exploring Sexual Minority Women's Cancer Care**

Although there is a body of research surrounding both reproductive cancer care and sexual minority women's interactions with health care providers, there is a gap in nursing research that explores the combination of these two important issues. However, it is important to note that at the time of my research undertaking, there was a three-year Canadian CIHR funded study underway by Mary Bryson and her team exploring LGBTQ communities and cancer. This study called Cancer's Margins, involves interviews occurring in Ontario, as well as four other Canadian provinces, exploring LGBQ women, trans men and women, and two-spirited individuals sharing of cancer knowledge and experience of breast and gynecologic cancer care. Due to the grand scale of this research project's recruiting efforts that were underway in Ontario, it was important to identify how my study differed in its investigation and how both our efforts were bringing unique insights to the body of knowledge in sexual minority women's cancer care.

Although both our research inclusion criteria was quite similar in that both my study and Mary Bryson's work was seeking LB women who have or had a diagnosis of reproductive cancer and are over the age of 19, our research purposes were examining two different areas. Specifically for my study, I was looking at the cancer care interactions between LB women and health care providers, and how these interactions might contribute to or challenge barriers to care. Conversely, Mary Bryson and her team were exploring knowledge sharing and the experience of cancer health, support, and care for LGBQ women, trans, and two-spirited people. Additionally, I recruited the insight from both LB women and health care providers and examined the similarities and dissimilarities in their perspectives on barriers to cancer care, while Cancer's Margins research focused on exploring only the experience from the individuals living with cancer who identify as LGBTTQ.

Christina Sinding and her team is another researcher who has made seminal contributions to research involving LB women and cancer care. Her work has mainly used Participatory

Action Research approaches to uncover LB women's meanings of cancer care, treatment, health systems, and identity from their own experiences (Sinding et al., 2004; Sinding et al., 2006).

Similar to Mary Bryson's work and my own, her inclusion criteria for participants also sought lesbian or bisexual identified women with breast or gynecologic cancers across Ontario.

Christina's work with LB women living with cancer was also initially conducted almost 10 years ago, which provides rationale for an updated inquiry into this area.

Christina Sinding, Mary Bryson, and their respective research teams have made great strides in establishing Canadian research initiatives to explore sexual minority women's experiences and insight into cancer care. It is my hope that I may also contribute attention and

focus to cancer care for sexual minority women, specifically in regards to health care providers' interactions and institutional policies that may influence nursing care.

#### **Implications of Literature Review Findings**

There are several limitations to some of the existing research in the area of reproductive cancers and sexual minority women, and a need to further examine structural and individual heterosexist assumptions in cancer care. Often studies that are examining reproductive cancers and LB women are using a quantitative approach to measure an increase in risk factors for cancer development (Cochran et al., 2001; Dibble et al., 2002; Grindel, McGehee, Patsdaughter, & Roberts, 2006; Matthews et al., 2004; Zaritsky & Dibble, 2010). They do not incorporate reasoning for why this may be the case, such as negative experiences with nurses or other health care providers contributing to unwillingness to seek regular cancer screening or physical assessments. The samples used within these studies also may lacks diversity in the LB women chosen, which make it difficulty to generalize findings to diverse women with variations in ethnicity, gender identity, socioeconomic status, or ability (Cochran et al., 2001; Dibble et al., 2002; Grindel et al., 2006; Matthews et al., 2004; Zaritsky & Dibble, 2010).

Another limitation to the existent literature is that many studies on health care interactions with LB women focus on those that occur with physicians or primary care providers (Boehmer & Case, 2004, 2006; Bonvicini & Perlin, 2003; Cochran & Mays, 1988; Stein & Bonuck, 2001; White & Dull, 1998). Much of the literature does not incorporate specific interactions with nurses, and therefore it is difficult to address the potential barriers that might occur during these interactions. Furthermore, the studies on interpersonal interactions with health care providers are often not cancer care specific, and examine short-term interactions or those

that do not involve life-threatening illness (Bonvicini & Perlin, 2003; Cochran & Mays, 1988; Klitzman & Greenberg, 2002; Stein & Bonuck, 2001; Stevens, 1994, 1995; White & Dull, 1998, Williams-Barnard et al., 2001). As there are often more long-term interactions with providers during the course of cancer care and follow up, it is difficult to generalize these studies' findings to those who are experiencing cancer. The studies reviewed were also one-sided, either incorporating narratives from LB women or providers only (Beagan et al., 2012; Boehmer & Case, 2004, 2006; Bonvicini & Perlin, 2003; Cochran & Mays, 1988; Klitzman & Greenberg, 2002; Stein & Bonuck, 2001; Stevens, 1994, 1995; White & Dull, 1998, Williams-Barnard et al., 2001). In order to capture an accurate picture of both sides of power dynamics and oppressive structures during cancer care, it is imperative to acknowledge both LB women's and providers' insights.

In terms of the literature examining cancer care and sexual minority women, many studies have focused more broadly on all cancers (Brown & Tracy, 2008; Dibble et al., 2008; Katz, 2009; Matthews, 1998), or specifically breast cancer (Barnoff, Sinding, & Grassau, 2005; Boehmer & Case, 2004, 2006; Boehmer et al., 2005; Lesbians and Breast Cancer Project Team, 2004; Sinding et al., 2004, 2006). Few studies have incorporated the experiences of women with other reproductive cancers as well. My study took into account reproductive cancers as a whole, in order to illuminate how sexual minority women may face unique barriers in comparison to diverse types of the disease. Additionally, many studies on cancer care lack inclusion of bisexual women, or have few participants who self-identify as such (Barnoff et al., 2005; Boehmer & Case, 2004, 2006; Boehmer et al., 2005; Brown & Tracy, 2008; DeHart, 2008; Dibble et al., 2008; Katz, 2009; Lesbians and Breast Cancer Project Team, 2004; Matthews, 1998; Sinding et

al., 2004, 2006). Bisexual women may face institutional and individual barriers that are unique, including lack of appropriate health information and societal oppression from both heterosexual and LGBTQ health services or communities (Dobinson et al., 2005). My study sought to include both self-identified lesbian and bisexual women to allow for adequate insight into barriers that may exist for both groups. Therefore, it is my hope that by addressing some of these limitations in existing literature within my study design, there is potential for more research and knowledge on sexual minority women and reproductive cancer can be generated. By answering my research questions based on my participants' unique insight, I hope to shed new light in areas that have previously been under researched in the nursing profession.

### CHAPTER THREE:

#### **METHODOLOGY**

In this chapter I discuss the chosen theoretical framework for my study, as well as the methods used for data collection, data analysis and achieving adequacy in findings. This chapter will help to outline the steps during the research process and the rationale behind these decisions.

### **Theoretical Framework**

It becomes evident upon review of the literature on sexual minority women's health, barriers to care and interactions during cancer care, that there is a need to examine these issues from a lens that will allow for exploration of heteronormative practices that may render these women invisible within the health care system, and how these can be improved to help promote structural change and foster further emancipation. A critical feminist lens incorporates the principles of both feminist and critical theory to uncover how the historical and political contexts that contribute to social dominance and gender play a role in the creation of unrecognized barriers by health care systems or institutions (Campbell & Bunting, 1991; Falk-Rafael, 2005; Fontana, 2004; Longo & Dunphy, 2012). For example, assumptions of heterosexuality from health care providers (HCPs) may create barriers for lesbian or bisexual (LB) women to receive appropriate information pertaining to their health and wellbeing (Barnes, 2012; Bjorkman & Malterud, 2009; Dobinson et al., 2005; Dibble et al., 2008; Fish, 2010; Irwin, 2007; Katz, 2009; Platzer & James, 2000; Sinding et al., 2004).

Traditionally, empirical research from a positivist paradigm has denounced the use of subjective accounts as valid evidence, and participants' social positions have been disregarded (Hall & Stevens, 1991). Conversely, the ontological and epistemological views present within

critical feminist methodology differ greatly from these traditional frameworks used in nursing research and there are specific implications during the data collection and data analysis process that value subjective insight. No one method for data collection or analysis is considered inherently "critical" or "feminist", but rather the ways in which the phenomenon are approached and interpreted dictate the critical feminist nature of the research (Fontana, 2004). In order to remain aligned with the tenets of a critical feminist methodology, which include addressing power imbalances, as well as basing my research within a naturalist paradigm, I chose to use one-on-one interviews as the primary method of data collection and conventional content analysis to guide data analysis, both discussed further in their respective sections of this chapter.

The tenets of critical and feminist methodologies stress the importance of approaching the research process as a collaborative effort between both researcher and participant (Campbell & Banting, 1991; Fontana, 2004; Hall & Stevens, 1991; Hesse-Biber, 2012; McCabe & Holmes, 2009; Reinharz, 1991). Rather than a hierarchal relationship in which the researcher dictates the direction of the research process, it is important that the researcher act as a "caring agent" assisting participants to view new insights from their own voice and experiences (McCabe & Holmes, 2009, p.1523). Entering a dialogue through the use of one-on-one interviews can allow participants a chance to express their insights both verbally and non-verbally, and feel more connected to the research process. In order to further facilitate this process, it is important to allow participants to ask questions, encourage self-exploration, and leave the research agenda open to suggestions from participants (McCabe & Holmes, 2009). In this manner, social change can occur not only following data analysis dissemination of findings, but also during the data collection process itself (Reinharz, 1991).

One-on-one interviews are also aligned with the epistemological and ontological assumptions of a naturalist paradigm, in which face-to-face interactions are critical to understanding meaning and social knowledge that is produced through interactions (Krauss, 2005). A naturalist paradigm as a research design stresses the assumptions that reality is complex and subjective in nature, the researcher is part of the process of inquiry, and truth is best encountered through interaction with participants of inquiry (Lincoln & Guba, 1985 as cited in Sandelowski, Davis, & Harris, 1989, p. 77). Within this research design, I aim to illuminate the barriers that may exist during interpersonal cancer care interactions between LB women and HCPs, yet doing so in a way without manipulation or research control either during data collection or analysis. The interviews took place in a "natural" environment and sought to invoke the diverse subjective experiences that create meaning for participants (Lee, 2006), which is an integral part of this study's investigation. Both this paradigmatic approach and critical feminist framework provided the basis and structure for my qualitative research design that is appropriate for illuminating participants' insights during cancer care interactions.

Critical feminist research also becomes a political endeavor by allowing the researcher to make their agenda known and included within the research process, rather than remaining neutral within the investigation (Campbell & Bunting, 1991; Fontana, 2004; Reinharz, 1991). This is an integral part of using a critical feminist lens, as it allows for transformative action with all previous assumptions and ideologies made explicit from the beginning of the research process (Kincheloe & McLaren, 2005). Within my own nursing practice, I have witnessed HCPs' heterosexist assumptions towards clients, as well as discrimination based on individuals' self-identified sexual orientation. Inequities in which I have witnessed in my own nursing practice

have been a catalyst in my desire to pursue research that illuminates these potential areas of injustice for LB women. Yet, I have also witnessed LB women advocating for their own health needs and have collaborated with other HCPs to help confront barriers through research. This also compelled me to uncover how other nurses and HCPs are challenging inequities in practice by including their insight within this study.

As both a self-identified lesbian woman and Registered Nurse, I position myself as a supporter of LGBTQ access and equity within the health care system, which influences my willingness to be involved in research of this nature. Using a critical feminist methodology within this research allows for raising consciousness of these issues to both health care communities and LB communities, which may assist not only in promoting social change inside diverse health systems, but also in creating knowledge for other LB women using their own voices. Social change within this research study may be promoted by advancing health care professionals knowledge of dominant ideologies that can silence sexual minority women, as well as creating knowledge specifically for these women that promotes their continued emancipation and action towards advocacy in cancer care.

### Sample and Inclusion Criteria

For the purpose of acknowledging both perspectives in uncovering barriers existent within interpersonal interactions and institutional practices, the populations of interest for my study were both self-identified lesbian and bisexual women (sample 1) and health or service providers (sample 2). Data collection occurred during a period between the beginning of November 2013 and the beginning of April 2014, for a total of approximately five months.

#### Sample one.

For sample one, I recruited women who self-identified as lesbian or bisexual and who had a history of any reproductive cancer. A total of seven women participated in individual interviews either over the phone or in person, with one participant being ineligible, bringing the total sample size to six. The inclusion criteria for this sample was: currently have or have had an emotional or sexual relationship with a woman and/or self-identify as lesbian or bisexual; have a history of any reproductive cancer (breast, cervical, ovarian, etc) in the past 10 years; experienced interactions with health care providers during their cancer care; and be 18 years or older. Participants were not required to currently be in a relation with a woman, nor were they required to be open about their sexuality with family or friends in order to be included in the study. The participant who was ineligible still completed 15 to 20 minutes of an interview, before disclosing that her diagnosis was not a cancer, but rather a cyst. This interview was not transcribed and the audio file was deleted.

### Sample two.

For sample two, I originally was recruiting only Registered Nurses who have worked with LB reproductive cancer survivors for this study. However in an effort to increase sample size, an amendment was submitted half way through the data collection period to include any health or service provider who has worked with this population of women. Ultimately, only one Registered Nurse was interviewed for this study, despite increased recruitment efforts. Some of the potential reasons for a lack of provider participation in this study are discussed in further detail within my limitations section in Chapter Five. The inclusion criteria for this sample was: experience working in any health or service provider role, including but not limited to nurses, physicians, social workers etc; and experience interacting with a lesbian or bisexual woman with

any reproductive cancer (breast, cervical, ovarian, etc.) during their role as a health or service provider. There was no exclusion of health or service providers based on age, gender, sexual orientation, level of experience, or area of work. It is important to note that although only one Registered Nurse who had experience working with sexual minority women with reproductive cancers participated, four of the cancer survivor participants also identified themselves as health or service providers in some capacity, although their work was not specific to cancer care.

An important distinction to make, especially as the one provider within my sample who was not also a cancer survivor was a Registered Nurse, is the various levels of nurses that exist within the province of Ontario and the difference in their educational preparation. The College of Nurses of Ontario (CNO) is the governing body for nurses (Registered Nurses [RNs], Registered Practical Nurses [RPNs], and Nurse Practitioners) within the province of Ontario and has a set of practice guidelines that outline the guiding principles for RNs and RPNs. As stated in these practice guidelines:

RNs and RPNs study from the same body of nursing knowledge. RNs study for a longer period of time, allowing for greater foundational knowledge in clinical practice, decision-making, critical thinking, leadership, research utilization and resource management. As a result of these differences, the level of autonomous practice of RNs differs from that of RPNs. (CNO, 2014, p. 3)

The guidelines also make recommendations for care based on the acuity and complexity of a patient's condition, with more complex patient situations and less stable environments requiring the presence of or consultation with an RN (CNO, 2014). Nurse Practitioners and Clinical Nurse Specialists are RNs who have even greater educational preparation and practice at an even more

advanced level with an extended class of registration (CNO, 2011). Highlighting these distinctions helps to provide context to the RN who was not also a survivor and how her experiences and insight represent her scope of practice and role within her health care setting.

Additionally, both samples were recruited through purposeful sampling (discussed further in setting and recruitment) and snowball sampling. In terms of snowball sampling for cancer survivors, all those women who participated in research interviews were given recruitment information to pass on to other sexual minority women they may have known who also have experienced a reproductive cancer. In terms of using snowball sampling for HCPs, I began by seeking those at health centers that have a focus on providing specific and inclusive LGBTQ health services, and then expanded more broadly to other health centers providing cancer care in the GTA. The Registered Nurse who participated in a research interview was also given recruitment information to pass along to other providers. I also gave a presentation for a panel of Registered Nurses and other health providers at a hospital within the GTA on this research and provided all individuals present with promotional material to pass along to other providers who may have been eligible to participate.

### **Setting and Recruitment**

Originally, sexual minority women and HCPs for this study were only recruited and eligible to participate if they currently resided in the Greater Toronto Area (GTA) in Ontario, Canada, a populated urban city centre with a variety of LGBTQ-specific health resources. However, in an effort to increase recruitment, an amendment was submitted half way through the data collection phase in order to allow any LB cancer survivors or HCPs across the province of Ontario to participate, with the majority of recruitment still to occur within the GTA. In order to

recruit two very specific samples I used criterion sampling, a form of purposeful sampling that selects informants based on predetermined criteria or inclusion criteria previously discussed (Polit & Beck, 2012).

In terms of sample one, often LB women can be a difficult population to access in research because of societal stigma forcing women to stay "closeted", making this group of women sometimes less accessible than self-identified heterosexual women (Boehmer & Case, 2006). Therefore, in an effort to reach a wider audience of diverse women who may or may not be openly expressive of their sexual orientation (i.e. "out") it was important to recruit in areas that serve LB women specifically, as well as areas that do not. I targeted areas that are LGBTQ inclusive or specific, such as local community centers, bookstores, the gay and lesbian archives, and LGBTO specific health centers in Toronto that may see a greater population of LB women. I used posted flyers (Appendix A) at these locations that included information on the study, inclusion criteria, and the research project's contact information. I disseminated the call for participants through a weekly flyer at an LGBTQ-inclusive church within the GTA. I also circulated recruitment information through my personal network of lesbian and bisexual contacts, and recruited two of the total seven participants in this manner. Additionally, flyers were posted at and distributed to cancer support groups for lesbian women, such as Wellspring Toronto, and also through networks such as Ovarian Cancer Canada and Canadian Breast Cancer Network.

As sexual minority women have historically been marginalized and made invisible within society and public spheres, they can often be a challenging or "hidden" population to recruit.

Disseminating a call for participation online is often recommended for hidden populations, as it

allows for increased accessibility and anonymity of a population who may be difficult to recruit (Sydor, 2013). Using online listservs is a way to distribute a recruitment email easily and quickly to a wide audience, as well as listing a call on a website or forum. Disseminating this call through LGBTQ listservs such as Rainbow Health Network, and on websites such as Rainbow Health Ontario, were two approaches used to increase online dissemination of the call. I used social networking websites, such as Facebook to promote my online presence and connect with LGBTQ interest groups and online networking forums. Furthermore, all interviews were conducted at a setting mutually agreed upon by both the cancer survivor and myself, at a time that was convenient for the participant. Five interviews were conducted in person and one was conducted over the phone due to the participant living outside the GTA.

Disseminating the call for HCPs to participate also occurred mostly within the GTA. I placed flyers (Appendix A) at an LGBTQ-specific health center and disseminated a call through a large city centre hospital. The flyers contained similar information to those created for sexual minority women, with the exception of including the inclusion criteria for HCPs. Listservs and email recruitment were also used for this population, especially as often a key stakeholder was needed to gain access to health care settings or organizations. Rainbow Health Ontario and Registered Nurses Association of Ontario (RNAO) Rainbow Nursing Interest Group (RNIG) were examples of two groups advocating for LGBTQ-inclusive health services that were also used to disseminate a call for participation to providers. I also used my personal networks through nursing in an attempt to recruit potential participants who may have worked with this population of women. The setting for the interview with the Registered Nurse also occurred at a location and time mutually decided between her and I. The option for a focus group with nurses

was also initially suggested as a way to generate discussion on the barriers for LB women's cancer care in an interactive manner, as well as the option for telephone interviews.

### **Data Collection**

As previously stated, no one method in a critical feminist methodology is considered more desirable or unique to the framework (Fontana, 2004). However, I chose to use individual interviews to best align with a naturalist research design (Sandelowski et al., 1989) and allow for a one-on-one collaborative approach to the research process with participants. Participants in either sample who volunteered to participate in this study were asked to complete a 60-90 minute individual audio-recorded interview, either in person or over the phone.

The interview guide (Appendix B) for sexual minority women involved responding to broad, open-ended questions to the best of their ability, recounting times of their interpersonal interactions with HCPs where barriers to their care may have occurred, been perpetuated, or challenged. The interview guide (Appendix C) for the Registered Nurse involved the same kinds of broad, open-ended questions, except that the questions involved reflecting on how equitable care is provided or inequities perpetuated during interpersonal interactions with LB women experiencing reproductive cancers. The discussions with all participants included certain questions that were unique to each interview by asking individuals to elaborate on certain points or experiences. The participants were all told that they may forgo answering any question, may opt not to be audio-recorded, and may withdraw from the interview at any time and I also offered a \$20.00 honorarium to all participants. The individual interviews, both over the phone or in person, were audio-recorded, transcribed, and assigned a code number, with no names or personal identifying information included in the completed transcripts. Only one participant

chose not to be audio recorded, in which case I took notes during the interview, which were then used for inclusion within the findings.

In using a critical feminist methodology, the incorporation of an interview structure involving a non-exploitative hierarchical relationship between the interviewer and interviewee is of the utmost importance (Reinharz, 1992). Qualitative interviews using shared information, openness, and relations of respect help to establish clear and trusting communication with participants that is not exploitative or oppressive (Reinharz, 1992). In terms of the interviews with the sexual minority women especially, this sample may have had a history of negative interactions with providers and it was important to stress to participants that this is a reciprocal process, in which they may ask general questions of me as well. It was equally important to stress to the Registered Nurse that I was seeking her valuable insight, and not in any way condemning any previous interactions that may have occurred. The interviewing process was mutual in nature, in the sense that it was important for me to disclose my sexual orientation and position as a Registered Nurse to all participants, in order to foster a relationship of trust.

Additionally, the semi-structured interview guides used for this study also reflected the research methodology of critical feminism. The open-ended questions asked of sexual minority women sought to uncover potential historical and socio-political barriers that may have been existent for these women within the broader societal context. It also attempted to delve into micro level barriers pertinent to individual interactions with health care providers. It is important to note that upon reanalysis of my LB reproductive cancer survivor interviews and interview guides, I noticed that I had not asked participants questions regarding the effects on reproduction or reproductive health after their cancer diagnosis. This may have contributed to a lack of

discussions on these issues, which is discussed further within the findings and discussions chapter.

Similarly, the interview guide that I created for HCPs also examined insights into some of the institutional or structural policy barriers that they may have saw as contributing to inequalities for sexual minority women during reproductive cancer care, how they have seen these barriers affect care during interpersonal interactions, and what can be done to help limit these barriers. The interview with the Registered Nurse also did not delve into the impact of infertility or reproduction problems that the women may have faced during their cancer care. However, this Registered Nurse may also not have brought up issues of infertility with her patients because she had not had these conversations with the patients themselves during her role as an intensive care nurse.

In addition to a 60-90 minute interview, participants were also asked to complete a brief demographic questionnaire in order to describe participant demographics within the samples. The demographic questionnaire remained separate from the audio-recorded interview data, being assigned a number only, and was anonymized. The questionnaire (Appendix D) for LB women included questions on age, self-identified sexual orientation, gender-identity, ethnicity, income, relationship status, number of years since cancer diagnosis, and type of cancer. The questionnaire (Appendix E) created for HCPs included similar questions, as well as those on their current employment role, years of experience, whether they have specific training providing care to LGBTQ communities, and if their place of employment offers specialized services for LGBTQ communities. Participants were told that they may chose to forgo answering any question on the questionnaire or opt not to complete the demographic questionnaire entirely. An important

omission to note within my demographic questionnaire was the unintentional exclusion of questions pertaining to education for both samples. This left a gap in terms of how the participants were described and the implications for this omission are discussed further within my limitations section.

### **Ethical Considerations**

This study explored the barriers that exist during reproductive cancer care interactions for a marginalized group of women who are often discriminated and persecuted, and therefore ethical consideration and confidentiality was of the utmost importance. Using a critical feminist methodology also demands the need for scrutiny in maintaining ethical research practice that does not further contribute to oppression for participants (Preissle, 2012; Reinharz, 1992). This study was reviewed and approved by The Faculty of Graduate Studies (FGS) at York University. The FGS follows the senate policy for the Ethics Review Process for Research Involving Human Participants, in which any funded or non-funded research must undergo an ethics review process and as such, this research also conforms to the standards of the Canadian Tri-Council research ethics guidelines.

Once participants began to contact me with interest to participate, they were given further information on what the interview would entail, and the risks and benefits of participation. In keeping cognizant of the complex events at time of oncology treatments, women were not recruited from any inpatient unit to avoid placing them through increased demands. Allowing participants to freely contact me if they wished to participate promoted power distribution to sexual minority women and the Registered Nurse to choose their willingness to participate in the research study without coercion (Preissle, 2012).

At the time of the interview, I presented participants with a written consent form (Appendix F and G), which was explained in detail and signed by both the participant and myself before the commencement of the interview. There were two parts to the consent form, including consent to participate and consent to be audio-recorded. Participants could choose not to be recorded, and also to withdrawal or terminate the interview at any time. All participants were informed that although there were no expected direct risks from their participation in the study, there is a risk that recounting past cancer care interactions may be difficult. Discussing past experiences of, or witnessing of, homophobia, biphobia, or discrimination could have been uncomfortable for the participants. In order to decrease these risks, participants were told that they may chose to forgo any question they did not feel comfortable discussing. They were also told that they may chose to withdraw from the study at any time, which would not affect their relationship with myself, my supervisor, or York University, and that forgoing any question or withdrawing from the study would not disqualify them from receiving the honorarium. All participants were provided with the names of some LGBTQ-positive support resources and cancer recourses (Appendix H) at the conclusion of the interview.

Furthermore, although there were no direct benefits to the participants, I explained that the benefits from this research were indirect. Some sexual minority women may have found it helpful to discuss their experiences with reproductive cancers, and the Registered Nurse may have found it helpful to discuss her experiences working with these women living with reproductive cancers. The findings from this research may also contribute to improvement of nursing cancer care for LB reproductive cancer survivors and dialogue created from the interviews may help to identify current gaps in care resulting from organizational policies,

potentially fostering further research in this area. This research goal remains aligned with the tenets of feminist research, in that this research sought to generate knowledge that would assist in benefiting marginalized women, while also acting as a resource for the women themselves (Edwards & Mauthner, 2012; Preissle, 2012; Reinharz, 1992).

Maintaining confidentiality and anonymity is especially important for both LB cancer survivors who may not be "out". In order to maintain confidentiality and anonymity, no names or identifying information were included in the transcribed interviews and all data including audio-recorded interviews were stored on a password protected, encrypted USB key. The USB key is stored in a locked cabinet in my home office. Any names of institutions or organizations in which LB women received cancer care or where they worked as a health care provider was also not included in the transcribed interviews. I also assigned all participants randomly chosen pseudonyms in order to facilitate reporting within the findings chapter, yet also retaining anonymity. A copy of the written transcripts, consent forms and demographic questionnaires are also stored in a locked filing cabinet in my home office and will remain for two years following completion of my Master's thesis.

### **Data Analysis**

In order to remain aligned with a naturalist paradigm as well as the guiding principles of critical feminist theory, the steps involved in the data analysis process must allow for data to emerge that is representative of women's voices and experiences. Therefore, I reviewed the interview transcripts for this research study using conventional content analysis in order to determine codes, categories, and ultimately themes that emerged from the data. Qualitative content analysis is used as a means to reduce large quantities of textual data into smaller units of

codes and categories in order to best facilitate the subjective interpretation of content (Flick, 2009; Hsieh & Shannon, 2005). Specifically, conventional content analysis is an approach that allows the categories and names for these categories to emerge from the data itself, assisting in the formation of new insights while also avoiding imposing themes on data from preexisting theory (Hsieh & Shannon, 2005). This approach is inductive in nature and allows for recommendations regarding future research, practice, and education of the phenomenon under analysis (Hsieh & Shannon, 2005). This approach is also well suited to the tenets of a critical feminist framework, as it allows lesbian and bisexual women's voices and interpretations of the cancer care experience to be analyzed clearly and directly, without imposing other theories onto their experiences.

In following with a conventional content analysis approach, all interview transcripts from participants were read and coded line by line, allowing myself to become immersed within the data (Hsieh & Shannon, 2005). Data analysis also occurred simultaneously with data collection in order to effectively modify the interview guides to delve deeper into early emerging concepts. Some of the changes I began to make involved adding questions that could focus in on details of women's cancer journeys and some of their emotions during that time. However, one aspect of the interview guide that I realized was lacking only upon completion of the research interviews were questions pertaining to reproduction and fertility. Despite a focus on reproductive cancers, I had not included questions on how concerns regarding reproduction may have impacted the women. Due to this, it was important for me to readdress my literature review section during the data analysis process in order to add a section on reproductive health for sexual minority women.

The initial codes that I began to use while analyzing the women's interviews were yielded directly from the transcripts and helped to capture key thoughts and possible concepts. Some of these initial codes included concepts directly related to specific issues such as cancer treatments, disclosing sexual identity, and relationships. These beginning codes were expanded more broadly to capture a larger picture of the emerging concepts following discussions with my thesis supervisor and as the number of research interviews increased. These codes were then grouped together into corresponding categories that could better capture the overall similarities or differences between them. Subsequently, these categories and codes were placed into larger themes that encompassed the concepts as a whole in terms of the LB survivors' experiences, the Registered Nurse's experience, and how these overlapped. These emerging themes are discussed in greater detail within the findings and discussion chapters.

An unexpected occurrence that happened during my recruitment and one that I did not intentionally plan for was the amount of LB cancer survivors I interviewed who were also health or service providers in some capacity. Although at the end of my recruitment process I was only able to recruit one Registered Nurse, I realized that I had interviewed four cancer survivors who were also providers in some capacity. This assisted in providing a rationale for completing the recruitment process at the time that I did, as I now could include insight from not only the one Registered Nurse, but also the four survivors who were also providers. Although not all of the survivors who were also providers had experience specifically working with LB reproductive cancer survivors themselves, their insight from their own experience as both a patient and provider still has important implications for how sexual minority women navigate through health care.

The demographic forms completed by all participants were also analyzed. Yet, because of the small sample size, computerized data analysis software was not required. The completed demographic forms were continually reviewed during the data collection process to help channel and target recruitment efforts to increase diversity of participants. For example, all but one cancer survivor identified as a lesbian woman, and therefore efforts were made in an attempt to target bisexual women during recruitment, such as posting to bisexual-specific Facebook groups. Furthermore, efforts were also made to extend the recruitment call to organizations for ovarian and gynecologic cancers, as the majority of participants were survivors of breast cancer. The results over the demographic questionnaire are used to contextualize the overall findings from the participants and are discussed further within the findings and discussion chapter.

# **Quality Appraisal and Adequacy**

A critical feminist framework allows for the analysis of a researcher's own standpoint, providing a starting strategy for development of research in an area that may be of specific importance to her or himself (Reinharz, 1992). As both a self-identified lesbian woman and RN, I find myself interested in uncovering perspectives from both these groups, as well as the intersections of the two. However, I understand that basing this research design within a naturalistic paradigm, in which epistemology underlies the importance of the inquiry eliciting change and discovery for both the interviewer and interviewee, I cannot enforce my assumptions about either role into the research process (Krauss, 2005). It is important to be aware of my own perceptions and place within society and how this may affect my analysis of the findings and how rigor may be ensured within the critical feminist framework and conventional content analysis.

Using the recommendations of Hall and Stevens (1991), there are specific ways of achieving "adequacy" in feminist research as a means for measuring rigor within the content (p. 20). Adequacy, as described by Hall and Stevens, "implies that research processes and outcomes are well grounded, cogent, justifiable, relevant, and meaningful" (1991, p.20). Within my research study, I will use selected criteria from Hall and Steven's recommendations for achieving adequacy in feminist research in order to maintain rigor in my findings.

# Achieving adequacy.

One of the recommendations for achieving adequacy in feminist research is developing rapport with participants in order to establish a trusting, open relationship that credibly represents women's voices (Hall & Stevens, 1991). Developing rapport with participants in a critical feminist study is especially important because if there is no established rapport, there is little trust that the findings accurately represents a woman's insight truthfully (Hall & Stevens, 1991). For this study, developing rapport was slightly challenging, as there was only one interview at one point in time with each participant. However, the interviews were accommodated to participants to the best of my ability, occurring during a time and at a place that was most convenient and comfortable for the individual. In an effort to create an atmosphere of trust and openness during one-time interactions, I also self-disclosed my sexuality to all participants and expressed a willingness to answer or respond to their questions or concerns during the interview. Sensitivity to the language used is also important (Hall & Stevens, 1991), and recognizing the diverse ways in which participants may refer to their sexuality, partner, ethnicity etc. was also important to take note of and incorporate into data analysis.

Honesty and mutuality are two other recommendations for achieving adequacy that closely relate to creating rapport in feminist research (Hall & Stevens, 1991). Honesty is important to maintain within critical feminist studies specifically, as deception goes against the very tenets of the inquiry. Participants' insights cannot adequately be interpreted if deception has been involved during the research process (Hall & Stevens, 1991). Mutuality is also an important recommendation in order to create an egalitarian collaboration within the research process, avoiding contributing to unequal power dynamics within the relationship (Hall & Stevens, 1991). Both these recommendations were stressed within my study to all participants, as they were informed in detail of all information related to the study, risks, and benefits, with no deception involved. Furthermore, in terms of mutuality within the research relationship, prior to beginning the interview I made sure to speak about my background as a nurse, why I was interested in conducting a study of this nature, and what I hope the study will achieve. The research process was also open to all input from participants and the guide was modified based on the responses from some of my early participants and how data was emerging.

Traditional empiric research methods typically use conventional research language and terms for describing the design and participants, at times not taking into consideration the language used by diverse genders, races, classes, ages, sexualities involved in their investigation (Hall & Stevens, 1991). Naming allows for participants' own terms and language to be used, helping to ensure adequacy in research by placing necessary value and emphasis on words selected by those who use them (Hall & Stevens, 1991). Naming was important specifically when using one-on-one interviews as my primary method of data collection and interviewing sexual minority women who have traditionally been medicalized within health research.

Therefore, to ensure adequacy in my findings, direct description and use of participant language was emphasized in all analysis.

Furthermore, critical feminist research explores the historical, political, and social structures that often contribute to social injustice or oppressive practices, making it quite complex in its inquiry (Campbell & Bunting, 1991; Falk-Rafael, 2005; Fontana, 2004; Hall & Stevens, 1991; Longo & Dunphy, 2012). Adequacy in feminist research can be achieved when this complexity is portrayed throughout the body of the research, demonstrating the avoidance of oversimplifying participants' experiences or insights (Hall & Stevens, 1991). Each participant's interpretation must be considered unique in its view on reality, with similarities and differences that may compare and contrast to other women who have encountered comparable situations or events. Within my study, I used a demographic questionnaire in order to explore and contextualize how participants' unique position in society may create similarities or dissimilarities between others in a comparable position. I have also provided historical, political, and social background on the current state of sexual minority women's health care interactions within the review of literature and explored these themes further within the interviews. Interviews also varied for every participant, as new questions emerged that were specific to the topics discussed with each individual.

Just as each participant may have different insight and interpretation, so may each researcher reviewing a research report. Collaborating with other researchers in the form of what Hall and Stevens (1991) deem as relationality, also helps to ensure research is well grounded and justifiably adequate. During this research process, dialogue with my supervisor and committee member created opportunity to critically question elements within the data analysis process,

which ultimately assisted in portraying participants' insights in a clear and accurate manner. As both my supervisor and committee member have extensive knowledge and research experience in LGBTQ-related inquiry, their expert insight was considered a valuable asset to the interpretation of results. This process of dialogue and collaborative efforts was incorporated throughout all stages of the development of this research, also assisting to increase rigor throughout my study.

### Reflexivity.

The final recommendation to ensuring adequacy is the use of reflexivity, which is often discussed as a method for ensuring rigor within many qualitative inquiries (Finlay, 2002; Fontana, 2004; Hall & Stevens, 1991; Hesse-Biber, 2012; McCabe & Holmes, 2009). Reflexivity is considered to be an ongoing process in which "researchers recognize, examine, and understand how their social background, location, and assumptions affect their research practice" (Hesse-Biber, 2012, p.17). This recommendation for ensuring rigor is especially important for research based within a naturalist paradigm, which values multiple realities and seeking subjective insight into meaning. Reflexivity in feminist research does not wish to eliminate researcher's attitudes and assumptions, but rather make their presence known and evaluated throughout the research process (Hall & Stevens, 1991). Eliminating researcher bias in critical feminist inquiry is not the goal in maintaining adequacy, but rather incorporating theses feelings and assumptions as a way to remain aware of how they may influence the research process.

Reflexivity was an effective method to ensure rigor within my research, as this criterion is well aligned with the tenets of a critical feminist framework. Reflexivity is concerned with maintaining equal power dynamics, and allowing participants to share their insights without the

researcher enforcing their assumptions or preconceptions (Hall & Stevens, 1991). It is also concerned with the interviewer-interviewee relationship, and how the two can be mutually influential (Finlay, 2002). As the researcher in this study, I had my own preconceptions of the state of patient-provider interactions for sexual minority women based on my own experiences and social knowledge. These assumptions have influenced my research questions, methods, and affect all facets of this inquiry. However, it was important to be aware of how my position as researcher could oppress the unique meanings cancer care interactions had for diverse sexual minority women if I was to attempt to persuade participants in certain directions (Finlay, 2002).

Thus, during the interview process it was important to maintain a dialogue that was open and allowed participants to speak freely about their insight, and recognize when my assumptions may be influencing direction. Reflexive journal writing during the research design and interview process was also an approach I used to ensure that my perceptions and assumptions were being recognized and documented. Reflexive journal writing involved describing my decision-making during the research process, my perceptions of data collection and early analysis, and how my research decisions are a reflection of my own social position (Finlay, 2002). For example, the following excerpt from my journal shows some of my reflection on how one of my research interviews unfolded.

This participant went into very deep detail about her experiences and for this reason at times it was difficult to keep the interview on track. I found myself becoming panicked and even slightly stressed as this was happening. However, I did a lot of self-reflection simultaneously, realizing that this is a woman's personal story of her journey with cancer and she can tell it however she sees fit. Once I was able to relax and not try so hard to

direct the interview one way or another, I realized how valuable the interview was to both her and my research. (Legere, 2014, p.7)

Memo writing after each research interview was also an extremely important approach to early data analysis and reflexivity. Memo writing was completed immediately upon completion of a research interview as a way to reflect on some elements that occurred during the interview, challenges that arose, and my personal thoughts or feelings surrounding participant's cancer care experiences. For example, one of my memo entries reflects that interviewing one of the survivors who was close to my age was particularly challenging. "This interview was especially poignant for me. For this reason, it was especially important that I did not try to assume what she was thinking or feeling at this time, but instead let her tell her story" (Legere, 2014, p. 2). When I was reviewing this participant's transcript, I referred back to this memo and tried to make sure that upon analysis I was best capturing the elements of what she was saying, and not my own feelings. These memos and reflexive journal were also used to supplement data analysis and help create an audit trail of my research process.

### Dissemination.

Dissemination of this research back to the participants is also a crucial aspect in helping to foster further action and advocacy for LB women's reproductive cancer care. Providing a written summary of results to those participants who wished to receive this information will be completed within the months following successful defense of my thesis. I believe it is also beneficial to consider submitting these findings for potential publication to scholarly journals. Conference presentations are another useful approach to disseminate findings to a large audience. Specifically, the only conference in Canada to focus on issues of health and wellness

for LGBTQ communities is the RHO conference, which is also the most relevant to my proximity as a researcher in Southern Ontario. (Rainbow Health Ontario, 2013). Two other conferences that may be a possibility for research dissemination include the Gay and Lesbian Medical Association conference and the Women and Medicine conference, both of which have an emphasis on lesbian health research (Gay and Lesbian Medical Association, 2012; Women in Medicine, 2012).

Another important group to disseminate these findings to are nurses who work specifically in an oncology setting, as well as those who work in areas that are not oncology-specific. Many reproductive cancer survivors may need assistance in their community, either through homecare visits or outpatient clinics, and therefore nurses who work outside of oncology-specific settings often still see those experiencing various types of cancer. I hope to present these findings for staff at some of the larger cancer centers within the GTA, while also making an effort to target conferences or seminars that are specific to nurses who work in a variety of settings, both in hospital and in public or community health. Ideally, I would also like to present these findings for students in health or nursing classes specifically, in an effort to promote awareness of reproductive cancer care for sexual minority women to new students.

### Summary.

It is my hope that this study will help to address some existing gaps in research not previously addressed by other work in areas of reproductive cancers and sexual minority women. Specifically, my focus on interpersonal interactions between sexual minority women with reproductive cancers and HCPs may provide new insight to how these interactions reflect the perpetuation of larger institutional barriers, but also how both these women and a Registered

Nurse are successfully challenging and overcoming these barriers in practice. Using a critical feminist framework allowed for the knowledge stemming from this research to be developed with and for sexual minority women, in order to foster their own action and advocacy towards potential changes in policies that have traditionally limited equality in their reproductive cancer care. My own social position as a white, middleclass, lesbian woman, and Registered Nurse frames all aspects of this research process, from conceptualization of research questions to analysis of findings. Thus, the recognition of my social position and using a collaborative approach with participants, as well as experts in LGBTQ research and education, was of the utmost importance to ensure adequacy within this study.

### **CHAPTER FOUR:**

#### **FINDINGS**

In this chapter, I outline the findings from my interviews with all seven participants. The participants included six sexual minority reproductive cancer survivors, four who also identified as health or service providers, and one Registered Nurse who was not a cancer survivor.

Provided below are the demographics from my samples, the emerging themes from the interviews, and a summary of the findings from this research.

# **Demographics from Samples**

Feminist and critical frameworks stress the importance of recognizing similarities, but also diversity between participants' experiences (Hall & Stevens, 1991; Reinharz, 1992). Lesbian and bisexual women of diverse classes, races, abilities, and ages may experience interactions with health care providers in different ways. Similarly, health care providers who self-identify as gay, lesbian, or bisexual may also approach cancer care interactions with LB women differently than those who identify as heterosexual. Portraying diversity within both samples may help to create a more holistic analysis of the barriers to care that may occur for individuals depending on intersections of marginalization. However, seeking a large diversity of participants within my study samples was challenging given the small size and the nature of sexual minority women often being members of a hidden population. Overall, eight interviews were conducted, seven with self-identified LB women, with one LB woman being ineligible, and one Registered Nurse who was not also cancer survivor. Therefore, a total of seven interviews were included in the findings of this study.

The following table outlines the descriptions of all seven participants based on their responses during the individual interviews, as well their open ended and multiple-choice responses on the demographic questionnaires. All participants were assigned randomly chosen pseudonyms to ensure anonymity and any specific identifying details have been modified or omitted.

Table 1: Participant Descriptions

Participant	Descriptions
Robyn	Self-identifies as a black, lesbian woman in her early 50s. She is a survivor of breast cancer and was single during her cancer care. She also worked as a health advocate in her city.
Tasha	Self-identifies as a lesbian woman in her early 20s with Canadian and Caucasian background. She is a survivor of ovarian cancer and had a female partner during her cancer care. She also works as a health provider.
Brenda	Self-identifies as a lesbian woman in her late 60s with Canadian and Caucasian background. She is a survivor of breast cancer and was married to her female partner during her cancer care. She is also a retired therapist.
Claire	Self-identifies as a Canadian lesbian woman whose mother has "Native background". She is in her mid 40s and a survivor of breast cancer. She was married to her female partner during her cancer care and has an adult child.
Anna	Self-identifies as a bisexual woman in her early 50s with Canadian background. She is a survivor of breast cancer and was single during her cancer care. She also works as an outreach worker and has an adult child.
Dani	Self-identifies as a black, lesbian woman in her early 20s. She was recently diagnosed with cervical cancer and is in a relationship with a female partner while currently undergoing cancer care.
Lucia	Registered Nurse who self-identifies as Eastern European heterosexual woman in her mid 20s. She has been working as a RN for between one and five years.

Five cancer survivors in my study self-identified as lesbian and female, one self-identified as bisexual and female, and the Registered Nurse identified as heterosexual and female. In terms of cultural identity, this question was left open on the demographic questionnaire in order for participants to freely describe however they culturally identify. The reproductive cancers represented within this research were breast cancer, ovarian cancer, and cervical cancer, with the majority of participants having had a form of breast cancer. At the time of the interview, two women had been diagnosed within six months to a year ago, three women received their diagnosis one to three years ago, and one woman was diagnosed five to ten years ago. During their cancer care, two women stated that they were single, one woman was dating a female partner, one woman was living with a female partner, and two women were married to a female partner. In terms of household income, two women preferred not to answer, three women had a household income of between \$10 000 and \$30 000, and one woman had a household income of greater than \$100 000. All of the participants were residents of Ontario, with six residing within the GTA and one in eastern Ontario.

An unexpected finding from this research was that four of the six survivor participants identified themselves as both cancer survivors, as well as health or service providers. This was not something I sought out during my recruitment, but rather an aspect of the women's identities that came up during our interviews. These participants provided an interesting insight into some of the issues associated with an understanding of both the health care system as a patient and provider of services.

In terms of the Registered Nurse who was not also a reproductive cancer survivor, Lucia worked as an RN within an acute care setting, primarily the intensive care unit, and resided in

Ontario. Due to the nature of her work where most of her patients are critically ill and unable to communicate, the majority of her interactions were with sexual minority women's families. She is not certified in oncology nursing, but her insight is important for nurses who work in a variety of settings and are seeing an increasing number of oncology patients on various inpatient units. At the time of the interview, she had been working as an RN for between one and five years, and had received some education on providing care to LGBTQ communities during her undergraduate education. She stated that she had a few experiences working with lesbian identified women, some of which who had a reproductive cancer, and no experience that she was aware of working with bisexual women. Lucia also has had experience working as an RN in both large urban city centres and smaller, more rural communities within the last five years.

## **Emerging Themes**

The findings from this research study demonstrate some of the unique stories of sexual minority women who have journeyed through a reproductive cancer diagnosis and how interactions with health care providers facilitated and hindered their cancer care experiences.

During the course of analysis, four main themes encompassing corresponding subthemes emerged from LB cancer survivors' interviews: 1) The reproductive cancer journey; 2)

Reproduction and the meaning of family; 3) Interactions with health care providers during cancer care; and 4) Environmental (institutional and organizational) barriers.

Within each of these themes, the survivors also spoke of the meanings of cancer that arose for them at varying times. This insight into some of the survivors' meanings of reproductive cancer and the elements related to it helped to give context to the whole journey. The interview with the Registered Nurse who was not also a survivor, yielded other important

insight surrounding interactions with sexual minority women undergoing reproductive cancer.

These insights and experiences from her own practice, as well as the survivors who also identified themselves as providers, are discussed at the end of each of the four themes.

Prior to discussion of the emerging themes, it is important to note who the participants are referring to when speaking about health care providers. The cancer survivors specifically provided examples from interactions with nurses, family physicians, oncologists, radiologists, ultrasound technicians, surgeons, and receptionists, while also sometimes using the terms 'health care providers' and 'health care staff' to speak broadly about anyone who worked within a health care setting. Participants also used the term nurses but often did not specify whether these were Registered Nurses (RNs), Registered Practical Nurses (RPNs), or unregulated personal support workers (PSWs). However, to provide some context, according to the College of Nurses of Ontario statistics from 2013, there were 33,855 RPNs working in nursing in Ontario, compared to 91,455 RNs working in nursing in Ontario (CNO, 2013). There were also an estimated 90,000 PSWs providing care in Ontario in 2011, but only about 7000 of these worked in a hospital setting (Ministry of Health and Long-Term Care, 2011), which according to participants was where the majority of their interactions occurred. Therefore, it is safe to assume based on my discussions with the participants that the term 'health care provider' within the context of my findings more commonly refers to physicians, RNs and RPNs, with a few more specific roles being directly stated by the participant.

### The reproductive cancer journey.

Simply hearing the word cancer can conjure up a variety of emotional responses and feelings for individuals, but none more powerful than from those who have experienced the

disease first hand. The sexual minority woman who participated in this study faced a unique journey through reproductive cancer care, as they begin to navigate not only what it meant to overcome the disease but also what the concept of health or health care meant to them and how it altered over time. Many participants addressed similar stories in relation to the course of their cancer, its physical and emotional effects, and their understanding of health during that time. These insights reflect some similar experiences, but also portray some of the unique ways in which each woman experienced their treatment and care.

Most women described their reproductive cancer journey initially in a chronological way, starting from discovery of cancer and then elaborating on their courses of treatment, the everyday implications of cancer, alterations to their physical health, and their understanding of health. However, no matter the order in which the women discussed their cancer journey, each gave unique insight into the impact that cancer had on their life and relationships. In order to best lay the foundation for the rest of the findings from my interviews, the cancer journey from the perspectives of these sexual minority women must first be described in detail.

### Discovery of reproductive cancer.

In terms of the discovery of their reproductive cancers, most participants echoed the feeling of being "shocked" upon finding out what the source of some of their physical symptoms were. One participant described discovering a lump in her breast while being intimate with her female partner and then upon receiving an ultrasound and mammogram, she was unintentionally told by the radiologist that she had breast cancer.

It was kind of interesting because the person who was doing the ultrasound had to go get the radiologist. So the radiologist came in and the technician left and I said 'Well, what do you think?' and he just kind of looked down. I said 'Is it cancer?' and he said 'I think you have breast cancer'. (Claire, p.3)

Another participant described how it was her female partner who prompted her to have a pelvic ultrasound that she had initially declined during a routine exam. "A few days later they called me back and said 'you have a tumor in your ovary the size of a pear and you have to go to into treatment immediately'. Within days I was waiting for surgery" (Tasha, pp. 3-4). Dani, who was undergoing treatment for cervical cancer during the time of the research interview, talked about some of the words that she commonly associated with cancer. "I thought cancer meant dying and pain" (Dani, pp. 4). She also said that she was "scared" when she was first told of her diagnosis and she thought cancer usually meant "people being really afraid" (Dani, pp. 4-5).

Most of the women who participated in this study did not have a previous chronic condition or family history of cancer, and therefore discovery of this reproductive cancer was especially devastating and shocking. Anna described the discovery of her breast cancer as unexpected.

It was my first mammogram; there was no family history or anything. So I went and then they called me right back and said I had to come in for another one. Within the hour they said I needed a biopsy. I had surgery [a month later] and they removed the lump and a lymph node from my arm. (Anna, p. 2)

Robyn described being slightly tired and having a fever but not thinking too much about it. Upon visiting friends and family in Canada, she went to the doctor to check about her fever and some swelling in her chest. "When I was actually diagnosed, even when I was actually told, I thought

perhaps it would just be a lump. So I think that I was in shock more than anything else" (Robyn, p. 3).

Brenda, who did have a family history of breast cancer, even losing her mother to the disease, described an agonizing wait to finally confirm her diagnosis. "From the time of the first mammogram to the time of finally hearing that 'Yes, this is [cancer], we probably recommend surgery', that was six to nine months, it was very long" (Brenda, p.4). This had implications for her in terms of the physical anxiety she experienced during that six to nine month wait as she struggled with the decision of whether or not to have a surgical biopsy. Brenda also went on to discuss some of the same sentiments voiced by other participants regarding surgery, in terms of how she did not "feel sick".

[It's] the shock of that they want to take off my breast but I feel fine, and that was part of my anxiety. They said 'We'd like to do a surgical biopsy', and I'm thinking '...but I don't feel anything and it took you a long time to be sure of what it was, why should I let you cut into my body?' (Brenda, p. 26)

The long wait time to confirm the breast cancer diagnosis, as well as her overall sense of feeling healthy, certainly caused some emotional strain for Brenda during this time in her cancer journey.

### Courses of treatment.

The courses of treatment described by women ranged from day surgery to mastectomies with chemotherapy and radiation, depending on the cancer severity, with most women in this study discussing the immediate courses of action that were taken upon diagnosis. However, it is important to note that this immediate treatment is not reflective of all individuals who receive

cancer diagnoses, as often there are barriers to health care access that can make immediate care for cancer challenging. Nevertheless, the stories of undergoing these treatments varied between women based on the type, stage, and grade of their cancer, and commonly their sexual identity also had implications for how they experienced these often aggressive and invasive treatments.

For example, Anna brought forth a unique aspect of her experience with cancer treatments. She described how during her cancer journey there were external stressors along with the obvious physical experience of the disease, including a recent separation from a male partner, which affected her ability to keep up with treatments. "I did get overwhelmed. I missed 2 radiation appointments, I missed a Friday appointment and then I missed Monday. My oncologist called me because he was really worried about me" (Anna, p. 4).

Tasha spoke about placing importance on remaining emotionally strong during her treatments. "I think I cried when I was first diagnosed and then I didn't until after everything was better, because I couldn't. If I did, than I wouldn't be able to get out of bed" (Tasha, p. 8). Tasha went on to describe how others' emotional reactions were difficult for her to witness and sometimes made interactions with family or friends challenging. She then spoke about how her partner became aware of this and was considerate to Tasha's emotions during her treatments. "She locked away all her feelings so that I wouldn't see it, because she knew I couldn't handle that. And then she'd cry on her own, like when I wasn't around. She stayed really strong about it" (Tasha, p. 38).

Additionally, Claire described a conversation she had with her oncologist which proved challenging.

I said to the oncologist when I was sitting in his office 'I have a question and I want you to be honest, is this going to kill me?' and he said 'Not this time, no'. And I asked '...but will it eventually?' and he said 'yes, I believe so'. Although I asked the question and wanted to know the answer, I wasn't ready for the answer. (Claire, p. 23)

Claire's excerpt portrays the very real and raw implications of reproductive cancers on one's life and future.

### Everyday implications.

All of the six survivor participants spoke to some capacity about how cancer changed their usual routines and had implications in their everyday life, either in terms of their employment, their activities of daily living, or their life as a whole. The women's accounts of cancer's everyday implications often reflected elements of their sexual identity as a lesbian or bisexual woman. Some women described having to "put life on hold" either while waiting for a diagnosis or while going through reproductive cancer treatment. For example, Robyn stated "Even from being diagnosed, I didn't remember anything afterwards. I'm thinking my whole life now is going to change, I have to put this on hold and that on hold" (p. 24). Additionally, Tasha received some home care services following her inpatient hospital stay and described an overall positive experience of having nurses come into the home that she shared with her partner. "It was usually the same nurse who would come and she was really very friendly. She saw the way my girlfriend and me lived with our cats, she seemed to think it was really sweet" (Tasha, p. 20).

Claire described wanting to stay active during her chemotherapy, and therefore scheduling her hockey practice and games around how she would feel following treatment. To her, she described playing hockey as a way to keep busy and also something that she had always

wanted to do prior to being diagnosed. Claire also gave an interesting insight to her sentiments regarding having a bilateral mastectomy and being a lesbian woman playing hockey.

I thought that it was kind of cool that I didn't always have to wear a bra when I was at home. Best thing was that I didn't have to wear one at hockey. In the latter parts when a lot of the women knew, I would whip my shirt off, put my jersey on, and it was great. (Claire, p. 21)

For women who were partnered or married to women, changes in usual routine meant navigating the changes in relationship dynamics and financial strain shared between both partners. For example, Tasha described financial strain within her relationship.

I was very, very upset to have to leave work because my girlfriend wasn't working either, so we had no money coming in. She had no way of getting a job either, and so it was sort of on me with that too. (Tasha, p. 9)

This financial stress shared between Tasha and her partner became a source of concern while undergoing her cancer treatment. Fortunately, Tasha also talked about her family assisting with extra costs as well as transportation to and from treatments in order to alleviate some of this stress.

In addition to financial stress, there was also the stress of ensuring that a relationship would be legally recognized in case of emergency. Claire feared that her wife might not be taken care of if anything were to happen to her during her cancer treatments.

It definitely made me prioritize because before that time we didn't have life insurance and we didn't have a will. So we had some papers drawn up and that's all been done and taken care of. So that's part of her being taken care of. (Claire, p. 35)

From this excerpt we see how the cancer experience actually prompted Claire and her wife to reevaluate their legal rights and protections as a couple. Additionally, for Robyn and Anna, who were both single during their reproductive cancer care, they described not having family who lived geographically close, and therefore having to undergo treatment and financial expenses independently. Specifically, Anna described becoming closer with her daughter during the cancer experience, but still having to navigate the changes to usual routine during cancer independently, as the rest of her family lived outside of her current place of residence.

### Changes to physical health.

In addition to the changes in usual routine, all the women also spoke of changes to their physical health and bodies. They described physical effects immediately following cancer treatments, as well as effects that lingered with them, representing some of the scars of their cancer journey that have not yet faded. As reproductive cancers affect the organs commonly associated with femininity and those that society deems are part of being a woman, some of these effects can have specific implications that may differ from other cancers. One of the most common physical effects the women discussed was the loss of hair following chemotherapy. They addressed how this impacted their body image and also made what was happening to their physical body very "real".

Tasha discussed specifically how her hair loss during chemotherapy played a larger role in how she believed others would perceive her.

I was too prideful to wear a wig when I was at school. I thought people would be able to see right through it, that they'd know I was wearing a wig and it would be more pitiful. So I just wore a hat, and it was very obvious because people saw me when I was in my

first week of school and I still had some hair left. Then within a week it had all fallen out. (Tasha, p. 16)

Specifically in terms of gender implications, Tasha also described how although it was "scary" for her female partner to witness her endure physical symptoms such as pain, her partner was also the one who ultimately shaved Tasha's head as her hair began falling out. In addition to hair loss, other participants spoke of the physical pain that affected them after treatments. Anna discussed how following radiation for breast cancer her chest remained sore and tender. "Right now I am in pain. I have exercises to do and my chest is filling up with fluid so it's very sore, it turned so red. So that doesn't feel too comfortable" (Anna, p. 12).

Interestingly, Robyn, who had attended a lesbian-specific cancer support group, spoke about some of the physical effects that other members of the group had described to her. "When they were talking about fatigue I was thinking I'm not going to be tired. But man, I was like ok this is what they are talking about" (Robyn, p. 23). Robyn spoke of how listening to accounts from other lesbian women was helpful in terms of having some idea of what to expect in terms of changes to her physical body. Robyn also described an emotional connection established with other lesbian women in the group, as this was the first place were she openly cried in public. When attending a group that was not lesbian-specific, she did not feel that she could establish these same types of connections, and actually ended up not returning to the group after one session.

Similarly, Tasha described her surprise upon a later realization of the severity of her physical symptoms.

It was only when I started feeling better that I realized how sick I was. I hadn't even realized how awful I felt. Like when I ran for the first time, after realizing that I hadn't actually even walked quickly in a really long time. (Tasha, p. 37)

Tasha also spoke of neurological symptoms as a result of her chemotherapy, which included tremors in her hands and memory problems. These lasted up to a year after her treatment and she feared that if these symptoms did not dissipate, it might affect her future career as a health provider.

An unexpected finding was that two of the six participants described feelings of "guilt" surrounding their cancer experience. This guilt seemed to form around an understanding that a reproductive cancer should be aggressive and life endangering, whereas these women's experiences were less invasive than others' they have witnessed. This guilt shaped their meaning during reproductive cancer in a unique way and how they may have missed opportunities to access resources, such as Brenda who avoided attending cancer support groups.

I preface it with that saying I wouldn't have thought that I had any place in any support group, given that others had gone through so much [with cancer]. I just couldn't go there, I would have felt ashamed to be asking for support, when others are going through so much. (Brenda, p. 11)

Anna also described feeling "guilty at first" for only having two months of treatment for her breast cancer. However, she said that she has since moved on from these feelings and understands that this is her story.

Understanding of the meaning of health.

One of the other commonalities that began to emerge from the women's interviews was a shift in their understanding or outlook regarding their meaning of health. Apart from reproductive cancer's physiological effects on women's bodies, many participants spoke in detail about the emotional effects of undergoing treatment and adjusting to a cancer diagnosis. They spoke of feeling "fear", "shock", and "panic" during various points in their care and treatment. These emotions represented unique meanings for sexual minority women, including Claire who worried not about herself, but for her partner and children. Her focus was on ensuring that her partner and children would be taken care of if she were no longer alive. This was a shift of not being afraid of an absence of life, but rather a focus on what would happen when she was gone.

I had never thought about being afraid of death before and I wasn't afraid of the actual dying part, I was afraid of leaving people behind. At that point, my son and his girlfriend were pregnant so I wanted to see my grandchildren and walk my son down the aisle and all the other stuff I was suddenly concerned that I would never do. (Claire, p. 9)

Tasha also described an understanding of what health meant to her during her cancer journey. "I didn't really want to be treated differently, like I was sick or weak. [...] It made me feel better to be able to go back to work, made me feel like I was strong enough" (Tasha, pp. 7-9). From this excerpt, Tasha explains how she wanted to reclaim as much control as possible, and retain those elements of health that existed prior to a diagnosis of ovarian cancer.

Some individuals described their meaning of health in a more holistic manner. For example, Robyn discussed her beliefs regarding the influence that mental wellbeing can have on physical health and healing. "I believe that 80% of your healing comes from your mind. So to keep my mind healthy and in good spirits, that was my outlook. And I think that because of that,

I had positive feedback" (Robyn, p. 7). Robyn's understanding of what health meant to her involved having a positive mind in order to promote a positive and healthy body, and she believed that this also promoted positive interactions with her health care providers. Moreover, Anna reflected similar insights regarding the importance of positivity on health and healing. "You have to stay positive because the negative energy is not going to make you better. I know it sucks when you first find out, but then you really, really have to be positive. You just have to be" (Anna, p. 11).

### Compartmentalized meanings of health and health care.

In addition to shifts surrounding the meaning of health for sexual minority women with reproductive cancers, there were also compartmentalized meanings of health and how health care providers should approach physical and emotional health concerns. Several participants expressed their perceptions on how reproductive cancer care's focus should be on physical health, with nurses' and physicians' focus being on healing of the physical body. The participants seemed to suggest that emotional health or resources could be sought through other means and that there should be a division between this realm and that of physical health. Robyn described that when it came to cancer specifically, nurses' and physicians' focus should be on the physical health of the body. "I think that the health care profession is dealing specifically with something. Not everybody might want to have support. So I think that unless an individual requires that, I think the health care professional has got enough to deal with" (Robyn, p. 30).

Tasha described how in some instances she appreciated when nurses were "professional", in the sense of not getting too personal during interactions. She found that sometimes it was nice to be treated with a focus on physical health and curing the cancer, as then she knew she would

be treated the same as everybody else, regardless of sexual identity or any other defining characteristics.

She elaborated further in regards to her perceptions of what nurses were available to assist with.

I didn't really feel like it was appropriate to ask for emotional support from the nurses, especially because it seemed like they were so busy. They had so much on their plates, I didn't really want to bother them with that. There are other people I could go to, to ask for that kind of thing. (Tasha, p. 28)

Similarly, Dani stated that although she was "stressed out" during her cancer treatment, she didn't want to talk to anyone about it. "I can't really open up, I don't feel open with them" (Dani, pp. 2-3) she said when asked if she ever discusses or opens up about her feelings to health care providers.

### Providers' perceptions of the cancer journey.

In regards to the cancer journey for sexual minority women, the Registered Nurse who was not a survivor, Lucia, addressed her own beliefs of how to provide care to those experiencing this journey. Some of the points Lucia made also interestingly aligned with some of what the survivors articulated in regards to their compartmentalized meanings of health and health care. Tasha, who was both a survivor and provider, spoke about how her own journey through cancer ended up being an influence on her professional practice and therapeutic interactions. These narratives provide an additional insight to what some of the survivors had articulated regarding their journey.

Lucia's experience is primarily as an intensive care unit Registered Nurse, and therefore the context of her interactions with her patients are often through their families or loved ones.

This is because often times the patients who Lucia cares for are extremely ill and unable to communicate. Her nursing practice and experience is not in oncology, but rather she cares for a variety of critically ill patients. Lucia spoke briefly of providing care to sexual minority women and her perceptions of the meaning of nursing practice.

I don't think the way I provide care as a nurse [to a LB client] is going to be any different. Like in terms of my therapeutic communication, and my caring, and all that jazz, it's all going to be the same regardless of the patient. (Lucia, p. 18)

To Lucia, the meaning of providing health care as a nurse was to treat all patients equally in terms of professionalism and care. She went on to express that she did not want any patient to feel as though she was making generalizations or altering their care based on elements of their identity, and therefore equality in providing care was important to her. This insight provides another dimension to some of the survivors' meaning and views of health and health care, which will be analyzed further within the discussion section.

For Tasha, one of the biggest impacts of being both a cancer survivor and a provider was on her professional practice. Specifically, she discussed how being a cancer survivor actually improved her ability to care for others in her role providing bodywork therapy. Although she does not specialize or work specifically with oncology patients, she does see them from time to time at the clinic where she works.

I try and remind myself of what cancer feels like, so I can sympathize with other people's suffering and use those experiences. [...] You sort of have an understanding of that feeling of helplessness; you both understand how that feels. Recently, I had a client with

breast cancer and I told her that I had cancer too and she started crying during treatment.

It was really nice that I could use that to help make a connection. (Tasha, pp. 14-15) Although this individual for whom Tasha cared for did not identify as a lesbian woman, from this except we see how an understanding of both sides allowed Tasha to create more intimate connections with clients and gain a unique perception into their journey.

Overall, the descriptions of the cancer journey for both the survivors and the perceptions from providers helps to give context to whom these participants are as individuals. As we can see from some of the preceding excerpts within the subthemes, the cancer journey is both similar and unique across sexual minority women. The following theme of reproduction and the meaning of family will now address some of the broader meanings of reproduction and family for sexual minority women.

#### Reproduction and the meaning of family.

For this study I was interested in sexual minority women's experiences with reproductive cancers specifically, as I suspected that these cancers might have unique implications when compared with cancers originating in other parts of the body. Within the research interviews, I found reproduction to encompass more than just fertility, but rather I found it to largely capture the meaning of family for many of the women. I have used this theme as a way to highlight the survivors' discussions of their sources of social support, meaning of family, effects of cancer on fertility, and heteronormative assumptions surrounding reproduction they have witnessed during cancer care.

### Sources of social support.

One of the interesting elements representing the experience of reproductive cancer specifically for sexual minority women was the descriptions of some sources of social support. Whether their support came from a female partner, a lesbian-specific support group, if they had family support, or if there was a lack of family support, these stories all had implications that defined their meaning of support during a reproductive cancer diagnosis. In terms of those participants who described social support from their female partners, four of the six women in this study were either in a relationship with a female partner or married to a female partner during their cancer care, and all of these four currently remained with the same partners. All of these women, whom also all identified as lesbian, discussed to some degree the impact that their reproductive cancer had on their partner, as well as the alterations to their relationship dynamic during this journey.

A few of the women spoke to the emotional strain, "stress", and "strength" that they witnessed from their partners during reproductive cancer treatment. Claire spoke of a surprising effect on her wife during her cancer journey.

She kind of picked up some of the things that I had. Like if I would have a headache, it was almost like sympathy pains, she'd get a headache. If I had a fever, she just felt like blah, she didn't necessarily run a fever, but she felt not well. I know this sounds crazy, but I felt like she was catching it from me, and I knew you just couldn't catch it like that, but that's what I felt. (Claire, p. 12)

Claire went further to describe how during times that she experienced nausea following chemotherapy and would lose her appetite, her partner felt as though she also did not want to eat as it would not be fair to do so in front of Claire.

In terms of changes to relationship dynamics, some of the women in relationships discussed how they were "glad" that they had their partner present during their cancer journey or how it has strengthened their relationship in some manner. Specifically Claire, who had been living with her partner during her breast cancer treatment, was scared for her partner and described a change in their relationship dynamic during the cancer experience.

I thought oh my god I'm dead. I'm not going to see my kids grow up, not going to see my grandkids grow up, I'm scared for my partner, I have to make sure she is taken care of.

So I said 'I want us to get married'. I said 'I want you to be taken care of, I'm in love with you'. (Claire, p. 23)

This change in relationship status to marriage helped to create a sense of security for Claire and a peace of mind that her spouse would be looked after. Conversely, Tasha described being grateful that her partner stayed with her during treatment, as they had not been in a relationship for a long period prior to diagnosis.

Well I mean we had only met [a few] months before this whole thing started. [...] A lot of people wouldn't have stayed. So, I was glad that she was so willing to support me through all of that and not get scared away, but she never even thinks about it like that. (Tasha, p. 38)

Following this excerpt, she went on to describe how their relationship has gotten stronger following her cancer journey.

Only one of the six participants in this study that I interviewed described seeking support services from a lesbian-specific support group. It is important to note that Robyn sought out these services independently and although she found a pamphlet on the group from one of the

hospitals where she was receiving treatment, information on the group was not directly provided or recommended to her by any health care provider. Interestingly, she also described not disclosing her lesbian identity to providers because she did not think that it was directly relevant to the care at hand, yet she spoke about attending the lesbian-specific cancer support group as a positive experience. "For me, it was important having someone who's experienced that to pass their knowledge on, or pass on their experience. Everyone's experience is a little bit different, but nonetheless, there are still similarities, right?" (Robyn, p. 23). Conversely, Brenda spoke of why she did not attend a support group.

I did not seek any support because I really had trouble even calling it cancer, because that's not what cancer meant to me. Cancer meant to me what my friends had gone through, what my sister went through and my mom (Brenda, p. 11).

To Brenda, because her cancer was not as aggressive and treatment not as extensive as what she had seen with others, she felt as though she did not have a place in a support group.

In terms of participants' other support systems, they described relationships with parents and family and how they may or may not have been supportive. The dynamics of their support systems were also unique to their experiences as women and as sexual minority women specifically, as some participants described conflict within families associated with sexual identity. Claire described how ordinarily her mother is quite supportive even though they do not "see eye-to-eye" on her mother's Aboriginal beliefs of using natural medicine for cancer treatment. Yet, Claire also talked about telling her mother that she wanted to undergo reconstructive breast surgery and being deeply upset by her mother's comments. "My mother

said 'I hope you're not doing it for your wife'. It's like [my wife] has been absolutely fabulous, we've been together forever and this is all you can say?" (Claire, p. 20).

Furthermore, Anna described how she is not "out" to her mother as a bisexual woman for personal reasons. "I just don't even go there with her. Not that I'm embarrassed or anything, its just that I just don't even want to go there and for me it just works this way" (Anna, p. 8). Dani described how although she is "out" to her parents as a lesbian woman, they have not been supportive of her or her partner. She also did not tell them about her cancer diagnosis, as she did not want to "stress them out". These unique barriers to adequate family support during reproductive cancer could create increased stressors for sexual minority women, although it did not seem to necessarily to be the case with the participants I spoke with.

## Meaning of family.

In addition to describing who became sources of social support during cancer care, the importance and meaning of family for many of the research participants was also expressed during the course of the interviews. As the majority of participants interviewed in my study were past the age of 40 and two participants spoke of having been separated from past male partners, the family make-up described by the survivors was not so much nuclear as it was of varied configurations. Four participants provided some detailed insight regarding their meaning of family and the value that they placed on family during their cancer experience. Brenda was one of the survivors who addressed what family meant in terms of a cancer journey and she talked about why this was an important piece for health care providers to be aware of.

My family makeup is as important to my wellbeing and my care, as whether my surgery heals. [...] My family situation and who my spouse is and whether I have children or not,

whether my children are children that we've borne, or whether they're children that came into the relationship from another situation, all that matters. It's who I am in my context. (Brenda, pp. 22-23)

Anna also spoke about how her and her daughter "bounce things off each other", but how her daughter and grandchildren live outside of where Anna resides. Therefore, Anna felt as though she had to go through much of the cancer journey by herself.

As previously discussed in the cancer journey theme, Claire had a wife and also a son from a previous marriage whom she was quite close with. Claire described that although she wasn't largely open in terms of displays of affection in public with her wife, she did do so when it came to her son and grandchildren. She didn't elaborate on why this was, but perhaps open affection with her son and grandchildren is more accepted within the context of public spheres and in society.

It is important to note that for some individuals, family does not always encompass those represented by blood relatives. Specifically for Robyn, who was also single during her cancer care, she described family as her gay male friends who were there to provide support to her.

Even when I was receiving chemo and all these guys came, it was never a problem. I don't know if it's specific to the lesbian and gay community, but often times a lot of lesbians and gays are ostracized from their families. And so, we tend to form our own little families, family units with our friends. (Robyn, p. 16)

This is an especially important description of family, as it is one that encompasses a realm of social support that may not be immediately noted by health care providers. Hearing that an

individual may not have any relatives present may not necessarily mean that a sexual minority woman does not have social support.

### Effects of cancer on fertility.

In regards to fertility changes as a result of reproductive cancers, this was a topic that I left out of my interview guide and questions for the survivors prior to realizing its importance within our discussions. Interestingly, it was also almost not brought up independently by the women in any of the interviews. Only one of the participants mentioned details regarding how her cancer would affect reproduction in the future and what this meant to her.

The oncologist asked if pregnancy was something I was concerned about or if I had any questions, and I said 'no I don't want kids, never did, can't have them anyway' [being a lesbian]. And she said 'Are you sure because you can still have kids with modern advancements', but I said 'no, no I'm not worried about that.' (Tasha, p. 19)

Her oncologist was one of the only providers with whom she openly disclosed she was a lesbian, whereas with her other providers she felt they might have assumed her sexual orientation by having her female partner present. Fertility was perhaps brought up in Tasha's case particularly because she mentioned that her oncologist told her that following her ovarian cancer she may have problems becoming pregnant in the future.

No other participants openly discussed any concerns regarding fertility or discussed it in any manner during our interview. However, Claire and Anna spoke of already having grown children from previous male partnerships and therefore the meaning of fertility or reproduction for them may not have been interpreted as one of significance. Furthermore, none of the participants with female partners discussed any concerns voiced by their partners regarding their

potential problems conceiving children or experiencing infertility following reproductive cancer treatment. It is also important to note that Robyn and Anna, who identified as single, also did not address any reproductive concerns for future relationships, nor did they mention this was something that has been addressed in relationships following their reproductive cancer treatments.

### Heteronormative assumptions surrounding reproduction.

Although only one participant spoke specifically regarding the effects on fertility following a reproductive cancer, two participants did address some heteronormative assumptions surrounding reproduction that they experienced. One of the accounts from Tasha involved some of her perceptions regarding what she believed would be assumptions from health providers and the other account from Robyn was regarding heteronormativity in public spaces. This excerpt from Tasha surrounding her conversations on fertility with her oncologist provides more context to her perception of this experience.

Maybe if I'd been heterosexual than I might have had more difficult time regarding pregnancy-related questions. They would have insisted probably that they talk to me about that kind of stuff. They were just like 'ok we trust you that you're probably not pregnant or that you don't want to know about children stuff'. (Tasha, p. 32)

This excerpt provides important insight regarding some of the perceptions on reproduction within health care and society. Perhaps the fact that information on pregnancy and family planning was more easily disregarded because Tasha identified as a lesbian portrays some of the assumptions that still exist in health care settings regarding lesbian and bisexual women's desire to reproduce.

Furthermore, Robyn described her feelings while in a cancer support group that was mostly occupied by heterosexual women. She said that she couldn't relate to any of the women there because they were largely dominating the discussion to focus on their husbands and children. She elaborated further by stating that "Well I know that there are gays and lesbians with kids and grandkids, but I don't know how to explain it, it's a little bit different" (Robyn, p. 12). Robyn felt that the atmosphere within the lesbian-specific support group was just "different", even if the lesbian women did speak about their children or grandchildren.

# Providers' understanding of the meaning of family for LB women.

Similarly to the responses from the sexual minority cancer survivors, the conversations with Lucia did not yield any specific stories or experiences of women who were struggling with infertility following a reproductive cancer, nor did I inquire about these instances in practice. Also, none of the participants who identified as both survivors and providers addressed any elements of reproduction or the meaning of family within their discussions. Nevertheless, Lucia did address aspects surrounding her understanding of the meaning of family for sexual minority women based on some of what she witnessed in her own practice. This included her perceptions on using inclusive language during interactions, awareness of LB family situations, and observing heterosexist attitudes towards LB families.

In terms of inclusive language, Lucia addressed the importance of not making assumptions about an individual's family.

Asking the question like 'are you in a relationship or is there a partner?' using those words rather than husband or wife I think is really important for health care professionals.

I think absolutely it does create a better dialogue, because then they trust you from the get-go that you aren't assuming. (Lucia, p. 21)

She went on to describe how not all nurses are accommodating to sexual minority women's families, and she discussed some remarks that she has heard in practice.

I was talking about the family of a lesbian patient [to the oncoming nurse] and I said 'The partner is really great, she wants to be at the bedside for a lot of stuff, if you have the time to tell her what's going on she really likes that'. And the nurse rolled her eyes and said 'like a difficult family'. (Lucia, p. 14)

Negative assumptions regarding sexual minority women's families such as this example, could prove detrimental to care. Although Lucia described how she did not necessarily think that the nurse's comments were specific to the patient's sexual orientation, it is difficult to say whether or not the nurse still provided equitable care to the patient and family.

During my interviews with both the cancer survivors and Lucia, it became evident that providers, including myself, may have overlooked the issues surrounding reproduction and the meaning of family for sexual minority women. These were not findings that I had anticipated or imagined prior to conducting the interviews, yet they provided another layer to the experiences of sexual minority women during their cancer care. As is now becoming evident, women's sources of support had a reoccurring presence throughout the discussions with all participants.

#### Interactions with HCPs during cancer care.

Now that I have provided some depth in terms of the cancer journey and the meaning of family for the cancer survivors, the next step is to explore the experiences these women had during their interactions with health care providers during care. This theme encompasses some of

the direct accounts of participants' interactions with various health care providers during different points of care. Furthermore, the perceptions surrounding when participant's sexual orientation was relevant to their interactions with health care providers and the factors influencing disclosure is also provided within this theme.

### Sense of inclusion during interactions.

Health care interactions as described by the cancer survivors occurred at various times and locations. Most often, interactions with health care providers occurred in hospitals, physicians' offices, and at outpatient clinics for chemotherapy and radiation. Depending on the courses of treatment, the interactions took place anywhere from multiple times a week to every six months for follow up after surgery. Yet, one consistent and surprising finding from my interviews with the six sexual minority women was that in some capacity almost all survivors addressed how positive they perceived their interactions and experiences with nurses, physicians, and other health care providers to be. Half of the participants elaborated further on this aspect and talked about inclusive practices that were done by nurses specifically that allowed them to feel as though their sexual identity was respected during interactions. The three participants who gave direct examples of inclusive practices done by nurses were also all in relationships with women during their cancer care. Therefore, acknowledgment and respect of participants' partners seemed to be the most recognized in terms of care that was inclusive. Tasha talked about this specifically, as well as expanded on receiving individual care from a nurse.

My girlfriend would sometimes stay in the hospital bed with me, just for the comfort, and nobody acted weird about that. [...] Also, a nurse helped me go to the bathroom, and

cleaned me up and everything and she didn't act weird about that either, even though I guess she would have already known that I was a lesbian. (Tasha, p. 19)

Additionally, Claire discussed her wife's interactions with nurses during her cancer treatment. "The nurses were all very, very helpful in that way, they would come over and ask her [my wife] how she's doing if she happened to come with me" (Claire, p. 31). Claire stated that she appreciated the nurses taking the time to include her wife, and that these interactions impacted her so much that she often went out of her way to send cards and flowers to the nurses following her treatments. Claire also expressed how she believed that if you need support during your cancer care, nurses and other health care providers could be a source for this. "You have to tell them [HCPs] if you're having a bad day. Maybe that person is the one that gives you that hug or says the thing that gets you through that day" (Claire, p. 29). Claire went into detail about many of her interactions with nurses and physicians and how the majority of these interactions were helpful on both a physical and emotional level.

Brenda also spoke of her interactions with nurses and how they were influential. Specially, she talked about how a nurse was instrumental in also passing along information to other health care providers during her cancer care. She described a time when a nurse informed an oncologist that Brenda's spouse was a woman, perhaps as a way to avoid incorrect labels during interactions. Brenda said she found this just to be a form of information that the nurse was passing along, and a way to prevent her from having to disclose this information herself. Brenda also discussed how her surgeon made her feel validated during an interaction.

One thing the surgeon did when I was all prepped for surgery was that he walked out, came to me, and said 'So do you have any thoughts, any concerns, anything you need to

know before we do this?' [To me that meant] I was more than just a breast that needed a piece out, and I really appreciated that. (Brenda, p. 23)

To Brenda, the meaning of receiving reproductive cancer care was more than being perceived as a surgery to complete. Although the actions of the surgeon in this instance may have been routine, to Brenda it was important to be recognized as an individual and this had implications in terms of her comfort and trust in her surgeon during this time.

## Heteronormativity/heterosexism during interactions.

Despite the resounding agreement the survivors' voiced in regards to their cancer care and interactions being positive, examples of heterosexism or heteronormativity during interactions with providers still emerged from the interviews. At times these were subtle examples, such as when Tasha described that her sexual orientation would only come up during interactions with providers at times in which they asked if she could be pregnant. Or when Brenda spoke about how she believed bisexual woman could become subtly invisible within health care systems. "I would say yes, bisexual women are invisible. I would say that if you have a female partner you're assumed to be lesbian, and if you have a male partner you're assumed to be heterosexual" (Brenda, p. 21).

Some examples of heterosexism were more overt and represented larger barriers within our health care institutions and communities. For example, a staff member working in reception at a health care setting refused to acknowledge Claire's spouse.

They asked for my emergency contact and I said 'My partner, Theresa'. 'Oh your husband?' they asked. I said 'No, my partner, Theresa. This is my partner, and this is her phone number'. But on the sheet the woman wrote 'friend' and highlighted it. So I got

rather upset and said 'You need to change that' but she wouldn't change it. 'Nobody needs to know that about you' she said. (Claire, p. 28)

Although Claire felt that this was just one individual's attitude and not representative of the institution where she was receiving care, it still had very upsetting implications for her. Furthermore, Dani described health care providers assuming her female partner was a boy. This response came forth when I asked Dani if health care providers ever assume that her partner is her friend or family member, to which she replied "They assume that she is a boy" (p.2). I asked her if they assume that she is her boyfriend and if she ever corrects them or says that this is her female partner. Dani replied that, "Yeah, people ask if she is my boyfriend. And no, we avoid the situation, its just kind of funny, but I don't want to go there" (p. 2). These gender assumptions from providers could further exclude or deter individuals from disclosing their sexual orientation and/or gender identity.

#### Sexual orientation relevancy during interactions.

When I initially asked participants if they discussed sexual orientation during their cancer care or if they could recall times when they felt that it was important to discuss this with health care providers, the answers to this question varied. Most lesbian participants felt that discussions surrounding their sexual orientation were not necessary. As Robyn explained, her focus was not on sexual orientation disclosure at the time of her cancer care. "I personally didn't think it was necessary, I'm looking more at getting care" (Robyn, p. 7). Dani voiced a similar thought on sexual orientation relevancy as well. "It's not important, it doesn't matter" (Dani, p. 3), she said in regards to her sexual orientation and interactions with health care providers. Tasha also agreed with this sentiment and elaborated further. "I was too focused on health concerns to be concerned

about that [disclosing sexual orientation]. Even if anybody was giving me weird looks or anything, I was too scared and in pain to even notice anyway" (Tasha, p. 20). Anna also felt similar in terms of discussions surrounding her bisexuality with health care providers. "I didn't bring it up [sexual orientation], it's not pertinent to anything that I'm doing" (Anna, p. 7).

However, Brenda, who also identified herself as also a former therapist, felt differently regarding health care providers knowing one's sexual orientation. "I think it matters enormously because I think its part of who we are, and psychosocial is as important as anything else in terms of wellness" (Brenda, p. 22). She also went on to discuss the importance of having sexual orientation asked during intake.

It would be so helpful if in the whole intake we were asked, you know, 'How do you identify?' and have heterosexual as one of the choices. 'Are you het, are you trans, are you lesbian, are you bisexual, are you fluid?' That would be just such a welcoming thing. (Brenda, p. 30)

Although there were three other participants who also identified themselves as service or health providers in some capacity, these providers/survivors did not see the relevancy of discussing sexual orientation during cancer care in the same way that Brenda did.

An important aspect to note from my interviews with lesbian and bisexual reproductive cancer survivors is that according to all six participants, at no point did a health care provider ask their sexual orientation. Therefore, participants discussed how they either disclosed this information themselves or they chose not to reveal their sexual orientation within the health care setting. There were also varied responses from participants surrounding whether they felt that their health care providers should have asked questions pertaining to sexual orientation or not.

For example, Dani, who wasn't asked about sexual orientation by any of her providers nor did she disclose, also felt that she wouldn't want her providers to ask those kinds of questions regardless.

Anna also described how her health care providers did not ask her sexual orientation, but also felt that perhaps they did not do so because it was not relevant to her cancer care and that their focus was on other concerns at the time. In addition to believing sexual orientation was not relevant to cancer care, Tasha expanded on this by also discussing how the interaction might change if this were asked. "It didn't seem to me like staff would ask my sexual orientation. [...]. I think I might find it more awkward if somebody actually needed to ask me about that because it's not really relevant to my care" (Tasha, p. 22).

Although the preceding participants may not have found inquiry from staff regarding sexual orientation relevant or necessary, not all participants agreed with these sentiments. Brenda described how health care providers' lack of professional inquiry into an individual's sexual orientation further emphasizes invisibility of sexual minority women.

No it wasn't [sexual orientation asked by providers]. It would have been good if it was actually, but it wasn't. It's always having to come out, as you know, we always have to come out. There's never the option to say 'who are you?' so you always feel that it's a heterosexist assumption. So it would have been good if it had of been there, I would have appreciated that. (Brenda, p. 18)

Additionally, Robyn believed that by her health care providers not asking about her sexual orientation, and therefore not knowing that she identified as a lesbian, there was potentially an unexpected effect on her care. "Sexual orientation didn't come up, not at all. So I

don't know if that's a factor that contributed to a positive experience. It could be a contributing factor, I don't know, but sexual orientation was never a question" (Robyn, p. 7). Overall, Robyn described how her interactions with health care providers were quite positive during her cancer care experience, but as we see, it is important to note that at no point was her sexual orientation ever discussed during care.

Another finding from my interviews regarding disclosure of sexual orientation during cancer care were the participants' thoughts surrounding how disclosure may also depend on circumstances, with some situations taking greater priority over disclosure. All six participants discussed these situation dependent instances to some extent in their interviews, with most participants agreeing that there are times during cancer care where disclosure of sexual orientation does not take priority over the focus on physical care. For example, Robyn talked about her priorities and main focus during her reproductive cancer care, and how sexual orientation may not have had relevancy in her circumstances.

To me, it's not important [to be asked my sexual orientation]. For some other people it's important, but for me it's not. I think in this situation, the most important thing is to receive the best care. [...] Individuals never go and say 'Hi I'm straight'. So to me it's like why am I saying 'Hi, I'm gay', you know? Unless the question comes up, then I address the situation. (Robyn, pp. 29-30)

Brenda often discussed how she believed sexual orientation was quite relevant to her reproductive cancer care; however, she also spoke of times when her focus was on physical care.

During the day surgery, it [sexual orientation] just didn't come up. I was just there as a body. I was well looked after and all of that, but my spouse wasn't anywhere around, she

dropped me off and picked me up. So there, it didn't seem to matter and I was probably anxious enough. (Brenda, p. 20)

Claire also raised an important point regarding the comfort level of some individuals to discuss their sexual orientation.

I think it depends on how the patient is with it and how the partner is with it. Some people don't want anybody to know what their orientation is, some people are ok but are very guarded, some people are not ready to talk about it or tell anybody. (Claire, p. 33)

Although Claire discussed being quite open discussing her own lesbian identity within a health care setting, she raised important points regarding how individuals' may not want to put a label on their identity or are not ready to discuss their sexual orientation at certain points in their life.

Furthermore, Anna brought up an interesting point regarding her perceptions on her bisexuality and the relevance of sexual orientation during care.

I think being bisexual is accepted more than being gay, but I don't know. It's not something that I just shake someone's hand and say. So I believe that unless that [sexual orientation] has something to do with something, then it shouldn't come up. (Anna, p. 10) Despite Anna's perception that being bisexual may be more accepted than being gay, as we see from this excerpt, she still did not necessarily think of her sexual identity as something that should always be discussed during cancer care.

In addition to situation-dependent instances of when disclosure took priority during cancer care, the participants also discussed the impact that relationship status had on discussions of sexual orientation within health care settings. Of the six participants, two participants were single and the remaining four were either in relationships or married to female partners. The two

women who were single, Robyn and Anna, did not discuss sexual orientation during their cancer care, whereas the majority of those who were in a relationship discussed their orientation in some way or believed that it was assumed when having their female partner present during health care interactions. Robyn described how sexual orientation may have been more relevant or may have come up if she had been in a relationship during her cancer care. "I don't know if it would have been different if I was in a relationship and I had my partner there. I'd say 'this is my partner' or whoever [to HCPs], so it probably would have made a difference" (Robyn, p. 9).

Brenda reflected similar sentiments when describing how she would identify her sexual orientation through identifying her female partner as her spouse.

When I say I'm out and I claim it, that's because it's important. I'm not trying to make a statement, it's because it is important to me. It's always important. I needed my spouse there just as much as anyone else needed their spouse there, you know? I needed it to be ok, so I just assumed it was ok. (Brenda, p. 18)

Claire also voiced similar feelings about identifying her partner during care. "...[disclosing sexual orientation] depends on the circumstance, because I wouldn't have a problem telling somebody that this is my wife, my partner, my husband, whatever" (Claire, p. 43). Tasha also seemed to feel similarly in regards to having her female partner present and acknowledged during her cancer care, yet with a slight variation.

It doesn't need to be seen necessarily as a negative thing that they [HCPs] don't ask [sexual orientation], because they are just being professional. On the other hand, allowing your partner to be there, treat them as if they're someone important who's supposed to be there for whatever reason. (Tasha, p. 39)

Unlike Brenda and Claire, Tasha stated that she didn't necessarily feel that it was detrimental if providers didn't ask one's sexual orientation. She explained that not asking these questions could be part of maintaining professional relationships and boundaries, even though others may consider it to be incomprehensive care.

Even though participants varied on their responses regarding disclosure of sexual orientation with health care providers, almost all of the participants spoke about their desire to receive care that would be equal to that of a heterosexual patient. There seemed to be a belief that disclosure of sexual orientation may be associated with altered treatment or treatment that was not equal to what heterosexual patients would receive.

Anna, who voiced how she believed some elements of identity are stigmatized within health care systems, portrayed this in the following excerpt.

I know that for homeless people and gay people when you put that out there people assume things. I think there shouldn't be questions that need to be asked unless it's somehow got something to do with your breasts or wherever. Everybody's entitled to the same care. (Anna, p. 9)

Anna felt that to avoid negative assumptions from health care providers, questions related to certain elements of one's identity should perhaps be avoided unless it is pertinent to the cancer care at hand.

Tasha discussed her feelings of a desire to receive equal care from providers, regardless of what information they knew about her. "I'm of the opinion that if they [HCPs] did know my sexual orientation, that it wouldn't change anything either way. So whether or not they knew, I wouldn't want to be treated any differently" (Tasha, p. 29).

Similarly, Robyn stated that she felt sexual orientation shouldn't "define you" and that she was focused on "just getting care". Yet, interestingly she had actively sought out a lesbian-specific support group to attend during her journey with cancer.

In terms of disclosure directly affecting care, Brenda described that she had felt that there were times she experienced adverse interactions based on her sexual orientation and having her partner present during her reproductive cancer care.

It's more what I picked up, rather than how I was treated. I picked up kind of a resonance and I'm old enough to know what violence against GLBT people has been and I've been part of that. [...] It's a look that crosses someone's face, it's handing something with a little more force than you'd expect, or a little less than you'd expect. (Brenda, p 20)

Brenda clarified that these adverse interactions were from volunteers rather than specific health care providers during her cancer care. Nevertheless, it was still something that she picked up on while within these health care settings.

#### Self-advocacy during interactions with providers.

Despite the varied responses surrounding disclosure of sexual orientation and when it may or may not be necessary to do so during cancer care, all but one of the participants spoke about a willingness to advocate for their care if faced with heterosexism or biphobia from health care providers during interactions. Unexpectedly, even those who felt that sexual orientation was not relevant to their cancer care or those who did not have partners during care still articulated that if they ever were to face heterosexism or biphobia in a health care setting they would openly advocate for acceptance and respect. This sentiment was seen from both the lesbian-identified participants as well as Anna who identified as bisexual. "I'm not ashamed of anything. If

anybody had of said something [about identifying as bisexual] I would have put in a complaint to have somebody else. I don't have time for that nonsense and it's not acceptable anyway" (Anna, p. 7). Brenda also described that she needed her wife present during her care, and therefore this was a priority. She described not feeling as though she needed "permission" to have this happen and would do what she needed to accommodate her own care.

Tasha also expressed her willingness to advocate for her own care, especially if she were to be confronted with judgments from others within a health care setting.

I had sort of lost all dignity at that point that it wouldn't have really made much of a difference if people were giving me weird looks for being a lesbian or not. If someone had been weird about it I think I might have just been more cuddly with her [partner] out of spite. (Tasha, p. 24)

Interestingly, Tasha also described that although she assumed hospitals were considered safe spaces, her parents were weary of how health care staff would react to her female partner. "[My parents] were worried that maybe she would do something or say something that would make people not treat me well I guess, either because she's being too romantic with me or because she's being too loud" (Tasha, p. 40). She explained that although her parents have been supportive of her sexual identity and her partner, they still were weary that health care providers may treat her differently for being a woman with a female partner.

Similarly to how women discussed their willingness to advocate for adequate treatment when disclosing their sexual orientation, half of the participants also described their advocacy for certain health related concerns during specific interactions with health care providers. The following instances of women self-advocating were not as a result of heterosexism or biphobia

during care, but rather their encounters with communication difficulties during interactions and their willingness to educate other women on breast cancer screening. For example, Robyn spoke of an interaction with a nurse in which she was not afraid to request alternate care. "I think if you're not comfortable with your care provider, just speak up and say like 'I don't want to interact with that person', nothing personal" (Robyn, p. 25). Robyn did not believe that the difficulties in this interaction had anything to do with her lesbian identity, as she was not "out" to staff, but rather communication difficulties that she could not pinpoint.

Claire also spoke of advocating for one's own care. She described that when speaking with physicians during early signs and symptoms of possible reproductive cancers, one must not be afraid to advocate for the tests they might feel they need. Specifically in her case, although she was under 40 years old and was not routinely screened for mammograms, the mammogram she received saved her life. Anna also expressed a similar opinion in terms of self-advocating for care, "A lot of women I've been passing my story on to. Those that haven't gone [for a mammogram] or don't have a doctor, [I tell them] it doesn't matter if you have a doctor or not, you have to go" (p. 5). Going through an experience of breast cancer has now influenced Anna to advocate to others on the importance of regular mammograms.

#### Providers' interactions with sexual minority women and families.

Interactions between patients and providers are indeed a two way street, in which both sides must be analyzed. Therefore, it is important to also discuss insight from those survivors who also identified as providers and Lucia, who had professional interactions with sexual minority women during cancer care. The survivors who were also providers addressed how their professional roles influenced their own self-advocacy during their cancer care, while the

interview with Lucia yielded many similar themes and subthemes as the cancer survivors discussed, such as assumptions regarding sexual identity, inquiry about sexual orientation, fear of generalization, and when responses to sexual orientation during inpatient stays may be detrimental to patients' care.

In terms of the survivors who were also providers, Robyn and Anna discussed how their professional advocacy work helped them to be empowered to address their own dissatisfactions in care and to educate others to receive regular cancer screening. Both these women who worked as outreach and advocacy workers also were part of groups that have traditionally been marginalized, one of the women being a woman of color and the other having a history of homelessness.

For me, advocacy was part of my job. I advocated for a lot of the clients, so perhaps my experience would have been a little bit different if I didn't have those skills. We always incite in the women to speak up in terms of their health care. If you want to see your file, ask to see your file, if you're not comfortable with the caregiver, than it's your right to decide what you feel comfortable with. So I think for me, it just came as second nature. (Robyn, p. 26)

From this excerpt, Robyn describes how her own self-advocacy during cancer care was fostered by her professional work. Similarly, Anna talked about how it was her own personal experiences that prompted her to work in outreach and how a lived experience of breast cancer also prompted her to help educate others on the importance of screening.

In terms of some of the issues discussed by Lucia, one of the first questions I had asked her during our interview was on average how many sexual minority women, not just with reproductive cancers, has she cared for in practice. She stated she felt it was "fairly rare" to work with these patients, yet also that sometimes she did not know for certain an individual's sexual orientation. Although Lucia said that the majority of her experience with sexual minority women was with those who had partners, she did have one client whom was single and she believed identified as a lesbian. She stated that it was some of the individual's actions and "comments she had made" regarding how she found other women attractive that made her believe this patient might identify as a lesbian.

Lucia said that although it is not in her institution's policy to ask sexual orientation, she often discovers this information through inquiry of a patient's substitute decision maker. When I asked Lucia if she thought sexual minority women who are not partnered are identified in practice, she stated "I think you just wouldn't know, unless they had said" (p.8). Furthermore, I asked Lucia if she had ever had a patient who openly disclosed their sexual orientation, or if it seems that this information comes up more with those who are partnered. Her initial perception of the identification of sexual orientation within a health care setting somewhat echoed similar responses from the cancer survivors. "In what I can say, it [sexual orientation] has never been openly disclosed. Which I guess makes sense because it's not like I walk through the hospital doors and say 'hey I'm heterosexual'" (Lucia, p. 9).

Although Lucia discussed elements of inclusive practice, she also talked quite a bit about her fear of generalizing lesbian and bisexual patients. She did not want her patients to feel as though because she was aware of their sexual identity, she would now be prone to passing judgments or making assumptions about their actions or appearances. She even described a feeling of "stress" surrounding these experiences in her nursing practice. Lucia further elaborated

that especially with intimate care in practice, such as providing personal hygiene, although she has no qualms with doing so, she fears that her patients will wonder if she does. "I don't know, I think that just the insecurities of 'how comfortable are they with me?' makes you uncomfortable" (Lucia, p. 29). As a Registered Nurse, it seemed that Lucia was most afraid of being perceived as homophobic, biphobic, or perpetuating heterosexism, to the point where it caused stress within some interactions.

Finally, also aligned with what some of the survivors spoke of, Lucia mentioned how she believed that at times health care providers' awareness of an individual' sexual orientation could be detrimental to care.

Yes, I think if the wrong person decides to get an opinion on it. There's a lot of cultural and religious diversity among nurses and it might be their personal belief to not be open minded to gay and lesbian relationships. (Lucia, pp. 18-19)

Lucia stated that although nurses must try and put their judgments aside, she still felt that this could be difficult for some individuals and therefore jeopardize equitable care for sexual minority women.

As we see from this theme addressing the interactions with health care providers during cancer care, there are some contradictions voiced by some survivors between their opinions on the relevancy of sexual orientation disclosure and sources of support during cancer care. This will be deconstructed further within the discussion section. The final theme of environmental barriers will provide context on some of the systemic factors that facilitated or hindered the cancer care experience.

**Environmental (Organizational and Institutional) Barriers.** 

Health care environments play a pivotal role in the delivery of equitable health care services, and often represent the higher system level barriers that can marginalize sexual minority women. From the survivors' interviews, the term environment is used to describe the public spaces where women received care, which may have included an organization or institution. In the context of these findings, organizations represented groups associated with providing support, such as formal support groups, while institutions were the establishments in which care or services are received, such as clinics or hospitals. Therefore, this theme highlights participants' experiences and witnessing of both inclusion within environments, heteronormativity or heterosexism within environments, issues of accessibility, and how reproductive cancer screening was taken up. I also discussed with participants whether or not they believed that health care providers' disclosure of sexual orientation would aid in creating a welcoming environment as a sexual minority woman.

#### Inclusion within environments.

The majority of participants did describe examples of inclusion within health care environments that allowed them to feel safe and welcome as sexual minority women, and most responded that there were never any elements present that would make them feel as though they were unwelcome as a lesbian or bisexual women. Tasha and Dani both described similar feelings regarding the institutions where they had received cancer care. Tasha said, "I guess maybe it's just the generation I grew up in, but I sort of assumed that if it was a hospital then it was a safe space" (p. 31). Dani expanded on this sentiment as well. When I asked her if she ever felt the hospital or clinics have been unwelcoming or made her feel uncomfortable about being a lesbian, she said she "never felt like that" (Dani, pp. 3-4). Claire also spoke briefly about some of the

hospital literature for reproductive cancer patients and post-operative patients. "I read probably every brochure because you sit there and read. I didn't really find anything [that would be unwelcoming]. It didn't really say anything about being straight or gay or transgender or anything else" (Claire, p. 36).

As I previously mentioned within the cancer journey theme and under the subheading of *social support*, Robyn discussed how she discovered a lesbian-specific support group through a pamphlet that was available at one of the institutions in which she received cancer care. This is important to note because even though no one directed Robyn to this literature, the fact that it was available and accessible to patients highlights this environment's attempt to promote a positive space for sexual minority women and perhaps other members of LGBT communities.

Expanding on inclusive practices within institutions and provided by organizations, Anna described how she specifically received care at a health care centre in her city with a positive reputation within the LGBT community. For Anna, sexuality was never something she worried would dictate her care in a negative manner at this institution. She said that, "nobody questions anybody's sexual orientation in that place" (Anna, p. 8), in the sense that nobody would challenge or oppress an individual based on how they identify. Although she stated that she did not know about the health centre's specific services prior to first receiving care there, she felt that it had been a welcoming place for her since going, and helpful in her rehabilitation following her cancer.

#### Heteronormativity/heterosexism within environments.

Despite all participants replying no to the question of "Did anything within the health care environment make you uncomfortable or feel unsafe as a lesbian or bisexual woman?"

stories of heterosexism, biphobia, and heteronormativity within health care environments still emerged. A few participants described the atmospheres of environments as unwelcoming in some capacity. For example, Robyn described her feelings while attending a support group that was not LGBT-specific.

They had a [support] group that I wanted to do, but it was for anybody, and I found it was so heterosexual-dominated. I just went once and then I never went back. I can't relate to any of the women there, they are all about their husbands and their kids, etc. (Robyn, pp. 11-12)

Additionally, Anna described a hospital in which she found to be unwelcoming for not only LGBT individuals, but also other marginalized groups such as those with addictions or who are homeless. "Some people like it, some people don't. In my opinion, it's not a welcoming place for the trans community or gay. Anything with addiction, homelessness, they just lump everybody into one" (Anna, p. 12). For Anna, because of some of her past negative experiences with this institution during her experiences of homelessness and addiction, this was an environment in which she did not wish to seek her cancer care.

## Issues of accessibility.

Another issue that was touched on by some of the participants in terms of environmental barriers was accessibility, either in the physical sense or financially. Two participants addressed some issues of both physical accessibility, such as transportation, and financial barriers that existed either for them or for friends whom also journeyed through a cancer diagnosis. For example, Claire discussed some of the financial issues that were present for her during cancer care.

It cost me \$684.00 to get it [a medication]. It wasn't covered by OHIP at the time, which I didn't know. I have good benefits at work, but at that point it was the newest and greatest drug, so that's what they wanted to give me and it wasn't covered. (Claire, p. 18) She elaborated further on the financial costs of this medication. "[With this drug], my benefits generally paid 80% for medication, buy my wife and I went into \$16 000.00 of debt because I wasn't working. I did get short-term disability but that's only 55% of your wages" (Claire, p. 38). Claire went on to say that her and her wife both are now employed and have since paid off the debt, but that for others who are experiencing a similar diagnosis, financial burdens may cause even greater problems.

Although Brenda stated that she was fortunate to not encounter any large barriers to access, she did discuss accessibility issues for her friend and how this was currently hindering some aspects of her cancer care.

My friend experiencing cancer would be going through a couple hundred dollars a month just in parking. On top of that, the bus service is not that good, and when you're not feeling well who wants to take public transportation? I mean as someone who is a driver, I can absorb that cost, but for someone who can't, I think there should be some relief for that. (Brenda, p. 28)

Claire also addressed issues of public transit. She talked about how there was a bus to take individuals to their treatments, yet the stops were frequent and long, and patients would have to be up quite early in order to travel this way.

#### Reproductive cancer screening.

More than half of the participants discussed reproductive cancer screening in some capacity and some of the institutional and organizational barriers that arose in terms of accurate information for lesbian or bisexual women. For example, there were instances described by two survivors regarding their health care provider's recommendations for PAP smears.

Before I'd been diagnosed, I was asking a doctor whether or not I should receive a PAP smear. He asked about my sexual activity and [I said] that I was with a woman. He said 'you don't need to worry about that stuff, you probably won't even need to get PAP smears that often, your risk of getting those kinds of diseases is low so you don't have to worry about it.' (Tasha, p. 32)

The same type of experience was recounted by Brenda, who described a similar conversation but with her family physician. "I must admit that my family doctor in doing PAP smears sort of went 'oh well, your partner is female' and I said 'well do it anyway', you know?" (Brenda, p. 18).

Moreover, Dani, who was currently being treated for cervical cancer, stated that her family doctor did not know she identified as a lesbian. She told me that she has "never" revealed that she was a lesbian prior to any PAP smear or to her family doctor, nor has she ever been asked (Dani, p. 4). In discussing this with Dani during our interview, we identified that this may actually have been beneficial to the discovery of her cervical cancer, as her doctor may have been recommending guidelines for PAP smears with the assumption that Dani identified as heterosexual.

In terms of breast cancer screening, Claire discussed some of the implications of being a younger woman and trying to receive the screening she felt she needed. "[The Physician said] 'There's no cancer in your family, so you don't need to be screened, you don't need a

mammogram until you're 50.' Well, if I had of waited until I was 50, I would be dead" (Claire, p. 42). This instance that Claire described was not specific to her lesbian identity, but it did have implications for how she had to advocate for her own cancer screening during the beginning of her cancer journey.

# Disclosure of sexual orientation by providers.

Finally, I discussed with participants whether or not they felt that health care providers disclosing their own sexual orientation would be beneficial to creating a welcoming atmosphere and would aid in increasing a sense of inclusive care. Surprisingly, only Brenda believed that this would be important or beneficial to care.

If I had an option, I would choose a lesbian doctor over a non-lesbian doctor, but we never had those choices. If I had a choice, I would choose a lesbian social worker over a non-lesbian. I've chosen lesbian psychologists over non-lesbian. I would make all my choices that way, all other qualifications being equal, I would absolutely make that choice. (Brenda, p. 31)

All other participants when asked this question stated that "it wasn't important", "wasn't any of their business", or said that, "it might be nice but doesn't really matter". These responses were voiced from those participants who also believed that sexual orientation disclosure was not relevant to their reproductive cancer care or interactions. Elaborating on this notion, Robyn provided insight surrounding what she believed was most important when it came to her providers.

I tend not to like to have your sexual identity define who you are. You are there doing your job and you're enjoying your career, and I'm there as a patient. So what should be, for me, the most important thing would be care. (Robyn, p. 15)

For Robyn, the sexual orientation of providers was not the focus of her care. However, prior to this statement she did say that if there were oncologists that dealt with gay and lesbians specifically and that a patient could make a choice to choose those providers, she would make that choice "by all means". Yet, she stressed that these choices do not exist at this point in time.

# Providers' perceptions of health care environments.

Registered Nurses and other health care providers who regularly interact with clients and work within health care environments may perhaps have broader insight into some of the policies and practices that exist within these institutions and organizations. Lucia and I spoke of some of the barriers she has encountered working within health care environments, and also how some of these barriers are challenged during practice. Specifically, Lucia addressed her experience working in different geographic locations, literature within health care environments, and preventative care and screening. Brenda addressed some of her thoughts on disclosing her sexual orientation as a provider during her experiences with clients as a therapist.

While discussing working with sexual minority women during her nursing practice, very early in our interview Lucia talked about some differences she has seen between larger urban centers and smaller, rural communities regarding discussions of sexual orientation.

I did find during my role working in [a smaller community], there was less openness to talk about sexual orientation and who the substitute decision maker was. I found they would give the name of a friend, even though it would later come out that they were

actually their partner. Whereas in both situations that I've had in [a larger, urban city centre], they've presented quite upfront that they are their partner. To me, it comes across as more of an open culture to talk about it. (Lucia, p. 3)

It is also important to note that regardless of the different areas she has worked, Lucia stated that she would only discover an individual's sexual orientation through inquiring about substitute decision maker or the relationship between the patient and her partner.

In terms of her current role, Lucia discussed some observations and subsequent changes in outlook regarding some elements within the health care setting. This response came as a result of asking Lucia if she had ever witnessed anything within health care environments that may not be inclusive to sexual minority women.

There was a pamphlet I read once for post surgical care after reproductive cancers. It was just about post-op care and resuming sexual activity, but I guess the way I interpreted it was that it was focused towards if you were a female wanting to resume sex with your male partner. (Lucia, p. 15)

She went on to elaborate a bit on this literature and how her outlook changed on it following a discussion with a coworker. "It's funny because I read it and didn't think much of it. I didn't even notice it at first; because that's not something I would necessarily take offense to. But she [a lesbian coworker] was very offended by it" (Lucia, p. 16). She stated that having this discussion alerted her to some of the barriers that do exist for lesbian and bisexual women within health care environments.

Another subtheme that Lucia brought up independently, as it was not part of my questioning, was regarding preventative care and cancer screening for sexual minority women.

She talked about her own discussions with women regarding cancer screening while they were in hospital.

It's interesting because when I was asking a [lesbian] woman who was a new cervical cancer diagnosis, 'out of curiosity where are you going for regular PAPs?' She told me 'well I don't have a doctor and I didn't really want to go to a women's health clinic because that's uncomfortable.' So she told me that it was sad for her to admit but she probably hadn't had one in 4 years. (Lucia, pp. 22-23)

Lucia said that she wasn't certain, but she wondered if the woman feared negative treatment from the health clinics if she were to disclose her sexual orientation. She said now whenever she cares for any woman who has cervical cancer, she is curious as to what or if barriers may be preventing them from receiving regular PAP smears.

In terms of Brenda who identified as both a therapist and a cancer survivor, she discussed some of her sentiments regarding disclosure of her sexual orientation as a provider.

Certainly it was for me, as a service provider, an ethical decision as to when I would disclose my sexual orientation and when I wouldn't. It always had to be for the good of the patient, I mean, that's what its about. (Brenda, p. 32)

Brenda strongly felt that as a patient it was important to disclose sexual orientation, but recognized that there could be ethical implications to disclosing as a provider who is in a role to assist individuals. She discussed how a provider's disclosure could create a welcoming environment for the patient, but it is also something that may need to be carefully assessed prior to doing so. It is important to consider that a provider's disclosure of their own sexual orientation may not always be permitted or safe for them within their work environment.

This final theme demonstrated some of the ways in which positive spaces are created within health care environments, but also some of the barriers that continue to confront sexual minority women at institutional and organizational levels. It becomes clear that patient-provider interactions within health systems can be representations of larger systemic issues within the environments, and this will be addressed further within the discussion section.

# **Summary**

The four themes that emerged from interviews with LB reproductive cancer survivors have helped to provide some context to their cancer journeys, their meanings of family, their interactions with health care providers, and their experiences within health care environments. I have also used the interview with the Registered Nurse who was not a survivor and the insight from survivors who were also providers, as a way to compare and contrast some of the themes and subthemes from a provider perspective. Together, I have used these themes and subthemes as a way to best represent and capture the experience of reproductive cancers for these women in their own words. In the next chapter, I will discuss how these findings addressed my research questions and the implications they have for both sexual minority women's cancer care and nursing practice.

#### CHAPTER FIVE:

#### DISCUSSION

In this chapter I discuss the answers to my four research questions based on my findings and also how these compared to and differed from existing literature on reproductive cancers and sexual minority women. I also include some of the ways gender, sexuality, and reproduction provided meaning for the participants, limitations of this study and directions for future nursing research and education.

## **Discussion of Findings**

Based on my research interviews with seven participants, six sexual minority women who have experienced reproductive cancer and one Registered Nurse who had not experienced cancer, four main themes and corresponding subthemes emerged that provided the basis for my research findings. These four themes included survivors' insights on the reproductive cancer journey, reproduction and the meaning of family, interactions with health care providers<sup>3</sup> during cancer care, and environmental barriers. The findings yielded from these four themes and their subthemes helped to answer my research questions, which will be discussed throughout this section, while also helping to outline how the intersections of gender, reproduction, and sexuality helped to shape the reproductive cancer experience for sexual minority women. Also within this discussion section, I will highlight how participants' excerpts reflected or differed from existing

<sup>&</sup>lt;sup>3</sup> Although the participants described their interactions with health care providers in a broad, yet primarily clinical, sense (e.g. family physicians, oncologists, radiologists, nurses), for the context of this chapter I will highlight only the implications for nurses. The decision for a nursing focus is in an attempt to avoid generalization of findings to all health care providers, when the discussion revolves primarily around nurses with only some brief mention of physicians.

literature on lesbian and bisexual health and cancer and what my findings indicate in terms of future nursing practice and research.

## What is the meaning of reproductive cancer?

My first research question for this study is: What is the meaning of health and reproductive cancer for sexual minority women? Many of the cancer survivors gave insight into what aspects of health care were important to them during their cancer journey, as well as what having a reproductive cancer meant in terms of reproduction and physical health. To answer this research question, I will touch upon many of the subthemes present within the themes of the reproductive cancer journey, as well as reproduction and the meaning of family. Understanding the meaning of health and reproductive cancer for lesbian and bisexual women in this study provides perspective for Registered Nurses to the unique ways in which the experience of cancer may be shaped for sexual minority women.

#### Health versus health care.

Based on discussions within the findings section, there was an interesting contradiction that emerged from the research interviews in terms of how the survivors' interpreted and compartmentalized the meaning of 'health' compared to their interpretations of receiving 'health care'. Overall, the survivors largely described health in a holistic manner, encompassing physical and emotional wellbeing. There were perceptions that to have cancer meant the absence of 'health' and to feel weak or sick. There was also a perception of guilt for some survivors whose cancer experience was not as aggressive as others they had witnessed. This was in part because of their perceptions that 'being healthy' and 'recovering quickly' were contrary to their notions of cancer.

This more holistic view of 'health' was contradicted with the participants' views of what the service of 'health care' meant. Participants often felt that nurses and physicians were not the appropriate resource in which to access emotional support, and that the focus during cancer care while in hospital should primarily be on physical care. In this sense, 'health' may have been broadly seen as a holistic concept, but 'health care' was narrowly compartmentalized. However, this focus on physical health when receiving health care from nurses and physicians voiced by sexual minority women was reflective of a larger issue related to sexual identity. Many of the women spoke of a desire to receive equal treatment as those who are heterosexual, and not wanting discussions surrounding their sexual orientation to negatively influence their care. These findings from my thesis slightly differed from those of an American study, which found that their lesbian participants desired more holistic health care and inclusive services provided by HCPs who were attuned to lesbian-specific health care concerns (Seaver, Freund, Wright, Tija, & Frayne, 2008). The lesbian women from Seaver et al.'s (2008) study preferred inclusive services and holistic health, which included non-discriminative care from their providers and receiving services that addressed the whole individual beyond sexual health, such as preventative health, nutrition, and mental health.

This focus on maintaining and protecting equality during health care was not only voiced by sexual minority women, but also by the nurse who was not a survivor. She spoke about her fear of generalizing or stereotyping her sexual minority patients by acknowledging their sexual orientation. She felt that she would provide the same care to all her patients, regardless of sexual orientation. Although this was only one response from one nurse, it reflected similar findings from a Canadian qualitative study by Beagan et al. (2012), who found that Registered Nurses she

interviewed commonly associated the acknowledgment of differences in patients, such as sexual orientation, to be discriminatory rather than helpful in therapeutic relationships. The findings from my study as well as Beagan et al. may reflect a larger gap in nursing education on sexual minority women's health, in which the focus may be from a problem-based perspective with emphasis on avoiding discriminative care, rather than focusing on ways to provide supportive, inclusive care.

# Reproductive cancer as a journey.

In terms of the participants' meanings of reproductive cancer, the survivors spoke of their cancer as a complex, on-going journey, rather than one specific destination or point in time. The cancer journey emerged as a theme in which the women described their reproductive cancer experience in the form of a story, starting with discovery and travelling through their experiences with treatment, physical health changes associated with treatment, and everyday implications. Throughout this journey, there were several pieces that made the meaning of reproductive cancer specific for them as sexual minority women by highlighting issues of gender, sexuality, and reproduction throughout. One of these pieces specific to sexuality included additional worries or stress regarding the legal rights and benefits of same-sex partners if they were to lose their battle with cancer. Undoubtedly, this is a worry for any and all couples where a partner is experiencing a life-threatening illness. However, the difference for sexual minority women is that historically same-sex couples have been denied the same legal rights as heterosexual couples, including marriage, and only within the last ten years have we seen a dramatic shift in regards to legal rights, equity, and protection across all Canadian provinces (Wintemute, 2004). There are still many other countries worldwide that do not grant these same legal rights and protections, and the additional stress or worry of real or perceived hostile treatment or discrimination experienced by sexual minority women could perhaps be more substantial for those experiencing cancer in other geographic locations.

Nevertheless, other external stressors can still exist for sexual minority individuals in Canada and impact their meaning of cancer. Specifically, bisexual women consistently face barriers to the access and equity of health care that heterosexuals and even other members of gay and lesbian communities do not face to the same extent. For example, the participant in my study who identified as a bisexual woman described missing some of her cancer treatments because of external stressors in her life. As previously discussed in the literature review, bisexual women often face higher risks for mental health issues, increased ostracism from within both the heterosexual and LGBTQ health spheres, and often also have less support from family and friends (Dobinson et al., 2005). These external stressors in addition to a reproductive cancer diagnosis could present even more serious consequences for a bisexual woman's health when compared to heterosexual or even lesbian women.

In addition to bisexual women and those in other geographic locations, there can also be unique stressors for individuals of diverse race, class, ability, and gender identity who experience a reproductive cancer. Within my sample, there were only two participants who self-identified as black women and one additional participant who identified her mother as having "Native background". Therefore due to the small number of participants, it is difficult to generalize their experiences to other women of diverse racial and/or cultural identities. However, these identities did have implications for care that provides insight into some of the experiences that other women may encounter. For example, one participant although primarily identified herself as

"Canadian", went on to talk about how her mother had "Native background" and how this shaped her mother's health care beliefs about cancer treatment. The survivor's mother felt that speaking with Aboriginal elders and participating in a smudging ceremony would perhaps be more effective than Westernized medicine for her daughter's cancer, but the survivor explained how she and her mother did not see eye-to-eye on these beliefs. This example contextualizes some of the implications that diverse cultural and/or racial identities can have during the reproductive cancer experience, and how it is important for nurses to recognize and respect diverse beliefs on health and healing.

Another participant who self-identified as a black lesbian woman described discovering her cancer while visiting Canada and suddenly having to undergo treatment while staying with family and friends. Yet, this was seen as an advantage in her case, as she felt fortunate receiving her care in Canada and had great confidence in the cancer care centers where she was treated. Although this was a positive aspect for her, others who are newcomers to Canada may see navigating our health care systems as a disadvantage. This could result in detrimental implications for care especially if English is not an individual's first language and limited services are in place to facilitate communication or advocacy for newcomers to Canada.

Furthermore, although not present within my sample, trans women who self-identify as lesbian or bisexual may face even greater barriers to access and equity of cancer care when compared with cisgender lesbians and bisexuals. Trans women are at risk for breast cancer, as well as cervical cancer if they have received a vaginoplasty (Canadian Cancer Society, 2014), and may experience challenges to receiving routine cancer screening attributed to real and perceived transphobia from health care providers. Trans men may also encounter barriers to

adequate cancer screening and may also be misinformed from their providers regarding screening guidelines (Canadian Cancer Society, 2014). Trans men who have undergone top surgery are still at risk for development of chest cancer, and those men who have a cervix and are sexually active also require PAP smears at routine rates (Canadian Cancer Society, 2014). These intersections of other sexual orientation and gender identity can create unique barriers that provide even greater stressors during reproductive cancer care and are important for nurses to recognize when providing care.

Another subtheme that gave context to survivors' meanings of reproductive cancers involved descriptions of the physical changes to women's bodies and the loss of visible reproductive organs following cancer treatment, which intersected aspects of gender, sexuality, and reproduction. For example, some of the survivors I spoke with who described losing their hair during chemotherapy found this to be a very difficult aspect of their treatment, both for themselves personally and how they felt others may perceive them as a woman. Some participants found the loss of hair to solidify the meaning and reality of their cancer, and a difficult part of the journey. Furthermore, although only one survivor had experienced a mastectomy, she gave interesting insight to what this meant for her by discussing both the advantages and disadvantages she experienced. One such advantage included challenging, perhaps more easily, traditional gender roles, as she described the benefits and simplicity of not having to wear a bra under her jersey while playing hockey. However, one of the disadvantages involved her decision to receive reconstructive breast surgery was the subsequent opposition she faced from her family questioning whether her motives for the surgery were to benefit her female partner.

This opposition from one survivor's family may represent either the desexualization or hypersexualization of lesbian women based on negative stereotypes often prevalent within the media and society. For example, desexualizing the survivor could have occurred from an assumption that having breasts as a part of one's sexuality within a lesbian relationship would not be as important, which could have undermined how a breast reconstruction could be relevant for the survivor. Lesbian women have traditionally been negatively stereotyped as masculine women and undesirable by men (Calhoun, 2000), which may further contribute to their desexualization within society. Conversely, hypersexualization could have occurred from an assumption that the survivor's partner saw reconstruction as a necessity within their sexual relationship and pressured her into doing so. Commonly, lesbian women remain hypersexualized within the media, often targeted for heterosexual male audiences, creating the perception that relationships between women involve hyperfeminine bodies and a focus on sex. It may have been overlooked how breast reconstruction could have less to do with the survivor's partner, and more to do with her own perception of self and sexuality, as well as part of the recovery process to feel "healthy" again. Both of these assumptions can have negative impacts on lesbian women who are trying to make the difficult choice on whether or not to receive breast reconstruction following mastectomy.

Expanding on the discussion of breast reconstruction, to date there is limited research exploring some of the reasons and concerns for sexual minority women who have undergone a mastectomy and consider breast reconstruction. Studies on the topic of sexual minority women and breast reconstruction suggest that women who choose breast reconstruction and those who do not tend to consider many of the same issues in regards to their decisions (Boehmer, Linde, &

Freund, 2007). Furthermore, one study also suggests that some of the reasons sexual minority women may opt for breast reconstruction may not be all that different when compared to heterosexual women, including wanting to feel 'whole', wanting to look normal, and transforming a sick body into a health body (Rubin & Tanenbaum, 2011). Based on these results and the discussions with the participant in my study, it is important that Registered Nurses have adequate information for sexual minority women on the types of surgeries and options available following mastectomy, regardless of gender presentation or sexual orientation. It is also important for nurses and physicians to remain unbiased and provide this information without judgment, as sexual minority women may also be hesitant to discuss the options available for breast reconstruction if they are also experiencing opposition from family or friends.

# Implications of cancer on reproduction.

As previously discussed, in terms of the meaning of reproductive cancers as they relate to reproduction, there was a lack of discussion during my interviews regarding the effects of these cancers on women's fertility in the future. This was based on both my unintentional exclusion of questions pertaining to fertility within my interview guide, discussed further in the limitations section, as well as an overall lack of discussion on this subject. Yet, one participant did bring up issues of fertility independently, as addressed in the subtheme of *effects of cancer on fertility*. This participant did not wish to conceive children and therefore fertility issues, as explained to her by her doctor, did not provide her with any additional worry or stress. Another reason that perhaps fertility and reproduction was not discussed in greater detail during my interviews was that the majority of my participants' ages were between early 40s and late 60s, with some already having grown children and even grandchildren. Perhaps the survivors felt as though they

were past the age of conception or that reproduction was no longer a priority for them at this stage in their life.

Nevertheless, the lack of conversation on conception or fertility was somewhat surprising based on the rates of pregnancy for sexual minority women within the existing literature. Studies have listed anywhere between 22% and 25% of women who have sex with women have been pregnant at least once (Marrazzo & Stine, 2004; Moegelin et al., 2010). Although some sexual minority women may not wish to conceive children, others may feel a loss if their ability to conceive children is effected following a reproductive cancer. As described under the subtheme of *heteronormative assumptions surrounding reproduction*, one participant in my study did express that it seemed as though her physician did not go into much depth once she stated that she was a lesbian and did not want children. She felt a different approach might have been taken if she identified as a heterosexual woman, such as a longer discussion on the topic or issues in the future. Therefore, discussions regarding fertility during reproductive cancer care should never be ignored or overlooked by nurses or physicians based on a woman's sexual orientation or sexual history, and it is important to discuss fertility issues on a case-to-case basis based on a woman's concerns.

#### What is the role of social support?

My second research question is: What role does social support play throughout the cancer journey for sexual minority women? Within the findings section, *social support* encompassed a large part of what made the reproductive cancer experience unique for sexual minority women and was a subtheme that appeared under the theme of reproduction and the meaning of family. Although the meaning of reproduction within reproductive cancer was not brought up in ways

specific to contraception or fertility as I discussed while responding to the first research question, it was brought up frequently in regards to family and the meaning of family for sexual minority women. Women described that having their partners and family involved in their cancer experience was important, and sometimes family was not necessarily described as blood relatives, but friends within LGBTQ communities or external support groups.

# Sources of social support.

Sources of social support described by the survivors intersected aspects of gender and sexual orientation and contributed significantly to the findings from this research. Four of the six women interviewed for this study were in relationships with female partners during their cancer care and remained in these relationships after treatment had finished. They described the importance of having their partner with them during all elements of the journey, even during the physical changes to their bodies. As one participant described, having her female partner shave her head as her hair began falling during chemotherapy out was an important part of the journey and their relationship. In fact, the survivors who were in relationships with female partners tended to agree that their relationships were strengthened in some way following a reproductive cancer journey. The Registered Nurse who was not a survivor also described witnessing supportive relationships between female partners more so than she has seen between heterosexual couples. I speculate whether this may have been due to past negative treatment for one or both of the partners, which may influence a woman to be more protective and present with her partner who is receiving cancer care. It also may be representative of women's socialization to be caregivers, and may allow them to be better equipped to provide ongoing care when a

partner is ill. It is important however, to reiterate that this was only the opinion from one nurse's practice, and the other survivors who were also providers did not provide input on this issue.

The findings from my research regarding the strength of social support are also aligned with other American research regarding the importance of social support, particularly from female partners, during a breast cancer diagnosis (Boehmer, Freund, & Linde, 2005; White & Boehmer, 2012). Other studies have found that sexual minority women indicated that their female partner was the most important and best form of support following breast cancer (Boehmer et al., 2005; White & Boehmer, 2012). The sexual minority women in one American study also tended to use support more frequently from family and friends when compared to heterosexual women (White & Boehmer, 2012). An area for further nursing research would be to analyze if this social support is as strong in regards to all reproductive cancers, as seemed to be the case from my findings, and not only breast cancer.

The discussion from the survivors regarding the strength of their relationships during a reproductive cancer speaks volumes about the role that social support played for them during care. Since the majority of the women also perceived health care environments and nurses/physicians as places and people whose focus should be on physical health, social supports seemed to be the primary avenue for any and all emotional support and wellbeing. The women I spoke to felt that emotional support was something sought outside of the health care institution, and that physical health and emotional or spiritual wellbeing were two separate entities. This was an especially interesting finding from participants because the professional standards developed by the College of Nurses of Ontario (CNO) (2002), the self-regulatory body for nurses in the province, discusses the importance of providing holistic care to the client on a bio-psychosocial

level. The Registered Nurses' Association of Ontario (RNAO) (2002) also developed a best practice guideline on client-centered care, which also discussed elements of incorporating clients' physical, emotional, and spiritual concerns into a framework to help patients make decisions and evaluate outcomes. This may indicate difficulties for nurses to work within their professional mandates based on workloads or work environments, and/or problems implementing these guidelines in practice.

As previously discussed in research question one, the avoidance of utilizing nurses or physicians as emotional supports was partly because of a concern that discussing elements of sexual orientation may alter care. Also, some participants voiced a belief that medical-based providers, such as nurses and physicians, may not have time to act as a social support within a hospital setting. Therefore, it is important that nurses acknowledge that sexual minority women may feel especially wary about discussing elements related to emotional or spiritual wellbeing, specifically in regards to their sexual orientation during their cancer experience, and inquiring about these elements rather than assuming patients will disclose them may create a more open dialogue. Establishing that the nurse is open and willing to discuss psychosocial issues may help sexual minority women to feel as though it is safe and beneficial to do so.

#### Barriers to adequate social support.

Although the role of social support was important to the reproductive cancer journey for the sexual minority women I spoke with, it did not come without its own unique obstacles. Specifically in regards to family as a form of social support, some of the sexual minority women in my study did not find this to be a helpful source of support. For example, some women described not disclosing their sexual orientation to their family at all, while others had negative

experiences upon disclosing this information. This is consistent with other findings that state lesbian women may face increased stigma from society, family, and friends (Barnes, 2012; Roberts, 2006), and that bisexual women face even less support from family and friends when compared to both lesbians or heterosexuals (Dobinson et al., 2005).

Therefore, because ostracism from sexual minority women's families may add increased stress for those who may be coping with a reproductive cancer, social support during cancer care can sometimes be found from external support groups. Even though only one participant spoke of attending a lesbian-specific cancer support group, yielded from her interview were several important insights. She spoke of having to find information about the group independently, but that she was able to locate it at the hospital where she received cancer care. This suggests that perhaps at this institution there were efforts in place to create a welcoming environment for lesbian and bisexual individuals. She also described the difference she felt between non-lesbian specific groups and those that were maintained as a space for lesbian women only. The non-lesbian specific cancer support groups did not make her feel welcome or that she could relate, and in fact these elements discouraged her from ever returning to the group.

The sense of feeling "out of place" and as though she "couldn't relate" to the others in the non-lesbian specific group suggests that providing support group information to individuals experiencing any form of cancer may be ineffective if nurses are not referring sexual minority women to groups which are relevant to them. This has also been supported by other Canadian qualitative research, specifically by Sinding et al. (2004), in which lesbian participants who had experienced a breast or gynecologic cancer spoke of feeling as though they could not relate to others in a non-lesbian specific support group, as well as experiencing some overt heterosexism

from facilitators. For this reason, nurses need to be aware of an individual's sexual orientation if they are to provide the most inclusive services following discharge, especially if the patient may already be ostracized from family.

## How do interactions with HCPs impact cancer care?

My third research question, which is strongly aligned with the goal of this study, is: How do interactions with HCPs perpetuate or challenge inequalities in cancer care for sexual minority women? In order to answer this question, it is important to look not only at the experiences shared by sexual minority women regarding their interactions with health care providers, but also at what elements of their identity they felt were relevant and important within their interactions. Therefore, in order to answer this research question, I will draw upon all the subthemes within the theme of interactions with HCPs during cancer care from my findings section. Also, as previously stated, the participants common referred to HCPs either in a broad sense as physicians or nurses, or making some specific references to radiologists, technicians, receptionists and surgeons. It is important to be aware not only of the negative barriers that can exist during interactions, but also the positive and unique ways in which sexual minority women and health care providers are challenging barriers to cancer care.

#### Relevancy of disclosure and inquiry by providers.

As discussed in the findings subtheme of *sexual orientation relevancy during interactions*, the majority of participants felt that sexual orientation was not relevant to their interactions with health care providers during reproductive cancer care. Their focus was primarily on receiving physical care and the majority felt that sexual orientation was not important. This varied slightly from a scholarly literature review on lesbian disclosure to health

care providers. In a review of 30 relevant empiric studies, seven studies addressed relevancy of disclosure and the results suggested that disclosure tended to be perceived as more relevant if it was associated with gynecologic or sexual health issues (St. Pierre, 2012). However, these studies did not focus on disclosure specific to cancer care, so perhaps with the severity of illness other priorities take precedence for the women in my study.

Perhaps one of the most important findings from my study that is consistent with other literature on sexual orientation disclosure in health care systems is that no nurse or physician that the survivors encountered asked about their sexual orientation directly, perhaps perpetuating some of the barriers to inclusion during cancer care. The participants either disclosed or chose not to disclose their lesbian or bisexual identity. The reasons for their decisions on whether or not to disclose ranged from necessity to their care, situation dependent, or greater priority to disclose if they were in a relationship with a female partner. This lack of inquiry by nurses and physicians is important to note as it may suggest that if providers are not asking these questions, it leaves patients to feel that it is either not relevant to ask or perhaps that it is not safe to discuss. This is also consistent with findings from an American study on breast cancer and sexual minority women. The authors found that physicians did not ask participants their sexual orientation and as a result, 28% of the sample did not disclose (Boehmer & Case, 2004). The persistent invisibility of sexual orientation discussions within health care settings may lead sexual minority women to believe that if providers do not ask about sexual orientation, it must not be relevant to my care and type of cancer.

Furthermore, by nurses not asking questions about an individual's sexual orientation, this may be a symptom of larger system level policies not in place to ask these questions during

admission or screening. If nurses do not seek to challenge these lack of policies, then patients may also feel as though the lack of sexual orientation questioning may represent an unsafe or unsupportive environment for them. Yet, as we have seen from discussions with my participants, developing such policies also requires sensitivity due to the possibility that some sexual minority women may be hesitant to disclose or simply not wish to do so. In relation to this, the Registered Nurse who was not also a survivor spoke of how she did not directly ask participants but rather found out by asking for their substitute decision maker, which was part of her institution's policy. However, this is often not the most reliable way to uncover a patient's sexual orientation, as it not only renders bisexual women with male partners or single lesbian and bisexual women invisible, but it also may lead to assumptions of a partner anytime a woman provides the name of a female friend.

Fortunately, RNAO (2007) does have a position statement on respecting sexual orientation and gender identity and gives recommendations such as client-centered inclusive and appropriate health care, in order to improve care for members of LGBTQ communities. CNO (2009) also has a set of practice guidelines on providing culturally sensitive care, which includes examples of using inclusive language when interacting with sexual minority patients.

Interestingly however, these documents do not specifically outline ways in which to inquire about an individual's sexual orientation or gender identity, which may mean that nurses are missing opportunities to connect with these patients in practice if they are not identifying them. Identifying ways to properly inquire about patient's sexual orientation can help nurses better accommodate care and provide all resources necessary for these individuals, and therefore is an

area that needs to be explored in order to further integrate into nursing research, practice, and education.

## Challenging barriers to care.

Fortunately, there were ways in which HCPs were challenging barriers to cancer care during interactions with sexual minority women, as discussed in the subtheme of sense of inclusion during interactions. All of the prominent examples of inclusion during interactions between sexual minority women and their HCPs during cancer care involved the participants who were in relationships with female partners and their examples of inclusion were marked by either an acknowledgement of or respect for their female partners. This finding also presented an interesting contradiction, which was that although the majority of survivors stated that they did not feel sexual orientation was relevant to their reproductive cancer care, half of these same individuals felt that inclusion and acknowledgment of their same-sex partner was an important part of their care and interactions from nurses and physicians. Also, one of the women who was single during her cancer care stated that she felt her sexual orientation might have been more relevant to her care if she had been in a relationship during her cancer treatment. Based on the findings from my study, it seems as though sexual minority women may feel that discussions regarding sexual orientation during cancer care are not relevant unless there is a tangible reason for them to be, such as having a same-sex partner present and acknowledged by staff.

Expanding further on this, although many of the survivors said that sexual orientation was not relevant to their reproductive cancer care, this may have been influenced by the fact that many also felt that, as previously discussed, disclosing sexual orientation could be detrimental to the care that they would receive from HCPs. This finding may suggest that if sexual minority

women feel that disclosure of sexual orientation is going to alter their care, there is even less willingness to openly discuss this information with nurses or physicians or see the relevance to doing so. The Registered Nurse who was not a survivor also felt that disclosure of sexual orientation could be detrimental to sexual minority women's care. The findings from my study are similar to several other Canadian, American, United Kingdom, and Swedish research studies from the past that suggest patients fear disclosing their sexual orientation within a health care setting because they believe it could result in negative treatment from health care providers (Cochran & Mays, 1988; Dobinson et al., 2005; Klitzman & Greenberg, 2002; Platzer & James, 2000; Rondahl et al., 2006; Stein & Bonuck, 2001; Stevens, 1994, 1995; Williams-Barnard et al., 2001; White & Dull, 1998).

#### Perpetuating barriers to care.

Unfortunately, some of the participants' concerns regarding detrimental care attributed to disclosure of sexual orientation were a reality, and there were ways in which HCPs were perpetuating barriers to care during interactions. As discussed within the subtheme of heteronormativity/heterosexism during interactions, there was overt heterosexist disregard for one woman's female partner and assumptions by some health care staff that one woman's female partner was male. The latter example represents barriers during interactions with health care staff that intersect sexual orientation and gender expression, and how women are expected to appear according to societal gender roles. Not only can these assumptions and language marginalize sexual minority women in health care, but it can also jeopardize interactions with providers and create a sense that there is a lack of support. The participants' reports of heterosexism during their cancer care is not an isolated finding, as my findings were similar to other Canadian and

American literature within the past ten years exploring both homophobia and heterosexism that exists for lesbian women undergoing cancer treatment (Boehmer et al., 2005; Boehmer & Case, 2004, 2006; Brown & Tracy, 2008; Dibble et al., 2008; Sinding et al., 2006).

Furthermore, both of these examples of heterosexism within my findings can be representations of ineffective training and education on the part of the providers and staff on how to create inclusive environments for lesbian and bisexual women. These may also be larger system level symptoms of health care culture, where there may not be policies for inclusive practices in place. Heterosexism and/or biphobia within cancer care can further marginalize sexual minority women and create perceptions that spaces are not safe or that there is a lack of support for sexual minority women. This may further delay women in seeking health care treatment for their symptoms, as well as delay women in seeking routine preventative cancer screening for reproductive cancers that often do not present with early signs and symptoms. Although all the participants who completed their treatment at the time of my study recovered, other sexual minority women may delay life-saving treatment as a result of real or perceived heterosexism or biphobia from their nurses or physicians.

## Sexual minority women's self-advocacy.

It is also important to note from my findings that many of the survivors spoke of their willingness to self-advocate if faced with heterosexism or biphobia. They spoke of things like being asked to have a different physician or nurse and not letting others' negative actions or words influence their right to have a partner present during care. This is also consistent with other qualitative Canadian literature that discussed lesbian women's self-advocacy during breast cancer and willingness to defend their care when confronted with heterosexism (Lesbians and

Breast Cancer Project, 2004). Also, this willingness to advocate by the majority of participants could have also been because four of the six survivors in this sample were also health or service providers in some capacity. Perhaps their own knowledge of the health or service systems and training assisted in their own empowerment. This again is an element of health care navigation unique to sexual minority women, and is something to consider in terms of education for sexual minority women on how they can navigate health systems and understanding their rights as patients. A current initiative that is trying to educate others in the LGBTQ communities on self-empowerment when it comes to cancer screening is the Get Screened project based in Ontario (Canadian Cancer Society, 2014). It is an initiative started by the Canadian Cancer Society (2014) and allows LGBTQ community members to help advocate for others in their communities to get screened and understand the importance of regular cancer screening.

## How do health care environments impact cancer care?

The final research question from my thesis is: How do health care environments and the cancer care interactions that occur within them perpetuate or challenge system level barriers for sexual minority women? This research question also corresponded to the final theme of environmental barriers within my findings section. Therefore, all of those subthemes are referred to in some capacity in order to best answer this final research question. The answers to this question help to provide a basis for Registered Nurses to question some of the existent policies or education from their associations or institutions that may facilitate or hinder appropriate access to resources for sexual minority women with reproductive cancers.

#### Inclusive environments.

As discussed within the subtheme of *inclusion within environments*, all participants generally felt that their health care environments where they received cancer care were welcoming, and therefore seemed to challenge system level barriers. Participants seemed to generally be referring to health care environments as the hospitals where they were an inpatient following surgery, clinics where they received radiation or chemotherapy, or their physicians' offices. This finding differs from some literature regarding safe spaces and health care environments for sexual minority women. There have been both past and recent studies that suggest that sexual minority women generally feel as though their health care environments are not welcoming or inclusive to them (McIntyre et al., 2010; Stevens, 1995).

However, the participants in my study could also have interpreted my question in the sense that there were no overt homophobic or discriminatory elements within the health care settings, rather than that there were inclusive elements present, as none of them were able to directly provide examples of how it was inclusive/welcoming. It may simply be that the health care environments where the women received care were not necessarily heterosexist or biphobic, but perhaps more heteronormative in the sense that the women were rendered invisible by the space not directly denoting LGBTQ-inclusion with posters or stickers for example. It may also have become normalized for participants to overlook elements within public spaces that are inclusive to them. This was also indicated to me by the lack of policies or lack of implementation of policies by staff at cancer care institutions to ask about sexual orientation, as confirmed by all survivors and the Registered Nurse who was not also a survivor. As previously stated, the

institution that is enforced or promoted, and therefore uncovering sexual orientation only through an often unreliable tactic of inquiring about an individual's substitute decision maker.

## Perpetuating environmental barriers to care.

Despite the participants' perceptions that their health care environments were generally welcoming, there were areas that arose within the subtheme of heteronormativity within environments that demonstrated perpetuation of barriers to care. In terms of the lesbian-specific cancer support group that only one survivor attended, she described the elements of the nonlesbian specific group as being unwelcoming and feeling almost as though she didn't belong. The interactions within this group seemed to perpetuate barriers to care through social support, as it was predominately heterosexual women who were discussing elements related to children and their male partners. Again, gender, sexual orientation, and reproduction had different meanings for the survivor who attended this group and she faced isolation that may not be present for heterosexual women with families. The survivor stated she found information on the lesbian-specific group independently within her health care institution without referral from an HCP, which suggests that there may have been intentional steps taken by the health care institutions to create a positive or 'safe' space. Perhaps nurses or physicians not referring this information directly to the participant was either because they assumed she was heterosexual or that they were not aware of the lesbian-support group literature themselves.

Some participants also spoke of issues of accessibility, within the subtheme of the same name, which could perpetuate system level barriers. Although these were examples of things such as financial costs that all individuals would incur, intersections of gender and sexual orientation compounded with these issues could make them more substantial for sexual minority

women. For example, it is important to note that although Canadian research suggested that there tends to be a 15% income premium for lesbian women when compared to heterosexual women, bisexual women have significantly lower personal incomes when compared to both heterosexual and lesbian women (Carpenter, 2008). This is another important area in which bisexual women may be more marginalized compared to lesbian women, and why access to services may be a larger issue.

## Barriers during reproductive cancer screening.

Another area where interactions within health care environments may have perpetuated system level barriers to cancer care for sexual minority women was during cancer screening. Two of the women described how they were told they did not require PAP tests at the same frequency as heterosexual women, and one woman described she was not "out" to her provider and was receiving PAP tests at the scheduled frequencies. The Registered Nurse who was not a survivor also spoke of a lesbian cervical cancer patient not having received routine PAP tests, which may also indicate the dangers in not receiving adequate screening.

The findings from my study were not isolated, as sexual minority women frequently report lower rate of PAP smears when compared to heterosexual women (Barnes, 2012; Matthews et al., 2004; Roberts, 2006; Tracy et al., 2010; Moegelin et al., 2010) and have received improper screening guidelines for PAP tests (Barnes, 2012; Flemmer et al., 2012; Roberts, 2006). A more recent American study actually found that a lack of referral for PAP tests from health care providers was one of the most commonly cited reasons why lesbian women do not receive routine screening (Tracy et al., 2013), which certainly seemed to also be the case for half of the women in my study. The improper guidelines communicated to sexual minority

women by their HCPs may be a result of a lack of education and training in medical and nursing programs, or a delay in making these changes to PAP testing policies into smaller clinics and physicians' offices.

## Provider disclosure to promote inclusive environments.

Finally, another aspect of interactions within health care environments that was brought up in the subtheme of the similar name was survivors' thoughts on whether or not their providers should disclose their own sexual orientation, particularly if the provider identified as gay, lesbian, or bisexual. The majority of participants said that 'it didn't matter' or was 'none of their business'. Yet, one of the survivors who was also a provider and the Registered Nurse who was not a survivor both felt that this would in fact be relevant and important to practice. These two participants felt that in their own practice they have seen better establishment of trust and therapeutic connection between gay, lesbian, and bisexual clients and gay, lesbian, and bisexual providers. The survivor who was a provider also felt that if clients were encouraged to selfdisclose their sexual orientation, it would only be fair for providers to do the same. However, it is important to note that there can be many unique barriers to HCPs disclosing their own sexual orientation to their patients and colleagues, which could include a lack of support or safety within their work place. The belief by the majority of participants that providers' sexual orientation was none of their business or didn't matter could also reflect their opinions on why they did not believe it was necessary to disclose their own sexual orientation within a health care setting and to their providers.

## Gender, sexuality, and reproduction.

It becomes evident through discussion of my research findings and providing answers to my proposed research questions that there are ways in which gender, sexuality, and reproduction have meaning for and shape the experience of reproductive cancers and cancer care for sexual minority women. There were many positive and unique ways that these elements influenced the cancer journey for lesbian and bisexual women, as well as some negative barriers that hindered equitable care. The influences of gender, sexuality, and reproduction also have implications for nursing research, education, and practice, which will be discussed in further detail in its respective section within this chapter.

# Unique and/or positive influences.

The unique ways that gender, sexuality, and reproduction influenced the participants' experiences were seen especially within the meaning of reproductive cancers and the role of social support. Within the meaning of reproductive cancer, there were elements such as the desire to receive care equal to that of what heterosexual individuals would receive, undergoing physical changes, and issues of fertility that were uniquely influenced by sexuality, gender, and reproduction respectively for the participants. Overall, the majority of participants desired that the focus of their cancer care be on physical health and felt that disclosure of their sexual orientation may impede their cancer care. This was an element of cancer care that had unique meaning for the sexual minority women I spoke with. In regards to gender, several participants spoke of the physical changes to their bodies as a result of cancer treatment, such as losing their hair following chemotherapy and decisions regarding breast reconstruction. Both of these examples had specific implications for women's bodies, societal gender roles, and how others would perceive them.

In regards to fertility and reproduction, the majority of sexual minority women did not address this issue and it did not come up in the same way that it may have for heterosexual women. As previously discussed, this may have been due to women not feeling a sense of loss in regards to fertility problems, partly because of the older age of the majority of survivors and many of them already having children from previous relationships with male partners. Another reason could have been that sexual minority women who do have children are more commonly comprised of varied family configurations, and therefore may not feel the same pressure to conform to the structure of a traditional nuclear family.

In terms of the role of social support during reproductive cancer care, sexuality, gender and their intersections often provided unique context to sexual minority women's experiences. As previously discussed, the majority of the participants I spoke with were in relationships with female partners during their cancer care and remained with these same partners following treatment, as well as at the time of our interview. They described the importance of having health care providers acknowledge and respect these relationships, while also navigating their legal rights as same-sex couples.

In addition to social supports in the form of relationships, one participant also spoke of a lesbian-specific support group and the importance of this resource for her as a lesbian woman experiencing breast cancer. Choosing a lesbian-specific group was a conscious choice for her, and she described her discomfort within a non-lesbian specific group. Gender, sexuality, reproduction and their intersections influenced the meaning of the support group for the survivor, as she spoke of the isolation created when heterosexual women with traditional families dominated conversations within the non-lesbian specific group. This choice of seeking out social

support groups that are denoted as inclusive spaces for sexual minority women demonstrates a unique component of reproductive cancer care for sexual minority women.

Finally, in terms of interactions with health care providers, another unique way that sexual minority women's experience with cancer was shaped by elements of their sexuality was in regards to their self-advocacy during care. Several of the participants discussed their willingness and potential to have to advocate for equal care if confronted with heterosexism or biphobia from their providers. The recognition and contemplation of these decisions shines an important spotlight on how sexual orientation may still influence care or sexual minority women's expectations of care. Although the majority of participants had positive interactions with their nurses and physicians in relation to their sexual orientation, they still recognized the potential for them to be required to advocate for their care if confronted with heterosexism or biphobia.

#### Negative influences.

Within my findings, and prevalent within existing literature, there are ways that gender, sexuality, and reproduction negatively affect and create barriers for sexual minority women, ultimately influencing their cancer journey in a detrimental way. These barriers created can influence the care women receive and the accessibility to certain resources, both in terms of preventative screening and follow up treatment, which ultimately can be detrimental to sexual minority women's health. The ways that gender, sexuality and reproduction created barriers appeared primarily in regards to the research questions of the role of social support, interactions with health care providers, health care environments, and briefly within the meaning of the reproductive cancer.

The one example that was evident within the discussion of the meaning of reproductive cancer was, as previously discussed, one participant's discussion of fertility problems with her physician and how this discussion may have been more in depth had she identified as a heterosexual woman. This barrier to adequate information or even counseling on the potential loss of fertility could be especially detrimental for sexual minority women who may desire to conceive children of their own. Also, in regards to social support, some of the participants described the negative reactions or lack of support from family as a result of their sexual orientation and thus had to navigate the journey with limited support or support from other resources. As several of the participants also did not believe that nurses or physicians were appropriate resources to discuss emotional wellbeing or seek support, it may leave sexual minority women to feel increasingly isolated and vulnerable. These additional barriers influenced by sexuality shaped the reproductive cancer experience for the sexual minority women in this study.

Some of the most influential barriers that were shaped by gender and sexuality were present in the discussions of interactions with health care providers during cancer care. As previously discussed, some participants experienced overt heterosexism from their providers, which created obstacles that would not otherwise have been present. Participants also were required to individually decide whether or not disclosure of their sexuality would be safe or relevant to their health care providers. As no provider inquired about sexual orientation for any of the participants, all sexual minority women were assumed heterosexual until otherwise disputed and they were required to navigate the decision to disclose on their own. As a result of

providers assuming a woman's sexuality as heterosexual, opportunities for discussions on social support, adequate resources, and preferences for cancer treatment can be missed.

Finally, barriers influenced by gender and sexuality also occurred within health care environments and represented some larger system level and policy issues. Although participants generally felt that the health care environments where they sought care were inclusive to them as lesbian and bisexual women, this may have been more reflective of a lack of discriminatory practices or homophobia rather than the presence of LGBTQ resources, literature or health care materials. Accessibility issues directly in reference to financial costs associated with travel to clinics and expenses of cancer treatment also presented ways that gender and sexuality influenced barriers, specifically for bisexual women who often have lower income and less social support. Furthermore, some of the participants spoke of receiving the wrong information regarding required frequency of PAP tests as a sexual minority woman. Inaccurate policies in place or lack of nursing and medical education on cancer screening for lesbian and bisexual women could place them at greater risk of missing early cervical cancer detection.

#### Summary.

By answering my research questions, which I originally proposed at the beginning of my thesis, I have demonstrated how my research findings have contributed to existing studies in the field of sexual minority women's health and reproductive cancers, while also highlighting areas that were unique to my study. The findings yielded from research interviews with my seven participants have addressed areas such as the meaning of reproductive cancer for sexual minority women, the impact of social support, barriers during cancer care interactions with HCPs, and environmental barriers within the health care environment. Across all four research questions

were also ways in which gender, sexuality, and reproduction provided meaning, either positively or negatively, to the experience of reproductive cancer for the participants. Although this study's findings may not be generalizable to all sexual minority women with reproductive cancer, it lends important insight into some of the barriers sexual minority women may face during their cancer journey and also the ways in which these barriers are challenged.

# Limitations

Although the findings from this thesis lend to the direction of future practice guidelines and research for nurses, it is not without some limitations. The small sample size of sexual minority reproductive cancer survivors predominantly from the Greater Toronto Area makes it difficult to classify these findings as transferable, as recruitment was not completed until data saturation was achieved. The diversity of this sample was also limited due to the small sample size, with four of the six participants being Caucasian and only one participant identifying as bisexual. The majority of participants also had experienced breast cancer, with only two participants having experienced gynecologic cancer. However, the findings gathered from the interviews with these women do provide insight to some of the concerns that may be expressed by other survivors and leave opportunity for further research on reproductive cancers beyond only breast cancer.

Another limitation was in regards to the challenges of recruiting Registered Nurses and other health care providers who had experience working with LB women with reproductive cancers in this study. Although I did recruit one RN, there was a notable lack of response to my extensive recruitment efforts for providers. This was surprising to me, having conducted this study in a large city with a variety of LGBTQ resources and anticipating that five HCPs would

participate. There is recent literature that suggests that despite increased visibility of LGBTQ health in North America, nurses and physicians are often still not aware that their patients may identify as members of LGBTQ communities (Abdessamad et al., 2013; Austin, 2013; Beagan et al, 2012). Upon reflection, recruiting providers with specific experience caring for LB women with reproductive cancer created even more challenges. It was unfortunate that a greater number of RNs did not participate, since their narratives could have contributed to a greater understanding of LB women's interactions with providers at various points in the system.

Nevertheless, the insights offered by one Registered Nurse were still valuable, but at the same time do not represent all nursing perspectives on providing care to sexual minority women with reproductive cancers. It must also be noted that this Registered Nurse did not work in oncology, nor was she certified in oncology nursing. However, with the growing number of hospital admissions in Canada and nursing staff shortages, more and more oncology patients are being treated on a variety of different units by a variety of different nurses. Therefore, the insights offered in this thesis from an intensive care unit Registered Nurse still have implications for nurses who are not specialized in oncology, and who may work in a variety of hospital and public health positions. Being aware of best practice for sexual minority women with reproductive cancers becomes important not just for oncology nurses, but nurses throughout health care institutions and communities. Furthermore, although the survivors who also identified as providers helped to provide some additional insight, another limitation was that their provider roles did not involve working with sexual minority women with reproductive cancers, and therefore cannot provide context to this area specifically.

Another study limitation was the unintentional exclusion of a demographic question, either for survivors or providers, about highest level of education completed. For survivors, this lack of information limits the analysis contributing to how education affects, for example, women's experience living with cancer, access to resources, or how it may impact their socioeconomic status. However, for providers, the demographic form did ask about professional designation. For nurses and other regulated health professionals, this question could offer an indirect measure of education, since for example, Registered Nurses in Ontario require a completed college diploma or university degree to practice. Yet, professional designation would not necessarily provide this information, for example, for PSWs who have a variety of educational background. Upon reflection, this was especially a limitation for the survivors who also identified as providers, as there was no question to capture their professional designation on the survivor demographic form and I did not offer them both forms to complete.

Finally, as previously stated within my methodology section, I did not include questions within my interview guides relating to fertility or problems with conception following reproductive cancer for either the sexual minority women or the Registered Nurse. This omission of fertility related questions also raises an important flag in terms of my own perceptions of sexual minority women and reproduction. Although I may not have been aware of it at the time, perhaps reproduction and fertility questions were unintentionally overlooked in my interview guides due to my own assumptions regarding LB women's indifference to reproduce. This was especially surprising to me as a lesbian woman who wants to have children of my own, and demonstrates that perhaps my own perceptions are sometimes influenced by prevalent societal stereotypes and assumptions regarding sexual minority women and reproduction. Because a

similar question was not included in my interview guide for providers, asking the Registered Nurse questions pertaining to sexual minority women's experiences with fertility issues would have also been beneficial to uncover ways in which she approaches this in practice. She may have had additional insight into addressing these issues and conversations with her patients who identify as lesbian or bisexual.

# **Directions for Future Nursing Research and Education**

The goal of my Master's thesis was ultimately to illuminate aspects of interactions between sexual minority women with reproductive cancers and health care providers that may perpetuate or challenge barriers to receiving equitable care. Upon having done so with a relatively small sample, there are undoubtedly directions that must be taken for future nursing research and education to expand on these findings in order to further benefit nursing practice for sexual minority women with reproductive cancers. Prior to delving into the specifics, first and foremost my thesis highlights a need for further nursing research in the area of all reproductive cancers, not solely breast cancer, and some of the unique ways that gender, sexuality, and reproduction influence the reproductive cancer experience for lesbian and bisexual women. In addition, bisexual women remain largely absent or invisible from research on sexual minority women, and having only one bisexual identified woman present in my thesis does not uncover all potential barriers that exist for women in this community. Therefore, further nursing research should also target bisexual women, or focus solely on their experiences in regards to reproductive cancers and interactions with Registered Nurses.

Within my thesis, the unique ways that gender, sexuality, and reproduction influenced the cancer journey had important implications for future nursing research, education, and practice.

One such example involved the perception that sexual orientation disclosure could result in detrimental treatment, from both sexual minority women and the Registered Nurse who was not also a survivor. In order to change the perception that acknowledging sexual orientation is jeopardizing care, nursing education must continue to identify ways to teach new nurses that ignoring sexual orientation is actually marginalizing care for sexual minority women. There are many existing resources that provide context on how to implement this content into nursing education, including a commentary by nurse educator Peggy Chinn (2013) on how this can be done within nursing curricula. In terms of nursing practice, including questions pertaining to an individual's sexual orientation during admission to a unit or visit to a clinic is a way to create a safe and trusting space, promote cancer screening, and encourage further dialogue on necessary resources during and after one's care. This also requires change at higher levels within institutions, in order to help solidify the importance of asking these questions and recognize the barriers to care when they are not asked. Teaching nursing students the importance of sexual orientation inquiry to care can also promote advocacy upon entry to practice and influence some of these policy changes from the ground up.

Additionally, further research needs to expand on how sexual minority women interpret the reproduction piece of their reproductive cancer, through discussions on their insights of problems with fertility, inability to conceive children in the future, unwanted pregnancy, and their interpretations of family. As this was an area largely absent from the discussions with my participants, as well as the existing reproductive cancer literature, this is an area for further research to examine how intersections of sexuality and gender influence perceptions regarding reproduction following a cancer that can create difficulties conceiving or even infertility. It is

also important for nursing education to teach and advocate for open conversations on the impact of fertility problems with sexual minority women experiencing a reproductive cancer, and avoid assumptions that reproduction is not of importance for lesbian or bisexual women.

One theme that was prevalent throughout my findings and discussion chapters was the impact of social support to sexual minority women with reproductive cancer, and is also another area for nursing research to further examine. For women who may not have female partners, further research is needed to examine the benefits of a lesbian-specific support group as a means for seeking social support following a cancer diagnosis. Also, additional nursing research is also needed to explore if the strength of female partner support is as strong for all cancers as it seems to be for breast and gynecologic cancers. Further nursing research and education on social supports for sexual minority women could create a better understanding of the impact of sexuality and gender on the meaning of a reproductive cancer for lesbian and bisexual women for new nurses. This increased understanding may further solidify the importance of acknowledging and respecting same-sex partners during cancer care, as well as avoiding assumptions about an individual's sexual identity or the gender of their partner.

Another area where nursing researchers could work collaboratively with multidisciplinary researchers would be surrounding sexual minority women's thoughts on nurses and other health care providers' role in emotional support. As previously discussed, the majority of women in my study spoke of their thoughts on nurses' and physicians' roles being focused on physical care and receiving social support from other resources. This can be especially detrimental to patient care if a sexual minority woman does not have any additional social supports, and is discharged home without the necessary support or resources. Further nursing

research, in collaboration with researchers from other disciplines, is required in this area to explore if the division of physical and emotional/spiritual wellbeing is a common perception for lesbian and bisexual patients based on some of the barriers shaped by gender and sexuality that they have previously encountered during care. A collaborative research effort is necessary in order to further explore how this issue could come up beyond the scope of nursing practice and how other health and service disciplines compare and contrast to patients' perspectives on nursing. Research is also need to build on how nurses can act as a source of social support for sexual minority women, or if there are opportunities to advocate for additional services outside of nursing that could prove beneficial to women.

Finally, as I described throughout my findings and discussion, there were areas in which gender, sexuality, and reproduction influenced the meaning of reproductive cancers in a negative way for sexual minority women, ultimately creating barriers to care. In an attempt to alleviate some of these barriers, further nursing education is needed in the area of reproductive cancer risks for sexual minority women. Although to date there are no exact percentages on the number of sexual minority women who have been diagnosed with a reproductive cancer, there remains a large literature base suggesting lesbian and bisexual women may be at increased risk for development of these cancers. If nurses are more aware of the ways in which sexuality and gender influence health and the increased risk factors that can make sexual minority women more vulnerable to reproductive cancers, perhaps more accurate screening guidelines and health promotion can be implemented and promoted to this population. Partnering with initiatives like the Get Screened (2013) campaign in Ontario to place LGBTQ-specific posters and pamphlets in

health care centers can also help sexual minority women to receive accurate and inclusive information from their health care providers and self-advocate for those services as well.

#### Conclusion

Although in recent years there has been an increase in research addressing the health needs of sexual minority women, there remains a gap in the area of reproductive cancers and how nurses can best provide care. In an attempt to address this gap, I have reviewed existing literature in the area of sexual minority women and reproductive cancer and subsequently conducted a qualitative study guided by a critical feminist framework. I have analyzed my findings from interviews with seven participants using conventional content analysis and organized these findings within four themes and corresponding subthemes. I concluded my thesis with a discussion on how my research questions were addressed, the ways in which gender, sexuality, and reproduction shaped the cancer journey for the participants, and how my findings contributed to existing research within the realm of sexual minority women's health and reproductive cancers. It is my hope that this Master's thesis will lend itself to future nursing research, education, and practice for sexual minority women with reproductive cancer, while also being used as an informative and helpful resource for other lesbian and bisexual women experiencing a similar journey through cancer.

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# Appendix A: Recruitment posters for participants

# Opening The Closet Door on Reproductive Cancer Care for Lesbian and Bisexual Women

# ARE YOU A REPRODUCTIVE CANCER SURVIVOR AND SELF-IDENTIFY AS A LESBIAN OR BISEXUAL WOMAN?



I am a Master of Science in Nursing student at York University and am completing a Master's thesis exploring aspects of cancer care interactions between lesbian and/or bisexual (LB) women and health care providers (HCPs) that may enable or challenge barriers to care.

## I am seeking women from Ontario who:

- Self-identify as lesbian or bisexual (and/or women who have had an emotional or sexual relationship with women),
  - Are 18 years or older, and
- Have a history of any reproductive cancer (e.g. breast, ovarian, cervical, etc.) in the past 10 years and had interactions with HCPs during cancer care

to participate in an individual audio-recorded interview of approximately **60-90 minutes** to discuss insights and experiences during their cancer care interactions. All participants will receive an honorarium of **\$20.00** for participation, and all information provided will remain **confidential**, with all documents anonymized.

For more information or to contact regarding participation, please feel free to email or phone me at:

Laura BN RN, MScN Student lbcancercare@gmail.com facebook.com/lbcancercaretoronto 647 236 4960

# Opening The Closet Door on Reproductive Cancer Care for Lesbian and Bisexual Women

# HAVE YOU HAD CANCER CARE INTERACTIONS WITH LESBIAN OR BISEXUAL WOMEN DURING YOUR ROLE AS A HEALTH CARE PROVIDER?



I am a Master of Science in Nursing student at York University and am completing a Master's thesis exploring aspects of cancer care interactions between lesbian and/or bisexual (LB) women and health care providers (HCPs) that may enable or challenge barriers to care.

# I am seeking HCPs in Ontario who:

- Have experience working in any HCP role including, but not limited to: nurses, social workers, physicians, etc.
  - Have experience interacting with either a lesbian or bisexual woman with reproductive cancer (e.g. breast, ovarian, cervical, etc.) during their role as a HCP

to participate in an individual interview of approximately **60-90 minutes** to discuss insights and experiences during cancer care interactions with LB women. All participants will receive an honorarium of **\$20.00** for participation, and all information provided will remain **confidential**, with all documents anonymized.

For more information or to contact regarding participation please feel free to email or phone me at:

Laura BN RN, MScN Student lbcancercare@gmail.com facebook.com/lbcancercaretoronto 647 236 4960

# Appendix B: Interview guide for cancer survivors

This study is looking at aspects of cancer care interactions between LB women and HCPs that may enable or challenge barriers to care. In this interview, I am interested in hearing about your experiences during cancer care interactions with HCPs and what elements may have advanced or hindered your care. Your insight is greatly appreciated.

- 1. Can you start by telling me a bit about your cancer experience and what this was like for you?
  - a. What diagnosis did you receive?
  - b. How long ago was this?
  - c. What kind of treatment did you require during your cancer care?
  - d. Did you have a partner at the time? Were they present during your cancer treatment?
- 2. What was your cancer experience like for you emotionally? What was your emotional wellbeing like during that time?
  - a. Where did you turn to for support and how did you locate it?
  - b. Was it formal (support groups) or informal (friends and family) support?
  - c. Were they LGBTQ specific or general and what did you take away from these groups?
  - d. Did anything talked about in these groups impact your expectations or interactions with health care providers?
- 3. Can you tell me a bit about some of the interactions you had with HCPs during your cancer care?
  - a. What kinds of HCPs (e.g. staff nurses, doctors, social workers, etc.) did you interact with during your care and how often did these occur?
  - b. How did your sexual orientation come up? Did you disclose or HCPs inquire?
  - c. Were there times or situations in which you found it more important to disclose your sexual orientation? Times you found it less important?
  - d. Are you comfortable being "out" to friends and family?
- 4. If you disclosed your sexual orientation to certain HCPs, did you ever feel that you were treated different by these professionals after doing so? Was it in a positive or negative way?
  - a. If you did not disclose, did you ever fear it would change the way you would be treated by HCPs?
- 5. Were there certain HCPs that you felt you could open up more with than others (either regarding sexual orientation or in general)? Why or why not? (E.g. increased interaction with these individuals, they used more inclusive language, etc)

- 6. What does "good" or "best" cancer care look like or mean to you? In your opinion, does "best" care include your HCPs knowing your sexual orientation? Why or why not?
- 7. Were there things within the health care environment that made you uncomfortable or nervous about discussing elements related to your sexual orientation during cancer care interactions?
  - a. Were there any elements that made you feel more comfortable?
- 8. Did you feel as though anything related to your sexual orientation prevented you from receiving care either before, during, or after your interactions with HCPs? (E.g. right information given to you, inclusive to your partner, etc.)
  - a. If yes, what did these look like?
  - b. If no, did any other things hinder care during interactions?
- 9. Were there areas addressed or things done by HCPs that helped you to feel heard as a lesbian, bisexual, or queer woman? What did these look like?
- 10. Were there other concerns related to the quality of your cancer care that surfaced for you (i.e. barriers relating to your ethnicity, income, ability, etc)? What did these look like?
- 11. Do you have any suggestions on ways to improve cancer care interactions between LB women and their HCPs?
- 12. Any other issues or concerns you would like to address? Thank you for your time in speaking with me. If you would like, a copy of the finalized report will be mailed to you following completion of this thesis.

# **Appendix C: Interview guide for HCPs**

This study is looking at aspects of cancer care interactions between LB women and HCPs that may enable or challenge barriers to care. In this interview, I am interested in hearing about your experiences during cancer care interactions with lesbian or bisexual women and what barriers you perceive as affecting their care. I am also interested in hearing how you have overcome some of these barriers during your interactions and work with these women. Your insight is greatly appreciated.

- 1. Can you begin by telling me about how long you have been in your current profession designation? And how long have you been working in your current role?
  - **a.** What type of institution or organization do you currently work for?
  - **b.** In what capacity do you (or did you) care for/interact with women who have reproductive cancers?
  - **c.** How often do you (or did you) typically work with lesbian or bisexual women with cancers?
  - **d.** Did you have other previous professional roles? Were these in rural or urban areas?
- **2.A** In the context of your current or past cancer care interactions with clients, as far as you know, did you work with lesbian women? How did you know?
  - a. Did they openly disclose this information to you?
  - **b.** Was there a partner present?
  - **c.** Did you inquire?
- **2. B** In the context of your current or past cancer care interactions with clients, as far as you know, did you work with bisexual women? How did you know?
  - **a.** Did they openly disclose this information to you?
  - **b.** Was there a partner present?
  - c. Did you inquire?
- **3.** Is inquiry of an individual's sexual orientation a regular part of your institution's screening? If so, what do the questions look like?
  - a. Does sexual orientation get documented in other ways, if so, how?
  - **b.** Is this information incorporated into your practice, if so, how?
  - c. Do you think asking these questions are important to your practice?
- **4.** Can you tell me a bit about the interpersonal interactions you have had with lesbian or bisexual women with reproductive cancers?
  - **a.** Can you think of specific examples of times you were able to provide supportive care to lesbian or bisexual women?

- **b.** Can you think of specific examples of times when you felt like you weren't sure what to do or how to interact with lesbian or bisexual women you were caring for?
- **5.** Does knowing a woman's sexual orientation influence your care or interactions with them? How so or Why not?
- **6.** Do you feel that being aware of a woman's sexual orientation was useful to know during your cancer care interactions with them? Why or why not?
- 7. Do you believe there are times when knowing a woman's sexual orientation can be detrimental to cancer care? Why or why not? Are there times or situations when it is more relevant to know than others?
- **8.** What is your sense of what it's like for lesbian or bisexual women during cancer care interactions?
  - **a.** Do you perceive there to be barriers or challenges? Have you witnessed any of these barriers for women first-hand?
  - **b.** Have you been able to assist with these barriers or challenges? How so?
- **9.** Do you believe there are other barriers related to quality of cancer care that affects lesbian or bisexual women (i.e. barriers related to ethnicity, income, ability, etc.)? Have you witnessed any of these barriers?
- **10.** Have you ever received any formal training on LGBTQ health issues or caring for this population?
  - **a.** Was it during your provider education/training?
  - **b.** Was it part of your institution's mandatory training?
  - **c.** Did you seek training or education independently?
- **11.** Do you have any suggestions on elements you have used or witnessed to improve cancer care interactions between lesbian or bisexual women and other HCPs?
- **12.** Any other issues or concerns you would like to address? Thank you for your time in speaking with me. If you would like, a copy of the finalized report will be mailed to you following completion of this thesis.

# Appendix D: Demographic questionnaire for cancer survivors

This is a brief questionnaire with questions focusing on your background. This information is anonymous, and you may skip any question.

Please place an "X" to mark your answer(s) to multiple-choice questions.

1.	V	What is your current age in years?												
2.	Please state how you would best describe your racial, ethnic, or cultural identity:													
3.	V	Which option best des	cribe	es you	r sexual o	rientation	1 (	(Check all the	ha	t app	ly)?			
		Heterosexual Queer Pansexual		Bises Ques Unsu	tioning			Gay Two-Spirit Other	ed			Lesb Asex	ual	
4.	Wł	hich option best desci	ribes	your g	gender ide	entity (Ch	e	ck all that a	pp	ly)?				
		Female Two-Spirited			r			Genderque		•		Tran	S	
5.	Wł	hat is your current rel	ation	iship s	tatus (Ch	eck all tha	at	apply)?						
		Single Living with partner Married Divorced			Commo Separate	n law ed		e)	(		Unio		lusiv	e)
6.	Wł	Which best describes your total household income before taxes?												
		Prefer not to answer \$30,000 - \$50,000					0					\$30,00 an \$10		)
7.	How long ago did you receive your initial cancer diagnosis from a health care provider?													
		Less than 6 months 3 – 5 years											years	
8.		nich category or categot apply)?	gorie	s of re	productiv	e cancer(s	s)	) did you red	cei	ive a	diagr	osis c	of (Cl	neck all
			Cervi Other			□ Uteri	in	ne 🗆	(	Ovari	an		□ V	aginal

# Appendix E: Demographic questionnaire for HCPs

This is a brief questionnaire with questions focusing on your background. This information is anonymous, and you may skip any question.

Please place an "X" to mark your answer(s) to multiple-choice questions.

V	Which option best	describ	es your sexual orio	entation	(Check all that ap	ply)?	
	Heterosexual		Bisexual		Gay		Lesbian
	Queer Pansexual		Questioning Unsure		Two-Spirited Other		Asexual
Wł	nich option best de	scribes	your gender iden	tity (Ch	eck all that apply)	?	
					Genderqueer		
	Third sex Other				Transman		Transwom
	w long have you b		ional designation( orking in your curr		th care role?		
Ho	w long have you b	een wo	orking in your curr	rent heal			
— Но	w long have you b	oeen wo	orking in your curr	rent head	$\Box$ 6 – 10 ye		
— Но	w long have you b	oeen wo	orking in your curr	rent head	$\Box$ 6 – 10 ye		ears
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Ho	w long have you be Less than 1 year 11 – 15 years es your place of energy yes, there are many	nployn	orking in your curr  1 - 5 year 16 - 20 year ent offer specialized	rent heads sears zed serv	☐ 6 – 10 ye. ☐ More that ices for LGBTQ communities	n 20 ye	
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Ho  Do  .	w long have you be Less than 1 year 11 – 15 years es your place of er Yes, there are mayes, there are so No, there are little	mployn any spe me spec	orking in your curr  1 - 5 year 16 - 20 year ent offer specialized	rent heads sears zed serv LGBTQ	☐ 6 – 10 ye. ☐ More that tices for LGBTQ of communities communities	n 20 ye	
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Ho  Do  .	w long have you be Less than 1 year 11 – 15 years  es your place of er Yes, there are may Yes, there are little Unsure Other: you have specific	mployn any spe me spece or no	orking in your curr  1 - 5 year 16 - 20 year services for I cific services for I LGBTQ specific	rent head sears zed serv LGBTQ Services	☐ 6 – 10 ye. ☐ More than lices for LGBTQ of communities communities	n 20 ye	unities?
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# **Appendix F: Consent form for cancer survivors**

#### Date:

**Study Name**: Opening The Closet Door on Reproductive Cancer Care for Lesbian and Bisexual Women: Barriers During Health Care Provider Interactions

**Researchers**: I understand that this research project is a Master's thesis undertaken by Laura Legere, BN RN, MScN student and supervised by Dr. Judith MacDonnell, School of Nursing, York University.

**Purpose of the Research:** I understand that the purpose of this Master's thesis is to address aspects of interpersonal interactions between health care providers (HCPs) and lesbian or bisexual women with reproductive cancers that perpetuate or challenge barriers to receiving care. I understand that the goal in exploring the insights of both lesbian and bisexual (LB) women with reproductive cancers and the HCPs who work with this population is to identify barriers that may occur as a result of interpersonal interactions, as well as ways in which these barriers are being challenged in order to help improve cancer care for this population.

What I Will Be Asked to Do in the Research: I understand that my participation in the study will involve taking part in an individual interview of approximately 60 - 90 minutes either over the phone or at a location mutually determined by the researcher and myself. I will be asked to respond to open-ended questions regarding my insight of barriers that may have occurred or were challenged during my cancer care interactions with HCPs. I understand that with my permission the interview will be audio-recorded and transcribed, and that if I do not wish to be audio-recorded during the interview, the researcher will take notes of the interview instead. I understand that no names or identifying information will be included in the final transcripts and that a code number will identify these documents, making my participation in the study confidential. I understand that I will be asked to complete an anonymous demographic questionnaire at the end of the interview and that I will receive a \$20 honorarium for my participation in this study.

Risks and Discomforts: I understand that although the researchers do not expect any direct risks from participation in the research, there is the risk that recounting cancer care interactions with HCPs may be difficult. I understand that recounting any past experiences with discrimination, homophobia, or biphobia during cancer care interactions may be uncomfortable. In order to decrease these risks, I understand that I may choose to forgo any question I do not feel comfortable discussing. I also understand that I may choose to withdraw from the study at any time, which will not affect my relationship with the Master's student, their thesis supervisor, or York University.

Benefits of the Research and Benefits to You: I understand that although there are no direct benefits to me, the findings from this research may contribute to improvement of cancer care interactions between LB women experiencing reproductive cancers and HCPs. The dialogue created from the interviews may help to identify current barriers in care resulting from the interactions between HCPs and lesbian or bisexual women, potentially fostering further research in this area. This research may also help to yield ways in which HCPs are challenging barriers during cancer care interactions, which through dissemination of findings may help to improve care for LB women.

**Voluntary Participation**: I understand that my participation in this study is completely voluntary and I may choose to stop participating at any time. I understand that I can choose to skip any question or stop answering questions at any time.

Withdrawal from the Study: I understand that I can stop participating in the study at any time, for any reason, if I so decide. I understand that if I decide to stop participating or skip any questions, I will still be eligible to receive the honorarium. I understand that my decision to stop participating, or to refuse to answer particular questions, will not affect my relationship with the Master's student, their thesis supervisor, or York University. I also understand that in the event I withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

Confidentiality: I understand that all names, personal identifying information, and names of health care institutions that are inadvertently mentioned during the interview will be deleted or transformed during transcription in order to ensure confidentiality. I understand that the digital audio recording of the interview and the transcribed recording will be identified by a code number only, maintaining confidentiality. I understand that I have the right to review the interview transcript and to ask for the removal or change of any personal information and or any other information. I understand that all research data including digital recordings and corresponding transcripts will be stored on a password protected, encrypted USB. I understand that hard copies of the interview transcript, consent forms, and demographic questionnaires will be stored in a locked cabinet in the Researcher's home office for 2 years. All audio recordings of interviews will be destroyed at the conclusion of the study. Electronic copies and hard copies of transcripts will be destroyed according to York policy. 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 Laura Legere either at 647-236-4960 or llegere@yorku.ca or Dr. Judith MacDonnell at 416-736-2100 Ext. 77515 or jmacdonn@yorku.ca. This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Faculty of Graduate Studies 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 Ms. Alison Collins-Mrakas, Senior Manager & Policy Advisor, Office of Research Ethics, York Research Tower, York University (telephone 416-736-5914 or e-mail <a href="mailto:acollins@yorku.ca">acollins@yorku.ca</a>) or the Graduate Program in Nursing office at 416-736-2100 Ext. 20362.

### **Consent for Audio-recording**

I understand that the interview will be digitally audio-recorded to facilitate the collection of information with the understanding that all information that I provide will be held in confidence and I will not be identified in the summary report or publications. I understand that if I do not want this interview to be audio-recorded that I am still eligible to participate in the study. I understand that I may withdraw this consent at any time.

Signature	<b>Date</b>	
Participant		-
Signature	Date	
Researcher		

Legal Rights and Signatures:		
for Lesbian and Bisexual Women c	articipate in Opening The Closet Door on Reproductive Cancer Canducted by Laura Legere and supervised by Dr. Judith MacDonne project and wish to participate. I am not waiving any of my legal nature below indicates my consent.	
Signature Participant	<u>Date</u>	
Signature Researcher	<u>Date</u>	

# **Appendix G: Consent form for HCPs**

#### Date:

**Study Name**: Opening The Closet Door on Reproductive Cancer Care for Lesbian and Bisexual Women: Barriers During Health Care Providers Interactions

**Researchers**: I understand that this research project is a Master's thesis undertaken by Laura Legere, BN RN, MScN student and supervised by Dr. Judith MacDonnell, School of Nursing, York University.

**Purpose of the Research:** I understand that the purpose of this Master's thesis is to address aspects of interpersonal interactions between health care providers (HCPs) and lesbian or bisexual women with reproductive cancers that perpetuate or challenge barriers to receiving care. I understand that the goal in exploring the insights of both lesbian and bisexual (LB) women with reproductive cancers and the HCPs who work with this population is to identify barriers that may occur as a result of interpersonal interactions, as well as ways in which these barriers are being challenged in order to help improve cancer care for this population.

What I Will Be Asked to Do in the Research: I understand that my participation in the study will involve taking part in an individual interview of approximately 60 - 90 minutes either over the phone or at a location mutually determined by the researcher and myself. I will be asked to respond to open-ended questions regarding my insight of barriers that occur or are perpetuated during interpersonal interactions with LB woman as a HCP. I understand that with my permission the interview will be audio-recorded and transcribed, and that if I do not wish to be audio-recorded during the interview, the researcher will take notes of the interview instead. I understand that no names or identifying information will be included in the final transcripts and that a code number will identify these documents, making my participation in the study confidential. I understand that I will be asked to complete an anonymous demographic questionnaire at the end of the interview and that I will receive a \$20 honorarium for my participation in this study.

**Risks and Discomforts**: I understand that although the researchers do not expect any direct risks from participation in the research, there is the risk that recounting cancer care interactions with LB woman may be difficult. I understand that recounting individuals' experiences with homophobia or biphobia expressed to me may be uncomfortable. In order to decrease these risks, I understand that I may choose to forgo any question I do not feel comfortable discussing. I also understand that I may choose to withdraw from the study at any time, which will not affect my relationship with the Master's student, their thesis supervisor, or York University.

Benefits of the Research and Benefits to You: I understand that although there are no direct benefits to me, the findings from this research may contribute to improvement of cancer care interactions between LB women experiencing reproductive cancers and HCPs. The dialogue created from the interviews may help to identify current barriers in care resulting from the interactions between HCPs and LB women, potentially fostering further research in this area. This research may also help to yield ways in which HCPs are challenging barriers during cancer care interactions, which through dissemination of findings may help to improve care for LB women.

**Voluntary Participation**: I understand that my participation in this study is completely voluntary and I may choose to stop participating at any time. I understand that I can choose to skip any question or stop answering questions at any time.

**Withdrawal from the Study**: I understand that I can stop participating in the study at any time, for any reason, if I so decide. I understand that if I decide to stop participating or skip any questions, I will still be eligible to receive the honorarium. I understand that my decision to stop participating, or to refuse to answer particular questions, will not affect my relationship with the Master's student, their thesis supervisor, or York University. I also understand that in the event I withdraw from the study, all associated data collected will be immediately destroyed wherever possible.

Confidentiality: I understand that all names, personal identifying information, and names of health care institutions that are inadvertently mentioned during the interview will be deleted or transformed during transcription in order to ensure confidentiality. I understand that the digital audio recording of the interview and the transcribed recording will be identified by a code number only, maintaining confidentiality. I understand that I have the right to review the interview transcript and to ask for the removal or change of any personal information and or any other information. I understand that all research data including digital recordings and corresponding transcripts will be stored on a password protected, encrypted USB. I understand that hard copies of the interview transcript, consent forms, and demographic questionnaires will be stored in a locked cabinet in the Researcher's home office for 2 years. All audio recordings of interviews will be destroyed at the conclusion of the study. Electronic copies and hard copies of transcripts will be destroyed according to York policy. 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 Laura Legere either at 647-236-4960 or llegere@yorku.ca or Dr. Judith MacDonnell at 416-736-2100 Ext. 77515 or jmacdonn@yorku.ca. This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Faculty of Graduate Studies 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 Ms. Alison Collins-Mrakas, Senior Manager & Policy Advisor, Office of Research Ethics, York Research Tower, York University (telephone 416-736-5914 or e-mail <a href="mailto:acollins@yorku.ca">acollins@yorku.ca</a>) or the Graduate Program in Nursing office at 416-736-2100 Ext. 20362.

### **Consent for Audio-recording**

I understand that the interview will be digitally audio-recorded to facilitate the collection of information with the understanding that all information that I provide will be held in confidence and I will not be identified in the summary report or publications. I understand that if I do not want this interview to be audio-recorded that I am still eligible to participate in the study. I understand that I may withdraw this consent at any time.

<b>Signature</b>	<u> </u>	
Participant		
-		
<b>Signature</b>	<u>Date</u>	
Researcher		

Legal Rights and Signatures:	
for Lesbian and Bisexual Women cond	icipate in Opening The Closet Door on Reproductive Cancer Calucted by Laura Legere and supervised by Dr. Judith MacDonne oject and wish to participate. I am not waiving any of my legal ure below indicates my consent.
Signature Participant	<u>Date</u>
Signature Researcher	<u>Date</u>

# Appendix H: LGBTQ-inclusive services and cancer resource list

## **Access Alliance Multicultural Health and Community Services**

A primary health care centre with community health programs for immigrants, refugees, as well as LGBTQ newcomers.

www.accessalliance.ca

### **Canadian Cancer Society**

A Canada-wide society with locations across the province, the Canadian Cancer Society website provides information on a variety of cancer diagnoses as well as links to support services and programs.

www.cancer.ca

### **Rainbow Health Ontario (RHO)**

A province-wide program founded by Sherbourne Health Centre in Toronto and the Rainbow Health Network. The RHO program helps to improve the health and wellbeing of members of LGBTQ communities across Ontario.

www.rainbowhealthontario.ca

## **Sherbourne Health Centre (SHC)**

A primary health care centre with a range of LGBTQ-specific health services. SHC also offers programs and community wellness initiatives committed to reducing barriers to health for LGBTQ populations.

www.sherbourne.on.ca

#### The 519

An LGBTQ inclusive community centre in Toronto's Gay Village that supports a variety of programs and services which promote healthy and welcoming spaces for LGBTQ communities.

www.the519.org

# Wellspring

A community organization of men and women living with cancer, Wellspring has a variety of programs and services throughout Ontario to help provide support to individuals living with cancer, including gay and lesbian specific support groups. www.wellspring.ca

### Women's Health in Women's Hands

A community health centre located in Toronto specializing in providing health and wellness to women of diverse cultural backgrounds. There are programs and services for women's primary health care, clinical services, and counseling.

www.whiwh.com