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# Coming Out in Primary Healthcare: An Empirical Investigation of a Model of Predictors and Health Outcomes of Lesbian Disclosure

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Coming Out in Primary Healthcare:  
An Empirical Investigation of a Model of Predictors  
and Health Outcomes of Lesbian Disclosure

by

Melissa St. Pierre

A Dissertation  
Submitted to the Faculty of Graduate Studies  
through the Department of Psychology  
in Partial Fulfillment of the Requirements for  
the Degree of Doctor of Philosophy at the  
University of Windsor

Windsor, Ontario, Canada

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29 April 2013

## **AUTHOR'S DECLARATION OF ORIGINALITY**

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## ABSTRACT

Researchers and health practitioners have emphasized the importance of disclosure of sexual orientation by lesbians to their healthcare providers (HCPs). Commonly known as ‘coming out’, during interactions with HCPs this behaviour has been linked to the receipt of appropriate and tailored care by lesbians, an increase in regular preventative healthcare seeking, and a more authentic relationship between patients and their physicians. The current study employed a mixed-methods design to provide a comprehensive understanding of what facilitates disclosure, and subsequently, what happens once lesbians come out to their HCPs. Of particular interest were patient (e.g., outness and other minority stressors such as internalized homophobia), HCP (e.g., LGBT-friendly), healthcare environment (e.g., a safe waiting room), and patient-provider relationship (e.g., women’s comfort with their HCPs) facilitators. Preventative health behaviours (e.g., cervical screening) were the outcomes examined. Over 400 lesbian women from across Canada and the USA contributed to the analyses, and allowed for the consideration of cross-cultural similarities and differences. Path analyses were conducted to test models of disclosure and healthcare seeking separately for each sample. Additionally, women’s narrative responses to the open-ended questions included as part of the study (i.e., their descriptions of what would influence their willingness to disclose to their HCPs and for those who had disclosed, their HCPs’ reactions to this information) supplemented the quantitative data by providing a closer look at context. For example, the contexts of when coming out is perceived by lesbian patients as relevant, and the contexts of unsafe and safe care environments. The current study’s findings suggested that a variety of factors influenced disclosure. Having an LGBT-friendly provider played a significant role in both countries’ models and had a stronger influence on disclosure than did patient characteristics. Though most processes in the models were similar for the Canadian and American samples, some unique pathways were also present and are explained in terms of differences in socio-political climate. Implications from this study are clear: HCPs who are LGBT-friendly have the potential to reduce the impact of minority stressors, encourage disclosure, and support an overall positive care experience for their lesbian patients.

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# CHAPTER I

## INTRODUCTION

The publication of the findings from the eminent National Lesbian Health Care Survey (Bradford, Ryan, & Rothblum, 1993; Ryan & Bradford, 1988) and the release of the Institute of Medicine (IOM, 1999) report on lesbian health spawned hundreds of publications on this topic. Lesbian health research has expanded from examinations of disease disparities between heterosexual and lesbian women, to a broader appreciation of the totality of lesbian health, including sexual minority women's health and healthcare needs, and the barriers we encounter when we attempt to secure care. Disclosure of sexual orientation by lesbians, which involves revealing one's lesbian identity to another person (herein referred to simply as disclosure, coming out, or outness), is one such barrier.

The decision to disclose is unique to lesbian women and other sexual minorities; that is, our sexual orientation is often presumed to be heterosexual unless we state otherwise. However, coming out to others is not always easy and often involves a stressful decision-making process, which is influenced by mainstream society's potentially negative views toward sexual minorities (Hitchcock & Wilson, 1992). Despite the complexities surrounding coming out, disclosure by lesbian women to their healthcare providers has been regarded by researchers and practitioners alike as critical to obtaining appropriate healthcare (Johnson & Guenther, 1987). For these reasons, it is clear that disclosure is an important focus for research on lesbian health. However, relatively few studies have been dedicated to more fully understanding disclosure in this context. The current study aims to fill this gap.

## CHAPTER II

### REVIEW OF THE LITERATURE

#### Foundational Work on Lesbian Health

Foundational work on lesbian health must first be mentioned in order to situate the current state of research in the area. The National Lesbian Health Care Survey (NLHCS; Bradford et al., 1993; Ryan & Bradford, 1988) was one of the first comprehensive, national, and large-sized convenience samples of lesbian women recruited in the mid-1980s for what is probably the most widely known and cited study on lesbian health. Lesbian women ( $N = 1,925$ ) from across the United States (US) participated. Few studies published since have been as extensive as the NLHCS. The NLHCS globally assessed lesbians' mental and physical health. Specifically, survey questions targeted a myriad of health-related constructs, including depression, anxiety, and general mental health, suicide, physical and sexual abuse, anti-gay discrimination, outness, use of medical and counseling services, general physical and gynecological health, AIDS, etc. Ryan and Bradford first provided an overview of the NLHCS findings in 1988. They reported that a significant proportion of lesbians, one out of 10, did not seek help for general health problems. Reasons for this included language barriers, negative past experiences and lack of trust with healthcare providers (HCPs), and financial reasons. Regarding gynecological problems, an even higher percentage of women reported not seeking treatment or resorting to treating themselves (over 20%); the reasons given were similar to the ones indicated above with the addition of feeling embarrassed, afraid, or uncomfortable. The authors concluded that lesbians experience

significant barriers to seeking medical attention due to the challenges associated with being a minority in a society predominantly built for and by heterosexual people.

Bradford et al. (1993) discussed the mental health findings from the NLHCS by comparing their results to US census data gathered on women. They positioned lesbians as similar to heterosexual women on rates of depression, suicide (although the impact of age was mentioned, with the possibility that more lesbian versus heterosexual girls attempt suicide), sexual abuse, and eating disorders. The authors suggested that lesbians are different from heterosexual women in their greater use of alcohol and drugs, higher frequency of use of counseling services, and experiences of minority stress (e.g., lesbians in their sample were often victims of verbal attacks, anti-gay discrimination resulting in job loss, etc.). Of note, greater outness was a protective factor for lesbians: those who had disclosed their sexual orientation more globally were more likely to seek and receive help from informal (e.g., friends) and formal (e.g., counselors) supports.

Approximately 10 years after the publication of the first set of findings from the NLHCS, the Institute of Medicine (IOM; 1999) released a report on lesbian health. The report included an overview of the empirical work on the topic, a critique of its methodological flaws, and suggested recommendations for advancing the field. The IOM offered a multifaceted definition of sexual orientation, which I have adopted in the current study. This definition included behavioural (e.g., who a person has sexual contact with), affective (e.g., desire), and personal identity components. The report discussed a number of problems, such as operational and measurement issues (a lack of standardized measurement tools more generally, but especially in relation to sexual orientation); the use of small, convenience samples, which included primarily White, middle class, and

well educated lesbians, limiting the generalizability of the results; the absence of heterosexual comparison groups (a major concern with the NLHCS); the lack of longitudinal data to capture lesbian health over time; and issues of trust as they relate to participants' willingness to disclose. Key recommendations included a call for additional work on lesbian health more generally, and research examining the intersections of sexual orientation, gender, race, and class on lesbian health more specifically. Perhaps in response to these recommendations, several population-based surveys now include questions on sexual orientation. Population-based surveys have addressed many, but not all, of the methodological limitations highlighted in the IOM report. These studies are discussed next.

### **Differences Between Heterosexual and Lesbian Women on Health and Healthcare**

We now have access to a limited number of studies using probability sampling techniques that illuminate the health and healthcare differences between heterosexual and lesbian women. Collectively, these studies suggest that lesbian women, when compared to their heterosexual counterparts, are disadvantaged on certain aspects of health and healthcare (Cochran, Keenan, Schober, & Mays, 2000; Cochran, Sullivan, & Mays, 2003; Drabble, Midanik, & Trocki, 2005; Heck, Sell, & Sheinfeld Gorin, 2006; Sandfort, Bakker, Schellevis, & Vanwesenbeeck, 2006; Tjepkema, 2008; Valanis, Bowen, Bassford, Whitlock, Charney, & Carter, 2000). Minority Stress theory (DiPlacido, 1998) offers some perspective to help make sense of these disparities.

Minority Stress theory, as articulated by DiPlacido (1998), posits that holding a minority status, in this case, being a lesbian woman in a society predominated by heterosexuals, adds stress that is above and beyond what is present for all people. Unlike

stress as we commonly know it (e.g., stress related to adaptation to a new situation), *minority* stress is uniquely related to holding minority status. However, holding minority status is not in and of itself a negative or stressful attribute; it is the majority society's devaluation and further, stigmatization of that particular attribute that makes it "discreditable" and "spoiled" (Goffman, 1963).

Due to the social stigma attached to lesbianism, minority stressors are often external in nature (DiPlacido, 1998). Rooted in our social environments, these include negative life events that are associated with a lesbian's minority status: heterosexism, or assumptions of heterosexuality and heteronormativity; homophobia, or negative attitudes toward sexual minority persons; discrimination based on sexual orientation; and hate crimes (DiPlacido, 1998). Some external minority stressors occur as isolated events (e.g., a hate crime), while others are chronic (e.g., heterosexism).

Compared to external minority stressors, internal minority stressors are the product of a woman's internalization of her society's devaluation of lesbians. Examples of internal stressors include: internalized homophobia, or internalized negative beliefs about lesbians; and decisions related to concealment or disclosure of one's lesbianism (DiPlacido, 1998). The hidden nature of sexual orientation means that concealment/disclosure is, for many of us, an ongoing and particularly significant internal stressor. Specifically, over the course of her lifetime, a lesbian must decide the parameters under which to reveal her sexual orientation. This is unlike the experience of heterosexual women, whose sexual orientation is usually left unchallenged due to its assumed pervasiveness and normativity (Rich, 1980). To further complicate the decision to disclose, coming out is influenced by society's views (an external stressor) of lesbians.

Due to the very real possibility of encountering external stressors in response to disclosure (e.g., heterosexism and homophobia), concealment of sexual orientation is a considerable internal stressor for lesbians because it requires, for many, the constant monitoring of details related to the self (DiPlacido, 1998).

As explained by DiPlacido (1998), lesbians experience excess stress related to their sexual minority status (i.e., minority stress). Excess stress can lead to adverse health outcomes for lesbians, explaining many of the findings that will now be reviewed on health inequities between heterosexual and sexual minority women. When trying to make sense of these disheartening conclusions, we should keep in mind Minority Stress theory and its applicability in the context of the health and healthcare disparities research.

Valanis et al. (2000) drew upon findings from the Women's Health Initiative's randomized control trial studies to examine the health and healthcare behaviours of older (aged 50-79 years) heterosexual ( $n = 90,478$ ) and sexual minority ( $n = 264$  "lifetime lesbian",  $n = 309$  "adult lesbian") women from across the US. Lesbians were more likely than heterosexual women to report having engaged in risky behaviours, including cigarette smoking and alcohol consumption. Furthermore, lesbians were less likely to have received recent preventative healthcare (e.g., Papanicolaou or Pap test and mammography). Higher rates of certain physical (e.g., breast cancer) and mental (e.g., depression) issues were also reported by lesbians.

Cochran et al. (2000) investigated alcohol use and dependency using population-based data collected in the US. Participants were classified as having at least one "same-gender sexual partner" ( $n = 194$ ) or only having "opposite-gender sexual partners" ( $n = 9,714$ ). Few differences were found between men. However, significant differences



were found between women, where women who had had sexual experiences with other women were more likely than those who had not to report greater and more frequent use of alcohol. As well, women who had sexual experiences with other women were more likely to meet diagnostic criteria for alcohol-related problems.

To investigate mental health disparities between sexual minority ( $n = 37$  each, men and women) and heterosexual men and women ( $n = 1,239$  and  $1,604$ , respectively), Cochran et al. (2003) used population-based data collected in the US. Notable differences between heterosexual and gay/bisexual men were found, including higher prevalence rates of certain mental disorders for sexual minority men (depression and panic attacks). Similarly, lesbian/bisexual women reported higher prevalence rates of generalized anxiety disorder and greater comorbidity. Sexual minority men and women were also more likely to use mental health services when compared to their heterosexual counterparts.

Drabble et al. (2005) examined alcohol consumption and alcohol-related problems among sexual minority and heterosexual respondents in a population-based data set in the United States. Findings followed the same pattern as Cochran et al. (2000). Few significant differences between men were found. In contrast, several key differences between women ( $n = 2,080$  heterosexual,  $n = 28$  lesbian) were revealed. Lesbian women were more likely to report lower abstention from alcohol. Of particular concern, lesbian women were also more likely than their heterosexual counterparts to meet diagnostic criteria for alcohol abuse/dependence.

A Dutch survey conducted by Sandfort et al. (2006) investigated whether minority sexual orientation could account for physical and mental health disparities. Of note, the

authors grouped gay and lesbian participants together. Compared to heterosexual men and women ( $n = 9,278$ ), sexual minority participants ( $n = 143$ ) had poorer overall mental and physical health (e.g., the presence of more chronic conditions). The role of sexual orientation in predicting engagement in risky behaviours, however, was less stable. Particularly, there were no differences between heterosexual and gay/lesbian participants on smoking behaviour, substance use, or obesity.

Heck et al. (2006) used population-based data collected in the US to determine whether individuals in “opposite-sex” relationships ( $n = 93,418$ ) compared to those in “same-sex” ( $n = 614$ ) relationships experienced differences in access to healthcare. Several significant differences were found between women in “same-sex” vs. “opposite-sex” relationships. Specifically, women in “same-sex” relationships were less likely to have health insurance and to have a regular source of healthcare, and were more likely to have unmet healthcare needs due to financial issues. Conversely, men in “same-sex” relationships were not negatively impacted by access to care; in fact, they fared similarly or better than men in “opposite-sex” relationships. Illustrated by this study are the complicated intersections between gender, sexual orientation, and class on healthcare access, which were obscured in Sandfort et al.’s (2006) study due to the collapsing of the small number of gay/lesbian participants.

Using Statistics Canada data, Tjepkema (2008) examined healthcare use patterns among sexual minority ( $n = 1,103$  gay, 498 bisexual men;  $n = 695$  lesbian, 833 bisexual women) and heterosexual ( $n = 72,972$ ) Canadians. Findings highlighted several key differences between these groups. Mental health diagnoses (mood and affective disorders) were more prevalent among sexual minorities. Similar to the results reported

by Heck et al. (2006), gay men were more likely to consult with a healthcare provider; the opposite was true for sexual minority women. Also akin to the findings of Heck et al., a greater proportion of sexual minority women, but not men, reported not having a regular physician. Regarding adherence to preventative healthcare standards, lesbians engaged in certain screening behaviours (mammography) at similar rates than heterosexual women, and engaged in others (Pap test) at lower rates.

Across these various studies, the best data we currently have indicate that lesbians, when compared to heterosexual women, experience inequities in some aspects of health and healthcare, at least in part due to their experiences of minority stress. First, lesbians tend to have poorer mental and physical health. Second, perhaps due to their struggles with psychological issues, lesbians seek mental health services more frequently than do heterosexual women (an alternative explanation proposed by Morgan in 1992 was that there is an overall greater acceptance of the use of mental health services within lesbian communities). Third, lesbians are less likely to seek out primary healthcare, and this includes engagement in important preventative screening behaviours. And finally, fourth, when lesbians do attempt to secure primary care for themselves, they frequently experience accessibility issues, such as lack of health insurance, or having access to a regular healthcare professional (note that while it appears that the issue of access is due to finances, Canadian research by Tjepkema (2008) suggests a more complicated picture). Not all of the findings on health disparities appear to be stable, however. Particularly, inconsistent findings have been reported on lesbians' engagement in risky behaviours, including cigarette smoking and alcohol use.

It is important to note that population-based studies in the context of lesbian health research are not without critique. As noted by the IOM (1999) report, probability sampling of lesbian women can be challenging because we represent only a fragment of the general population, thus oversampling must occur to avoid small sample sizes (note that Cochran et al., 2003 and Drabble et al., 2005 had less than 50 women in their studies) with little representation of the variability in lesbian women's experiences. Cochran et al. (2003) advised that only when studies using probability sampling techniques target larger samples of sexual minority participants will the findings in the health disparities research be more concrete. More recent studies suggest that we are moving in that direction (e.g., Heck et al., 2006; Tjepkema, 2008).

DiPlacido (1998) proposed Minority Stress theory to explain how lesbians encounter significant internal and external stressors related to their minority status, which in turn can have an impact on their overall mental and physical well-being, as seen in the population-based research reviewed earlier. However, what tends to be missing from the research on health and healthcare inequities is a discussion of how lesbian women can be resilient in the face of marginalization. DiPlacido suggests that positive factors, such as social support, which can include receiving affirmative responses from family, friends, and others to the revealing of our sexual orientation (an internal minority stressor), can buffer the negative effects of minority stress.

### **Benefits of Lesbian Disclosure**

The literature on coming out by lesbians consistently suggests that, given an affirmative response from the recipient, disclosure can be a safeguard for lesbians. Models of lesbian identity formation have long emphasized the salience of disclosure as a

pivotal developmental milestone (one of the earliest and most commonly cited models being the work of Cass in 1979). Most of these models (and there have been many; see McCarn & Fassinger, 1996 for a good overview) theorize that lesbians who have disclosed widely are more accepting of themselves and are better integrated into their communities as well as into the larger mainstream society. Indeed, the empirical research on lesbian disclosure to friends, family, and coworkers indicates that disclosure leads to health benefits, including reduced psychological discomfort and symptoms, receiving social support, and engaging in help-seeking for mental and physical health related problems (Bradford et al., 1993; Morris, Waldo, & Rothblum, 2001; Steele, Tinmouth, & Lu, 2006).

Within the context of consulting a primary healthcare provider, defined here as the professional whom a patient sees for routine healthcare (Bergeron, 1999), Johnson and Guenther (1987) have argued that disclosure of sexual orientation by lesbians is critical for two reasons. One, disclosure is thought to promote smooth sexual identity development, and two, it is a precursor to receiving healthcare that is tailored to meet lesbian patients' specific needs. The empirical research on lesbian disclosure in primary healthcare supports Johnson and Guenther's claims on the significance of this transaction (Bergeron & Senn, 2003; Brown, Hassard, Fernbach, Szabo, & Wakefield, 2003; DeHart, 2008; Diamant, Schuster, & Lever, 2000; Steele et al., 2006; White & Dull, 1998). In short, two tangible benefits of lesbian disclosure have been reported in the literature: preventative self-care, and preventative healthcare seeking (i.e., obtaining screening, such as the Pap test; consulting one's primary healthcare provider when needed).

**Preventative self-care.** Two published studies examined lesbian disclosure in primary healthcare and its potential association with a patient's engagement in preventative self-care. Using a convenience sample of 324 self-identified lesbian women living in the US, White and Dull (1998) found that lesbians who disclosed were more likely than non-disclosers to be current non-smokers. When considering the finding reported earlier that lesbians may be more inclined to smoking when compared to their heterosexual counterparts (Valanis et al., 2000), this suggests the protective effects of disclosure on this aspect of health.

A more recent study by DeHart (2008) sought to understand what factors contribute to lesbians' engagement in self and clinical breast health behaviours. A convenience sample of 173 self-identified lesbians living in the US participated. A multivariate regression analysis revealed that the perceived benefits associated with breast self-exams, self-efficacy or confidence in relation to performing this behaviour, and frequency of disclosure to healthcare providers predicted engagement in this important type of preventative self-care.

**Preventative healthcare seeking.** Only a handful of published studies have investigated lesbian disclosure in relation to preventative healthcare seeking. In addition to finding that disclosure was related to lesbians' engagement in preventative self-care (i.e., non-smoking), White and Dull (1998; sample described in greater detail above) reported that lesbians who disclosed were also more likely to seek preventative healthcare services (e.g., Pap test).

Diamant et al. (2000) also assessed lesbians' engagement in preventative healthcare screening, specifically, the Pap test and mammography, as well as what factors

contributed to their utilization rates. A large convenience sample of 6,935 self-identified lesbians from across the US contributed to the research. Findings revealed that disclosure was related to engagement in the Pap test, but not in the use of mammography. The authors speculated that lesbians may not perceive sexual orientation to be as closely linked or relevant to breast screening behaviours as it is to gynecological care. Later in the document I discuss the interesting connection found in empirical work between certain body parts and whether or not disclosure is perceived as relevant by the women patients themselves.

Bergeron and Senn (2003) recruited a convenience sample of 254 self-identified sexual minority women from Canada to participate in a study investigating the factors associated with lesbians' healthcare seeking. A path analysis revealed that disclosure by lesbians to their healthcare providers lead directly to their use of preventative healthcare screening (e.g., Pap test, clinical breast exam, and mammography).

Brown et al. (2003) surveyed a convenience sample of 384 self-identified lesbians in Australia to investigate whether they were receiving regular Pap tests, or, if not, what were the barriers they encountered in seeking this type of preventative screening. Results indicated that lesbians who were well screened (i.e., those who received a Pap test once every two years) were 3.7 times more likely to have disclosed their sexual orientation to their providers.

In a more recent study by Steele et al. (2006), a convenience sample of 387 self-identified sexual minority women recruited from Ontario investigated a variety of factors predicted to affect lesbians' use of regular healthcare (defined by the authors as the use of healthcare more often than every few years). A path analysis showed how disclosure

lead directly to healthcare use. Specifically, lesbians who disclosed to their healthcare providers, compared to those who did not, were more likely to be regular consumers of healthcare services.

In summary, the small collection of studies on lesbian disclosure in the context of supportive environments links positive health benefits with outness to others, including healthcare providers. Specifically, lesbians who disclosed to their healthcare providers tended to engage in preventative self-care behaviours. Lesbians who came out in healthcare were also more likely to engage in important screening behaviours, including the Pap test. Now that we know that disclosure in the healthcare milieu is a critical behaviour, what factors have been theorized to facilitate the coming out process for lesbians?

### **Theorizing Lesbian Disclosure in Primary Healthcare**

To better understand lesbian disclosure in the context of primary care seeking, a thorough consideration of the factors influencing the coming out process for lesbians in healthcare is needed (Fogel, 2005). To guide this discussion, Hitchcock and Wilson's (1992) Personal Risking theory is introduced and elaborated.

Grounded in interview data collected from 33 self-identified lesbians in San Francisco who were predominantly White and well-educated, Hitchcock and Wilson (1992) generated theory on lesbian disclosure in healthcare. They proposed that decisions to disclose involve an ongoing process that occurs and reoccurs over the lifespan; lesbians make decisions about where, when, with whom, and how to disclose on a daily basis. When seeking healthcare, one barrier to coming out involves fears regarding the consequences of disclosure to healthcare providers (e.g., anticipated



negative reactions, including pathologization of identity by the provider; receipt of substandard care; and refusal of care; Lehmann, Lehmann, & Kelly, 1998; Stevens, 1994; Stevens & Hall, 1988; Williams-Barnard, Mendoza, & Shippee-Rice, 2001). To manage their disclosure-related fears, lesbians engage in a social process Hitchcock and Wilson call Personal Risking. Personal Risking involves a cost-benefit analysis of the risks that are perceived to be associated with disclosure in healthcare settings. There are two phases involved in the decision to disclose process: the anticipatory phase and the interactional phase. Additionally, there are several conditions that interact with these two phases to influence whether or not lesbians decide to disclose.

**The anticipatory phase.** During the anticipatory phase, which occurs before contact has been made with the healthcare provider, the lesbian woman creates imaginative scenarios, and she engages in cognitive strategies. Creating an imaginative scenario involves visualizing how a healthcare interaction will proceed. Cognitive strategies involve the use of self-protective strategies, which are essentially behaviours she may engage in to ensure her safety. Examples of protective strategies include networking, that is, obtaining a referral for a sensitive provider from a friend, and screening or interviewing healthcare providers beforehand to tap into their attitudes toward sexual minorities.

**The interactional phase.** During the interactional phase, the lesbian woman has entered the healthcare setting. She scans the healthcare environment, staff, and the healthcare providers for clues indicative of a safe environment. The decision to disclose is based on the outcome of the anticipatory phase and the scanning process that occurs in the interactional phase. If she perceives the healthcare environment to be safe, then she

may disclose. Should she choose to disclose, the healthcare provider's response to the disclosure is closely monitored, and is then incorporated into the anticipatory phase for future contact with other providers. In other words, positive responses from the provider may affect a lesbian's willingness to disclose in future healthcare interactions; however, each interaction is a new one requiring the lesbian to re-calculate her personal risk.

**Interacting conditions.** Personal Risking theory suggests that disclosure related decisions are based on extensive, active efforts by lesbians prior to entering, as well as during contact with, the healthcare setting. Additionally, Hitchcock and Wilson (1992) describe three conditions that interact with the anticipatory and the interactional phases to encourage (or discourage) disclosure. These are: the lesbian patients' personal attributes, characteristics of the healthcare context, and patient perceptions regarding the relevancy of disclosure.

**Patient attributes.** The first patient attribute elaborated by Hitchcock and Wilson (1992) was comfort with and acceptance of one's lesbianism. The authors explained that the more comfortable a woman is with her sexual orientation, the more likely she is to come out to others around her. The second patient attribute was relationship status. Lesbian women who disclosed also tended to be in a relationship, and coming out was a way to ensure that her healthcare provider acknowledged her partner (Hitchcock & Wilson, 1992). Beliefs about vulnerability to illness was the third patient attribute. Specifically, women who believed that they were susceptible to illness sought routine contact with health professionals, and consequently were much more concerned about disclosure than those who sought irregular care.

***Healthcare context.*** The characteristics of the healthcare provider also influenced whether or not patients disclosed. Hitchcock and Wilson (1992) suggested that healthcare providers who were women, and to a lesser extent, lesbians, were preferred by lesbian patients. When compared to male health professionals, women were considered to be more accepting of lesbians, which in turn facilitated disclosure. A number of practical factors (e.g., keeping eye contact, empathy) were also important behaviours for providers to exhibit.

Finally, the healthcare environment, including the type of healthcare setting (e.g., an organization known to serve lesbians), affected disclosure. Waiting rooms with reading materials relevant to lesbians, and those that used intake forms with inclusive language (e.g., an option to indicate a lesbian sexual orientation), alleviated the burden of disclosure through instilling a sense of safety (Hitchcock & Wilson, 1992).

***Perceived relevancy.*** Hitchcock and Wilson (1992) described relevancy as the lesbian patient's perception that there is a good reason to disclose. The authors indicated that relevancy is personally determined by each individual woman.

I have drawn upon Hitchcock and Wilson's (1992) Personal Risking theory to illustrate how the decision to disclose one's lesbian identity is a process that is affected by both internal and external factors at various phases, before, during, and after healthcare seeking. Specifically, Hitchcock and Wilson theorized that characteristics of the lesbian patient, including her use of protective strategies before she makes an appointment with a healthcare provider, and her comfort with her sexuality, as evidenced by how out she is to others, influence her willingness to disclose to her HCPs. As well, characteristics of the healthcare environment are pertinent to lesbian disclosure in this

context, and these include a lesbian patient's perceptions regarding the safety of the healthcare waiting room, and whether or not she believes her provider, based on her consultation with her or him, is accepting of her sexuality. Personal Risking theory provides a good foundation to start discussing the factors influencing disclosure. The next step is to discuss the empirical findings that support, and extend beyond, Hitchcock and Wilson's preliminary work.

### **Building on Personal Risking Theory**

Research on the factors facilitating lesbian disclosure to primary healthcare professionals provides further validation for Hitchcock and Wilson's (1992) Personal Risking theory (see Table 1 for a complete list of citations). Correspondingly, the literature mentions three dimensions affecting whether or not lesbians disclosed to their healthcare providers: the lesbian patient's personal attributes, the healthcare environment, and the characteristics of the healthcare provider. One additional dimension not considered by Personal Risking theory was found to be relevant in this context: the patient-provider relationship. Because many of the studies investigated one or more of the dimensions (but rarely all) described above in relation to disclosure, rather than discussing each study individually and repeatedly, an overview of these studies is provided in Table 1.

**Patient attributes.** The literature on lesbian disclosure suggests that a lesbian patient's socio-demographics, as well as her perceptions, attitudes, and her behaviours, may contribute to her willingness to disclose to healthcare providers.

**Socio-demographics.** Not considered by Hitchcock and Wilson (1992), a lesbian woman's age, her ethnicity, her educational background, and her income have been

Table 1: Details on Studies of Lesbian Disclosure in Healthcare

<b>Authors</b>	<b>Sample</b>	<b>Design</b>	<b>Dimensions Investigated</b>
Barbara, Quandt, & Anderson (2001)	32 self-identified lesbian women; diverse ages; most well-educated; most White	Qual	Healthcare environment Healthcare provider
Bergeron & Senn (2003)	254 self-identified lesbian women; M age=39; most well-educated; most White	Quant	Patient attributes Patient-provider relationship
Bjorkman & Malterud (2007)	6 self-identified lesbian women; M age=41; all well-educated; all White	Qual	Patient attributes Healthcare environment Healthcare provider
Brotman, Ryan, Jalbert, & Rowe (2002)	? self-identified gay/lesbian/bisexual/two-spirited men/women; diverse ages; education=?; race=?	Qual	Healthcare environment Healthcare provider
Cant & Taket (2006)	23 self-identified gay/lesbian/bisexual men/women; diverse ages; education=?; race=most White	Qual	Patient attributes Healthcare environment Healthcare provider Patient-provider relationship
Dardick & Grady (1980)	622 self-identified gay/lesbian men/women (73% male); most between 22-41 yrs; most well-educated; most White	Quant	Patient attributes Healthcare provider Patient-provider relationship
DeHart (2008)	173 self-identified lesbian women; median age=30; most well-educated; most White	Quant	Healthcare provider
Diamant et al. (2000)	6935 self-identified lesbian women; median age=34; most well-educated; most White	Quant	Healthcare provider Patient-provider relationship
Edwards & van Roekel (2009)	10 same-sex attracted women; most in their 50's; education=?; race=most White	Qual	Patient attributes Healthcare provider Patient-provider relationship
Eliason & Schope (2001)	88 self-identified gay/lesbian/bisexual men/women; M age=42; education=?; race=most White	Mixed	Patient attributes Healthcare environment Healthcare provider Patient-provider relationship
Fogel (2005)	13 self-identified gay/lesbian men/women; age=?; most well-educated; racially diverse	Qual	Patient attributes Healthcare environment Healthcare provider Patient-provider relationship
Geddes (1994)	53 self-identified lesbian/bisexual women; M age=37; most well-educated; most White	Mixed	Patient attributes Healthcare environment Healthcare provider Patient-provider relationship
Johnson, Guenther, Laube, & Keetel (1981)	117 self-identified lesbian/bisexual/no label women; M age=29; most well-educated; most White	Quant	Patient attributes Healthcare environment Healthcare provider Patient-provider relationship
Klitzman & Greenberg (2002)	94 self-identified gay/lesbian/bisexual men/women; M age=35; education=?; racially diverse	Quant	Patient attributes Healthcare provider Patient-provider relationship
Lehmann et al. (1998)	53 self-identified lesbian/bisexual women; median age=23; most well-educated; most White	Quant	Healthcare provider Patient-provider relationship

*Notes:* Qual = qualitative, quant = quantitative. ? = unspecified by authors.

Table 1

*Continued*

<b>Authors</b>	<b>Sample</b>	<b>Design</b>	<b>Dimensions Investigated</b>
Lucas (1992)	178 self-identified lesbian women; M age=28; most well-educated; most White	Quant	Healthcare environment Healthcare provider
Mathieson (1998)	98 self-identified lesbian/bisexual/no label women; M age=37; most well-educated; most White	Mixed	Healthcare environment Healthcare provider
Mulligan & Heath (2007)	47 self-identified lesbian/bisexual/queer women; diverse ages; education=?; race=?	Qual	Patient attributes Healthcare environment Healthcare provider
Neville & Henrickson (2006)	2269 men/women attracted to same-sex/had same-sex sex; age=?; most well-educated; race=?	Quant	Patient attributes Healthcare provider
Politi, Clark, Armstrong, McGarry, & Sciamanna (2009)	40 women who partner with women, men, or both; M age=55; most well-educated; most White	Qual	Patient attributes Healthcare environment Healthcare provider
Robertson (1992)	10 self-identified lesbian women; between 26-40 yrs; most well-educated; all White	Qual	Patient attributes Healthcare provider Patient-provider relationship
Saulnier (2002)	33 self-identified lesbian/bisexual women; demographics not collected	Qual	Healthcare environment Healthcare provider
Smith, Johnson, & Guenther (1985)	2345 self-identified lesbian/bisexual women; M age=28; most well-educated; most White	Quant	Patient attributes Healthcare environment Healthcare provider Patient-provider relationship
Steele et al. (2006)	387 self-identified gay/lesbian women; M age=36; most well-educated; most White	Quant	Patient attributes Healthcare environment Healthcare provider
Stein & Bonuck (2001)	575 self-identified gay/lesbian/bisexual men/women; M age=45; most well-educated; some racial diversity	Quant	Patient attributes Healthcare provider
Stevens (1994)	45 self-identified lesbian women; M age=36; most well-educated; racially diverse	Qual	Patient attributes Healthcare environment Healthcare provider
Stevens & Hall (1988)	25 self-identified lesbian women; M age=30; most well-educated; most White	Qual	Patient attributes Healthcare provider
Tiemann, Kennedy, & Haga (1998)	8 women known as lesbians to authors; between 20-40 yrs; all well-educated; race=?	Qual	Patient attributes Healthcare environment
van Dam, Koh, & Dibble (2001)	1161 self-identified lesbian/heterosexual women; M age=40; education=?; most White	Quant	Patient attributes Healthcare environment Healthcare provider
White & Dull (1998)	324 self-identified lesbian/bisexual/other women; M age=41; most well-educated; most White	Quant	Healthcare environment Healthcare provider Patient-provider relationship
Zeidenstein (1990)	20 self-identified lesbian women; between 31-49 yrs; most well-educated; most White	Mixed	Patient attributes Healthcare environment Healthcare provider

*Notes:* Qual = qualitative, quant = quantitative. ? = unspecified by authors.

investigated by others (Bergeron & Senn, 2003; Eliason & Schope, 2001; Klitzman & Greenberg, 2002; Neville & Henrickson, 2006; Stein & Bonuck, 2001). With the exception of income, inconsistent findings have been reported on all of the above socio-demographics. Only one study considered income, and found that it was associated with disclosure, where lesbians who were higher earners (and thus experienced greater class privilege) were more likely to disclose to their healthcare providers (Eliason & Schope, 2001).

Consistent with Personal Risking theory (Hitchcock & Wilson, 1992), health status influenced disclosure in three studies. Specifically, lesbians who had a serious medical condition or who needed an invasive medical procedure were consistently more likely to disclose (Fogel, 2005; Stein & Bonuck, 2001; Stevens & Hall, 1988). Also consistent with Hitchcock and Wilson's (1992) work, lesbians who were in a relationship were more likely to disclose in a mixed-method study conducted by Zeidenstein (1990).

***Perceptions.*** Perceptions regarding the relevance of disclosure influenced women's willingness to come out to their healthcare providers. Similar to what was suggested by Personal Risking theory, women who perceived a good reason for coming out were more likely to do so in seven studies (Bjorkman & Malterud, 2007; Edwards & van Roekel, 2009; Fogel, 2005; Mulligan & Heath, 2007; Politi et al., 2009; Stevens, 1994; Zeidenstein, 1990). Although Hitchcock and Wilson (1992) believed that relevancy is personally determined by each individual, findings from three qualitative studies suggest a distinctive pattern in women's perceptions regarding good reasons to disclose (Bjorkman & Malterud, 2007; Edwards & van Roekel, 2009; Politi et al., 2009). Specifically, lesbians perceived disclosure to be more relevant when a gynecological

ailment rather than a non-gynecological one was presented for consultation.

Consequently, lesbian women in these studies perceived their sexuality to be tied to certain body parts (e.g., genitalia) but not others (e.g., arm, leg, throat).

**Attitudes.** Bergeron and Senn (2003) tested a path analysis of factors hypothesized to predict healthcare seeking by lesbian women. They found that participants who adopted feminist ideals were more likely to be out lesbians, which in turn led them to disclose to healthcare providers and subsequently seek preventative healthcare. Perhaps through the process of reclaiming a “loud and proud” lesbian identity for political reasons (e.g., increased visibility of lesbians in the public sphere), an affinity with feminism offered a protective buffer against internalized homophobia, an internal stressor discussed earlier in Minority Stress theory. Women who were low on internalized homophobia also tended to disclose more widely and to be healthcare seekers. Although not investigated by Hitchcock and Wilson (1992), the divergent effects of feminism (buffer) and internalized homophobia (stressor) on lesbian disclosure to their healthcare providers make sense in light of Minority Stress theory—which considers stressors as well as buffers—and offers additional insight into what personal attributes affect lesbians’ decisions to disclose.

**Behaviours.** Personal Risking theory suggests that women use self-protective strategies prior to contacting a healthcare provider to ensure their safety. Thirteen studies also reported on lesbians’ use of precautionary measures (Bjorkman & Malterud, 2007; Cant & Taket, 2006; Edwards & van Roekel, 2009; Eliason & Schope, 2001; Fogel, 2005; Geddes, 1994; Johnson et al., 1981; Mulligan & Heath, 2007; Smith et al., 1985; Stein & Bonuck, 2001; Stevens, 1994; Tiemann et al., 1998; Zeidenstein, 1990). Early



qualitative research by Stevens (1994) offered insight into the types of protective strategies women exercise. These included: seeking referrals for lesbian-positive healthcare professionals from members of the lesbian community; screening, or interviewing healthcare providers beforehand to tap into their attitudes toward lesbians with the goal of weeding out homophobic practitioners; scanning the waiting room and monitoring staff behaviour for signs of a safe environment; and bringing partners or other witnesses to consultations. Eliason and Schope (2001), drawing upon Personal Risking theory and Stevens' work, provided the most detailed quantitative information on the use of precautionary measures by both gay men and lesbian women. They reported that 36% of participants in the past had monitored medical staff behaviour, 30% had sought referrals from friends, 18% had scanned the healthcare environment for signs of safety, and 6% had brought along someone for support. Of note, lesbian women indicated greater use of precautionary measures than did gay men. Along with Eliason and Schope, other researchers have speculated that because they are marginalized on both gender and sexual orientation, lesbian women consider disclosure to be more risky than do gay men (e.g., Beehler, 2001).

Hitchcock and Wilson (1992) stated that women who were more comfortable with their sexuality were more likely to be out to others, including their healthcare providers. Global outness to others was found in six studies to have an impact on disclosure in the healthcare context, where women who had disclosed more broadly tended to also come out to healthcare professionals (Bergeron & Senn, 2003; Dardick & Grady, 1980; Eliason & Schope, 2001; Robertson, 1992; Steele et al., 2006; van Dam et al., 2001).

**Healthcare environment.** The literature on lesbian disclosure suggests that characteristics of the healthcare environment may also influence a lesbian patient's willingness to disclose to her healthcare providers. Perceptions of safety, confidentiality, the type of service, and whether or not inquiry of sexual orientation has occurred, are all important considerations for lesbian women.

**Safety.** Similar to what was proposed by Personal Risking theory (Hitchcock & Wilson, 1992), a healthcare environment that was perceived by lesbians as safe was conducive to lesbian disclosure in 11 empirical studies (Barbara et al., 2001; Bjorkman & Malterud, 2007; Brotman et al., 2002; Fogel, 2005; Geddes, 1994; Mathieson, 1998; Mulligan & Heath, 2007; Politi et al., 2009; Stevens, 1994; Tiemann et al., 1998; Zeidenstein, 1990). A "safe" environment was one that was without heterosexism and homophobia. Furthermore, women reported that the presence of gay and lesbian symbols, as well as affirmative information on sexual minority health in the waiting area, encouraged disclosure.

**Confidentiality.** Although not identified by Hitchcock and Wilson (1992), being in a healthcare environment where discussions about confidentiality took place was important for lesbian women who were deciding whether or not to disclose. Nine empirical studies found that discussions about confidentiality, including if the patient's sexual orientation would be documented as well as who would have access to this information, influenced women's willingness to disclose to their healthcare providers (Barbara et al., 2001; Cant & Taket, 2006; Johnson et al., 1981; Lucas, 1992; Politi et al., 2007; Saulnier, 2002; Smith et al., 1985; Tiemann et al., 1998; Zeidenstein, 1990).

***Type of service.*** Consistent with Hitchcock and Wilson (1992), the type of healthcare service was relevant to whether or not lesbian disclosure occurred in three empirical studies (Mulligan & Heath, 2007; Smith et al., 1985; White & Dull, 1998). Specifically, lesbian women were more likely to disclose to alternative healthcare providers or to professionals working at women's or sexual health clinics than they were in more mainstream settings (e.g., private clinic to general practitioner).

***Inquiry.*** In addition to Hitchcock and Wilson (1992), 14 other studies found that women who were asked about their sexual orientation verbally or via forms, rather than being assumed to be heterosexual, were more likely to disclose (Barbara et al., 2001; Bjorkman & Malterud, 2007; Brotman et al., 2002; Cant & Taket, 2006; Eliason & Schope, 2001; Fogel, 2005; Geddes, 1994; Lucas, 1992; Mathieson, 1998; Mulligan & Heath, 2007; Politi et al., 2009; Steele et al., 2006; van Dam et al., 2001; Zeidenstein, 1990). In fact, in one of these studies, all of the women who had been provided with the opportunity to disclose via inquiry had come out to their healthcare providers (Steele et al., 2006).

***Healthcare provider.*** The literature on lesbian disclosure suggests that a healthcare provider's socio-demographics, their attitudes, and their behaviours, may contribute to a lesbian patient's willingness to disclose to them.

***Socio-demographics.*** Hitchcock and Wilson (1992) suggested that lesbian patients would be more willing to disclose to female HCPs who were also self-identified lesbians, due to their anticipated sensitivity toward minority sexuality. Similarly, 22 studies investigated whether lesbians would be more willing to disclose to lesbian women healthcare providers; the majority of these studies found that this was indeed the case

(Barbara et al., 2001; Cant & Taket, 2006; Dardick & Grady, 1980; Diamant et al., 2000; Edwards & van Roekel, 2009; Fogel, 2005; Klitzman & Greenberg, 2002; Lucas, 1992; Politi et al., 2009; Robertson, 1992; Saulnier, 2002; Stein & Bonuck, 2001; Stevens, 1994; Stevens & Hall, 1988; Zeidenstein, 1990). However, in one study, gender of the healthcare provider was not significantly related to patient disclosure (DeHart, 2008). In other studies, other factors, such as whether or not the provider was easy to communicate with, were more important considerations for women before they disclosed (Geddes, 1994; Johnson et al., 1981; Lehmann et al., 1998; Mathieson, 1998; Smith et al., 1985; White & Dull, 1998).

Stevens (1994), in her ethnically diverse sample of lesbian women interviewees, found that patients sought “mirrors of their experience” (p. 222) when seeking healthcare. Many women felt safer with female HCPs who matched them on key socio-demographics, including race/ethnicity. The importance of race, particularly for ethnic minority women, was not elaborated by Hitchcock and Wilson (1992), perhaps due to the preponderance of participants who were members of the ethnic majority in the study used to develop the theory.

***Attitudes.*** As described in Personal Risking theory, healthcare providers who were minimally tolerant of lesbians encouraged disclosure. Several other empirical studies have found the same (Barbara et al., 2001; Bjorkman & Malterud, 2007; Brotman et al., 2002; Dardick & Grady, 1980; Edwards & van Roekel, 2009; Fogel, 2005; Geddes, 1994; Johnson et al., 1981; Mulligan & Heath, 2007; Neville & Henrickson, 2006; Politi et al., 2009, Robertson, 1992; Saulnier, 2002; Stevens & Hall, 1988; van Dam et al., 2001; Zeidenstein, 1990). In these studies, HCPs who were comfortable being around

lesbians and did not exhibit homophobic or other negative attitudes toward them facilitated disclosure.

Ideally, a healthcare provider should move beyond tolerance—which I personally consider to fulfill only the bare minimum of my expectations as a healthcare consumer—to exhibiting displays of sensitivity. Lesbian sensitivity was not addressed by Personal Risking theory, however, in 14 other empirical works, lesbian sensitive providers facilitated disclosure through their knowledge of lesbian health and healthcare needs, as well as through their appreciation for the lived reality of marginalized women (Barbara et al., 2001; Cant & Taket, 2006; Edwards & van Roekel, 2009; Eliason & Schope, 2001; Fogel, 2001; Geddes, 1994; Klitzman & Greenberg, 2002; Mathieson, 1998; Mulligan & Heath, 2007; Robertson, 1992; Saulnier, 2002; Steele et al., 2006; White & Dull, 1998; Zeidenstein, 1990).

Although not elaborated by Hitchcock and Wilson (1992), some (but not all), lesbian women participants preferred feminist or social-justice oriented healthcare providers in three studies (Edwards & van Roekel, 2009; Mathieson, 1998; Zeidenstein, 1990). However, the majority of women in Mathieson's (1998) study indicated that a provider who was lesbian sensitive was the ideal HCP.

***Behaviours.*** Personal Risking theory (Hitchcock & Wilson, 1992) considers the influence of a variety of practical factors that can facilitate lesbian disclosure in the healthcare milieu. Likewise, other empirical studies have found that providers who were competent, and those who took time with their patients in order to listen to their complaints, made coming out easier for lesbians (Bjorkman & Malterud, 2007; Edwards & van Roekel, 2009; Eliason & Schope, 2001; Fogel, 2005; Geddes, 1994; Mulligan &

Heath, 2007; Robertson, 1992; Saulnier, 2002). The aforementioned behaviours are not uniquely important to lesbian women; other researchers have talked about these in relation to promoting positive behaviours such as adherence to treatment protocol with all patients (e.g., Beck, Daughtridge, & Sloane, 2002).

Because lesbian women often feel unsafe in healthcare settings (e.g., they fear encountering hostile responses to their sexuality), they often bring another person with them (partners, friends, or advocates) as a form of self-protection. Healthcare providers who included a lesbian woman's companion in her healthcare decision-making facilitated disclosure (Barbara et al., 2001; Fogel, 2005; Geddes, 1994; Saulnier, 2002; Smith et al., 1985). The inclusion of a woman's companion by healthcare providers, however, was not mentioned by Hitchcock and Wilson (1992).

**Patient-provider relationship.** The literature on lesbian disclosure suggests that aspects of the patient-provider relationship may influence a lesbian patient's willingness to disclose to her healthcare providers, including patient comfort and familiarity with their healthcare provider, ease of communication, and trust. Of note, the patient-provider relationship was not considered by Personal Risking theory (Hithcock & Wilson, 1992).

***Patient comfort with their healthcare provider.*** Four out of the five studies investigating patient comfort with their healthcare providers found that this aspect of the patient-provider relationship was indeed associated with lesbian disclosure in healthcare (Edwards & van Roekel, 2009; Johnson et al., 1981; Smith et al., 1985; White & Dull, 1997). However, Bergeron and Senn (2003) found that lesbians' reports of comfort with their healthcare providers were not directly associated with disclosure, though comfort was related to seeking previous healthcare.

***Patient familiarity with their healthcare provider.*** Four out of the five studies investigating patient familiarity with their HCP found that this characteristic of the patient-provider relationship was important for disclosure (Diamant et al., 2000; Fogel, 2005; Lehmann et al., 1998; Robertson, 1992). Specifically, patients who knew their providers from other social or political settings, or who had the same provider over a period of time, were more willing to disclose. In contrast, Geddes (1994) found that the length of the relationship with one's provider was not related to disclosure. This non-significant finding could be due to the lack of variability found in her sample on this particular variable: almost 90% of lesbian women had regular healthcare providers.

***Ease of communication.*** Five studies considered ease of communication between patient and provider in relation to disclosure (Cant & Taket, 2006; Dardick & Grady, 1980; Eliason & Schope, 2001; Klitzman & Greenberg, 2002; White & Dull, 1998). Consistent findings suggested that lesbian women who had an easier time communicating with their healthcare providers, as well as those who felt able to dialogue about other sensitive topics, were more willing to disclose.

***Trust.*** Two studies considered trust and its potential association with disclosure (Cant & Taket, 2006; Fogel, 2005). Both of these studies found that lesbian women who trusted their healthcare providers were more likely to come out to them.

I have drawn upon Personal Risking theory (Hitchcock & Wilson, 1992) to provide a framework for theorizing the complexities of lesbian disclosure in the context of healthcare seeking. Although Personal Risking theory is a good point of departure for conceptualizing this issue, it is missing a discussion of the important health outcomes for women that may follow disclosure. Specifically, in past research, lesbians who have

disclosed have tended to engage in preventative self-care and healthcare seeking (Bergeron & Senn, 2003; Brown et al., 2003; DeHart, 2008; Diamant et al., 2000; Steele et al., 2006; White & Dull, 1997). Also missing from the theory was a consideration of a number of factors known to influence disclosure in the healthcare setting, as identified by other researchers. There appear to be four dimensions of the healthcare context that are relevant to lesbian disclosure, and these are: patient attributes, the healthcare environment, healthcare provider attributes, and the patient-provider relationship. Within each of these dimensions, the literature suggests that there are factors that may be associated with disclosure above and beyond those suggested by Personal Risking theory. There were, however, several contradictions in the findings reviewed above (e.g., on whether certain patient socio-demographics are related to disclosure). To gain insight into possible reasons for these contradictions, a discussion of the limitations with the current body of lesbian disclosure in healthcare research follows.

### **Limitations with Lesbian Disclosure in Healthcare Research**

The research on lesbian disclosure in healthcare has several limitations, which may explain the contradictions in the findings reported above. It is important to note that the following critique is not unique to the literature on lesbian disclosure but is also applicable to the broader realm of lesbian health research. I also want to make clear that the critique I offer here is not new but rather one that has been identified previously by others (particularly, the IOM report on lesbian health released in 1999, but also, Dean et al., 2000; Mayer et al., 2008; Roberts, 2001).

The samples of women recruited to participate in lesbian disclosure research in healthcare settings were generally small (notable exceptions were: Bergeron & Senn,



2003; Diamant et al., 2000; Neville and Henrickson, 2006; Smith et al., 1985; Steele et al., 2006; Stein & Bonuck, 2001; van Dam et al., 2001; White & Dull, 1998) and biased toward those who tended to be amongst the most privileged. Overwhelmingly, participants were well-educated, high income earners who were also White and lived in metropolitan areas in the United States (notable exceptions were: Fogel, 2005; Klitzman & Greenberg, 2002; Stevens, 1994; Tiemann et al., 1998). Consequently, our understandings of other marginalized women, such as women of color, poor women, or women who live in smaller communities (as well as those who are disadvantaged on one or more of these dimensions), is restricted.

Many of the studies on lesbian disclosure were atheoretical. That is, reasons for including certain variables at the expense of others were unclear due to the lack of rationale or theory provided by the researchers (notable exceptions were: Eliason & Schope, 2001; Stevens, 1994; Stevens & Hall, 1988). Personal Risking theory, useful in its conceptualization of the decision to disclose as a process, as well as its consideration of the many factors affecting disclosure, even though generated over 20 years ago, was rarely elaborated in the literature, perhaps due to disciplinary divides (i.e., Hitchcock and Wilson's 1992 article was published in a nursing journal; researchers who mentioned Personal Risking theory also tended to be from the discipline).

There were also measurement issues. Specifically, the majority of quantitative studies created their own measurement tools to capture the variables of interest (a notable exception was Bergeron & Senn, 2003). Ways of measuring disclosure, as well as other key variables, differed across studies. Additionally, many researchers did not provide details regarding the psychometric properties for their newly created scales, therefore,

reliability and validity of these measures is questionable (again, Bergeron & Senn, 2003 were an exception; they provided reliability information for their Perceived Adherence Scale, a new measure of engagement in preventative self-care and healthcare seeking). And finally, a number of qualitative researchers did not provide adequate detail on their methodology (notable exceptions were: Fogel, 2005; Stevens, 1994; Stevens & Hall, 1988).

The majority of the studies on disclosure in healthcare relied on unsophisticated data analysis techniques to explore findings. More commonly, univariate (e.g., frequency) and bivariate (e.g., correlation) analyses were conducted rather than multivariate ones (notable exceptions were: Bergeron & Senn, 2003; Brown et al., 2003; DeHart, 2008; Diamant et al., 2000; Steele et al., 2006; van Dam et al., 2001). Very few studies considered the joint influence of all of the dimensions affecting disclosure described earlier: patient attributes, healthcare context, healthcare provider, and patient-provider relationship. Research examining all of these dimensions is still needed to provide a more complex understanding of lesbian disclosure in healthcare settings.

### **The Current Study**

The primary goal of this research is to present a detailed analysis of the predictors and health outcomes of lesbian disclosure of sexual orientation to their primary healthcare providers. Based on past theory and empirical research, the current study aims to provide researchers and practitioners with a broader appreciation of the variety of factors that may facilitate disclosure, as well as the important health outcomes that may result from this critical behaviour.

## **Rationale for the Current Study**

The current study was designed to address many of the limitations of previous research on lesbian disclosure in healthcare outlined above. To address the problem of small sample size, I employed a combination of recruitment strategies to attract a large sample. Internet or online survey research has been regarded as appropriate and effective at targeting “hidden” and stigmatized populations (Kraut, Olson, Banaji, Bruckman, Cohen, & Couper, 2004; Riggle, Rostosky, & Reedy, 2005). In the past, for my Master’s research, I successfully used the Internet, in tandem with other strategies, to help me recruit a large ( $N = 300$ ) sample of gay men and lesbian women for a sensitive study on same-sex intimate partner violence. In my experience, using the Internet to recruit lesbian women allows researchers to gain access to a variety of resources and organizations for sexual minorities, through which study information can be widely (and quickly) circulated via key contacts. In the particular case of lesbian women, researchers have reported that sexual minorities who are not open about their sexual orientation consider the World Wide Web a critical, private tool they can use to access information on sexuality (Garry et al., 1999). Therefore, for women who are not out about their sexual orientation, the World Wide Web may be an important gateway for them to learn about important resources, including research.

To recruit my sample, efforts beyond those opportunities provided by the World Wide Web were required to ensure a diverse representation of lesbian women. It is typical for lesbian health researchers to use a combination of two or more of the following to gain access to participants: network with relevant organizations, purchase advertisements in gay and lesbian publications, communicate with their personal contacts

and key members of the community, and snowballing (i.e., request that potential participants forward information about the study to others who meet the inclusion criteria). Rothblum, Factor, and Aaron (2002) offered advice based on their past research experiences recruiting sexual minority women on what methods worked best to reach particularly disadvantaged participants. In their work, they found that advertisements in national publications were the most successful at attracting women of color and women with less education. Postings through university lesbian, gay, bisexual, and transgender groups also proved effective at targeting women of color. Rothblum and her colleagues urged that the most diverse representation of women would be achieved when recruitment efforts were vast and varied. Consequently, I engaged in all of the recruitment strategies described above with the hope of gaining access to an even more heterogeneous sample than the one obtained for my Master's research.

Although online survey research has been considered a promising avenue for researchers working with stigmatized populations, within the realm of lesbian disclosure research it appears to have been rarely used. In the past I have found that, when given the choice between an online or paper survey, 90% of participants will prefer, and are able, to complete the survey online. Perhaps the greatest advantage of an online survey is that responses can be anonymous, protecting the identity of participants who are otherwise reluctant to participate in any kind of research that has the word "lesbian" attached. I have also found that, probably due to its anonymous nature, an online survey is effective at attracting women who do not otherwise tend to disclose. For example, in my Master's research, one-quarter of participants were not out. For the current study on lesbian disclosure in the context of primary healthcare seeking, variation on experiences of

disclosure was important. Therefore, the use of an anonymous online survey I hoped would prove helpful in attracting participants who are particularly closeted in terms of their sexual orientation.

### **Research Questions and Hypotheses**

The current study aimed to provide a comprehensive understanding of the predictors of lesbian disclosure in primary healthcare. Therefore, the first research question was: What are the predictors of lesbian disclosure to their primary healthcare providers? Based on past research, I hypothesized that four dimensions would be associated with greater disclosure to primary healthcare providers: patient attributes, the healthcare environment, healthcare provider attributes, and the patient-provider relationship. Details on hypotheses 1a-1d can be found below (please note that for some of the following hypotheses, I have specified direction based on consistent findings, but for others I have not specified direction due to the inconsistency of previous findings).

Hypothesis 1a: Certain patient attributes would be associated with greater lesbian disclosure to primary healthcare providers. These included: *socio-demographics*, specifically, age, education, higher income, ethnic background, being in an intimate relationship, and having health problems; *perceptions*, specifically, greater perceived relevance of disclosure; *attitudes*, specifically, a more positive regard for feminism, and lower internalized homophobia; and *behaviours*, specifically, the use of self-protective strategies (i.e., obtaining a referral from a friend), and greater outness to others (e.g., family, friends, work supervisor).

Hypothesis 1b: Certain aspects of the healthcare environment would be associated with greater lesbian disclosure to primary healthcare providers.

Specifically: patient perceptions of a safe environment; healthcare services that are confidential; alternative as opposed to more traditional healthcare services; and direct verbal or written inquiry on patient sexual orientation.

Hypothesis 1c: Certain healthcare provider attributes would be associated with greater lesbian disclosure to primary healthcare providers. These included: *socio-demographics*, specifically, the HCP being a woman, being a lesbian, and shared ethnic background between the patient and the provider; *attitudes*, specifically, patient perceptions of providers' tolerance and sensitivity toward lesbians, and providers who have social justice values; *behaviours*, specifically, patient perceptions regarding the presence of practical factors (e.g., empathy, listening) in the HCP; and patient perceptions regarding the inclusion of their same-sex partner (if relevant) in healthcare.

Hypothesis 1d: Certain aspects of the patient-provider relationship would be associated with greater lesbian disclosure to primary healthcare providers. Specifically, patient comfort with their provider; patient familiarity with their provider; patient trust in their provider; and patient perceptions regarding easier communication with their providers.

Past research on lesbian disclosure in healthcare has tended to focus on only a few of the above outlined facilitators of disclosure. An understanding of the most important facilitators of lesbian disclosure in primary healthcare is still unclear. This led to my second research question: What are the most influential facilitators of lesbian disclosure

to their primary healthcare providers? I hypothesized that external as opposed to internal factors would be more important to facilitate lesbian disclosure in primary healthcare.

Details on hypothesis 2 can be found below.

Hypothesis 2: A combination of external factors, including the characteristics of the healthcare environment, the healthcare provider, and the relationship between patient and provider, would be more influential on level of disclosure than internal factors, that is, patient attributes, alone.

To examine the first and second research questions, a variety of pre-existing measures with available psychometrics were used. A modified version of the Disclosure Questionnaire (Fogel, 2001, 2005) was used to capture many of the facilitators of disclosure to healthcare providers described above. To assess the factors not identified by the Disclosure Questionnaire, other valid measures targeting patient attitudinal (e.g., the Attitudes Toward Feminism and the Women's Movement Scale by Fassinger, 1994 to measure affinity toward feminism; the Lesbian Internalized Homophobia Scale by Szymanski & Chung, 2001 to assess internalized homophobia) and behavioural (Outness Inventory by Mohr & Fassinger, 2000, to capture outness to others) components were also used. Patient-provider relationship factors not assessed by the Disclosure Questionnaire were measured using modified scales taken from the general health literature (e.g., the Approachability of Family Practice Consultations by Hackett & Jacobson, 1995 to evaluate patient perceptions of comfort with their provider; the Questionnaire on the Quality of Physician-Patient Interaction by Bieber, Muller, Nicolai, Hartmann, & Eich, 2010 to assess provider communication).

Relatively few studies have systematically examined the various health outcomes that have been found to be associated with lesbian disclosure in primary healthcare. Therefore, my third research question was: What are the health outcomes of lesbian disclosure to their primary healthcare providers? Based on the literature available, I anticipated that there would be positive health outcomes associated with disclosure to primary healthcare providers. Details on hypothesis 3a and 3b can be found below.

Hypothesis 3a: Lesbian disclosure to their healthcare providers would lead to engagement in more preventative self-care behaviours (e.g., breast self-exams), and fewer unhealthy behaviours (e.g., cigarette smoking, consumption of alcohol).

Hypothesis 3b: Lesbian disclosure to their healthcare providers would lead to engagement in more frequent preventative healthcare seeking (e.g., seeing a healthcare provider when needed, cervical screening).

To evaluate the third research question, a modified version of the Perceived Adherence Scale by Bergeron and Senn (2003) was used to assess lesbian women's perceived adherence to as well as engagement in a range of preventative self-care and healthcare seeking behaviours. The scale was developed and subsequently tested and validated in an empirical research study examining the factors influencing lesbian women's healthcare seeking in Canada.

A key part of this research was an attempt to put the pieces of the puzzle together by testing a new, integrative model of lesbian disclosure in healthcare. I proposed the Lesbian Disclosure in Healthcare model (LDH; see Figure 1 for a parsimonious representation of the model), informed by the foundational work of Hitchcock and



Wilson's (1992) Personal Risking theory as well as the findings from other critical studies reviewed in this document. The LDH model considers what comes before (predictors), and what may subsequently follow (health outcomes), lesbian disclosure (see Figures 2-5 for a detailed representation of individual predictors and health outcomes). As can be seen from Figure 2, it was expected that disclosure would mediate the relationship between predictors and health outcomes. More generally the LDH model was developed in response to a need for theoretically driven research on lesbian health. More specifically the LDH was developed in response to a call for a more holistic understanding of lesbian disclosure in healthcare (Fogel, 2001).

Finally, in the current study I also considered the potential impact of political climate on lesbian women's willingness to reveal sensitive information in healthcare by including the experiences of both Canadian and American lesbian women for comparison. To date, the majority of the research on lesbian disclosure in healthcare has been conducted in the United States, with very few studies highlighting the Canadian context, and none examining the similarities/differences between the two countries. This is worth mentioning for several reasons. First, the Canadian context is such that, in theory, lesbian women have access to free healthcare. In contrast, American lesbian women's access to care is influenced by the type of health insurance they have (if any). Some researchers have reported that American lesbian women are at a disadvantage when compared to their heterosexual counterparts because they are less likely to have health insurance, and consequently, they may experience more restricted access to healthcare. Therefore, a significant barrier to receiving quality primary healthcare for American lesbian women, but not Canadians, is economic. Second, related to access to health

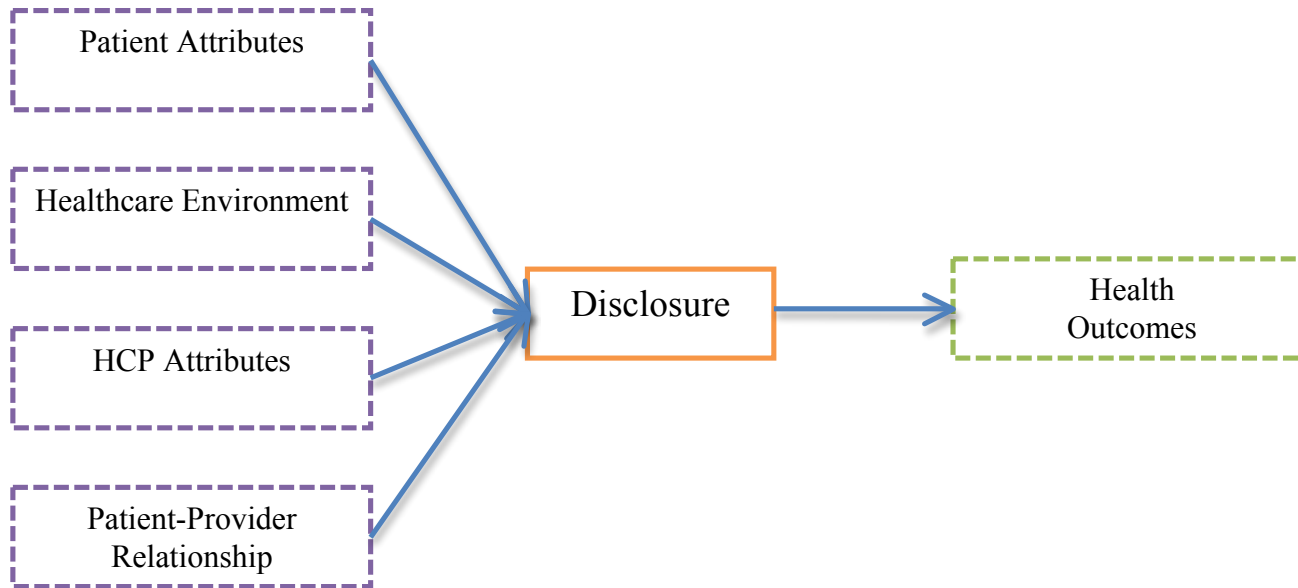


Figure 1: Lesbian Disclosure in Healthcare (LDH) model

This figure illustrates a parsimonious representation of the LDH model. The dotted lines are used to denote the categories referred to throughout the document to meaningfully organize the predictors and outcomes of disclosure.

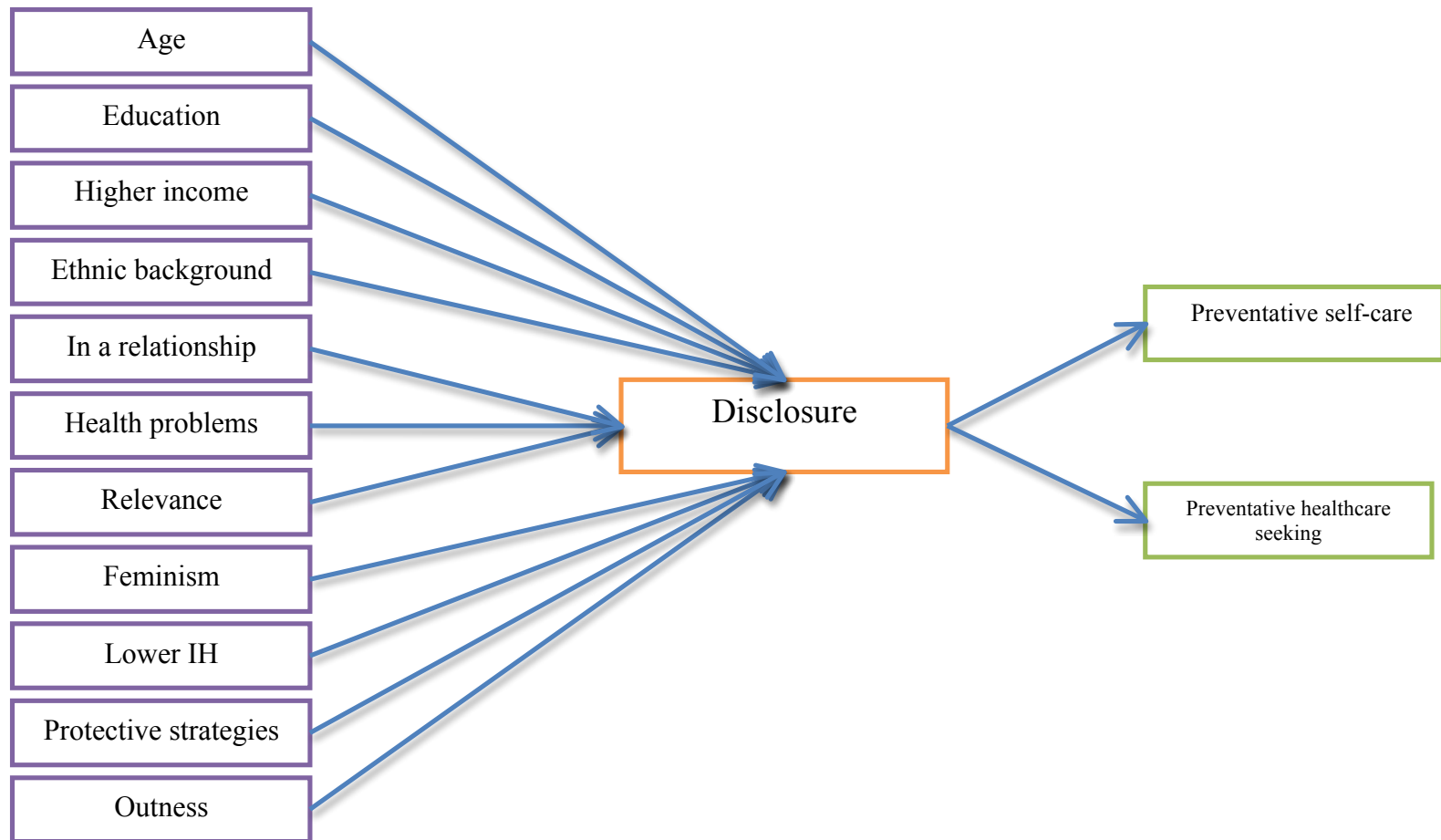


Figure 2: Predictors (patient attributes) and outcomes of lesbian disclosure

This figure illustrates a detailed representation of the predictors and health outcomes of lesbian disclosure in healthcare, with a focus on predictors falling under the category “patient attributes”. IH = internalized homophobia.

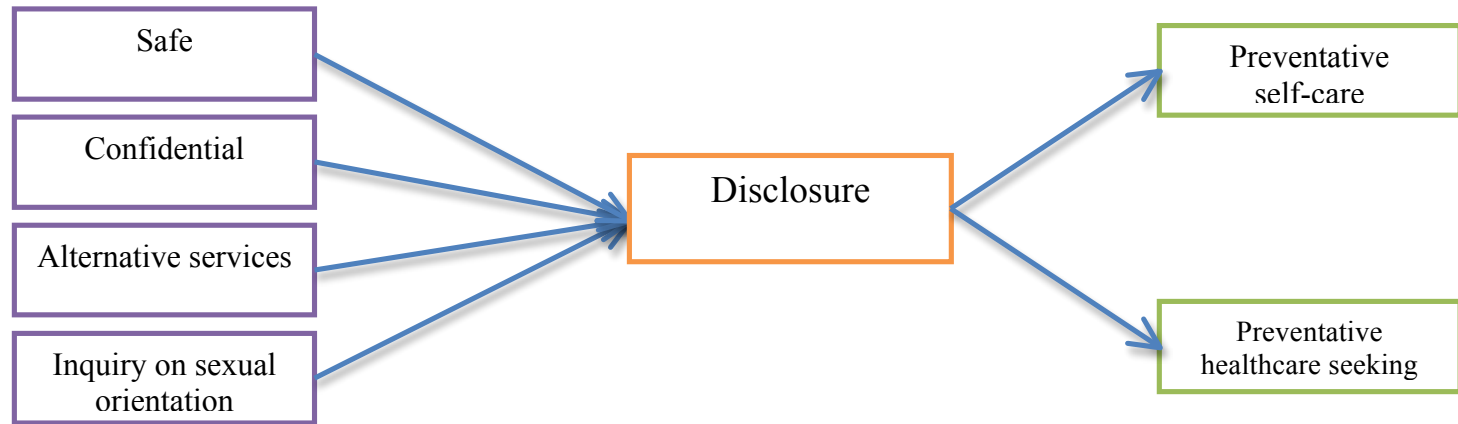


Figure 3: Predictors (healthcare environment) and outcomes of lesbian disclosure

This figure illustrates a detailed representation of the predictors and health outcomes of lesbian disclosure in healthcare, with a focus on predictors falling under the category “healthcare environment”.

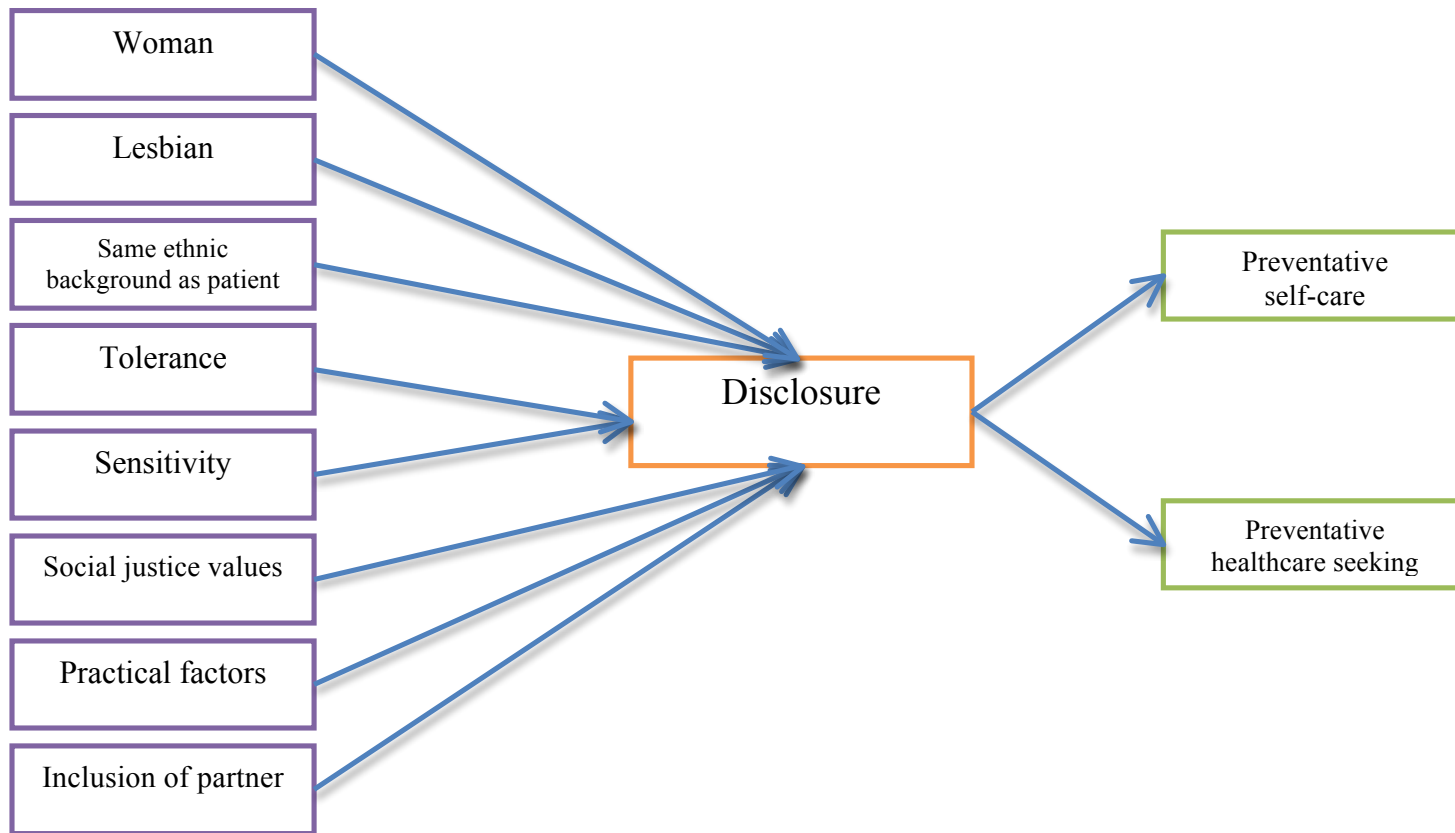


Figure 4: Predictors (healthcare provider attributes) and outcomes of lesbian disclosure

This figure illustrates a detailed representation of the predictors and health outcomes of lesbian disclosure in healthcare, with a focus on predictors falling under the category “healthcare provider attributes”.

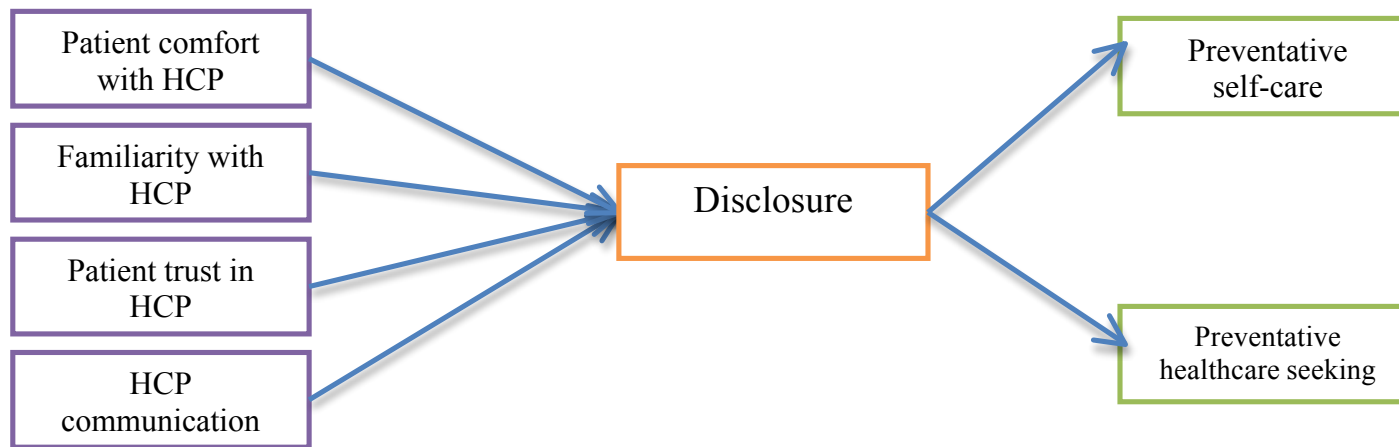


Figure 5: Predictors (patient-provider relationship) and outcomes of lesbian disclosure

This figure illustrates a detailed representation of the predictors and health outcomes of lesbian disclosure in healthcare, with a focus on predictors falling under the category “patient-provider relationship”.

insurance is a lesbian woman's legal right to marry her intimate partner. Through marriage (and also through civil partnerships or cohabitation in some cases), couples will often profit from access to health insurance and other benefits. Same-sex marriage is available across Canada; however, in the United States, even civil partnership status is limited. And finally, third, in Canada, laws and policies protecting against discrimination based on sexual orientation exist to protect sexual minorities across the country. However, in the United States, this is not the case, where several states have no such human rights policies or laws in place. Clearly there are some notable social and political differences between the United States and Canada that have been left unexplored in the context of this area of research. This study aimed to fill this gap by considering these differences on lesbian women's experiences of disclosure to their primary healthcare providers. Therefore, my fourth and final research question was: How might the healthcare seeking experiences of lesbians living in Canada be similar to or different from those of lesbians living in the United States? Specifically, I investigated how well the proposed model fit the healthcare experiences of Canadian and American women.

## CHAPTER III

### DESIGN AND METHODOLOGY

#### **Participants**

The original sample consisted of 618 (287 CAN, 331 USA) women respondents<sup>2</sup>, with 98% participating in the online version of the survey. The final sample (described in depth in the section on Preliminary Data Analyses) was reduced to 416 respondents (204 CAN, 212 USA). To reach the target *N*, a variety of recruitment strategies were employed over the span of nearly one year (May, 2011-March, 2012). Hundreds of emails were circulated through personal networks, online listservs, social networking sites (e.g., Facebook), dating sites (e.g., superdyke.com), and various gay and lesbian organizations across North America (e.g., social and political groups). Advertisements in national and international LGBT magazines were purchased, including one each in *Wayves*, *Xtra Ottawa*, and *Xtra Vancouver*, and three in *Lesbian Connection* (international).

The average age of Canadian and American respondents was 37.63 years ( $SD = 13.86$ ) and 36.64 years ( $SD = 14.30$ ), respectively. Most Canadian participants lived in Ontario or British Columbia, while Americans were scattered across 39 states. The majority of women from both countries identified their ethnic/racial background as White/European (90.8% CAN; 85.7% USA). A small number of Canadian women identified their ethnic/racial background as ‘other’ (e.g., ‘mixed’; 2.5%), Aboriginal/First Nations/Métis (1.8%), Black/African/Caribbean (1.8%), East Asian/Chinese/Japanese

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<sup>2</sup> This total includes only the participants who completed the majority of the survey. An additional 116 participants had incomplete surveys (i.e., no data after the demographics section), so were not included in any of the analyses. Participants who identified countries other than Canada or the USA ( $n = 2$ ) were also excluded from analyses. Three participants voluntarily withdrew from the study.



(1.4%), South Asian/Indian/Pakistani (1.1%), and Arab/Middle Eastern (0.7%). A small number of American women identified their ethnic/racial backgrounds as: Black/African American (4.3%), Hispanic/Latina (3.4%), 'other' (e.g., more than one identity category; 2.4%), American Indian/Alaska Native (2.1%), Asian (1.8%), and Native Hawaiian or Other Pacific Islander (0.3%). Of note, although the recruitment call was specifically for lesbian-identified women, other labels (e.g., queer, gay, bisexual) – or no labels at all – resonated better with approximately 27% of respondents from both countries. Responses to the behavioural measure of sexual orientation revealed that about 19% and 28% of the Canadian and American samples respectively were bisexually active – that is, they reported being currently sexually active with both women and men. Yet, less than 10% of both samples labeled their sexual identity as bisexual. Please see Table 2 for complete demographic characteristics of the women who completed this study.

On a scale from 1 (*poor*) to 5 (*excellent*), participants rated their health on average as good:  $M = 3.42$  ( $SD = .85$ ; CAN);  $M = 3.31$  ( $SD = .90$ ; USA). Nearly one-third of Canadians reported having a chronic disease; for Americans, this figure was just over 40%. A wide range of chronic physical and mental conditions were specified (often more than one), including but not limited to: arthritis, asthma, cancer, diabetes, endometriosis, fibromyalgia, heart disease, hypertension, multiple sclerosis, irritable bowel syndrome, depression, and anxiety. Almost 90% of women from both countries reported having a healthcare provider in the past year, and for the vast majority a physician was visited most often. For those who did not report having a healthcare provider in the past year, the most common reasons were relocation for Canadians, and financial for Americans. Please see Table 3 for complete health descriptive information for the women who participated in this research.

Table 2: Demographic Characteristics of Participants

	Canada				United States			
	Original sample		Final sample		Original sample		Final sample	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Province								
ON	117	40.9	87	42.6				
BC	78	27.3	53	26.0				
AB	31	10.8	23	11.3				
NS	23	8.0	17	8.3				
NB	12	4.2	8	3.9				
NL	7	2.4	4	2.0				
SK	5	1.7	4	2.0				
YT	5	1.7	3	1.5				
PEI	3	1.0	2	1.0				
QC	3	1.0	2	1.0				
MB	2	0.7	1	0.5				
State								
VA					34	10.5	25	12.1
MI					29	9.0	23	11.1
NY					29	9.0	19	9.2
CT					25	7.7	13	6.3
CA					22	6.8	15	7.2
FL					21	6.5	13	6.3
GA					15	4.6	7	3.4
OH					13	4.0	7	3.4
IN					12	3.7	6	2.9
OR					12	3.7	8	3.9
MA					11	3.4	4	1.9
IL					10	3.1	8	3.9
NC					9	2.8	6	2.9
MN					8	2.5	5	2.4
MT					7	2.2	3	1.4
MD					7	2.2	7	3.4
HI					7	2.2	3	1.4
VT					6	1.9	4	1.9
PA					6	1.9	5	2.4
AZ					5	1.5	4	1.9
WI					5	1.5	3	1.4
NJ					4	1.2	3	1.4
TX					3	0.9	3	1.4

Notes: Original samples:  $N = 287$  (CAN) and  $N = 331$  (USA). Final samples:  $N = 204$  (CAN) and  $N = 212$  (USA). Some variables have a few missing cases.

Table 2

*Continued*

	Canada				United States			
	Original sample		Final sample		Original sample		Final sample	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
State								
DC					3	0.9	1	0.5
CO					2	0.6	0	0.0
ID					2	0.6	2	1.0
KY					2	0.6	1	0.5
RI					2	0.6	2	1.0
WA					2	0.6	0	0.0
TN					1	0.3	1	0.5
AL					1	0.3	0	0.0
DE					1	0.3	0	0.0
KS					1	0.3	1	0.5
ME					1	0.3	1	0.5
NH					1	0.3	1	0.5
SC					1	0.3	0	0.0
SD					1	0.3	1	0.5
MO					1	0.3	1	0.5
OK					1	0.3	1	0.5
Ethnic background								
White	258	90.8	187	92.6	281	85.7	179	85.2
Women of color	26	9.2	15	7.4	47	14.3	31	14.8
Education								
Some high school	6	2.1	4	2.0	0	0.0	0	0.0
Completed high school	10	3.5	7	3.4	10	3.0	6	2.8
Some college/uni	57	19.9	37	18.2	54	16.4	36	17.0
College degree	28	9.8	20	9.9	36	10.9	21	9.9
Uni degree	75	26.1	57	28.1	44	13.3	31	14.6
Some graduate school	27	9.4	16	7.9	44	13.3	24	11.3
Master's degree	53	18.5	40	19.7	106	32.1	71	33.5
Doctoral degree	17	5.9	12	5.9	24	7.3	16	7.5
Professional degree	13	4.5	10	4.9	12	3.6	7	3.3

*Notes:* Original samples:  $N = 287$  (CAN) and  $N = 331$  (USA). Final samples:  $N = 204$  (CAN) and  $N = 212$  (USA). Some variables have a few missing cases.

Table 2

*Continued*

	Canada				United States			
	Original sample		Final sample		Original sample		Final sample	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Household income								
Under \$10K	22	7.7	14	6.9	45	13.8	23	11.0
\$10K-\$19K	34	11.9	22	10.8	40	12.3	21	10.0
\$20K-\$29K	30	10.5	15	7.4	31	9.5	16	7.7
\$30K-\$39K	25	8.7	19	9.4	39	12.0	22	10.5
\$40K-\$49K	28	9.8	20	9.9	40	12.3	27	12.9
\$50K-\$79K	56	19.6	43	21.2	60	18.5	47	22.5
\$80K or +	91	31.8	70	34.4	70	21.5	53	25.4
Sexual identity								
Lesbian	211	73.5	156	76.5	242	73.1	175	82.5
Queer	36	12.5	22	10.8	45	13.6	13	6.1
Gay	15	5.2	12	5.9	13	3.9	11	5.2
Bisexual	14	4.9	6	2.9	21	6.3	5	2.4
Unsure	4	1.4	3	1.5	1	0.3	1	0.5
Multiple	4	1.3	4	2.0	4	1.2	3	1.4
2-spirit	1	0.3	0	0.0	3	0.9	3	1.4
Other	2	0.7	1	0.4	2	0.8	1	0.5
Behavioural sexual orientation								
At first only with men now only with women	144	50.3	130	63.7	121	36.6	111	52.4
Women only	81	28.3	69	33.8	108	32.6	91	42.9
Both men & women	50	17.5	0	0.0	77	23.3	0	0.0
Not sexually active	6	2.1	5	2.5	11	3.3	9	4.2
At first only with women now with both men & women	3	1.0	0	0.0	7	2.1	0	0.0
At first only with men now with both men & women	2	0.7	0	0.0	6	1.8	0	0.0
At first with both men & women now only with women	0	0.0	0	0.0	1	0.3	1	0.5

Notes: Original samples:  $N = 287$  (CAN) and  $N = 331$  (USA). Final samples:  $N = 204$  (CAN) and  $N = 212$  (USA). Some variables have a few missing cases.

Table 2

*Continued*

	Canada				United States			
	Original sample		Final sample		Original sample		Final sample	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Currently partnered								
Yes	208	72.7	153	75.4	251	76.1	157	74.1
No	78	27.3	50	24.6	79	23.9	55	25.9
Partner sex								
Woman	202	97.5	151	98.7	238	95.2	154	98.7
Man	0	0.0	0	0.0	4	1.6	0	0.0
Other (e.g., trans)	5	2.5	2	1.3	8	3.2	2	1.3
Marital status								
Single	133	47.0	92	45.8	225	68.0	137	64.6
Common-law	66	23.3	45	22.4	7	2.1	5	2.4
Married	59	20.8	47	23.4	36	10.9	26	12.3
Civil union	3	1.1	2	1.0	19	5.7	14	6.6
Other (e.g., engaged, separated, widowed)	22	7.8	15	7.4	44	13.3	30	14.1
Hear about study								
Friend	101	35.2	74	36.3	69	20.8	39	18.4
Social networking site	64	22.3	45	22.1	33	10.0	25	11.8
Electronic listserv	47	16.4	38	18.6	87	26.3	49	23.1
Org/group	44	15.3	30	14.7	61	18.4	41	19.3
Publication	31	10.8	17	8.3	80	24.2	57	26.9
Other (google search)	0	0.0	0	0.0	1	0.3	1	0.5

*Notes:* Original samples:  $N = 287$  (CAN) and  $N = 331$  (USA). Final samples:  $N = 204$  (CAN) and  $N = 212$  (USA). Some variables have a few missing cases.

Table 3: Health Descriptives of Participant

	Canada				United States			
	Original sample		Final sample		Original sample		Final sample	
	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%	<i>n</i>	%
Chronic disease								
No	194	68.3	128	63.4	195	59.5	114	54.3
Yes	90	31.7	74	36.6	133	40.5	96	45.7
HCP								
Yes	255	89.2	204	100.0	293	88.5	212	100.0
No	32	10.8	0	0.0	38	11.5	0	0.0
Reasons for not having HCP								
Relocation	22	71.0	-	-	20	52.6	-	-
Accessibility	7	22.6	-	-	3	7.9	-	-
Financial	4	12.9	-	-	21	55.3	-	-
Other (e.g., no need, not sick)	9	29.0	-	-	17	44.7	-	-
Type of HCP								
Physician	225	88.2	177	86.8	223	76.1	167	78.8
Naturopath	8	3.1	8	3.9	5	1.7	4	1.9
Nurse practitioner	7	2.7	6	2.9	26	8.9	19	9.0
Gynecologist	2	0.5	1	0.5	16	5.5	6	2.8
Midwife	0	0.0	0	0.0	1	0.3	1	0.5
Other (e.g., specialist)	14	5.5	12	5.9	23	7.8	15	7.1
Health insurance								
Yes	234	81.8	170	83.3	292	88.2	195	92.0
No	52	18.2	34	16.7	39	11.8	17	8.0
Benefits covered								
Medical	231	82.2	166	81.4	288	98.6	192	91.0
Dental	219	76.3	160	78.4	209	71.6	146	69.2
Vision	212	73.9	154	75.5	185	63.4	130	61.6
Professional	200	69.7	153	75.0	193	66.1	143	67.8
Other (e.g., additional professional services)	17	5.9	13	6.4	5	1.7	4	1.9

Notes: Original samples:  $N = 287$  (CAN) and  $N = 331$  (USA). Final samples:  $N = 204$  (CAN) and  $N = 212$  (USA). Some variables have a few missing cases.

## Measures

**Demographics and descriptives.** The following demographic and descriptive information were collected: age, race/ethnicity (separate questions for US and Canadian participants; question for US participants adapted from US Census Bureau), income, current relationship status, sex of current intimate partner and length of relationship, country of residency, estimated population, highest level of education completed, and the presence (or absence) of children in the household. Two dimensions of sexual orientation are relevant in the current study and were assessed: self-identity (and how long women identified as such) and behaviour (i.e., sex of lifetime sexual partners; measure adapted from Bergeron, 1999). Information regarding where participants heard about the study was also collected. See Appendix A for questions capturing demographics and descriptives.

**Health information and descriptives.** Information was collected on health. Participants were asked how they would rate their overall current health, as well as how they would rate their health in comparison to other women their age (1 = *poor* to 5 = *excellent*). In addition, women were asked to compare their health now to five years ago (1 = *a lot less healthy now* to 5 = *a lot more healthy now*) (set of questions taken from Bergeron, 1999). Information regarding the diagnosis of chronic diseases (*yes* or *no* and if *yes*, what type) was also sought (Fogel, 2001). Participants were asked whether or not they have had a primary healthcare provider in the past year (*yes* or *no*, and if *no*, what are the reasons for this), as well as the type of provider they see most often for their primary healthcare needs (mainstream or alternative; Bergeron, 1999). Information on whether or not participants have a prescription drug plan/health insurance (as well as type

of plan and benefits covered) was also collected (questions adapted from Statistics Canada and US Census Bureau). See Appendix B for questions capturing health information and descriptives.

**Facilitators of disclosure.** The Disclosure Questionnaire (DQ; Fogel, 2001, 2005; see Appendix C) assesses many (but not all) of the hypothesized facilitators of disclosure falling under the dimensions of: patient attributes, healthcare environment, healthcare provider attributes, and patient-provider relationship. The DQ was developed to capture the likeliness of a lesbian woman's disclosure to healthcare providers, given a number of hypothetical situations. It is a 30 item, 7 point Likert scale (1 = *extremely unlikely to tell* to 7 = *very likely to tell*). The DQ uses if/then statements, i.e., *if the healthcare provider or the patient were to behave a certain way or exhibit certain traits, then disclosure would be more or less likely to occur*. The DQ is composed of two subscales, one assessing the facilitators of disclosure (18 total), and the other assessing the barriers (12 total). Facilitator items are summed to produce an overall likeliness to disclose score, where a higher score indicates greater likeliness of disclosure. Barrier items are summed to produce an overall unlikeliness to disclose score, where a lower score indicates greater unlikeliness of disclosure. Fogel (2001, 2005) reported strong psychometrics: Cronbach's alpha was .95 for the total scale (.93 for each subscale), and construct validity was supported.

The DQ is the most comprehensive and psychometrically sound tool available to assess the facilitators of lesbian disclosure in healthcare settings (Fogel, 2001). However, in its original form the DQ is not appropriate for assessing the real behaviours and traits (rather, its focus is on hypothetical situations) that are expected to be associated with



disclosure, which is one of the goals of the current study. Furthermore, the DQ captures *intentions* to disclose (i.e., what is the likelihood of disclosure) rather than *actual* disclosure (i.e., has disclosure to the patient's healthcare provider occurred or not), the focus of the current study. Consequently, some modifications to the DQ were required, and permission to alter the scale was obtained from the scale's author. First, the instructions for participants were adapted to reflect the focus on the presence of real and not hypothetical behaviours and traits. Instruction wording was changed from: "Given the situations below, how likely would you be to tell a healthcare provider your sexual orientation?" to "To what extent have you experienced the situations below?" Second, the question wording for all of the items was also altered from hypothetical situations (e.g., "If my healthcare provider treats me like everyone else, then I would be"; #1) to reflect participant perceptions regarding the presence of behaviours and traits (e.g., "My primary healthcare provider treats me like everyone else"; #1). Third, the Likert scale was changed from intentions (1 = *extremely unlikely to tell* to 7 = *very likely to tell*) to reflect whether or not a number of situations were untrue or true (1 = *completely untrue* to 7 = *completely true*). Fourth, additional items were added to the DQ to address facilitators that were found to be relevant to disclosure, but were not addressed in the original DQ. These items tap into participant perceptions of relevancy and disclosure (in addition to #12 which addresses the relevance of disclosing general personal information, a more specific question was added: "My sexual orientation is relevant to my healthcare"; #26; item falls under patient attributes); the primary healthcare provider's inclusion of the patient's partner ("My primary healthcare provider includes my partner (or would if I had a partner) in health related decision-making"; #27; item falls under HCP attributes), and

adherence to social justice values by the primary healthcare provider (“My primary healthcare provider has social justice values”; #28; item falls under HCP attributes). Fifth, two questions from the DQ related to health status were not included in the MDQ because they did not make sense in the context of the new format (“I need to have a test, such as a Pap test or rectal exam”; #22; and “I am in need of serious medical care, such as surgery”; #23; both items fall under patient attributes). It was expected that #14 (“My sexual behaviours put me at risk for HIV or other sexually transmitted diseases”) and questions from the health information and descriptives section would capture this facilitator of disclosure. And finally, sixth, the items from the barriers subscale were reverse coded to reflect the current study’s focus on facilitators of disclosure. The resulting measure is the Modified Disclosure Questionnaire (MDQ; see Appendix D).

Items from the MDQ also assess the following: use of self-protective strategies (#22; item falls under patient attributes); inquiry (#4), confidentiality (#17, #18), and safety (#19, #20, #21; items fall under healthcare environment); gender (#29), race (#30), and sexual orientation of the HCP (#31), as well as tolerance of and sensitivity toward lesbians (#1, and #2, #8, #9), and practical factors (#3, #5, #6; items fall under HCP attributes); and patient familiarity with their primary healthcare provider (#10, #24), as well as trust (#11; items fall under patient-provider relationship).

In summary, the Modified Disclosure Questionnaire is a 31 item scale that was adapted for the current study to assess whether patients’ perceptions of the presence of real behaviours and traits predict their actual disclosures to their primary healthcare providers. Higher scores indicate a greater presence of facilitators of disclosure. To determine the influence of each unique predictor of disclosure captured by the MDQ, I

initially planned to use average scores on individual items to represent certain facilitators, while creating subscales by averaging within subscales for others. However, there were problems with how I intended to use the MDQ, which led me to use individual items only, as described in depth in the section on Preliminary Data Analyses.

*Additional measures needed to assess facilitators of disclosure.* Some additional measures were needed to capture patient attributes not addressed by the MDQ. Patient socio-demographics (specifically, age, education, income, race, relationship status, and health status) were described previously in the Demographics and Health sections.

Two different patient attitudes were measured. An assessment of lesbian women's identification with feminism was captured by the Attitudes Toward Feminism and the Women's Movement Scale (FWM; Fassinger, 1994; see Appendix E). The FWM is a 10 item, 5 point Likert scale (1 = *strongly disagree* to 5 = *strongly agree*). Items are summed, and a higher score indicates a more positive attitude toward feminism and the women's movement. Fassinger (1994) reported strong psychometrics for the FWM: Cronbach's alpha for the scale was .89, and convergent and discriminant validity were supported.

An assessment of women's internalized homophobia was captured by the Lesbian Internalized Homophobia Scale (LIHS; Szymanski & Chung, 2001; see Appendix F). The LIHS is composed of five subscales, each assessing a distinct dimension of internalized homophobia: "(a) connection with the lesbian community: isolation versus social support; (b) public identification as a lesbian: passing and fear of discovery versus disclosure; (c) personal feelings about being a lesbian: self-hatred versus self-acceptance; (d) moral and religious attitudes toward lesbianism: condemnation versus tolerance and

acceptance; and (e) attitudes toward other lesbians: horizontal oppression/hostility versus group appreciation.” (Szymanski & Chung, 2001, p. 41). The LIHS is a 52 item, 7 point Likert scale (1 = *strongly disagree* to 7 = *strongly agree*). Items are averaged within and across subscales, and a higher score indicates a higher level of internalized homophobia. Szymanski and Chung (2001) reported strong psychometrics for the LIHS: Cronbach’s alpha for the total scale was .94, and construct validity was supported.

An assessment of lesbian women’s level of outness was captured by the Outness Inventory (OI; Mohr & Fassinger, 2000; see Appendix G). The OI has 11 items that assess the degree to which an individual is open about her sexual orientation, in different spheres of her life: family, religion, and world. The items are rated on a 7 point scale, ranging from 1 (*person definitely does not know about your sexual orientation status*) to 7 (*person definitely knows about your sexual orientation status, and it is openly talked about*). There is also another option, 0, for items that are not relevant to the participant (*not applicable to your situation; there is no such person or group of people in your life*). OI score is calculated by averaging within and across subscales, and a higher score indicates a higher level of openness about sexual orientation. In my previous work, Cronbach’s alpha for the OI was .95 (St. Pierre & Senn, 2010). Mohr and Fassinger (2000) also reported good discriminant validity for the OI.

Additional measures were needed to assess two aspects of the patient-provider relationship. An adaptation of the Approachability of Family Practice Consultations (AFPC; Hackett & Jacobson, 1995; see Appendix H) was used to measure patient comfort with and perceptions regarding approachability of their primary healthcare providers. The AFPC is composed of three subscales, each assessing distinct dimensions

of approachability: The Doctor, The Consultation Environment, and Emotions. There are 17 items on the original AFPC dichotomous (*agree* or *disagree*) scale. For the current study, The Consultation Environment subscale is not relevant (questions are too general for this study's focus, e.g., "Consultations with my doctor are a nice experience"; "My doctor's surgery is a nice place to be"; more specific questions on the literature in waiting room areas and the presence of gay and lesbian symbols were captured by the MDQ). Consequently, identical modifications made by Bergeron and Senn (2003) were adopted here. Specifically, The Consultation Environment subscale was removed and was not administered to participants; the dichotomous subscale was changed to a 5 point Likert scale (1 = *strongly disagree* to 5 = *strongly agree*) to be consistent with other measures employed in the current study; and the question wording was changed from "doctor" to "primary healthcare provider" to be more inclusive of all types of healthcare professionals. Also consistent with Bergeron and Senn, the resulting nine item scale was used as a single measure (e.g., "Being with my primary healthcare provider is not stressful"; #2; "I do not worry about making an appointment to see my primary healthcare provider"; #9). Items are summed, and a higher score indicates greater approachability of healthcare providers. Cronbach's alpha for the modified version of the AFPC was high (.94; Bergeron & Senn, 2003).

An adaptation of the Questionnaire on the Quality of Physician-Patient Interaction (QQPPI; Bieber et al., 2010; see Appendix I) was used to measure ease of communication between healthcare provider and patient. The QQPPI was developed to assess physician-patient interactions in the context of routine healthcare seeking. The scale evaluates, from the patient's perspective, the physician's communication skills, the

extent of patient involvement, and shared decision-making. It is a 14 item, 5 point Likert scale (1 = *I do not agree* to 5 = *I fully agree*). A few minor modifications to the instructions for completing the QQPPI were required because the scale was developed to assess physician-patient interactions immediately following patients' experiences with physicians. Specifically, "The following are a series of statements and assertions concerning today's consultation, including decisions and results" was changed to "The following are a series of statements and assertions concerning a typical consultation with your primary healthcare provider, including decisions and results" to tap into women's past interactions with primary healthcare providers. Correspondingly, item wording was also changed from present tense to past tense, and from "physician" or "doctor" to "primary healthcare provider". Finally, item wording for two questions (#10, #14) was changed from "illness" to "health-related issues" to be more inclusive of patient complaints which may not comprise illness. Examples of items from the QQPPI include: "My primary healthcare provider gives me detailed information about available treatment options" (#2) and "My primary healthcare provider gives me enough time to talk about all my problems" (#11). Items are averaged, and a higher score indicates a higher quality interaction between provider and patient, including better communication. The QQPPI was chosen for its good psychometrics and its ability to avoid ceiling effects. Cronbach's alpha was .95, and construct validity was supported.

**Disclosure of sexual orientation.** Disclosure of sexual orientation by lesbians to their primary healthcare provider was assessed by a question adapted from Johnson et al. (1981; Appendix J). The question inquires about the specifics regarding the context of the non/disclosure, and the options are as follows: *yes, I volunteered the information*

*without being asked; yes, I told when I was asked; I was asked but did not reveal this information; No, I have not told but I would like to; No, I have not told and would prefer not to; and other.* Individual levels were used in analyses.

**Health outcomes of disclosure.** A modified version of the Perceived Adherence Scale (PAS; Bergeron & Senn, 2003; see Appendix K) was used as a health outcome measure to report on the frequency of and perceived adherence to engagement in preventative self-care (take vitamins and herbs, exercise regularly, eat healthy foods, avoid unhealthy foods, get plenty of sleep, and do breast self-exams) and healthcare seeking (physical exam, cholesterol check, blood pressure check, mammogram, Pap smear, clinical breast exam). Three additional items were added to reflect other preventative self-care behaviours not captured by the PAS: avoid smoking cigarettes, excessive alcohol use, and illegal drug use. These unhealthy behaviours have found by some researchers to be particularly problematic in lesbians (e.g., Valanis et al., 2000). Also, one item was added to preventative healthcare seeking to reflect overall use of healthcare when needed. The modified PAS is a 17 item, 5 point Likert scale (1 = *never* to 4 = *frequently*, with an additional response option, 5, where a woman can indicate that she has engaged in the target preventative care behaviour, *as often as suggested*). As per the authors' recommendations, for women under the age of 50 who are not required to obtain mammograms, this item was recoded to 5 to reflect adherence to recommended care standards. In the original study, all items were summed to provide an overall engagement in preventative self-care and healthcare seeking score, where a higher score indicated more engagement in these positive health behaviours. In the current study, total engagement in preventative self-care was summed separately from total engagement in

healthcare seeking behaviours to obtain different scores for these two different types of behaviours. Bergeron and Senn (2003) reported that Cronbach's alpha for the PAS was high ( $> .85$ ).

**Open-ended questions.** Two open-ended questions were included as part of the current study. First, near the beginning of the survey women were asked to describe in their own words what factors would influence their decision to come out to their healthcare providers (see end of Appendix A). This question was meant to assess women's perceptions/experiences in an unstructured way that was unaffected by the survey's various measures. The second open-ended question was asked of participants who had disclosed their sexual orientation. Those who had disclosed were asked to describe the reactions of their HCP to this information (question adapted from Smith et al., 1985; see Appendix J).

## **Procedures**

Self-identified lesbian women aged 16 years or older currently living in Canada or the United States were invited to complete a password-protected online survey<sup>3</sup> titled: "An Online Study of Lesbians' Experiences with Healthcare Professionals" (see Appendix L for recruitment letter). Participants were asked to read and provide consent (see Appendix M for consent form) by clicking on the "I agree to participate, please take me to the survey!" link. The password for accessing the survey was included at the end of the online consent form. The demographics and descriptives section was presented first, followed by the open-ended question asking participants to describe what factors

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<sup>3</sup> The online survey was programmed manually. An HTML editor (Crimson Editor) was used to create the survey and files were uploaded to the University of Windsor server using file transfer protocol (ftp) software. Sherri Simpson, who was Senior Web Developer (Web Services Group at the university) at the time the survey was developed, contributed extensive support and guidance.



would influence their willingness to disclose to healthcare providers. The section on health information and descriptives was presented next, followed by the disclosure questions and the Modified Disclosure Questionnaire. To control for possible order effects, the following scales were presented in a randomized order: Attitudes Toward Feminism and the Women's Movement Scale, Lesbian Internalized Homophobia Scale, Outness Inventory, Approachability of Family Practice Consultations, Questionnaire on the Quality of the Physician-Patient Interaction, and the Perceived Adherence Scale. Of these scales, participants who did not have a primary healthcare provider completed the Attitudes Toward Feminism and the Women's Movement Scale, Lesbian Internalized Homophobia Scale, Outness Inventory, and the Perceived Adherence Scale. Upon exiting the survey, participants were provided with the resource letter (see Appendix N). For the few women who preferred to complete a paper copy of the survey, a survey package with pre-paid postage was mailed to them (consent was implied if the survey was completed and returned).

## CHAPTER IV

### RESULTS

#### Preliminary Data Analyses

SPSS version 21 was used to conduct all univariate and bivariate analyses. To justify the examination of two separate samples (CAN and USA), bivariate analyses (*t*-test for continuous and chi-square for categorical variables) were conducted on key variables. Several significant differences between the two countries were found, including a greater proportion of Americans having some graduate training or higher,  $\chi^2(2, N = 616) = 19.95, p < .001$ ; a greater proportion of Canadians earning in the highest income quartile  $\chi^2(2, N = 611) = 8.16, p < .05$ ; a greater proportion of Americans indicating that they had a chronic disease,  $\chi^2(1, N = 612) = 5.16, p < .05$ ; a greater proportion of Canadians not having a prescription drug plan,  $\chi^2(1, N = 617) = 5.00, p < .05$ ; a greater proportion of Americans not having access to vision [ $\chi^2(1, N = 616) = 21.82, p < .001$ ], dental [ $\chi^2(1, N = 616) = 12.67, p < .001$ ], or professional services [ $\chi^2(1, N = 616) = 8.69, p < .01$ ] covered as part of their health insurance plan; a greater proportion of Americans reporting financial barriers as a reason why they did not have a healthcare provider [ $\chi^2(1, N = 69) = 15.64, p < .001$ ]; and Americans engaging in preventative health behaviours more frequently [ $t(539.50) = 2.73, p < .01$ ]. These significant differences confirmed the distinctness of the samples. Subsequently, all analyses were conducted separately on each sample.

Given the notable proportion of bisexually active women, potential differences between these women and those reporting exclusive involvement with other women were explored. Researchers tend to lump sexual minority women together; however, without

justification this is not considered best practice as some studies reviewed earlier in this document suggest important variations within these diverse communities. No significant differences were found for the Canadian sample. However, three important differences – all favouring women who have sex exclusively with women – were found for the American sample: a greater proportion of these women earned in the highest income quartile [ $\chi^2(2, N = 325) = 8.24, p < .05$ ]; a greater proportion had access to professional services as part of their health insurance plan [ $\chi^2(1, N = 330) = 10.92, p < .01$ ]; and their average scores on the QQPPI, assessing ease of communication between practitioner and patient, were significantly higher than were those of bisexually active women [ $t(114.94) = 2.62, p < .05$ ]. As this research was conceptualized and designed to specifically focus on the experiences of lesbian women who are intimate with other women, it is beyond this study's scope to examine and compare the health and healthcare seeking experiences of various sexual minority groups. Therefore, bisexually active women (about 20% and 30% of the Canadian and American samples respectively:  $n = 56$  CAN;  $n = 91$  USA) were excluded from all subsequent analyses, leaving the  $N$ s for each sample at 231 (CAN) and 240 (USA).

Other women who were excluded from *quantitative* analyses were those who did not have a primary healthcare provider at the time data collection took place (about 12% of each sample:  $n = 27$  CAN;  $n = 28$  USA). These women would not have had the opportunity to disclose their sexual orientation and so their experiences were not relevant to testing the LDH model. Of note, differences on key variables were found between those who reported having an HCP and those who did not. These included: women earning in the highest income quartile being more likely to have an HCP, for both

countries [ $\chi^2(2, N = 229) = 7.81, p < .05$  for CAN;  $\chi^2(2, N = 237) = 11.98, p < .01$  for USA]; for the American sample only, women who did not have health insurance were less likely to have an HCP [ $\chi^2(1, N = 240) = 14.90, p < .01$ ]; for the American sample only, women who had higher scores on global outness were more likely to have an HCP [ $t(35.78) = 1.96, p = .06$ ; please note that this finding was approaching significance]; and for both countries, women who had an HCP engaged in preventative healthcare seeking behaviours more frequently than those who did not [ $t(35.95) = 6.60, p < .001$  for CAN;  $t(33.40) = 6.76, p < .001$  for USA]. Excluding women who did not have a primary healthcare provider left the total, final sample *Ns* at 204 (CAN) and 212 (USA).

The assumptions of Structural Equation Modeling (SEM) were examined to ensure that no serious violations occurred. The assumptions of linearity and homoscedasticity were met. Regarding normality, all variables were normally distributed, with the exception of a few items from the MDQ (#7, #14, and #15 for both countries, with the addition of #6 for USA), and scores on the LIHS. Using Kline's (2005) criteria, skewness and kurtosis values for the MDQ items were not considered a serious violation of this assumption. However, the skewness and kurtosis values for the LIHS, measuring internalized homophobia (IH) were problematic for the American sample. Specifically, scores were clustered toward the lower end of the scale, indicating lower levels of IH. An examination of the five subscales of the LIHS was undertaken to determine whether one subscale was more normally distributed, had better variability in scores, and could be used as a proxy for internalized homophobia. Scores from the public identification as a lesbian subscale were normally distributed and had the greatest variability in scores. Of the five LIHS subscales, concerns about publically identifying as

a lesbian to others may be one of the most relevant dimensions of internalized homophobia in the context of healthcare seeking. For these reasons, scores on this subscale were used in all analyses as a snapshot of internalized homophobia. It is worth noting that the correlations between the LIHS public identification subscale and global outness were moderate for both samples ( $<.50$ ), suggesting that actual fears related to public disclosure (e.g., actively trying to ‘pass’ as heterosexual; worrying about being seen in public with other lesbian women and being ‘guilty by association’) are distinct from the construct ‘global outness’ (i.e., how open women are about their sexual orientation to family, friends, acquaintances, and at work).

Z-scores were computed to search for univariate outliers, and Mahalanobis distance was calculated to assess for multivariate outliers. Only the former were found. Several transformations were performed to try to reduce the impact of these outliers; however, none of these eliminated the extreme scores. More problematically, though, the transformations made previously normally distributed variables non-normal. Because Tabachnick and Fidell (2007) suggest that some univariate outliers are to be expected with large data sets, these were included in main analyses. It is also worth mentioning that lesbian women are typically considered “outliers” in standard psychological research; therefore, the inclusion of experiences that are considered “outliers” here is important if we are to a) appreciate the full scope of women’s lived experiences; and b) more fully understand the health and healthcare experiences of diversely-situated lesbian women.

Patterns of missing data were explored for every variable in the dataset. All key variables had less than 5% of data missing. Missing data is a problem when employing

SEM procedures. Specifically, SPSS Amos, the statistical software package used to run all SEM analyses, will not accept a data file with even one missing value. Because so few data points were missing, mean replacement was used. [It is worth noting that preliminary findings reported here were similar, regardless of whether listwise deletion or value estimation through mean replacement was implemented.] Listwise deletion was not an option in the current study as many participants had only one or very few missing data points; deleting these participants listwise for SEM analysis purposes would have depleted the samples.

Internal consistencies of all scales used in the current study were evaluated using Cronbach's alpha. All scales, except for the PAS and the MDQ, showed adequate to excellent reliabilities. One of the PAS subscales, self-care, showed marginally acceptable Cronbach's alphas for both samples. This scale was originally used by Bergeron and Senn (2003) as an overall scale (not two separate subscales) to provide an assessment of women's engagement in preventative behaviours. Thus, the internal consistency of the overall scale was computed and found to be considerably better. As the use of psychometrically sound measures is a key principle in SEM, all analyses were conducted using the overall PAS scale as the outcome measure.

Similarly, subscales from the MDQ were found to have poor reliabilities. Smaller subscales were created for the current study by averaging within these subscales; however, most of these had low reliabilities (e.g., .40 or lower for the safety and confidentiality subscales). Clearly, the newly created subscales did not hold together well; therefore, an exploratory factor analysis (EFA) was conducted to examine the factor structure of the MDQ. Before conducting the EFA, each item on the MDQ was

examined for variability in scores, and any item with limited variability (80% or more of scores clustered at low or high end of scale) was excluded from the EFA. For both samples, there were issues with variability on items 1, 5, 7, 14, 15, 19, 20, 22, 23, 29, 30, and 31. [For example, the majority of women reported that: they had never heard their HCPs make negative comments about LGBT people (#7); their sexual behaviours did not put them at risk for HIV or other STIs (#14); none of their HCPs had mostly religious-based materials in their offices (#19); none of their HCPs had LGBT positive symbols in their offices (#20); and that most shared the same gender (#29) and ethnic background as their HCPs (#30), but almost none had sexual minority HCPs (#31)]. Thus, correlation matrices were analyzed for the 19 items on the MDQ that had good variability using the principal components method. These items included: 2-4, 6, 8, 9-13, 16-18, 21, 24-28 for both samples. Consideration of the Kaiser criterion and scree plot revealed a 2-4 factor model. Direct Oblimin rotation was used to facilitate interpretation, yet it still was not clear whether 2, 3, or 4 factors best represented the dimensions of the MDQ. Each solution was examined independently, as well as the associated internal consistencies of each dimension. The Cronbach's alphas were still unacceptably low. When considering the initial purpose of the Disclosure Questionnaire – to measure facilitators and barriers of disclosure (i.e., two subscales) – it would make sense that additional dimensions would not be present. In the current study, all barrier items were reverse coded so that only facilitators were considered, and so only one scale was used. When the internal consistency of the MDQ as an overall scale was examined, Cronbach's alpha improved substantially for both samples and was acceptable. Consequently, the 19 items with good variability from the MDQ were used as indicators of the latent factor “facilitators of

disclosure”, so that the extent to which each represents this unobserved variable could be assessed. Table 4 shows the reliability coefficients, means, standard deviations, and the actual and possible ranges for all scales used in the current study.

Table 4: Reliability Coefficients, Means, Standard Deviations, and Ranges for Scales Used in Analyses

Measure	Cronbach's alpha	Mean	Standard deviation	Possible range	Actual range
Current health	.77	3.46	.81	1-5	1-5
	.81	3.26	.93		1-5
FWM	.81	40.72	5.62	10-50	25-50
	.80	41.09	5.68		16-50
LIHS public subscale	.90	1.94	.95	1-7	1-5.63
	.90	1.99	1.00		1-6.44
OI	.73	3.90	1.24	0-7	1.10-7
	.78	4.05	1.47		.80-7
MDQ	.75	85.68	13.42	19-133	47-114
	.73	85.47	13.17		50-117
AFPC	.93	35.79	8.58	9-45	13-45
	.90	36.09	7.67		11-45
QQPPI	.97	3.94	1.05	1-5	1.29-5
	.97	4.14	.90		1.14-5
PAS	.82	62.99	10.45	17-85	35-85
	.81	63.92	10.00		30-85

*Notes:* A higher score on the LIHS public identification subscale indicates higher levels of IH. The statistics for the Canadian sample are presented first, followed by the statistics for the American sample.

To screen for multicollinearity, and also, the possibility that there would be no relationship between the predictors (facilitators of disclosure), the mediator (disclosure), and the outcome variable (preventative self-care/healthcare seeking), intercorrelations were examined (please see Tables 5-8). There was no evidence of multicollinearity. There were, however, a few predictor variables that were not significantly associated with disclosure or the health outcome. Predictors not significantly associated with the



mediator and the outcome were excluded from testing the LDH. For both samples, these were:

- Patient's ethnic background (white/women of color; Table 5);
- Health insurance (yes/no; Table 5);
- Negative reactions by past HCPs to disclosure of sexual orientation (MDQ #25; Table 7).

For the Canadian sample only:

- Current relationship status (in relationship/not in relationship; Table 5).

For the American sample only:

- Current health (Table 5);
- Affinity toward feminism (score on FWM; Table 5);
- Confidentiality (MDQ #17; Table 6);
- Type of HCP (traditional/non traditional; Table 6);
- Practical factors (MDQ #3; Table 7);
- Familiarity with HCP (MDQ #10; Table 8);
- Trust in HCP (MDQ #11; Table 8).

Table 5: Intercorrelations Between Patient Variables, Disclosure, and Preventative Care

Variable	Disclosure	Preventative care (score on PAS)
Age	.39**	.50**
	.36**	.49**
Education	.22**	.26**
	.27**	.36**
Income	.34**	.29**
	.25**	.27**
Ethnic background (white/women of color)	.13	.00
	.08	.10
Relationship status (in relationship/not)	.07	.09
	.30**	.09
Current health	.10	.29**
	.03	.13
Health insurance (yes/no)	.05	.13
	.05	.11
Relevance (MDQ #12)	.37**	.45**
	.43**	.26**
Relevance (MDQ #26)	.39**	.21**
	.33**	.17*
Feminism (score on FWM)	.20*	.13
	-.06	-.02
IH (score on LIHS subscale)	-.30**	-.29**
	-.42**	-.17*
Degree of outness (degree of outness)	.29**	.22**
	.30**	.24**

Notes: \* $p < .05$  level. \*\*  $p < .01$ . The correlations for the Canadian sample are presented first, followed by the correlations for the American sample.

Table 6: Intercorrelations Between Healthcare Environment Variables, Disclosure, and Preventative Care

Variable	Disclosure	Preventative care (score on PAS)
Safety (MDQ #21)	.17* .22**	.16* .12
Confidentiality (MDQ #17)	-.14* .06	-.17* -.02
Confidentiality (MDQ #18)	-.60** -.48**	-.40** -.18*
Type of HCP (traditional/non-traditional)	.04 .04	.16* .01
Inquiry on sexual orientation (MDQ #4)	.28** .32**	.26** .11

Notes: \* $p < .05$  level. \*\*  $p < .01$ . The correlations for the Canadian sample are presented first, followed by the correlations for the American sample.

Table 7: Intercorrelations Between Healthcare Provider Variables, Disclosure, and Preventative Care

Variable	Disclosure	Preventative care (score on PAS)
Sensitivity (MDQ #2)	.39** .39**	.31** .29**
Sensitivity (MDQ #8)	.28** .30**	.32** .19**
Sensitivity (MDQ #9)	.48** .49**	.38** .23**
Negative reaction (MDQ #25)	-.11 -.01	.00 -.03
Social justice (MDQ #28)	.32** .39**	.35** .25**
Practical factors (MDQ #3)	.27** .08	.26** .00
Practical factors (MDQ #6)	.25** .25**	.32** .03
Inclusion of partner (MDQ #27)	.39** .38**	.48** .33**

Notes: \* $p < .05$  level. \*\*  $p < .01$ . The correlations for the Canadian sample are presented first, followed by the correlations for the American sample.

Table 8: Intercorrelations Between Patient-Provider Relationship Variables, Disclosure, and Preventative Care

Variable	Disclosure	Preventative care (score on PAS)
Patient comfort (score on AFPC)	.36** .37**	.53** .32**
Familiarity with HCP (MDQ #10)	.20* .10	.25** .14
Familiarity with HCP (MDQ #13)	.07 .12	.15* .17*
Familiarity with HCP (MDQ #24)	.10 .19**	.26** .13
Patient trust in HCP (MDQ #11)	.30** .09	.43** .12
HCP communication (score on QQPPI)	.29** .32**	.47** .25**

*Notes:* \* $p < .05$  level. \*\*  $p < .01$ . The correlations for the Canadian sample are presented first, followed by the correlations for the American sample.

### Main Analyses: Quantitative

**Structural equation modeling.** SPSS Amos version 20 was used to run all SEM analyses. Relationships between the predictors, the mediator, and the outcome were specified separately by country. Model specification was based on theoretical considerations as well as preliminary bivariate data analyses. Hypothesized relationships between variables were estimated through Maximum Likelihood (ML), the most common method of parameter estimation (Kline, 2005). What is of primary interest in SEM are the path coefficients – interpreted as regression weights – associated with each parameter estimate.

Several steps were involved in SEM analyses to assess how well the LDH model fit the data for each sample (Byrne, 2010). First, estimates were calculated simultaneously for each model using ML procedures. Individual estimates (e.g., unstandardized and standardized regression weights) were next reviewed for their

significance. Several goodness-of-fit indices were consulted to determine how well the overall model fit the data for each sample (please see Table 9 for an overview of some of the most commonly used goodness-of-fit indices and their cutoff values). The model fit for both countries was not acceptable, therefore, modifications were considered to improve fit. At that point, analyses became exploratory and post-hoc (Byrne, 2010). Non-significant paths were first dropped from the model. Next, I attempted to further improve model misspecification by consulting modification indices (MIs), and paths were added to the model based on how much improvement these added to overall model fit. An overview of model specification and evaluation, presented separately by country, follows.

Table 9: Evaluation of Goodness-of-Fit Indices

Goodness-of-fit index	Evaluation	Interpretation
$\chi^2$	Non-significant ( $p > .05$ )	Validity in specification of model
Comparative fit index (CFI)	0 no fit 1 perfect fit	$\geq .95$ good model fit
Tucker Lewis Index (TLI)	0 no fit 1 perfect fit	$\geq .95$ good model fit
Root mean square error of approximation (RMSEA)	0 perfect fit .08 acceptable fit	$< .05$ good model fit $> .08$ poor fit

*Notes:* Byrne (2010) and Kline (2005) were consulted for the evaluation and interpretation of goodness-of-fit statistics.

***The LDH model for the Canadian sample.*** The LDH model for the Canadian sample ( $N = 204$ ) is specified in Figure 6. The specified LDH model for the Canadian sample poorly fit the data, as can be seen from the goodness-of-fit statistics shown in Table 10. Post-hoc modifications were required. A review of individual parameter

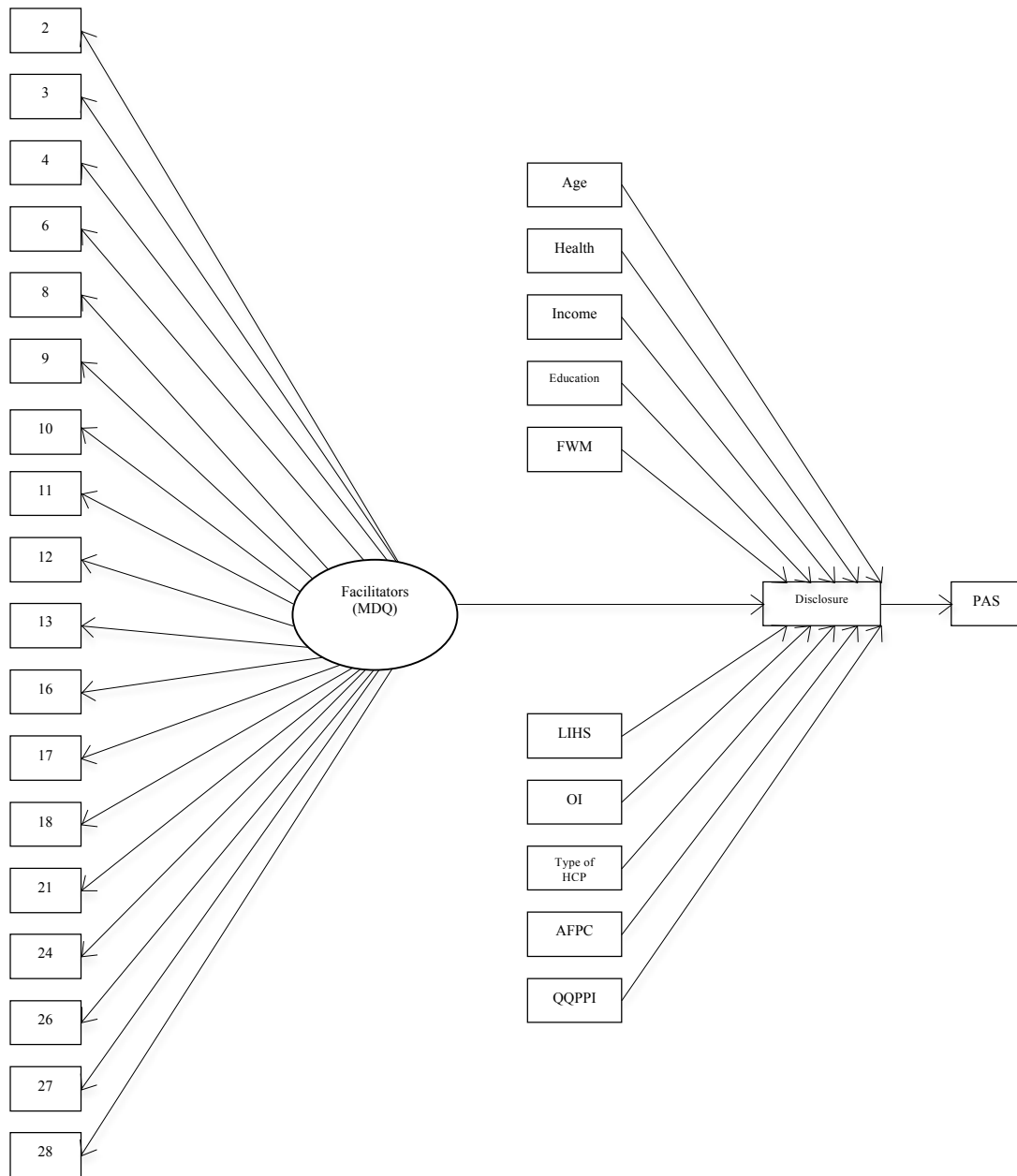


Figure 6: Initial LDH model (Canadian sample)

This figure illustrates the initial LDH model specified for the Canadian sample. As is standard in SEM literature, a rectangle represents an observed (directly measured) variable, whereas, an ellipse represents an unobserved (latent, not measured) variable. Variables on the far left represent items from the MDQ, which are considered to be reflections of the latent variable ‘facilitators’.

Table 10: Summary of Goodness-of-Fit Indices for LDH Model (Canadian Sample)

Model	$\chi^2$ (df)	CFI	TLI	RMSEA
Hypothesized model	1467.19(402) <i>p</i> < .001	.477	.434	.114
Dropped health, education, FWM, LIHS, OI, type of HCP, MDQ17	1095.61(230) <i>p</i> < .001	.511	.462	.136
Added direct paths from age, AFPC, and QQPPI to PAS	780.51(225) <i>p</i> < .001	.686	.647	.110

estimates revealed several non-significant paths, including: health, education, feminism, internalized homophobia, outness, and type of HCP to disclosure, and facilitators to MDQ17. These seven pathways were trimmed from the model, and estimates were recalculated. Model fit marginally improved. A review of the MIs suggested that the following direct pathways should be added to the PAS: age, AFPC, and QQPPI. Once again, model fit improved, but still did not meet acceptable cut-off levels. Clearly, there were issues with the conceptualization and specification of the LDH model. The final, closest fitting model with standardized regression coefficients is depicted in Figure 7. As can be seen from the model, the latent construct ‘facilitators’ (represented by items from the MDQ) was positively and directly associated with greater disclosure, as were older age, higher income, greater comfort (score on AFPC; not significant), and poorer communication with one’s HCP (score on QQPPI). Older age, greater comfort, and better communication with one’s HCP (not significant) were directly related to greater engagement in preventative health and healthcare seeking behaviours (PAS). And finally, greater disclosure was associated with higher scores on the PAS. The items from the MDQ which best represented (i.e., had the highest factor loadings on) the construct ‘facilitators’ were: #2 (HCP is sensitive to LGBT issues), #8 (HCP has experience

treating LGBT), #9 (HCP is LGBT friendly), #11 (patient trust in HCP), #27 (HCP inclusion of partner), and #28 (HCP has social justice values).

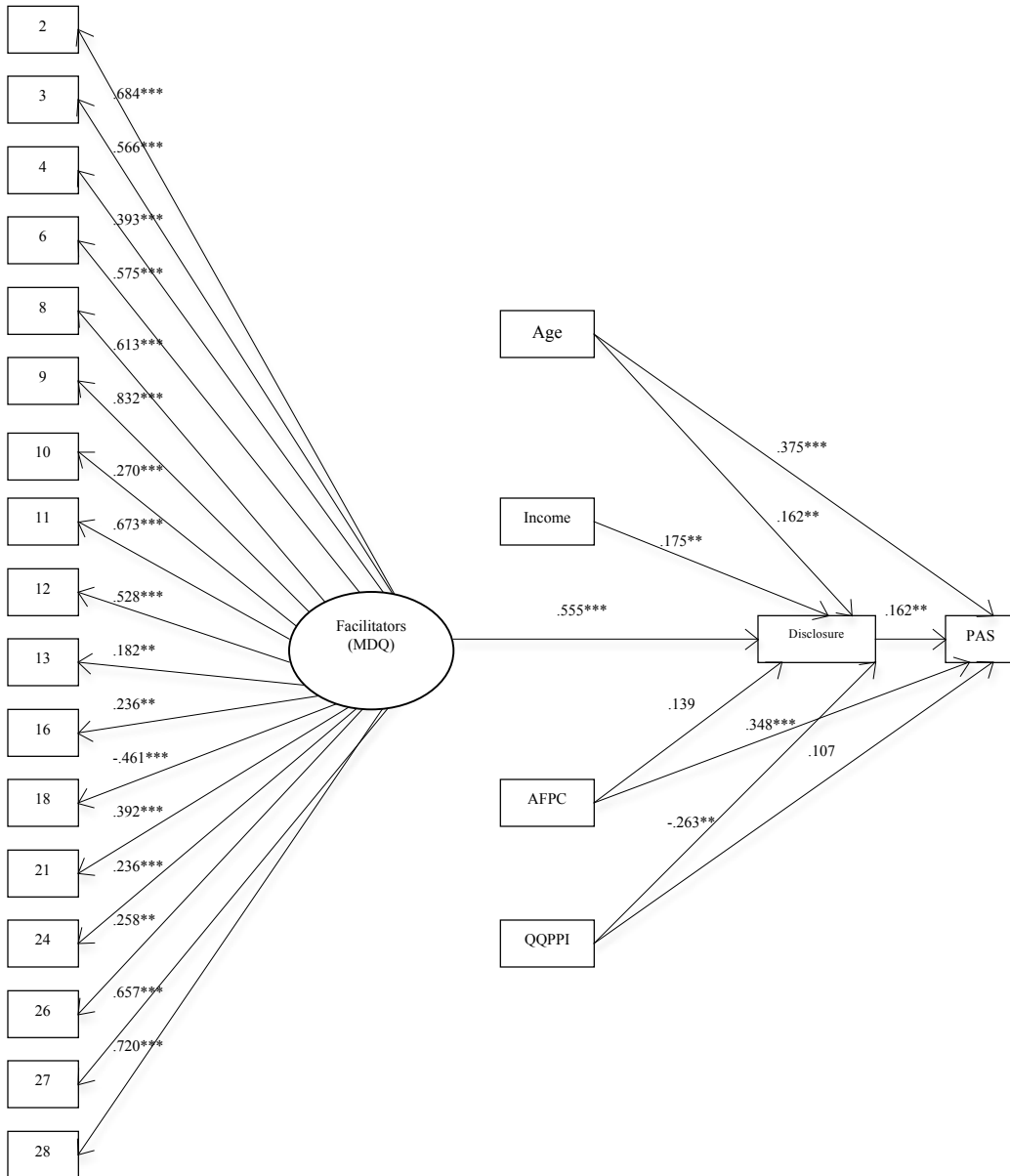


Figure 7: Best fitting LDH model (Canadian sample)

This figure shows the best fitting LDH model for the Canadian sample. Standardized regression weights are included to depict the strength and direction of relationships. All pathways except AFPC to disclosure, and QQPPI to PAS, are significant at the .01 (\*\*) or .001 (\*\*\*) level.



***The LDH model for the American sample.*** The LDH model for the American sample ( $N = 212$ ) is specified in Figure 8. The specified LDH model for the American sample poorly fit the data, as can be seen from the goodness-of-fit statistics shown in Table 11. Post-hoc modifications were required. A review of individual parameter estimates revealed several non-significant paths, including: education, income, outness, AFPC, and QQPPI to disclosure. These five pathways were trimmed from the model, and estimates were re-calculated. Model fit improved but was still inadequate. A review of the MIs suggested that a direct pathway from age to the PAS should be added. Once again, model fit improved, but still did not meet acceptable cut-off levels. Clearly, there were issues with the conceptualization and specification of the LDH model for the American sample as well. The final, closest fitting model with standardized regression coefficients is depicted in Figure 9. As can be seen from the model, the latent construct ‘facilitators’ (represented by items from the MDQ) was positively and directly associated with greater disclosure, as were being older, being partnered, and lower internalized homophobia. Disclosure and being older were linked with greater healthcare seeking.

Table 11: Summary of Goodness-of-Fit Indices for LDH Model (American Sample)

Model	$\chi^2$ (df)	CFI	TLI	RMSEA
Hypothesized model	1022.547(250) $p < .001$	.520	.470	.121
Dropped education, income, OI, AFPC, and QQPPI	447.721(152) $p < .001$	.719	.684	.096
Added direct path from age to PAS	408.794(151) $p < .001$	.755	.723	.090

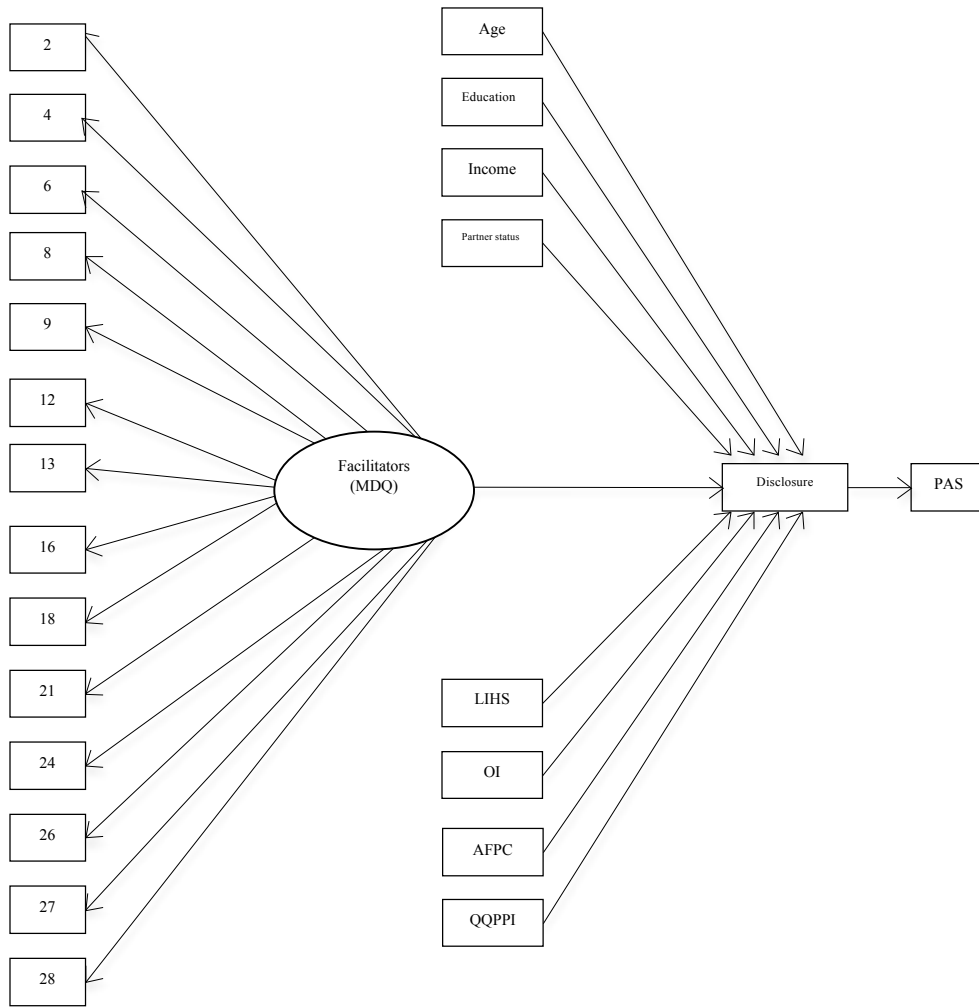


Figure 8: Initial LDH model (American sample)

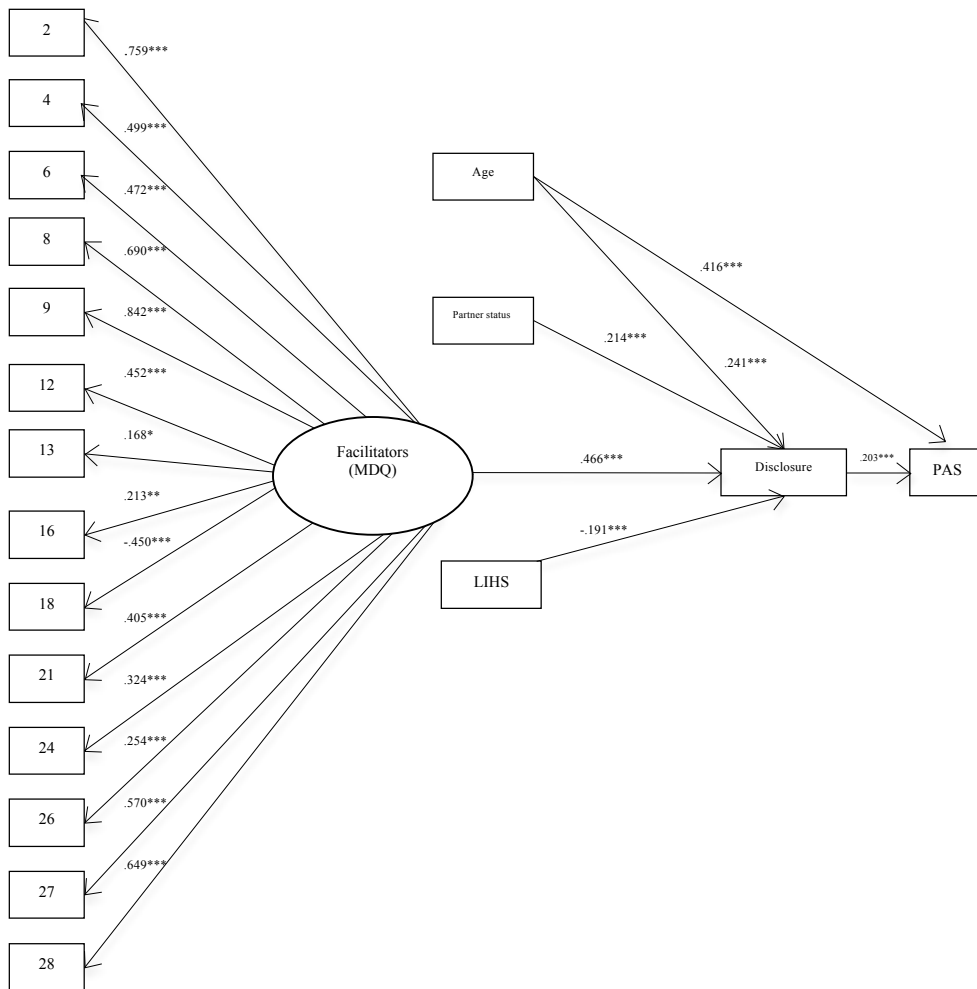


Figure 9: Best fitting LDH model (American sample)

This figure shows the best fitting LDH model for the American sample. Standardized regression weights are included. All pathways are significant at the .05 (\*), .01 (\*\*), or .001 level (\*\*\*).

The items from the MDQ which best represented (i.e., had the highest factor loadings on) the construct ‘facilitators’ were: #2 (HCP is sensitive to LGBT issues), #8 (HCP has experience treating LGBT people), #9 (HCP is LGBT friendly), and #28 (HCP has social justice values).

In summary, the modified LDH models did not represent the data well for either sample, likely due to model misspecification. Because I ultimately wanted to build a model of facilitators to and health outcomes of disclosure that best represented the data, I went back to the literature to see whether I could start by specifying a model that had already been found to be empirically valid, and work on adding key variables to this model based on my own work. Reviewed earlier in this document, two such path models were closely related to the current study and were thus considered and tested separately with both samples: a simple model of factors predicting regular healthcare use by Steele et al. (2006) and the more comprehensive healthcare utilization framework postulated by Bergeron and Senn (2003). All subsequent analyses were exploratory and post-hoc.

*Steele et al. (2006) model.* The specified model of factors predicting regular healthcare use from Steele et al. is depicted in Figure 10. In their study, global outness and provider gay-positivity were positively and directly related to disclosure, which in turn was associated with greater healthcare use. Global outness was also directly associated with healthcare use, albeit in a negative way. And finally, poorer health was associated with greater healthcare use. None of the variables in the current study were measured in the same way as compared to Steele et al., who developed most of their survey items for their study.

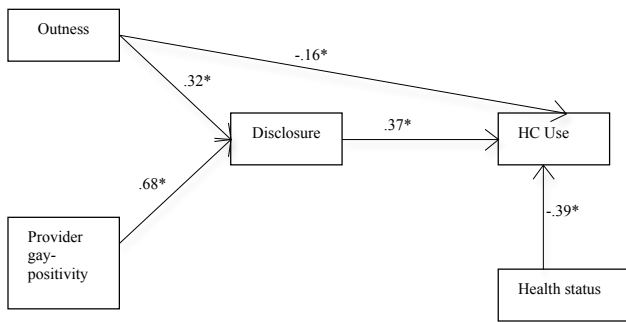


Figure 10: Specified path model predicting healthcare use (Steele et al., 2006)

This figure shows the specified model of factors predicting regular healthcare use from Steele et al. This model was tested and found valid with 387 Canadian lesbian women. Path coefficients, as reported by the authors, are included. All pathways were significant at the .05 (\*) level.

***Steele et al. model (2006) tested on Canadian sample.*** The Steele et al. model was tested on the Canadian sample. The original model as specified by the authors did not fit the data adequately, as can be seen from the goodness-of-fit statistics shown in Table 12. Post-hoc modifications were required. A review of individual parameter estimates revealed that all paths were significant. Consulting the modification indices indicated that a direct pathway from MDQ9 to PAS should be added. Fit improved and met cutoff criteria. The final, adapted version of the Steele et al. model is depicted in Figure 11.

Table 12: Summary of Goodness-of-Fit Indices for Steele et al. (2006) Model (Canadian Sample)

Model	$\chi^2$ (df)	CFI	TLI	RMSEA
Model as specified by Steele et al.	11.158(4) $p < .05$	.946	.866	.094
Added direct path from MDQ9 to PAS	3.096(3) $p > .05$	.999	.998	.013

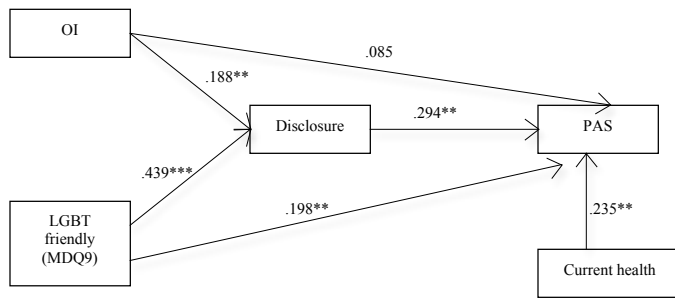


Figure 11: Final model adapted from Steele et al. (2006) (Canadian sample)

This figure shows the final model adapted from Steele et al. Standardized regression weights are included. All pathways except OI to PAS are significant at the .01 (\*\*) or .001 (\*\*\*) level.

There are three differences between this version of the model and the original. For the current study: better health (as opposed to poorer health) lead to greater healthcare use; the direct relationship between outness and healthcare use was not found to be significant; and there is a direct path from LGBT-friendly to healthcare use.

***Steele et al. model (2006) tested on American sample.*** The Steele et al. model was tested on the American sample. The original model as specified by the authors fit the data well, as can be seen from the goodness-of-fit statistics shown in Table 13. The replicated Steele et al. model is depicted in Figure 12. This version of the model was similar to the original, with two exceptions: in the current study, current health was not significantly associated with healthcare seeking, and outness was positively (as opposed

Table 13: Summary of Goodness-of-Fit Indices for Steele et al. (2006) Model (American Sample)

Model	$\chi^2$ (df)	CFI	TLI	RMSEA
Model as specified by Steele et al.	2.197(4) $p > .05$	1.000	1.041	.000

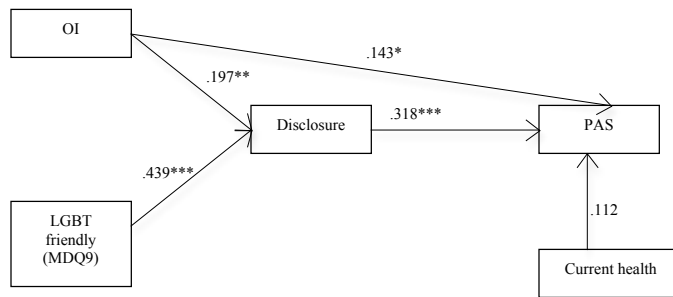


Figure 12: Final model replicated from Steele et al. (2006) (American sample)

This figure shows the final model replicated from Steele et al. Standardized regression weights are included. All pathways except current health to PAS are significant at the .05 (\*), .01 (\*\*), or .001 (\*\*\*) level.

to negatively) related to healthcare seeking.

**Bergeron and Senn (2003) model.** The specified healthcare utilization path model from Bergeron and Senn is depicted in Figure 13. In their study, higher education was directly related to: greater affinity toward feminism, disclosure, and greater use of healthcare services. Feminism (FWM) was associated with lower levels of internalized homophobia, which in turn predicted greater global outness. A feminist identity was also directly related to greater outness, which thereafter predicted greater disclosure. Higher levels of disclosure to one's HCPs predicted greater healthcare use. And finally, comfort with HCPs (score on AFPC) lead directly to healthcare use. All variables, except for global outness, were measured using the same scales as Bergeron and Senn.

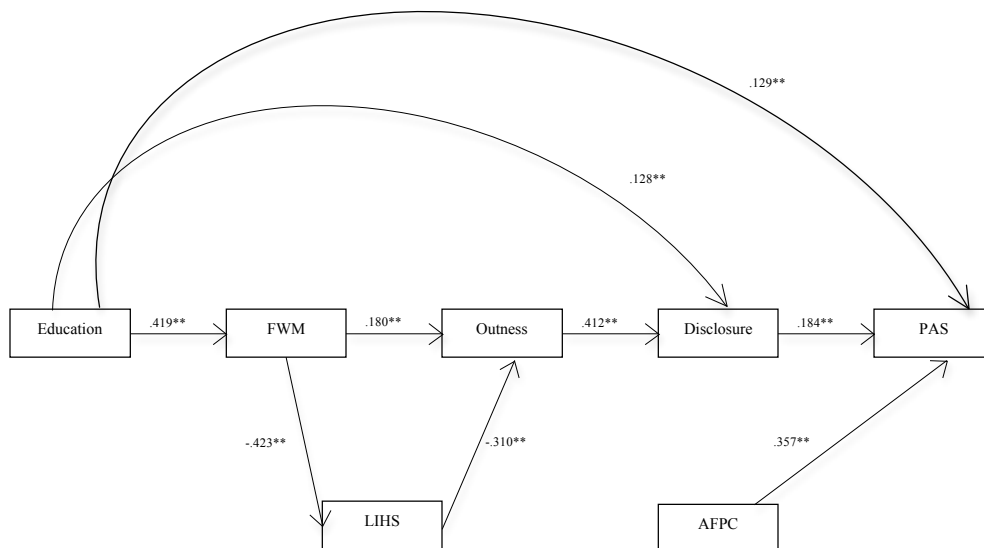


Figure 13: Specified path model predicting healthcare use (Bergeron & Senn, 2003)

This figure shows the specified healthcare utilization path model from Bergeron and Senn. This model was tested and found valid with 254 Canadian lesbian women. Path coefficients, as reported by the authors, are included. All pathways are significant at the .01 (\*\*) level.

***Bergeron and Senn (2003) model tested on Canadian sample.*** Bergeron and Senn’s model was tested on the Canadian sample. The original model as specified by the authors did not fit the data well, as can be seen from the goodness-of-fit statistics shown in Table 14. Post-hoc modifications were required. A review of individual parameter estimates revealed that all paths were significant. Consulting the modification indices indicated that a direct pathway from LIHS to AFPC, and one from AFPC to disclosure, should be added. Estimates were re-calculated, and fit improved to the point where cutoff criteria were met. The final, adapted version of the Bergeron and Senn model is depicted in Figure 14. There are three differences between this version of the model

Table 14: Summary of Goodness-of-Fit Indices for Bergeron & Senn (2003) Model (Canadian Model)

Model	$\chi^2$ (df)	CFI	TLI	RMSEA
Model as specified by Bergeron and Senn	58.206(12) $p < .001$	.797	.645	.138
Added direct paths from LIHS to AFPC and AFPC to disclosure	14.411(10) $p > .05$	.981	.959	.047



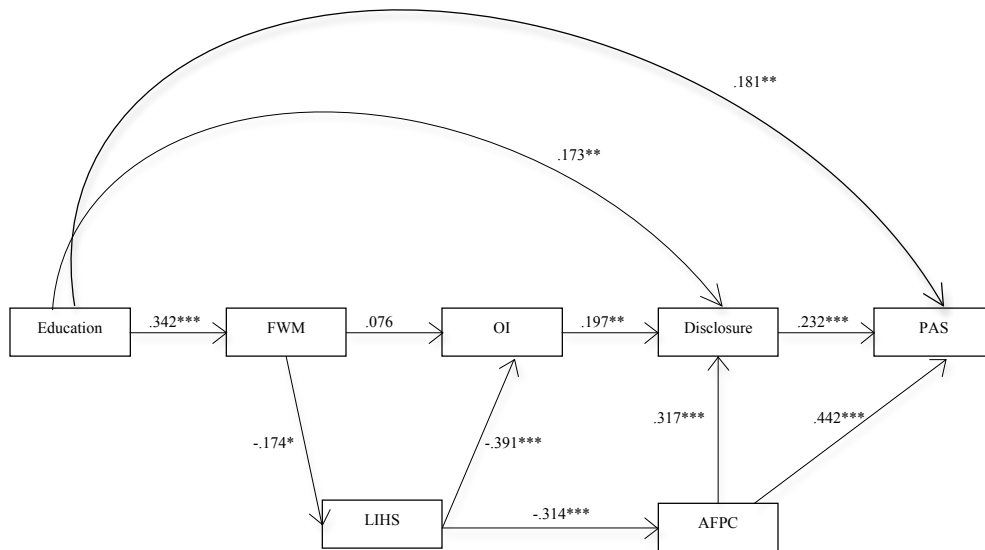


Figure 14: Final model adapted from Bergeron and Senn (2003) (Canadian sample)

This figure shows the final model adapted from Bergeron and Senn. Standardized regression weights are included. All pathways except FWM to OI are significant at the .05 (\*), .01 (\*\*), or .001 (\*\*\*) level.

and the original. For the current study: lower internalized homophobia lead to greater comfort with one’s HCP; greater comfort with one’s HCP was directly related to increased disclosure; and the relationship between feminist identity and outness was found to be not significant.

***Bergeron and Senn (2003) model tested on American sample.*** Bergeron and Senn’s model was tested on the American sample. The original model as specified by the authors fit the data poorly, as can be seen from the goodness-of-fit statistics shown in Table 15. Post-hoc modifications were required. A review of individual parameter estimates revealed that education to feminism and feminism to outness were not significant. These pathways were trimmed, and estimates were re-calculated. Fit

Table 15: Summary of Goodness-of-Fit Indices for Bergeron and Senn (2003) Model (American Sample)

Model	$\chi^2$ (df)	CFI	TLI	RMSEA
Model as specified by Bergeron and Senn	96.434(12) $p < .001$	.622	.338	.183
Deleted paths from education to FWM and FWM to OI	96.493(14) $p < .001$	.630	.445	.167
Added direct paths from education to OI, from LIHS to disclosure, and from LIHS and disclosure to AFPC	13.736(10) $p > .05$	.983	.965	.042

improved slightly. Consulting the MIs indicated that a direct pathway from education to OI, from LIHS to disclosure, and from LIHS and disclosure to AFPC should be added. Estimates were re-calculated, and fit substantially improved; the model now fit the data. The final, adapted version of the Bergeron and Senn model is depicted in Figure 15.

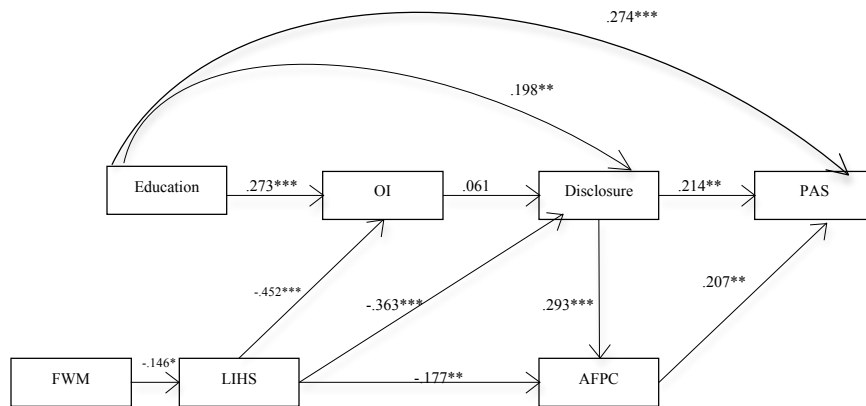


Figure 15: Final model adapted from Bergeron and Senn (2003) (American sample)

This figure shows the final model adapted from Bergeron and Senn. Standardized regression weights are included. All pathways except OI to disclosure are significant at the .05 (\*), .01 (\*\*), or .001 (\*\*\*) level.

The modified version of the Bergeron and Senn (2003) model differed from the original in several important ways. Specifically, in the current study the direct paths from education to feminism, and from feminism to outness, were not included in the final model. In the American sample, higher levels of education were linked directly with greater outness. Lower levels of internalized homophobia were associated with increased likelihood of disclosure, which was in turn associated with greater comfort with one's HCP. And finally, lower IH predicted greater comfort with one's HCP.

*Amalgamation of Bergeron and Senn (2003) and Steele et al. (2006) models.*

Because the path models specified by Steele et al. and Bergeron and Senn were so similar, these models were combined to produce a new one. Specifically, the Steele et al. model is a simplified version of Bergeron and Senn, with the addition of the variables LGBT-friendly HCP (MDQ #9) and current health. These two variables were thus added to the more comprehensive and adapted versions of Bergeron and Senn's model and tested separately for each sample. Next, amalgamated models are presented and evaluated.

*Amalgamated model tested on Canadian sample.* Figure 16 depicts the amalgamated model for the Canadian sample. Essentially, two variables have been borrowed from Steele et al.'s (2006) work and added here: MDQ #9 (direct pathway to disclosure) and current health (direct pathway to PAS).

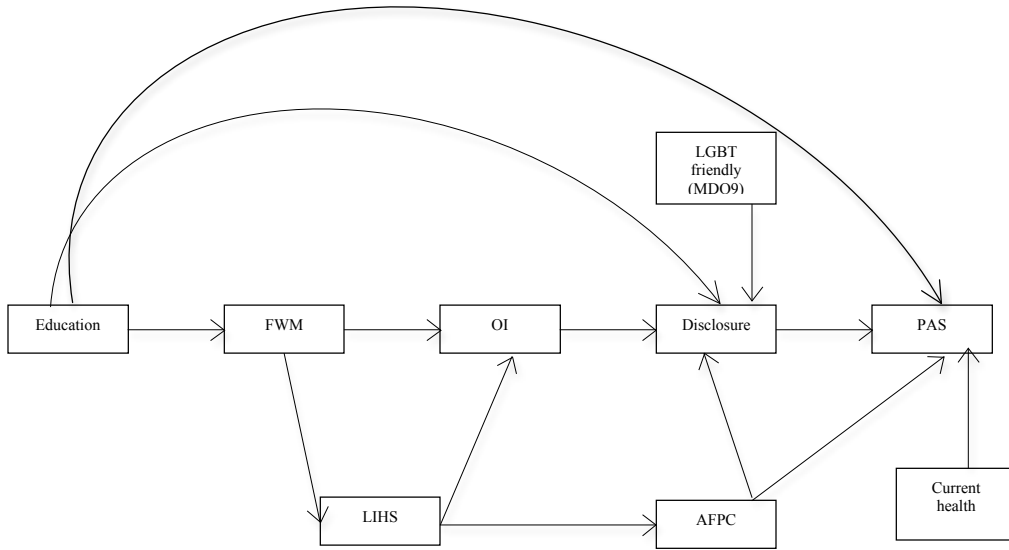


Figure 16: Amalgamated model (Canadian sample)

This figure depicts the amalgamated model for the Canadian sample.

The amalgamated model as specified above did not fit the data well, as can be seen from the goodness-of-fit statistics shown in Table 16. Post-hoc modifications were required. A review of individual parameter estimates revealed that all pathways were significant. Consulting the MIs indicated that a direct pathway from MDQ9 to LIHS, and one from MDQ9 to AFPC, should be added. Estimates were re-calculated, and the amalgamated model fit the data well. The final path model for the Canadian sample is illustrated in Figure 17.

Table 16: Summary of Goodness-of-Fit Indices for Amalgamated Model (Canadian Sample)

Model	$\chi^2$ (df)	CFI	TLI	RMSEA
Amalgamated model	102.182(23) $p < .001$	.764	.631	.130
Added direct paths from MDQ9 to LIHS and AFPC	27.641(21) $p > .05$	.980	.966	.039

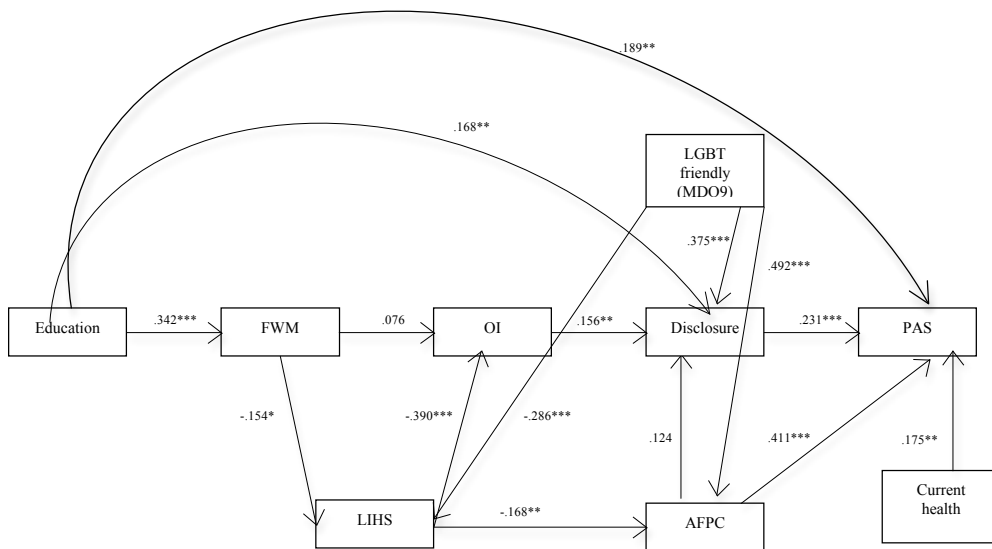


Figure 17: Final amalgamated model (Canadian sample)

This figure depicts the final, amalgamated model for the Canadian sample. Standardized regression weights are included. All pathways except FWM to OI and AFPC to disclosure are significant at the .01 (\*\*) or .001 (\*\*\*) level.

As shown in the amalgamated model, higher education was directly related to: greater affinity toward feminism, a higher likelihood of disclosure, and increased use of healthcare services. Feminism was associated with lower levels of internalized homophobia, which in turn predicted greater global outness (the direct path from feminism to outness was not significant). Greater outness lead to a higher likelihood of disclosing to HCPs, which in turn predicted greater healthcare use. Lower levels of internalized homophobia were linked to greater comfort with one’s HCP, and the latter was directly associated with disclosure (not significant) and greater engagement in preventative health and healthcare. Better health was also associated with more regular healthcare seeking behaviours. And finally, having an HCP who was LGBT-friendly lead to reduced internalized homophobia, greater disclosure, and greater comfort with HCPs. The strongest pathways in the model were both positive in direction, from LGBT-

friendly to comfort with HCP, and from comfort with HCP to engagement in regular health and healthcare behaviours.

*Amalgamated model tested on American sample.* Figure 18 depicts the amalgamated model for the American sample. Once again, two variables have been borrowed from Steele et al.'s (2006) work and added here: LGBT-friendly (direct pathway to disclosure) and current health (direct pathway to PAS).

The amalgamated model as specified above did not fit the data well, as can be seen from the goodness-of-fit statistics shown in Table 17. Post-hoc modifications were required. A review of individual parameter estimates revealed that the current health to PAS parameter was not significant, therefore, this path was trimmed (current health was consistently found to be not significant for the American sample, both in preliminary bivariate analyses and in the Steele et al. (2006) model tested earlier).

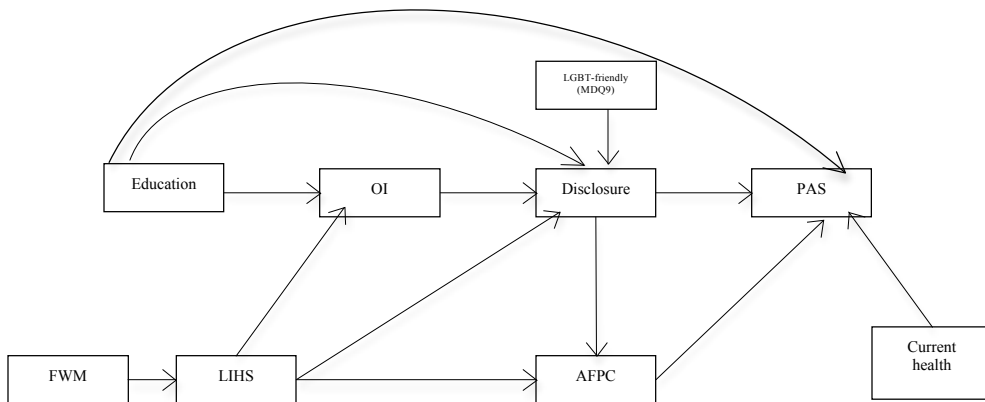


Figure 18: Amalgamated model (American sample)

This figure depicts the amalgamated model for the American sample.

Table 17: Summary of Goodness-of-Fit Indices for Amalgamated Model (American Sample)

Model	$\chi^2$ (df)	CFI	TLI	RMSEA
Amalgamated model	88.704(23) $p < .001$	.796	.680	.116
Deleted path from current health to PAS	81.275(16) $p < .001$	.796	.644	.139
Added direct paths from MDQ9 to LIHS and AFPC	16.821(14) $p > .05$	.991	.982	.031

Estimates were re-calculated, though model fit actually worsened. Consulting the MIs indicated that a direct pathway from MDQ9 to AFPC, and one from MDQ9 to LIHS, should be added. Estimates were re-calculated, and the amalgamated model fit the data well. Figure 19 shows the final amalgamated model for the American sample.

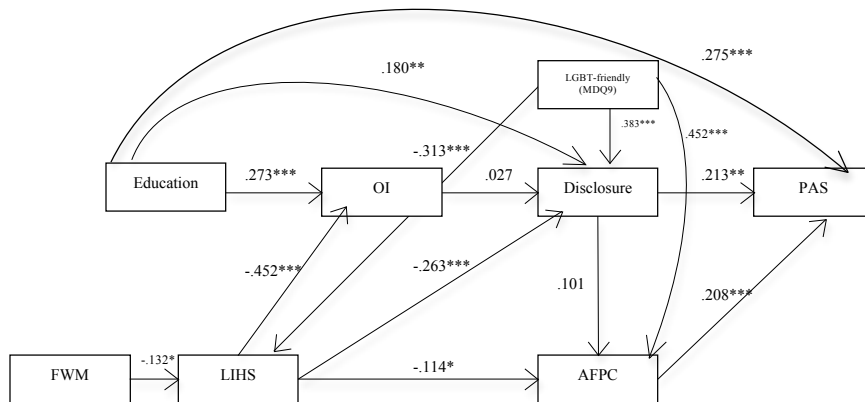


Figure 19: Final amalgamated model (American sample)

This figure depicts the final, amalgamated model for the American sample. Standardized regression weights are included. All pathways except OI to disclosure and disclosure to AFPC are significant at the .05 (\*), .01 (\*\*), or .001 (\*\*\*) level.

As can be seen from the amalgamated model, higher levels of education were linked directly with greater outness, disclosure, and engagement in regular healthcare seeking in the American sample. Greater outness lead to an increased likelihood of

disclosure (NS path), which in turn predicted greater engagement in regular healthcare seeking. Feminism was inversely related to internalized homophobia, which in turn was inversely associated with both outness and comfort with one's HCP. Lower IH predicted a higher likelihood of disclosure. Having an LGBT-friendly provider not only predicted disclosure, it further decreased internalized homophobia and increased comfort. And finally, disclosure lead to greater comfort with one's HCP (NS path), and the latter was connected to greater preventative health and healthcare behaviours. The strongest pathways in the model were from LGBT-friendly to comfort with HCP, and from lower internalized homophobia to outness.

A final set of post-hoc analyses were conducted to determine whether key variables from the initially proposed LDH models could be added to the amalgamated models without sacrificing fit. That is, income, as well as the most representative items from the MDQ, were added to each model with direct pathways leading to disclosure. Fit severely worsened. Despite attempts to improve model fit, it remained unacceptable. It was concluded that the best models to fit the data – for both samples – were the amalgamated, modified versions of Bergeron and Senn (2003) and Steele et al. (2006).

### **Main Analyses: Qualitative**

Due to the volume of detailed open-ended responses to the two qualitative questions received (approximately 750 for both countries), content rather than purely thematic analyses were undertaken to give a flavor for the contexts of women's disclosures of their sexual orientation to healthcare practitioners. The process undertaken was similar to the conventional form of content analysis described by Hsieh and Shannon (2005), and only one coder (me) was involved. The main goal of the content analysis



was to let “the categories and names for categories flow from the data.” (Hsieh & Shannon, p. 1279).

For each question, women’s responses were read once to obtain an overall picture of what would affect their willingness to disclose to their HCPs, and for those who had disclosed, their HCPs’ reaction to this information. Women’s narratives were then reviewed again several times, and a list of categories was developed stemming directly from women’s responses. This was a relatively straightforward process, since both questions probed women to essentially describe categories – categories of things that would make disclosure easier or harder for them, and types of HCP responses to their disclosures. After writing an initial draft of the qualitative section of my results, the similarities in meaning across some of the initial categories became apparent; it was clear that a smaller number of overarching categories could represent women’s responses to the first question. Thus, I condensed the number of categories by about half for the first question by combining ones with similar meaning (e.g., those sharing the common element of ‘heterocentrism’; behaviours congruent with LGBT-friendly environments into one category). A Word document (separate file for each sample) was maintained for each open-ended question, identifying the name of each category, and the participant ID for the women indicating responses that fit within each category. From these Word documents, frequency counts were tabulated for each category, separately by country.

For the first question, where participants were asked to describe the factors influencing their willingness to disclose their sexual orientation to HCPs, 12 categories

were classified<sup>4</sup>. The same 12 categories were found in the experiences of women from both countries. For the second question, where participants were asked to describe their healthcare provider's reaction to the disclosure of their sexual orientation, five categories were identified<sup>5</sup>. All five categories were found in the experiences of women from both countries. Please see Tables 18-19 for an overview of these categories.

Table 18: Qualitative Responses to Factors Influencing Disclosure to HCPs

Category	CAN <i>n</i> (%)	USA <i>n</i> (%)
Relevance of sexual orientation to healthcare visit	87(39.0)	60(25.4)
LGBT-friendly healthcare environment	78(35.0)	77(32.6)
Policy is to disclose	52(23.3)	59(25.0)
HCP socio-demographics	35(15.7)	27(11.4)
Patient-centered care	30(13.5)	30(12.7)
Heterocentrism from HCPs	27(12.1)	33(14.0)
Homophobia from HCPs	26(11.3)	26(11.0)
Type of healthcare setting/HCP	24(10.8)	29(12.3)
Policy is not to disclose	11(4.9)	17(7.2)
Accompaniment of same-sex partner	5(2.2)	18(7.6)
Intuition	4(1.8)	3(1.3)
Poor health	2(1.0)	8(3.4)

*Notes:* *N* = 223 responses for CAN; *N* = 236 responses for USA. Totals do not add up to 100 as some participants described more than one facilitator and/or barrier to disclosure.

Table 19: Qualitative Responses to Healthcare Provider Reaction to Patient Disclosure

Category	CAN <i>n</i> (%)	USA <i>n</i> (%)
Neutral	67(48.2)	79(51.6)
Positive	41(29.5)	45(29.4)
Other (e.g., HCP lack of awareness)	18(12.9)	15(9.8)
Both neutral or positive and negative	7(5.0)	9(5.9)
Negative	6(4.4)	5(3.3)

*Notes:* *N* = 139 responses for CAN; *N* = 153 responses for USA.

Before continuing, I would like to take a moment to acknowledge the depth and quality of participant responses to the open-ended questions included as part of this study.

Women discussed a variety of reasons why they would or would not tell their HCPs

<sup>4</sup> Responses from women who did not have an HCP were included in this analysis because they too completed this question.

<sup>5</sup> Only women who had an HCP and reported disclosing were asked this question.

about their sexual orientation, and they described in detail both positive and negative past experiences with healthcare professionals. Selecting only a few quotations to best illustrate each category was extremely challenging. I could have easily filled over 60 pages with participants' own words, descriptions, and stories concerning both the facilitators of and barriers to disclosure; however, in an effort to keep focus and prevent losing readers somewhere in these next thirty or so pages, I have tried my best to select quotations that represent the diversity of women's backgrounds and experiences. The participant's ID number<sup>6</sup>, their age, sexual identity, race/ethnic background, and province or state follows each quotation.

### **Qualitative Responses to Factors Influencing Disclosure to HCPs**

**Relevance of sexual orientation to healthcare visit.** Women's perceptions regarding the relevance of their sexual orientation to their healthcare visit was the first and second most common category reported by Canadian and American respondents, respectively (39.0% vs. 25.4%). Some participants did not provide explicit examples of when they thought disclosure was relevant; they simply noted that they would disclose their sexual orientation if they felt there was a good reason to do so. Healthcare visits that were centered around sexual health (e.g., pregnancy, cervical screening, STI testing) were overwhelmingly mentioned as relevant reasons for disclosure; whereas, non-sexual health related complaints, such as those involving the common cold, were not considered relevant reasons for disclosure. In their own words:

I would only disclose if it were relevant to the medical care needed. Genital exams, yes; broken bones, no. (ID 588, 55, gay, White, British Columbia)

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<sup>6</sup> The original ID number assigned to each participant is used throughout this document to easily identify participants. Specifically, ID numbers were retained due to the volume of responses in conjunction with the iterative nature of qualitative analysis.

I would inform a healthcare provider of my sexual orientation if I was dealing with reproductive issues that required a detailed medical history or documentation of sexual behaviour to aid with differential diagnoses. (ID 500, 41, lesbian, White, Alberta)

I would probably only tell a health care provider about my sexual orientation if I felt it was important to my health care. So only in circumstances where my health would intersect with my sexuality - which could be many instances or just a few depending on one's view. Also I feel it is important for gynecologists to know. (ID 857, 24, lesbian, 'other' race, Oregon)

A few participants discussed sexual orientation as relevant in the context of mental health. Disclosure was also perceived to be relevant when women were partnered. In case of emergency, some participants explained that it would be important for an HCP to have prior knowledge regarding their significant others/next of kin:

Whether it is relevant to my situation. So, for example, if I thought that I would be hospitalized and wanted to ensure that my partner could visit me in the hospital and be present during medical decisions or information, I would bring it up. (ID 1136, 35, lesbian, White, Texas)

I would never hesitate to tell an HCP about my sexual orientation if it was relevant to the area of health they were examining. When I'm having a Pap smear done, my HCP needs to know to use a smaller speculum. They also need to know to check for signs of ovarian cancer, as I'm at higher risk than the average female population. My sexual orientation can also impact my mental health - 12 years ago, I sought treatment for what turned out to be chronic depression. The triggering event was my break-up with my girlfriend, so I needed to be able to tell the various HCPs I dealt with that this was the case. On the other hand, I wouldn't bring up my sexual orientation if it wasn't relevant. Since I'm not in a relationship (for example, don't need to have my female partner/spouse recognized as next of kin for health purposes) the areas of relevancy are fewer than they would be otherwise. (ID 553, 53, lesbian, White, New Brunswick)

Other women felt that there are few or no good reasons to disclose to healthcare providers, and/or that information about sexual orientation is too risky to reveal:

I would disclose this information only if it is relevant to my health problem in some way due to fear of prejudice/judgment. (ID 858, 19, lesbian, White, Virginia)

I don't like telling doctors about my girlfriend because their attitude often changes. I don't see why it's relevant half the time; straight people don't have to explain their relationship. (ID 971, 26, lesbian, White, Connecticut)

It has never been asked and there has never been a logical moment where it felt relevant to mention. (ID 504, 21, lesbian, White, Georgia)

Is it really relevant? (ID 924, 21, queer, Black/African American, Georgia)

**LGBT-friendly healthcare environment.** An environment that was described as 'LGBT-friendly', or welcoming of LGBT people, was one that facilitated disclosure and was the most prevalent reported by 32.6% of Americans and the second most common category reported by 35.0% of Canadians. Characteristics of LGBT-friendly healthcare environments included those that were inclusive of sexual orientation, gender identity, and other forms of diversity (e.g., through posted diversity and other relevant policies, messages aimed at LGBT audiences via promotional materials or health posters/brochures, symbols recognized by LGBT communities, the use of inclusive language, and out LGBT staff), and where HCPs had knowledge of and experiences with working with LGBT people. The following quotations best illustrate what is meant by an LGBT-friendly healthcare environment:

The majority of the people I know know I am gay, but when it comes to a healthcare provider, I am still very nervous about coming out to them in case their homophobia and heterosexism affects the way they will treat me medically. They would have to make it a point that their office is a safe space or that they are pro-diversity of many kinds. They need to make it clear that there is no judgment in their office or place something on their wall that indicates that to me. (ID 498, 21, lesbian, White, Ontario)

Make advertising for safe sex inside and outside medical centres applicable for any types of sex between same sex couples...I currently only see advertisements with photos promoting safe sex of heterosexual couples; this can create an assumption that healthcare providers do not consider gay/lesbian couples. (ID 594, 25, lesbian, White, British Columbia)

Non-discrimination policy visible in office. Inclusive environment (example, LGBTQ magazines such as Advocate in waiting room). (ID 894, 30, lesbian, White, New York)

I would not go to a healthcare provider unless I were certain they had knowledge or experience with the LGBT community. I would not want to see a professional who would lack knowledge about my lifestyle and therefore lack knowledge about my health concerns. (ID 1060, 28, lesbian, White, New York)

Women explained how LGBT affirmative practitioners inquired about sexual orientation, and what is more, they asked assumption-free questions:

The best example is with my current primary care physician. On my first meeting with her, she went through a rigorous set of questions to gather about my background, etc. She asked specific questions about my sexual orientation, if I have been sexually active with men, women, or both in the past and what I had been doing currently. Asking these questions without judgment made me instantly feel comfortable in disclosing to her. (ID 856, 35, lesbian, White, Ohio)

Participants also noted that they would come out to their healthcare providers if they felt the latter were accepting of and open-minded about diversity. On the other hand, women were reticent to come out to HCPs who were perceived to be prejudiced toward LGBT people:

Whether or not I feel they are accepting or non-judgmental of gay/lesbian people. Also, if I feel they would be judgmental I fear that I would receive lesser care or intentional mis-care. (ID 1118, 26, lesbian, White, Ontario)

If a healthcare provider was openly accepting of all sexual orientations and identifications, and specifically asked me about my orientation, I would tell them. I would most likely not just come out with this information, and if they showed any signs of being prejudice against any sexual orientations then I would definitely hide this information from them. (ID 1083, 19, lesbian, White, Ohio)

The provider needs to convey to me that it is ok to be lesbian. (ID 1085, 58, lesbian, White, Massachusetts)

Fundamentally, an LGBT-friendly environment was one that was described as safe.

Participants explained how feeling safe or unsafe in healthcare contexts weighs in to their decisions regarding disclosure:

I definitely always withhold this information until I feel safe. (ID 462, 29, lesbian, White, Ontario)

I would only withhold this information if I felt specifically unsafe. This could be triggered by homophobic remarks by the provider. I would hesitate to disclose if receiving health care in the United States where I believe my human rights are not fully protected. (ID 544, 61, lesbian, White, British Columbia)

If I was in a country that was not my own, did not speak the language and felt concerned for my safety in some way. (ID 1032, 58, lesbian, White, Texas)

Participants 544 and 1032 chose not to disclose in countries outside of their own due to legitimate concerns about their rights as sexual minority women. Other participants also spoke of their apprehensions with traveling abroad with their same-sex partners; in the event of an emergency, they were wary of not only their personal treatment and safety but also that of their partners.

Some women alluded to the importance of recommendations for LGBT-friendly HCPs – received from LGBT organizations or other sources – which were valuable in deciding whether or not to come out:

If the healthcare facility was one that was recommended by my local Pride organization. (ID 458, 28, lesbian, White, Ontario)

If the health provider was recommended by a friend or family member. (ID 558, 60, lesbian, White, British Columbia)

I seek out professionals that do not assume I am straight and are open enough to diversity to know to ask. In a small conservative community that is not always available, so I talk to women in the LGBT community and ask who they recommend and bring it up right away. (ID 666, 42, lesbian, White & ‘other’ race, California)

As can be seen from some of the quotations above, lesbian communities are often tight-knit spaces, where women talk openly about their experiences with healthcare providers – both the good and the bad. Women make decisions about whom they should seek out and whom they should avoid based on the experiences of others in the community. In

this way, lesbian community members often protect each other from exposure to heterosexual/homophobic HCPs – and point each other in the direction of affirmative providers.

**Policy is to disclose.** The third most common category reported by respondents encompassed the attitude that under most if not all circumstances, women had a personal policy to disclose their sexual orientation to their healthcare providers (23.3% CAN; 25.0% USA). Many women felt that disclosure was needed to maintain an authentic relationship with and receive tailored care from their HCPs:

I have been completely open with my previous doctor and my current doctor. I am aware that there are different health considerations for lesbians so I believe that my doctor needs to know who I am. I would not consider not telling my doctor. (ID 1035, 53, lesbian, White, Ontario)

I have always been open and honest with all my health care providers. Most of the time it doesn't phase them and I/we have had times where we as a couple, individual, or family have been treated different especially when it has come to our family. My son has had to have multiple surgeries and there has been several times one or the other of us have been banished to the waiting room, even though straight family next to us was able to have both parents and or extra family like grandparents. (ID 659, 29, lesbian, White, Idaho)

I would tell a health care provider that I am a lesbian. Most studies aren't even done on women let alone lesbian women; I find it's important for my treatment. (ID 608, 58, lesbian, White, Pennsylvania)

I know that some things need to be told to the Doctor and I am very proud of the fact that I am a lesbian. (ID 805, 47, lesbian, White, Indiana)

Canadian residents noted that they have the right to access equitable healthcare under the Canadian Charter of Rights, therefore, being on the receiving end of a disclosure should not be an issue:

I see healthcare providers in Canada as being obligated to treat me (regardless of my sexual orientation) with respect and professional conduct. I would never not tell my healthcare provider about my sexual orientation as, in some cases, it may directly relate to my health. If a problem or conflict regarding my healthcare



provider's opinion of my sexual orientation were to arise, I would likely take action with that individual's senior or, potentially, take legal action, as I am protected by our charter of rights. (ID 485, 29, lesbian, White, Ontario)

Women commented on the politics of disclosure, and/or the educator role they often played as part of the coming out process to their HCPs. Some highlighted the significance of disclosure, and felt a personal responsibility to be out:

I disclose my sexual orientation always because visibility is paramount. (ID 518, 28, White, queer, Ontario)

Mostly, I'm out and I'm an educator so I use opportunities that arise to educate health care providers to enhance (hopefully) the service the next LGBT person receives. (ID 492, 47, lesbian, White, British Columbia)

I would tell them anything. The problem is that they don't ask, or they make presumptions. They assume that you are sexually active with a member of the opposite sex. They assume that you want some form of birth control. I have to speak up and correct them. (ID 706, 62, lesbian, White, Hawaii)

I don't believe I have ever made a conscious decision NOT to tell ANY healthcare provider of my sexual orientation. I have found this information is taken in stride when I say it with humor, such as, when asked if I think I could be pregnant, I usually answer with 'No, definitely not as my wife only shoots blanks!'. Whether I am aware of full Gay/Lesbian support from a professional OR I am fully aware of a healthcare professionals negative attitude towards Gays and Lesbians, I do not allow their beliefs and/or judgments to influence my disclosure of being lesbian, it is simply a part of me as my limbs are. Personally, I have my own Zero Tolerance Policy. Therefore, when I do run into intolerance, I choose to educate!! (ID 740, 42, lesbian, White, Alberta)

One American participant highlighted the caveat that would interfere with her personal policy to disclose:

I would always tell them regardless of what they think or say. Unless my employer would discriminate against me for being a lesbian. My job or housing situation being threatened would stop me from being so open. (ID 616, 53, lesbian, White, California)

Beyond the healthcare sphere, participant 616 identifies some of the various environments women operate within, including the workforce; all of these contexts are

subject to evaluations regarding the risks associated with disclosure. A few other participants – all American – discussed fears regarding disclosure in their respective employment settings, despite being generally open about their sexual orientation. In the United States, LGBT employment anti-discrimination laws exist on a state-by-state basis; this means that a person who is known or suspected to be LGBT can be denied promotion or even fired (for example, in the Southeast states; The Guardian, 2012). Similarly, certain States do not have laws protecting LGBT people from housing discrimination, let alone visitation or medical decision-making rights for same-sex partners (The Guardian, 2012; see <http://www.guardian.co.uk/world/interactive/2012/may/08/gay-rights-united-states> for an excellent, interactive overview of LGBT rights in the United States).

Women operate within several milieus, with the potential for risky overlap in some instances. For many women in the United States, private health insurance through employment often dictates the HCPs that can and cannot be consulted. Therefore, if a woman lives in a State that does not have LGBT employment anti-discrimination laws, and she is not out at work, she may exert caution about disclosing her sexual orientation to an HCP she has had no choice in selecting for fear that this information might travel back to her employer.

**HCP socio-demographics.** Four HCP socio-demographic characteristics (gender, age, race, and sexual orientation) were specified as mattering – or not mattering – in the context of disclosure. This was the fourth most common category for Canadian respondents, and the seventh for American women, discussed by 15.7% and 11.4% of each sample, respectively.

Although some women were ambivalent about the gender of their HCPs, most felt more comfortable disclosing to female professionals. Many respondents indicated that they would feel safer coming out to younger as opposed to older HCPs, presuming that the latter would hold more negative attitudes toward lesbians. Matching race and sexual orientation of the HCP and the patient were noted by a few participants as being important. A number of women did not specify what HCP gender, age, race, and/or sexual orientation were preferred, but merely stated that these were factors they considered. The following quotations illustrate how HCP socio-demographics – and the intersections between these – can have an impact on whether or not women choose to disclose:

I would definitely not tell a healthcare provider I am a lesbian if they were older (50+) or male (regardless of age)...I do tend to trust younger female healthcare professionals with the disclosure of my orientation. (ID 453, 25, lesbian, White, British Columbia)

Not a deal breaker, but gender and orientation of provider could be helpful. (ID 846, 30, lesbian, White, Massachusetts)

It would depend on whether I perceived them to be LGBTQ positive. Really it would be based on stereotypes and or/my assumptions about them. If they come from a background (ethnic or religious) that is generally not LGBTQ positive for example. (ID 895, 30, lesbian, White, Ontario)

I would not be comfortable informing the doctor I have now, a male, about my orientation for any reason – even if my health depended on it. (ID 459, 17, lesbian, Métis, Alberta)

**Patient-centered care.** Various elements of patient-centered care were discussed by 13.5% of Canadian and 12.7% of American women participants, making this among the top five most commonly discussed categories. These included active listening, validation of women’s experiences, availability, and the overall approachability of the

HCP, among other aspects. These and other patient-centered behaviours exhibited by the HCP were noted as influencing coming out:

How much they show me that they care and are interested. (ID 408, 24, lesbian, White, Ontario)

Approachability and amicability of healthcare provider. (ID 444, 20, lesbian, White, New Brunswick)

The willingness to hear and treat me as an equal with respect to decision making. (ID 465, 49, unsure, French, Saskatchewan)

If they actually LISTEN (instead of finishing my sentences with the probable conclusion), if they really seem to be present in the appointment (i.e., not distracted or uninterested). (ID 479, 24, lesbian, White, British Columbia)

Along these same lines, establishing patient comfort and trust were important for many women. Participants described feeling ‘comfortable’ with their providers as simply a sense of ease between two people:

I would say the sort of working relationship you have with them, your level of comfort has to be first and foremost, if you wouldn’t talk about your sexual history cause you’re not comfortable with them, why would sexual orientation come up either? (ID 1111, 26, White, Nova Scotia)

One positive provider behaviour was the sharing of personal information with their patients. Indeed, forming a meaningful, long-term relationship with their HCPs was important for some participants, as women did not tend to disclose to HCPs they only saw once:

If I know part of my doctor’s personal life. (ID 408, 24, lesbian, White, Ontario)

Generally I see health care providers regularly, for chiropractic, massage, and get to know them so I chat about my life including my sexual orientation. For single visit stuff like specialists, it would depend on whether it’s relevant to why I am seeking healthcare (ID 658, 47, lesbian, White, British Columbia).

If my health issue was not a sexual health issue, and I did not previously know or work with the provider, I might not share that information. (ID 845, 31, lesbian, Black/African American, Maryland)

What is clear from women's narratives is that decisions related to disclosure are not unilateral. Multiple factors affect disclosure, as can be seen from participant 845's response, which sheds light on the significance of a good working relationship with her provider, as well as her perceptions regarding the relevance of sexual orientation to her health complaint.

**Heterocentrism from HCPs.** Heterocentrism from HCPs had one of two opposing effects on women: it either pushed them to disclose their sexual orientation, or it prevented them from doing so. This was among the top six categories discussed by American and Canadian respondents (14.0% vs. 12.1%). First, an illustration of how women felt forced to come out because their providers assumed they were heterosexual.

Two examples of heterocentric questions, mentioned by nearly all of the women whose experiences fit under this category, are the ubiquitous "are you sexually active and if so, what kind of birth control are you using" and "is there a chance you could be pregnant". These questions were typically asked of women during cervical screening or other visits related to gynecological health:

Usually the only reason I would tell a healthcare provider about my sexual orientation is if they asked me why I am not taking birth control. (ID 727, 27, gay, White, Nova Scotia)

I have told doctors when they ask if I have a boyfriend or ask if I could be pregnant (some give me funny looks after I tell them I'm a lesbian and ask 'but, could you be pregnant?'). (ID 499, 19, lesbian, White, British Columbia)

Most doctors in the area assume that as a young female I am sleeping around with a lot of men, and ask continuous pressuring questions about whether or not I am SURE that I am not pregnant. Whenever I have told them that I am a lesbian, they

laugh, and ask again whether or not I am pregnant. (ID 816, 20, lesbian, White, Virginia)

I have always disclosed my sexual orientation to my healthcare provider, since I have been sexually active (17 years). When I was younger I would wait for the sexual activity questions to come up before I said anything, but the surprise that usually registered on the physician's (or nurse's) face made it feel like a cat-and-mouse game...so I started disclosing immediately and asked that they please put a note on my file so it wasn't a surprise any more. (ID 860, 34, lesbian, White, Ohio)

If they ask if I'm married, I'll say yes. Then they ask what my husband's name is – then I tell them I'm married to a woman. GYN doctor asking me what I use for birth control and when I tell them nothing, they ask how do I prevent pregnancy. I say having sex with a woman. (ID 679, 34, lesbian, White, New Jersey)

Because I am a woman, every visit I have addresses the pregnancy topic. Today, my provider kept asking questions using the term partner. Then she asked if I use condoms. When I said no, she asked again, you are sexually active x 2+years and you don't use condoms. Is this correct? I responded with my partner is a woman. Sometimes I say my girlfriend doesn't have sperm...whichever I'm in the mood for. (ID 886, 30, lesbian, White, Virginia)

Once I had a doctor who was concerned that because I'm sexually active that I may be at risk for pregnancy and asked me several times if I was sure that I could not be pregnant and I finally disclosed my sexual orientation. (ID 1077, 32, lesbian, White, Florida)

The above quotations show how women were often pressed to the point of disclosure – whether they entered the encounter with the intention to do so or not – due to assumptions made about their sexual orientation and the apparent attached need for birth control. In a few of the examples above, HCPs responded inappropriately or even disrespectfully when women came out. In many of these instances women were placed into a position where they had to convince their HCPs that they knew their own bodies best (i.e., they were *not* pregnant), while simultaneously defending their decision not to use birth control. Notwithstanding, some of these women effectively used sarcasm and humour to deal with what must have been at the very least supremely awkward situations.

Assumptions of heterosexuality had the opposite effect on some women by preventing disclosure rather than pushing for it. These respondents explained that assumptions made about their sexual orientation would shove them back into the closet:

If they assume I will have children and tell me that I'll change my mind about it when I get a husband, I assume they're not very tolerant of LGBT patients and I usually don't disclose. (ID 804, 28, lesbian, Black/African American, California)

Assuming language - e.g., what does your husband do? That kind of thing makes me clam right up. Although, lately, I just challenge them on it. What makes you assume that I have a husband? And, here in a teaching medical environment, I usually will take med students to task for assuming language or attitudes. (ID 803, 41, lesbian, White, Minnesota)

Depends on level of comfort with the health provider...For instance my family doctor whom I have had since I was born, I do NOT feel comfortable disclosing my sexual preference. Both my parents are also patients of his. Although I am OUT to my parents now, during early teen years I was not and knew that until I reached the age of 16, the age of consent, and thereby discussing sex and whatnot with my doctor without my mother or father was between myself and the doctor. As a teenager he would ask me if I was having sex, which I assumed he was referring to traditional sex between a man/woman, so I told him NO. This was usually followed up by a lecture about safe sex and birth control. He went on to tell me/scare me that he had just delivered a baby in his office from a 15-year old girl, and that this was most likely something that I did not want in my future. Meanwhile, I had been sexually active with females since the age of 16...but did not disclose this to him, and still have not to this day. As a result of this, or me denying having sex, I have never had a pap smear or pelvic examination...which I am honestly somewhat angry/frustrated about to this day. (ID 519, 26, lesbian, White, Ontario)

As illustrated by participants 803 and 519, beyond assumptions of heterosexuality, there are other intersecting factors influencing disclosure, including the patient's comfort and/or familiarity with their HCPs, touched upon previously. What is particularly disturbing in participant 519's narrative is the role played by the assumptions made about her sexuality, which served to deny her access to important preventative, potentially life saving cervical screening. Despite the barriers to receiving LGBT-affirmative care, both courage and self-advocacy are demonstrated in many of these women's stories (e.g.,

participant 803, who talks about no longer putting up with assumptions being made about her sexuality).

The above quotations show how assumptions of heterosexuality are layered and pervasive; these range from the most obvious (i.e., all women are and should be in relationships with men), to the more subtle (i.e., all women want to be and should be mothers).

**Homophobia from HCPs.** Just over 10% of respondents (11.3% CAN; 11.0 USA) discussed how a decision not to come out would be made in the context of negative, hostile, and homophobic responses from their healthcare providers. In addition, some women stated that negative past experiences could influence their willingness to disclose in future interactions with new HCPs:

Sometimes poor reactions make the next visit very difficult to disclose in, so a doctor who does not react differently to that information than they would to a heterosexual woman helps me feel at ease as well. (ID 450, 22, lesbian, White, Alberta)

If I had heard them bashing on gays in the past, I would not disclose my sexuality. (ID 667, 27, lesbian, White, Michigan)

If the person made disparaging remarks or jokes about homosexuality. (ID 810, 47, lesbian, White, Florida)

I wouldn't tell a healthcare provider if I figured out they were homophobic and I needed their services. (ID 635, 54, queer, Arab/Middle Eastern, British Columbia)

Participant 635 speaks of a situation where services are needed from a particular HCP, perhaps due to lack of availability of other options. Lack of other options meant some participants were 'stuck' with their HCPs. Consequently, these women felt that if they needed services from a homophobic HCP, and had no other options, they could not disclose to this person for fear that they would receive inappropriate or sub-standard care.



Finding a new healthcare provider if they had a negative experience with a previous one was a course of action some Canadian and American women were prepared to take to secure the care they deserved:

I would always tell my primary health giver my sexual orientation. If they were uncomfortable with it, or I was uncomfortable with their response, they would no longer be my healthcare provider. (ID 429, 53, lesbian, White, Ontario)

I am very open. If the healthcare provider did not have a reaction that I liked I would inform them, make a complaint to the office, and find an alternative provider. (ID 525, 25, queer/gay, White, Ontario)

Care should be the same for people of all sexual orientations/backgrounds. If I had reason to believe that I would not be provided with adequate care I would go to another healthcare provider. (ID 1107, 24, gay, White, Ontario)

If I wasn't comfortable telling my healthcare provider I was gay, I would find one that I was comfortable with because I'm not hiding who I am. (ID 760, 39, lesbian, White, Michigan)

**Type of healthcare setting/HCP.** Just over 10% of participants explained how the type of healthcare setting/HCP they were visiting would influence their willingness to disclose (10.8% CAN; 12.3% USA). Some did not specify the type of healthcare setting that would increase their chances of coming out, while others did. Typically sexual health or community health centres were considered legitimate places to disclose, while walk-in clinics were not. Similarly, family physicians were told, but doctors they only saw once at walk-in clinics, or other kinds of HCPs (e.g., dentists), were not:

Always if they were to be my 'family doctor'. (ID 539, 55, lesbian, White, British Columbia)

I wouldn't mention it to a health care provider I was only seeing briefly for a non-relevant issue (e.g., a walk-in clinic doctor for strep throat). (ID 556, 32, lesbian, White, British Columbia)

The type of facility where my healthcare provider practices (i.e., a community health centre with a well publicized policy of welcoming LGBT clients). (ID 571, 45, lesbian, South Asian/Indian/Pakistani, Ontario)

What kind of healthcare provider (doctors such as eye doctors and dentists need not know). (ID 953, 23, lesbian, White, New York)

Women generally did not see the relevance in disclosing their sexual orientation to healthcare professionals they consulted for vision or oral health, for example. Also, it was noted by some participants that they generally did not know/would not interact with walk-in clinic HCPs in the future, and as such, they did not feel it necessary to disclose to someone they would not be forming a lasting relationship with.

Some stated that religious and/or conservative healthcare institutions or providers would make them reluctant to come out. They were worried that HCPs with visible religious affiliations and/or conservative politics would hold less than favourable beliefs about sexual minorities:

I might not go out of my way to share my sexuality if I notice a lot of religious publications (readers digest, bible, chicken soup for the soul, etc.), the doctor wearing a cross or a religious symbol, pro-life posters, and/or exclusive images of hetero relationships (family photos, posters, brochures, etc.) in the office. (ID 906, 31, lesbian, White, Ontario)

Knowing the HCP is of a particular religious affiliation or has professed political leanings contrary to embracing equality make me hesitant to open up. (ID 814, 44, lesbian, White, Florida)

Would not easily reveal if confined to a religious-based medical facility, confined to a psych facility. (ID 793, 58, lesbian, White, Massachusetts)

In general, religious doctrine across diverse religions and faiths has historically viewed 'homosexuality' as morally deviant and has been used to justify the condemnation of sexual behaviour between two people. As such, it is no surprise that many participants in this study mentioned being hesitant of religiously affiliated institutions/healthcare providers. Before the early 1980's, conceptualizations of what it meant to be 'homosexual' shifted from committing 'sin' to being 'sick' (i.e., being

afflicted by mental illness; IOM, 2011). Based on her responses to other questions in the survey, it was possible to determine that participant 793 grew up and came out at a time when ‘homosexuality’ was considered a mental illness and diagnosed as a sociopathic personality disturbance [alongside substance abuse and sexual disorders] starting with the 1952 edition of the Diagnostic and Statistical Manual for Mental Disorders (IOM, 2011). Many other women who participated in this survey would have also been a part of the same cohort (including participant 9, a 51 year old woman who spoke of a psychologist who attempted to convert her sexuality during her youth). During that time, women were confined to psychiatric institutions – by family, for example – simply for being lesbian, and were subjected to inhumane treatments to try to cure them of their ‘disease’ (American Psychological Association, 2009; IOM, 2011). The language of ‘confinement’ used in participant 793’s narrative suggests that we cannot separate women from the zeitgeist during which they came of age. The history of treating lesbianism as a psychiatric disorder would certainly follow some of these participants today and affect their willingness to trust healthcare professionals enough to disclose what was not so long ago considered morally ‘deviant’ and/or ‘sick’ behaviour – and still is in some parts of the world, including North America.

Some women brought up the geographic location of healthcare institutions. Healthcare institutions located in the heart of large urban centers were perceived as safe places to come out, whereas, smaller rural settings were not:

Location. Toronto or Vancouver (or Montreal) = fine. A small town = I doubt it. (ID 538, 30, lesbian, White, Ontario)

If I am in my hometown (rural Alberta, population > 4000), I will never disclose that I am a lesbian. (ID 450, 22, lesbian, White, Alberta)

If I were in San Francisco or somewhere liberal I would, if not it might be a little scarier. (ID 415, 27, queer/bisexual/dyke, White, California)

My situation is rather unique. I realized I was gay only after falling in love with my best friend. After my divorce from a long term marriage, we have been very open about our relationship. We live in a conservative small town. If I were on my own without her support, I would be hesitant to reveal my orientation if I felt any uncertainty about the provider's possible reaction. I would not set myself up for scorn. (ID 1013, 60, gay, White, Oregon)

Rural dwellers were thought to possess more conservative attitudes and values in general. Additionally, the context of rurality is such that lack of anonymity complicates the social and personal lives of lesbian women who are concerned about others discovering their sexual orientation. In a rural community, where 'everybody knows everybody else', the quick, unsolicited dispersion of personal information is a very real possibility.

**Policy is not to disclose.** A handful of women (4.9% CAN; 7.2% USA) explained that they made a habit of *not* disclosing to HCPs. These women felt that sexual orientation was unrelated to health; they did not feel that telling would influence the type of healthcare they received, and so they preferred not to disclose:

I have never disclosed my sexuality to my healthcare provider; I don't feel it makes a difference if they know or not. (ID 795, 34 yrs, Black/African Caribbean, lesbian, Ontario)

I don't like to tell them because I have had bad experiences in the past, plus my health does not have anything to do with my sexuality. (ID 1066, 40, two-spirited, Aboriginal/First Nations, Ontario)

More nuanced decisions were made by some women who stated that they would only tell their healthcare providers about their sexual orientation if they felt that this was absolutely necessary. Like situations that were perceived to be relevant to coming out, disclosures that were 'necessary' were usually those related to gynecological health. Unlike the relevance category, however, these women's responses suggested that they

exerted particular caution when coming out – and that they also seemed to make it their policy not to disclose:

I would likely not tell the person that I was a lesbian unless it was medically necessary to tell them. (ID 685, 25, lesbian, White, Newfoundland and Labrador)

If it was necessary for the sake of my health. (ID 850, 30, lesbian, White, Illinois)

If it was necessary to diagnosing me or keeping my health up to date (i.e., in a gynecological exam). (ID 854, 20, lesbian, White, Virginia)

Obligation to disclose (OBGYN). (ID 1024, 41, queer, Hispanic/Latina, Connecticut)

A few women believed that sexual orientation was a private matter, not to be shared with healthcare providers. In one extreme case, healthcare services were never voluntarily sought by the participant, perhaps due to her stance on discussing sexual orientation with HCPs:

It's none of their concern so I don't tell them. But I don't go to the doctor or hospital unless I am physically unable to stop someone else from taking me. (ID 437, 28, lesbian, White, Newfoundland and Labrador)

I wouldn't discuss my sex life with my doctor. (ID 503, 32, gay, White, Québec)

I can't think of anything. It's none of their business. (ID 1040, 45, lesbian, White, Pennsylvania)

**Accompaniment of same-sex partner.** A less popular category for Canadian (2.2%) vs. American (7.6%) respondents was the importance of their partners accompanying them to healthcare visits; the presence of partners typically prompted an outing. Many of these women talked about disclosing to ensure that their partners would be acknowledged as such, as well as included in health decision-making. It seemed quite commonplace for some lesbian couples to be active participants in each other's healthcare consultations, particularly when these were ongoing:

When I want my partner to be able to attend a medical exam or a medical consultation with me, I identify her as my life partner. (ID 601, 61, lesbian, White, British Columbia)

It would usually be a given that I would identify as having a female partner. My partner has had numerous surgeries so I am usually very involved in doctor's appointments, hospital stays, emergency notification, etc. (ID 4, 59, lesbian, White, British Columbia)

When I had knee surgery my partner at the time was going to go with me to appointments and my doctor that referred me to an orthopedic surgeon knew the person she was referring me to, and I wanted to make sure there wouldn't be any issues. Anytime I have surgery or some sort of procedure done, if I'm in a serious relationship, I make it very clear that my girlfriend is allowed to see me and that they are the main point of contact. (ID 657, 26, lesbian, White, Idaho)

I always tell my family Dr. since my partner always accompanies me to these visits; all my Drs. know all about us. (ID 668, 60, lesbian, White, California)

Every situation. She is my medical power of attorney and participates in all aspects of my healthcare, as I do hers. (ID 1032, 58, lesbian, White, Texas)

In addition to offering support during consultations, when women brought their partners to appointments etc., this action also seemed to serve the purpose of informing HCPs of the significance of the relationship, to ensure that the first person contacted in the case of a medical emergency was a woman's same-sex partner.

**Intuition.** Just over 1% of Canadian and American respondents said that they relied heavily on something like intuition when deciding whether or not to disclose to their HCPs. In a few of these examples, women's 'feelings' toward or their 'sense' of their HCPs was the only factor listed as influencing disclosure:

Would want to disclose, and would always do so unless I felt uncomfortable doing so (i.e., because I had the sense that the healthcare person would be hostile or make me uncomfortable). (ID 436, 44, lesbian, White, Ontario)

I would only tell my healthcare provider if I got a feeling from them that they would be cool with me being a lesbian. (ID 1076, 30, lesbian, White, Nova Scotia)

My gut reaction to the individual. (ID 823, 41, lesbian, White, Alberta)

**Poor health.** A few respondents (1.0% CAN; 3.4% USA) spoke of disclosing – or not disclosing – in the context of seeking medical care for potentially serious health issues (as opposed to routine care):

Until age 40, I never told any healthcare provider about being a lesbian. I had no health issues to speak of and so it was unnecessary to identify my orientation one way or the other. At age 40 I experienced some severe gyn issues and I did not hesitate to inform my male ob-gyn that I was a lesbian. So I guess the short answer is once my health was at issue it was definitely time to declare myself a lesbian. (ID 794, 55, lesbian, White, Connecticut)

In more serious procedures or hospitalization with regards to making sure my partner can get in to visit with me or to make decisions for me including end of life decisions. (ID 718, 53, lesbian, White, Michigan)

I would not if I were at such a health disadvantage so as to not be able to enforce my own visiting rights, I would claim my wife to be my sister or another family member (even though we have full healthcare and power of attorneys). I've heard stories of health care providers deliberately keeping same sex couples and their families apart in emergency situations, and would not want to put either myself or my family in such a situation. (ID 989, 28, lesbian, White, Florida)

Rather than being denied access to her family in a time of need, participant 989 would claim a blood relationship to her same-sex partner to ensure that her partner's visitation rights were upheld. As explained earlier in this chapter, medical personnel can legitimately deny a same-sex partner visitation in certain parts of the USA, without legal repercussion due to lack of state-level regulations allowing women to choose who they want their visitors to be (including Florida, this participant's home state).

### **Qualitative Responses to Healthcare Provider Reactions to Patient Disclosure**

In the previous section, an overview of the factors women mentioned as either facilitating or preventing them from disclosing their sexual orientation to healthcare providers was presented. Next, what happens when women decide to come out to their

HCPs – what kind of response do they receive? HCPs reacted in a variety of ways to patient disclosures, ranging from neutral, positive, a combination of responses, negative, and those that did not seem to fit any of these categories. These are reviewed next.

**Neutral responses.** The most common healthcare provider response to patient disclosure of sexual orientation, reported by about half of both samples (48.2% CAN; 51.4% USA), were ones that could be characterized as ‘neutral’. The language used here included explicit references to ‘neutral’ reactions; providers who were ‘unaffected’ by their patient’s coming out; HCPs who considered the disclosure ‘no big deal’ or ‘not an issue’; and those who treated coming out as ‘just another piece of information’ during intake. As described by these participants, examples of neutral reactions were as follows:

My healthcare provider had no reaction; it was like telling her I eat whole wheat bread. (ID 423, 36, lesbian, White, Ontario)

I have changed doctors twice in the last year, due to a change of residence. The first one made no noticeable response. The second had seen my partner first & simply confirmed the length of our relationship - she was in all respects very personable. I can't say that there was any particular reaction; she seemed to take this as just another piece of information. (ID 490, 47, lesbian, White, Nova Scotia)

He asked what my current form of birth control was – I responded women. We left it at that. (ID 640, 23, queer, White, British Columbia)

My current doctor is a woman and she didn't even blink. (ID 604, 50, lesbian, White, South Dakota)

It was just a matter of course. Its New York City and I go to doctor at a the largest public hospital here so there are far more interesting things he hears than one patient being a lesbian. (ID 1009, 48, queer, White, New York)

There did not seem to be any particular valence attached to these reactions – they were neither positive nor negative. And for some participants, this was exactly the type of reaction they were hoping for and felt comfortable with:



As I recall, my doctor was completely unphased by this information. She noted it and moved on to the next question, which was great. There was no negative reaction. (ID 14, 32, lesbian, White, Rhode Island)

It was no big deal, information was provided and we continued on as expected. This is the response I would want. (ID 462, 29, lesbian, White, Ontario)

**Positive responses.** Just about 30% of participants from each sample (29.5% CAN; 29.4% USA) reported that their HCPs reacted positively to their coming out. Words to describe positive responses included: ‘comfortable’, ‘accepting’, ‘respectful’, ‘safe’, and ‘supportive’. Here, these participants describe the affirmative responses they received to their disclosures:

I feel very fortunate to have an incredible attentive and welcoming family physician. My doctor responded favorably, and asks about my partner(s) at my yearly physical. (ID 470, 25, bisexual, White, Ontario)

My family doctor was perfectly fine with my sexual orientation. She took on both my spouse and myself as new patients in the fall. I don't get any sense of discomfort from her about our sexual orientations. In fact, I would say that she is actively positive - although perhaps has not had a lot of experience with lesbian couples in her practice. (ID 492, 47, lesbian, White, British Columbia)

I'm from a small town, so my family doctors were curious and a little shocked because they never expected it, but they were still very professional. They asked me a lot of questions to know more about it, and were very good. My gynecologist had a similar reaction, but she's been absolutely wonderful. She wasn't that knowledgeable about it, but she really tried to learn. (ID 530, 24, queer, White, Ontario)

Thanked me and said it was important to know. (ID 559, 64, lesbian, White, British Columbia)

My primary physician is a male and he had very little reaction other than he took an interest in my life in terms of asking about legal standing etc. After initial disclosure he always asked about my partner/wife. He has been very accepting and in the past couple of years my wife has also started to go to his practice. (ID 794, 55, lesbian, White, Connecticut)

Relaxed; I told her lesbianism was a good form of birth control. She agreed. (ID 1132, 28, queer, White, New York)

As can be seen from some of the above quotations, although accepting in their attitude, many HCPs were not necessarily culturally competent regarding lesbian health.

However, a few HCPs went beyond showing a typical ‘accepting’ and ‘supportive’ response by demonstrating a solid knowledge base on LGBT health. A few participants explained how their HCPs had a nuanced understanding of sexual orientation as a social determinant of health:

There was no reaction, my GP was fabulous. In fact, if I recall, she asked two really important questions - asked if I am out and comfortable with being out, and if I had a good social network, social supports, to call on when needed. She doesn't shy away from emotional or mental health issues such as stress, and is not uncomfortable when I talk about relationship issues that may be impacting my health. (ID 1090, 49, lesbian, White, Ontario)

I only see specific LGBT friendly health care providers. They addressed specific needs and questions that came with me disclosing my sexual orientation. (ID 1108, 29, lesbian, White, Ontario)

Good and affirming - redirected thinking about STD testing and focused on issues relevant to lesbian health. (ID 832, 32, queer, White, California)

I go to a LGBT clinic in New York and am very fortunate in this regard. My doctor asked what types of genders I am sexually active with and didn't have a response except to tailor my healthcare needs to my response. (ID 982, 24, queer/lesbian, White, New York)

**Other types of responses.** Responses that did not fit any of the other categories were reported by 12.9% of Canadian and 9.8% of American women. Some women did not explicitly answer the question of how their HCPs reacted to their disclosure and instead told random stories about various interactions with HCPs. Others admitted that they could not recall how their providers had responded. Still others reported that their HCPs were not expecting to learn that their patients were anything but heterosexual:

My current family physician was fresh out of med school – I saw her for the first time in her first month of practice. She was asking me routine questions about my health for my file, writing things down, and she asked, Are you married? I said

Yes. To a woman. The pen flew out of her hand and she said Oh! I laughed. She carried on with the interview with no change in demeanor. She has been my doc now for 3 years and seems to take my orientation as a simple matter of course. (ID 669, 45, lesbian, White, Ontario).

Our current healthcare provider I met first in a joint appointment with my wife. One of the first questions she asked upon entering the room was, are you two twins? This was reasonably embarrassing for my partner and I, and I gathered for our physician as well who, at the end of the visit, sincerely apologized for her slip-up. (ID 485, 29, lesbian, White, Ontario)

Participant 485 tells a common tale, where lesbian couples are read as siblings or friends by others but not as intimate partners because they are two women. A few other women described their providers as being okay with their sexual orientation on the surface, but at a deeper level seemingly uninformed about sexual minorities:

Seemed open and accepting to a degree but uneducated and unfamiliar with lgbt people. Made a couple of comments revealing ignorance and stereotypes. (ID 666, 42, lesbian, White & 'other' race, California)

Her reaction was neutral but ignorant (in the best sense of the word). (ID 780, 35, queer, White, Ontario)

**Both neutral or positive and negative responses.** Less than 5% of participants from each sample (4.4% CAN; 3.3% USA) talked about their experiences with multiple healthcare providers. Women reported that some of their HCPs responded either neutrally or positively to their coming out, while others had less than favourable reactions to this information:

There have been varying reactions. Most recently it wasn't a big deal and I was happy with the reaction. Previously I have had problems with convincing healthcare providers that I should still be tested for STI's if I am only having sex with women. (ID 594, 25, lesbian, White, British Columbia)

I have had several family physicians over the course of the last 22 years. The first doctor nearly screamed 'YOU'RE GAY?'. The three doctors I have had since then seemed to totally accept it without any fuss or bother and have been quite supportive of my relationships. (ID 675, 50, lesbian, White, Nova Scotia)

Nonplussed. If anything, she was enthusiastic about being able to be so open with me, and that I was so open with her. This established trust and transparency. My previous doctor was a bit stunned, as if she didn't think it was important. Ok, so what? I think it's very relevant because there can be potential links with specific health issues, e.g., the estrogen/cancer equation in women who've never had children. (ID 932, 32, lesbian, White, California)

I am not aware of any issues that my current family Dr. has with my sexuality and I feel comfortable and safe with her. In the past, 10 + years ago, I lived in Vancouver BC and did have a family physician who made me feel very uncomfortable. Particularly when she asked me when I decided I was gay. (ID 1061, 44, lesbian, White, Nova Scotia)

Despite having received inadequate and sometimes inappropriate responses to their coming out in the past, these women showed resiliency as they continued to seek healthcare until they eventually found providers who were supportive of them as sexual minority women.

**Negative responses.** The remainder of women who had disclosed their sexual orientation to their HCPs and who answered the second open-ended question (4.1% CAN; 3.1% USA) described provider responses to the revealing of their sexual orientation that they were dissatisfied with and upset about:

Blank face, no reaction, from my female physician...about 15 yrs ago...she has never mentioned her again...I am open and am not ashamed (at this time of my life) so it is quite disconcerting that she treats me like I am a single woman. (ID 457, 61, lesbian, White, New Brunswick)

My old psychiatrist told me because I was gay I deserved to get kicked out of the house and yelled at, that wasn't so okay. I had JUST come out. I've had male doctors roll their eyes when I tell them I'm queer, or even question several times after this if I'm sexually active with a man. It's rude. (ID 598, 26, queer, White, Ontario)

I did see a gynecologist for pelvic pain, who told me I should see a therapist because I may have been sexually abused as a child and could be imagining pain. (I ended up in the emergency room soon after diagnosed with an infection. I told her I was pretty sure I had an infection.) So, homophobia, I imagine that probably something to do with it. Though it could have just been gross incompetence. In an emergency room an old straight White male doctor, who forgot the name of a pap

smear and couldn't recall it, insisted on giving me a pregnancy test even though I told him I hadn't had sex with men and COULD NOT be pregnant. I was in no position to fight. I found that pretty offensive. Also I believe I have seen some discomfort in another straight White male doctor, but maybe that was just his demeanor. It's hard to tell whether it's personal/homophobia or just a few crazy/bad doctors, but yeah, I have experienced at least some homophobia, I'm pretty sure. (ID 538, 30, lesbian, White, Ontario)

They said it was not a big deal because I said it and then stared at them waiting for a response...and my current physician (I just switched) was embarrassed (turned red) and still said it was not a problem. Other non-primary providers have asked the question about sexual orientation and her response to saying I am a lesbian was oh, so you've probably been sexually assaulted and I asked for her supervisor immediately after verbally shredding her...fun. (ID 1047, 39, lesbian, White, Virginia)

[My past doctor] asked if I was married and I said yes to a woman and I asked if this would make a difference in the care he would provide me if I was ill. He then proceeded to state that he did not support same sex marriages and felt the government had made a mistake. (ID 949, 64, lesbian, White, Ontario)

Though very few women reported solely experiencing negative responses from HCPs, some of the examples included above are disturbing. Particularly, participants whose healthcare providers assumed that all lesbians are damaged women who have been sexually assaulted by men in the past, and the overt prejudice and discrimination displayed by some healthcare providers. The above are short yet painful accounts of what women still contend with when they try to provide complete and accurate pictures of themselves as patients to access the best healthcare possible.

### **Research Questions, Hypotheses, and Summary of Main Findings**

Due to issues with specification of the original Lesbian Disclosure in Healthcare (LDH) framework, an amalgamated version of models adapted from Bergeron and Senn (2003) and Steele et al. (2006) was tested and validated separately on each sample.

These frameworks were much simpler than the initially proposed LDH, and when further post-hoc analyses were conducted to expand these models, fit deteriorated.

Consequently, the amalgamated models best represented the collective processes relevant to decisions related to disclosure as well as engagement in preventative health and healthcare for the women who participated in the current study. To answer the research questions and hypotheses, consideration of these models, as well as the qualitative findings, follows.

**Research question #1.** The first research question was: *What are the predictors of lesbian disclosure to their primary healthcare providers?* Hypothesis 1a predicted that certain patient attributes would be associated with greater lesbian disclosure to primary healthcare providers. Partial support was found for this hypothesis. Specifically, for the Canadian sample, only higher education and greater outness were directly linked with disclosure in the model. Lower internalized homophobia was indirectly relevant to disclosure through outness, which mediated the relationship between IH and disclosure. In the American sample, higher education and lower internalized homophobia were the only significant, direct pathways to increased disclosure. Though it did not seem to have a place in either model, perceived relevance of sexual orientation was among the top two reasons for choosing to disclose (or not) in women's narratives. Contrary to predictions, other factors, including income, ethnic background, being in an intimate relationship, etc., were not relevant to disclosure for either sample.

Hypothesis 1b predicted that certain aspects of the healthcare environment would be associated with greater lesbian disclosure to primary healthcare providers. These included: a safe and confidential healthcare environment; alternative as opposed to more traditional healthcare services; and inquiry on patient sexual orientation. Partial support for hypothesis 1b was found. That is, these factors were not represented in either model;

however, the qualitative data clearly pointed to their importance. Specifically, an environment that was LGBT-friendly, aka, one that was safe, and where service providers knew how to ask the right, assumption-free questions, were important for disclosure to occur. Type of healthcare setting too was considered, with some women commenting on this aspect by saying that they would disclose to HCPs who worked in large urban centers, who represented liberal institutions that were not affiliated with religious doctrine.

Hypothesis 1c predicted that certain healthcare provider attributes would be associated with greater lesbian disclosure to primary healthcare providers. Partial support was found for this hypothesis. The models included only one of these hypothesized factors: providers who were LGBT-friendly, or sensitive to lesbians. In both models, having an HCP who exhibited LGBT-friendly behaviours was directly connected to disclosure in a supportive way. Women's narratives further confirmed this. Participants' explanations of what would encourage or impede their decision to disclose also included all of the other HCP attributes hypothesized to be relevant here, for example, the HCP's background characteristics (i.e., younger age, female, same ethnic background and sexual orientation). Also mentioned were the HCP displaying patient-centered behaviours, and the inclusion of same-sex partners during the interaction.

Hypothesis 1d predicted that certain aspects of the patient-provider relationship would be associated with greater lesbian disclosure to primary healthcare providers. Specifically, patient comfort with their provider; patient familiarity with their provider; patient trust in their provider; and patient perceptions regarding ease of communication. Partial support was found for this hypothesis through the qualitative findings only.

Though increased patient comfort was present in both models, it was not significantly linked to disclosure in either framework. Through reading through women's narratives, it was clear that comfort, trust, and having a lasting patient-provider relationship were relevant to disclosure.

**Research question #2.** The second research question was: *What are the most influential facilitators of lesbian disclosure to their primary healthcare providers?* I hypothesized that external as opposed to internal factors would be more predictive of lesbian disclosure in primary healthcare. This hypothesis received full support for both samples. In the Canadian and American amalgamated models, the strength of the relationship between having an LGBT-friendly provider to disclosure was stronger than from global outness or education (direct links present in both models) or internalized homophobia (direct link present in American model only) to being out to one's HCP.

**Research question #3.** The third research question was: *What are the health outcomes of lesbian disclosure to their primary healthcare providers?* Hypotheses 3a and 3b predicted that there would be positive health outcomes associated with disclosure to primary healthcare providers, such as engagement in behaviours related to regular self-care and healthcare seeking. Both models confirmed these hypotheses: disclosure was directly linked with higher scores on the Perceived Adherence Scale, indicating that lesbian women who had disclosed to their HCPs were more likely to exercise regularly, eat healthily, avoid smoking cigarettes, receive regular Pap smears, and see their HCP when needed.

**Research question #4.** The fourth and final research question was: *How might the healthcare seeking experiences of lesbian women living in Canada be similar to or*



*different from those of lesbian women living in the United States?* Preliminary data analyses showed that there were significant differences between the two samples, including Americans having more education than Canadians, though the former were more likely to earn lower incomes. Although the vast majority of women in both samples reported having health insurance coverage, Americans were more likely to indicate that they had less comprehensive plans. Of the women who were excluded from main analyses because they did not have an HCP, many more Americans than Canadians reported economic reasons as being the reason why they did not have access to a primary healthcare provider. However, women from both countries who earned incomes in the highest quartile were more likely to have a healthcare provider. Relatedly, women who did not have health insurance – but only for the American sample – were less likely to have access to a primary healthcare provider. Overall, economics seemed to play a role in accessing healthcare services, particularly for the American sample.

When considering each model in its entirety, the role played by economics was absent, perhaps because the overwhelming majority of the women had health insurance plans that at the very least covered access to primary caregivers, and the women who were without healthcare providers also tended to be from lower income backgrounds and were excluded from path analyses. Though all of the same components except for current health (missing from the American model) were represented in both models, some processes were distinct. Particularly, in the Canadian model, the links between higher education and greater affinity toward feminism paralleled Bergeron and Senn's (2003) original work. In the American model, however, this link was missing, where education instead directly impacted outness, and feminism entered the equation through lowering

internalized homophobia (same as Canadian model). The presence of internalized homophobia in the American model appeared to be more potent through its direct, inverse relationships with outness (same as Canadian model), comfort with HCP (same), and disclosure (unique). Common to both models was the prominence of provider LGBT-friendliness through its effects on being associated with lower internalized homophobia, encouraging disclosure, and increasing comfort with one's HCP. And finally, what can also be found in both models are the direct relationships between both disclosure and increased comfort to regular healthcare seeking.

## CHAPTER V

### DISCUSSION

Using a mixed-methods approach, the main goal of the current study was to investigate a variety of facilitators to and health outcomes of lesbian women's experiences of coming out to their primary healthcare providers. Collectively, the findings show how beyond the patient, physicians, the environment they and their staff operate within, and the working relationship between physicians and their patients all contribute to our understandings of coming out and lesbians' adherence to preventative health standards. By considering the disclosure experiences of both Canadian and American lesbians, the present study makes a unique contribution to the literature by being one of the first to explore potential cultural differences in the healthcare sphere.

#### **Benefits of Lesbian Disclosure to Healthcare Providers**

Previous research has suggested that disclosure of sexual orientation by lesbian women to their primary healthcare providers promotes positive health behaviours related to self-care (e.g., abstinence from cigarettes and illicit drugs, consuming alcohol in moderation, regular exercise, and healthy eating) and healthcare seeking (e.g., obtaining regular cervical screening, seeing a healthcare provider when needed) (Bergeron & Senn, 2003; Brown et al., 2003; DeHart, 2008; Diamant et al., 2000; Steele et al., 2006; White & Dull, 1998). Findings from the current study offered additional support for the link between coming out and health. Specifically, women from both Canada and the United States who had disclosed to their physicians were more likely to report greater adherence to preventative health standards.

As explained by Johnson and Guenther (1987), through disclosure, healthcare providers (HCPs) obtain important contextual information that facilitates the delivery of

advice tailored to meet the specific needs of lesbian women. Even if few in number, some women's narratives highlighted their physicians' awareness of sexual orientation as a social determinant of health. For these women, their coming out prompted HCPs to ask important questions, such as the sex of their current and past partner(s), the presence of social supports, and any concerns about concealment of sexual orientation from others. These areas of inquiry are included as part of the Gay and Lesbian Medical Association's (GLMA, 2006) guidelines for appropriate care of LGBT patients (see: [http://www.glma.org/data/n\\_0001/resources/live/GLMA%20guidelines%202006%20FINAL.pdf](http://www.glma.org/data/n_0001/resources/live/GLMA%20guidelines%202006%20FINAL.pdf)). Findings from the current study show how lesbians can benefit not only from being supported through a healthcare professional's positive response to disclosure, but also by receiving specific information relevant to their health. In tandem, the quantitative and qualitative data indicate that disclosure is beneficial for women in the healthcare milieu, and the GLMA (2006) guidelines summarize why: "Coming out safely to a health care provider may be the single most important thing lesbians and bisexual women can do in order to maximize the quality of their health care and reduce the associated risk factors for health problems." (p. 23).

### **Facilitators of Lesbian Disclosure to Healthcare Providers**

It is not only important to look at coming out and its health benefits, but also the antecedents to this critical behaviour. A main goal of the current study was to better understand the facilitators of disclosure by lesbian women to their primary healthcare providers. The Lesbian Disclosure in Healthcare (LDH) model was proposed, to simultaneously investigate the relationships between an array of facilitators to and health benefits of disclosure, which were found in separate studies to promote coming out and healthcare seeking. The facilitators fell into the following four broad categories: patient

(e.g., public outness, affiliation with feminism), environmental (e.g., a safe, confidential healthcare space), healthcare provider (e.g., physicians who hold positive attitudes toward lesbians), and relational (e.g., patient comfort with their physician).

The hypothesized LDH model did not represent the experiences of either the Canadian or the American lesbian women who participated in this study, despite a series of attempts to improve how well the model supported the data. As writers of Structural Equation Modeling (SEM) theory and application explain, when a model cannot be adjusted to represent a dataset, this is evidence of model misspecification (Byrne, 2010; Kline, 2005). Measurement issues can also present challenges for researchers applying SEM techniques; however, all of my measures were known in past research and found in the current study to have adequate to excellent psychometrics. With the exception of the Modified Disclosure Questionnaire (MDQ), the measures used in the current study had been previously validated (note that the Disclosure Questionnaire or DQ, the original version on which the MDQ was based, had also been found to be psychometrically sound in Fogel's 2001 research). It is possible that the specification of a complex model is too early given the current state of lesbian health research, which is still in its infancy, especially regarding multivariate and mixed-method approaches to data analysis. It is also possible that the processes specified by the original LDH model – namely, that disclosure mediates the relationship between various facilitators and health outcomes – was a simplified version of what actually happens. In other words, the various components included as part of the LDH model may contribute to a coming out and healthcare seeking framework for lesbian women, though perhaps not through the originally identified routes. For these reasons, the hypothesized LDH model was set

aside, and the extant research was consulted to find an alternative way of testing the research questions and hypotheses proposed by the current study.

There were very few SEM studies in the lesbian health literature to draw from, and only two were located that approximated my focus on coming out and healthcare use: Bergeron and Senn (2003) and Steele et al. (2006). These studies examined some of the same factors explored in the current study, and they also proposed that coming out would mediate the relationship between various facilitators and health outcomes. This was a good place to start model building – by specifying processes that had already been tested and validated, to see whether these would reflect the experiences of lesbian women from two different countries between 2011-2012. Conveniently, Steele et al. was a more simplified version of Bergeron and Senn, with the addition of two factors (LGBT-friendly physician and patient health status). Thus, because the processes considered by these frameworks were so similar to each other, these models were combined, tested, and validated separately on the Canadian and American samples.

**Patient-level facilitators.** The first set of facilitators of interest was characteristics of the lesbian patient herself. For Canadian lesbians, it was found that higher levels of education and greater public outness increased the likelihood of coming out to their physicians. Internalized homophobia was only indirectly related to disclosure to HCPs by its influence on outness. For American lesbians, higher education and lower internalized homophobia were directly related to higher disclosure. Public outness helped explain the model in its entirety, though its relationship with coming out to one's physician was not significant. For both samples, identifying with feminist principles played an indirect, protective role through its association with lower internalized homophobia. For the most part, the findings on education, outness, and internalized

homophobia were consistent with those reported by other researchers (Bergeron & Senn, 2003; Dardick & Grady, 1980; Eliason & Schope, 2001; Hitchcock & Wilson, 1992; Robertson, 1992; Steele et al., 2006; van Dam et al., 2001). However, the direct impact of internalized homophobia on disclosure in the American sample is a newer finding, consistent with two recently published American studies focusing on this as well as other patient-level characteristics and their power to predict disclosure (Austin, 2013; Durso & Meyer, 2013).

For American women, internalized homophobia as it relates to public disclosure of one's sexual identity was important to understanding decisions to come out to HCPs. Minority Stress theory explains how external perceptions attached to being a lesbian will influence how a lesbian woman sees and feels about herself through the process of internalization (DiPlacido, 1998). Though public attitudes toward lesbians and other sexual and gender minority groups in the United States have improved over the years, they are still lagging in comparison to how Canadians view LGBT people (Andersen & Fetner, 2008). Less favourable public attitudes toward lesbians in the United States may be a reason for the salience of internalized homophobia in American lesbian women's decisions to disclose to their physicians.

Andersen and Fetner (2008) examined trends in tolerance of homosexuality in both Canada and the USA from 1981-2000. These authors explored whether Canada and its greater support of LGBT rights through laws (e.g., same-sex marriage) and policies (e.g., Canadian Human Rights Act includes protection from discrimination based on sexual orientation) would translate into Canadians possessing more favourable public attitudes toward homosexuality. Analyses were conducted on a large archival dataset, where a random sampling technique had been employed to ensure representativeness.

Factors known to predict social attitudes (e.g., gender, education, class, religion, etc.) were held constant. Findings showed how attitudes toward homosexuality became more favourable over time for respondents from both countries. However, Canadians showed higher tolerance of homosexuality, at two different time points. Speculating the reasons for these cultural differences, the authors discussed quicker policy uptake in Canada in response to gay and lesbian social movements (e.g., housing and employment discrimination; same-sex marriage). If public attitudes toward homosexuality are less than favourable in the United States, American physicians and other healthcare providers would not be exempt from these discourses and perceptions about lesbians. Consequently, American lesbians may have access to fewer options in terms of lesbian-positive physicians when compared to their Canadian counterparts. Exposure to negative public attitudes may increase the internalization of homophobia for an American lesbian, as she ponders whether or not it is even an option to be herself in public settings with fewer options for sensitive care. In a socio-political context where negative public attitudes may match internal perceptions, lesbian women living in the United States may work through their internalized homophobia at a slower rate than their Canadian counterparts. Still, it is worth mentioning that there continue to be gains in other areas of social policy in the USA (e.g., the repeal of Don't Ask, Don't Tell in 2011, allowing gay men and lesbians to openly serve in the US military), which may trickle down to influencing public (including physician) attitudes and eventually, what lesbian women internalize about themselves.

Higher levels of education had a place in both models in predicting the likelihood of disclosure. Similar to the link proposed between higher education and patients who seek health-related information on their own (e.g., Diaz et al., 2002; Dickerson et al.,



2004), lesbian women who are highly educated may be more likely to know about both the benefits of disclosure and the importance of seeking healthcare services when needed through their readings of relevant resources. As explained by Bergeron and Senn (2003), education is further related to exposure to feminism, which can act as a buffer against internalized homophobia through support offered to lesbians from their feminist politics and community. For American lesbians, the direct link between education and feminism was missing, suggesting that women were exposed to feminism through more varied routes. Affinity with feminism improved health outcomes by having the potential to lower negative beliefs about the self, which in turn facilitated disclosure for women living in the USA. Lower levels of internalized homophobia were associated with greater public outness, and those who were more out in other contexts were more likely to mirror this pattern in the healthcare sphere. Feminist politics are often concerned with issues of visibility and representation, so it was surprising that the link between greater affinity toward feminism and outness found by Bergeron and Senn was either not significant (Canadian model) or completely absent (American model). As the women in the current study on average showed a high regard for feminism, perhaps lack of variability masked this relationship.

Some important facilitators of disclosure were captured by the qualitative data but did not emerge in either quantitative model. Contrary to Hitchcock and Wilson's (1992) contention that women individually determine whether revealing their sexual identity is relevant to their health complaint, lesbians in the current study showed distinctive patterns in their responses, such that disclosure was perceived as usually only relevant in encounters related to sexual health. These findings are consistent with more recent qualitative work (Bjorkman & Malterud, 2007; Edwards & van Roekel, 2009; Politi et al.,

2009), and could reflect a change in viewing coming out to physicians as more or less pertinent, depending on context. The majority of the women who commented on relevancy linked certain parts of their body to sexuality (e.g., vulva) but not others, and this connection was the most important factor in their decisions about disclosure to physicians. A few women did not consider sexual orientation to be relevant in any healthcare situation. In the realm of healthcare seeking, perhaps these women best understood sexuality as something one does (sex with women, men, or both), rather than who one is (a holistic sense of lesbian identity as being one key component to the self; one of many topics that is important to discuss in a healthcare setting). The qualitative data provided a nuanced understanding of *when* lesbian women perceived their sexual orientation to be relevant. The context for women's healthcare visits were not investigated through quantitative measures in the current study, and this may be a reason for the exclusion of women's perceptions of the relevance of coming out from the quantitative models.

We now know that holding a lesbian identity can have an impact on health (IOM, 2011), but perhaps women patients themselves could benefit from an understanding of sexual orientation as a social determinant of health through targeted community education. The various health campaigns lead by Rainbow Health Ontario and the Queer Women's Health Initiative are excellent examples in a Canadian context of current targeted efforts to educate lesbian communities about the importance of seeking preventative healthcare (e.g., Pap test; see 'Check it Out': <http://www.check-it-out.ca>), lesbian health concerns that might be more problematic in the community (e.g., smoking rates) and generally speaking, what lesbians need to know about their own health.

If perceived relevance is so critical to understanding disclosure as suggested by some women's narratives, implications for healthcare providers include a need for knowledge transfer to their patients regarding the pertinence of knowing about sexual orientation (identity and behaviour) in both gynecological and non-gynecological matters. Indeed, physicians need this information to assess social supports, be aware of the presence of significant others for emergency purposes, to screen for certain cancers for which women who only have sex with women may be at increased risk of developing, and more generally to encourage an authentic relationship with their patients.

Though women's health was not directly related to disclosure in either quantitative model, it was connected to engagement in preventative behaviours for Canadian lesbians, such that women who reported being healthier tended to be regular healthcare consumers. Contrary to what was found in Steele et al. (2006), better as opposed to poorer health lead to regular engagement in preventative self-care and healthcare seeking. These divergent findings could reflect a difference in measurement: in Steele et al.'s work, 'regular healthcare seeking' was operationalized as seeing one's HCP "more than every few years" (p. 632), whereas, in the current study, a more comprehensive approach to assessing both healthcare seeking and self-care was taken. It is a promising finding that women who report being healthier also engage in regular health behaviours; in other words, women who are in good health may be seeking services for proactive, preventive reasons. This also means, however, that lesbians who report poorer health may not engage in regular positive health behaviours such as healthy eating, drinking alcohol in moderation, and not smoking, nor might they seek preventative healthcare services when needed (GLMA, 2006). The missing link between health status and adherence to preventative health standards may reflect the significantly

higher levels of engagement reported by the American sample, once again suggesting the potential masking effects of restricted variability.

Hitchcock and Wilson's (1992) Personal Risking theory explains how women use self-protective strategies to ensure that they will be safe in healthcare encounters. In particular, the theory shows how women are active in selecting HCPs who will be sensitive to sexual minority women, through interviewing their providers beforehand, scanning waiting room areas, and obtaining referrals for lesbian-sensitive providers. This variable was not included in the quantitative models, due to lack of variability (e.g., the majority of women had not received recommendations for sensitive providers from a friend). In the qualitative responses, only a few participants discussed seeking recommendations for LGBT-friendly providers through women in their community networks. These findings parallel the work of other researchers who have also shown that some women do extensive homework to ensure their psychological and physical safety prior to setting foot in a potentially hostile environment (Cant & Taket, 2006; Edwards & van Roekel, 2009; Eliason & Schope, 2001; Fogel, 2005; Geddes, 1994; Mulligan & Heath, 2007; Stein & Bonuck, 2001; Stevens, 1994; Tiemann et al., 1998). However, the use of precautionary measures, such as knowing about where and how to seek a referral, may be more likely to be taken by well educated women who are also more comfortable with outing themselves. Indeed, the literature on lesbian health has been criticized for including the voices of highly educated lesbians at the expense of women who experience less privilege in terms of education and willingness to be out (IOM, 1999). The women in the current study who described their use of self-protective strategies also tended to be well-educated and very open about their sexual orientation, suggesting that the ability to carry out these initiatives intersects with layers of privilege.

This study did not find that age, ethno-racial background, or income directly affected women's decisions to disclose their lesbian identity to their physicians. However, economics did matter in terms of access and health insurance, particularly for American women. In both countries, economics played a role in accessing a healthcare provider. Specifically, women whose earnings placed them in the highest income bracket were more likely to report having a primary healthcare provider. This is consistent with past research, which suggests that economically privileged women tend to have access to a wider range of healthcare providers including specialists (Ayanian, Weissman, Schneider, Ginsburg, & Zaslavsky, 2000; Dunlop, Coyte, & McIsaac, 2000). There was a further link between health insurance and having a physician for the American sample only, which was not surprising: women who did not have health insurance were less likely to have an HCP, and were at the same time more likely to list financial reasons for this being the case. For this small group of American lesbian women, basic access to a healthcare provider presented a significant barrier to healthcare seeking, and by extension their ability to find someone to come out to. As expected, whether Canadian women had an HCP was unrelated to whether they had health insurance, due to their access to 'free' universal healthcare delivered through a publically funded system.

Domestic partnership or marriage has been found to be a predictor of a person's access to health insurance coverage and other benefits (Cohen & Martinez, 2006). In Canada, same-sex marriage has been federally recognized since 2005 (CBC News, 2012). In comparison, same-sex marriage is currently recognized on a state by state basis in the

USA, with 10/52 states supporting equal marriage rights<sup>6</sup>. Alternative ways of legally recognizing an intimate relationship, such as through domestic partnership or civil union, are also limited in the USA (The Guardian, 2012). In the United States, The Defense of Marriage Act (DOMA, established in 1996: see <http://www.gpo.gov/fdsys/pkg/BILLS-104hr3396enr/pdf/BILLS-104hr3396enr.pdf>) prevents federal recognition of same-sex marriage, and further, permits each state to determine whether it will recognize a same-sex marriage performed in another state. Although DOMA continues to be challenged (and won) as unconstitutional, it also endures in many American jurisdictions. In the current study, more Canadians reported being in a common-law partnership or married than did Americans; therefore, Canadian respondents may have been more likely to have had access to comprehensive health insurance packages through their partners, though this could not be determined as these questions were not asked as part of the survey. Because access to a primary healthcare provider happens through basic health insurance coverage in the United States, enacting equal marriage legislation throughout the country would be one way of improving access and equity for lesbian women seeking healthcare services (Ponce, Cochran, Pizer, & Mays, 2010).

Returning to a discussion of the specific relationships between patient socio-demographics (age, ethno-racial background, and income) and disclosure for women who have access to a primary healthcare provider, these have yielded inconsistent findings in the extant literature and were immaterial in the current study's quantitative models and qualitative responses. Taken together, the quantitative and qualitative findings of this study suggest that beyond individual patient background characteristics, there are other

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<sup>6</sup> By January, 2013, Connecticut, Iowa, Maine, Maryland, Massachusetts, New Hampshire, New York, Vermont, Washington, and the District of Columbia recognized same-sex marriage.

factors more important to understanding women's coming out experiences to their physicians. Particularly, the environmental context where women received their healthcare services contributed to supporting disclosure – or did not.

**Environmental facilitators.** Some women explained in their narratives that the healthcare environment, including the waiting room or physician's office, had an impact on their willingness to come out to their physicians. In women's unstructured responses, it was clear that an environment that was perceived as safe was key to facilitating disclosure. Feeling safe, women explained, was an absence of hostility toward lesbians specifically, and more generally the presence of a welcoming environment for LGBT people (discussed in depth in the next section on provider characteristics and disclosure). Contextual factors and physician behaviours that were considered to promote a 'friendly' environment for lesbian women and other sexual and gender minority communities were described by a little more than 30% of each sample. As expected, women appreciated when their healthcare providers asked about their sexual orientation, particularly when they inquired by asking non-judgmental questions. For instance, women preferred that HCPs asked about identity and sexual behaviours in open-ended ways and when they did not presume heterosexuality. These qualitative findings are analogous to previous research, which has shown that both feelings of safety and careful inquiry about sexual orientation are paramount to facilitating patient disclosure (Barbara et al., 2001; Bjorkman & Malterud, 2007; Brotman et al., 2002; Cant & Taket, 2006; Eliason & Schope, 2001; Fogel, 2005; Geddes, 1994; Lucas, 1992; Hitchcock & Wilson, 1992; Mathieson, 1998; Mulligan & Heath, 2007; Politi et al., 2009; Steele et al., 2006; Stevens, 1994; Tiemann et al., 1998; van Dam et al., 2001; Zeidenstein, 1990). The concept of 'safety' was missing from the quantitative models, perhaps due to the limited focus on

measuring safety in the MDQ. Additionally, only one of the three items assessing safety had enough variability to be included in model testing.

I anticipated that the type of healthcare setting or healthcare provider would be related to whether women were willing to come out, where non-traditional as opposed to traditional settings or HCPs are more likely to ease disclosure. This was true in the qualitative data only, where women tended to disclose in sexual health centers rather than in traditional walk-in clinics. This is comparable to the findings reported by four other studies (Mulligan & Heath, 2007; Hitchcock & Wilson, 1992; Smith et al., 1985; White & Dull, 1998). In quantitative analyses, this factor did not surface in the models, once again potentially due to reduced variability, such that most women reported accessing traditional types of healthcare providers only.

Contrary to what was hypothesized in the current study based on the findings of past qualitative research (Barbara et al., 2001; Cant & Taket, 2006; Johnson et al., 1981; Lucas, 1992; Politi et al., 2007; Saulnier, 2002; Smith et al., 1985; Tiemann et al., 1998; Zeidenstein, 1990), confidentiality did not enter the models nor did women systematically speak to being worried about assurances of discretion. Perhaps since these earlier studies were carried out, better confidentiality policies have evolved and are being consistently, explicitly shared by physicians with their patients. Thus, worries about patient confidentiality may be less of a concern now to lesbians than they were in the past.

**Healthcare provider facilitators.** Previous studies have found that the characteristics of women's healthcare providers have influenced coming out in positive and negative ways. First, consistent with some past research, it was found in the qualitative data only that HCP socio-demographics, and specifically, gender (being female), age (being younger), race (same as patient), and sexual orientation (being



lesbian), mattered for some women as explained in their open-ended responses (e.g., Barbara et al., 2001; Cant & Taket, 2006; Dardick & Grady, 1980; Diamant et al., 2000; Edwards & van Roekel, 2009). Though there were a few respondents who were ambivalent about their HCP's background characteristics, most women preferred sameness between themselves and their physicians. Other quantitative studies have suggested patterns in women's preferences, such that concordance between physician and patient gender is especially important in the context of gynecological health (e.g., Fennema, Meyer, & Owen, 1990). In my quantitative analyses, HCP socio-demographics were not included in model testing due to lack of variability – most women had HCPs who were also White women, but very few had sexual minority physicians. Thus, the majority of women in the current study already matched their physician on gender and race (for White women, who represented the majority of the sample). However, matching on sexual orientation, although preferred by some women, was perhaps not possible due to lack of options as well as physician willingness to be open about their own sexual orientation with their patients. Physicians who are willing and able to be visibly out in their practice may increase patient comfort and openness about their own sexual orientation through shared identity and experience.

Second, in their qualitative responses, women explained how HCPs who exhibited patient-centered behaviours, such as active listening, taking adequate time with their patients, and validating their experiences, made them feel more at ease to disclose, similar to what has been found by other researchers (Bjorkman & Malterud, 2007; Edwards & van Roekel, 2009; Eliason & Schope, 2001; Fogel, 2005; Hitchcock & Wilson, 1992; Geddes, 1994; Mulligan & Heath, 2007; Robertson, 1992; Saulnier, 2002). Not unique to lesbians, patient-centered behaviours have been shown to contribute more generally to the

quality of the patient-provider relationship and more specifically to increasing adherence to treatment protocol with all patients (e.g., Beck et al., 2002). This aspect of physician comportment was absent from the models. Potentially, too few items from the MDQ focused on assessing ‘patient-centered behaviours’. Indeed, the qualitative data pointed to the gamut of patient-centered behaviours women considered critical to supporting disclosure. Including a measure targeting patient-centered behaviours may have pointed to the importance of these in understanding coming out and the endorsement of preventative health and healthcare seeking by lesbian women.

Third, social-justice oriented HCPs were expected to influence disclosure, based on a few studies reviewed (Edwards & van Roekel, 2009; Mathieson, 1998; Zeidenstein, 1990). In the current study, however, this was not the case. Upon closer examination of the quantitative data, the most popular response to the question asking about the extent to which physicians held social justice values was ‘neutral’, endorsed by about 50% of American and 40% of Canadian women. This means that women perceived their physicians as neither holding nor rejecting social justice values, or that respondents simply did not know their physicians’ politics. These findings suggest that healthcare providers may not explicitly discuss their personal politics with patients. Given that the majority of the women in this study tended to endorse feminist and perhaps by extension, social-justice values, access to physicians who a) endorse such values and b) are willing to be overt about these may be important for lesbian women who seek reassurance that they will receive equitable care in healthcare settings.

And lastly, a provider who was LGBT-friendly promoted disclosure in the current study, as evidenced by both the quantitative data and reinforced by women’s narratives. Consistent with previous research, ‘LGBT-friendly’ HCPs and environments (there seems

to be some overlap between these) were described as being inclusive of multiple forms of diversity, including sexual orientation and gender identity. LGBT-friendly providers demonstrated inclusivity through posting non-discriminatory policies that contained explicit references to sexual orientation and gender identity; incorporating LGBT-positive symbols into their practice environments; and using non-heterosexist language on intake forms and through verbal inquiry. In these ways, LGBT-friendly HCPs created spaces for lesbians to disclose, but further, they supported disclosure through their affirmative responses to this information as well as their knowledge of lesbian-specific health concerns and minority stressors. These findings coincide with previous research, and point to the utility of physician diversity training with particular focus on LGBT people (Barbara et al., 2001; Cant & Taket, 2006; Edwards & van Roekel, 2009; Eliason & Schope, 2001; Fogel, 2001; Geddes, 1994; Klitzman & Greenberg, 2002; Mathieson, 1998; Mulligan & Heath, 2007; Robertson, 1992; Saulnier, 2002; Steele et al., 2006; White & Dull, 1998; Zeidenstein, 1990).

Beyond influencing disclosure, having an LGBT-friendly provider had a positive impact on women's experiences in other ways. Specifically, for both American and Canadian lesbians, having an LGBT-positive provider was associated with lower internalized homophobia, which is a significant stressor in the lives of sexual minority people (further discussed in the upcoming section on Minority Stress theory). Having an LGBT-friendly provider was also associated with increased comfort with one's physician. The potential for LGBT-positive providers to make a difference in lesbians' lives was apparent from both women's narratives and the quantitative findings.

**Patient-provider relationship facilitators.** Aspects of the patient-provider relationship in the context of coming out by lesbian women to their physicians were

examined. Specifically, patient comfort with their HCP, communication between provider and patient, trust, and patient familiarity were all found in previous studies to influence coming out. In the current study, this was not the case in the quantitative models, but all of the above were highlighted in the qualitative findings. Interestingly, in the overall models, comfort played an important, direct role with increasing preventative healthcare behaviours, but was not significantly linked to disclosure itself. This is similar to the findings of Bergeron and Senn (2003), who initially proposed a direct link from comfort to disclosure, but through post-hoc analyses discovered that comfort best predicted healthcare seeking in their overall model. They explained how experiencing comfort is likely an important component to all women's (sexual minority and heterosexual) regular healthcare seeking, and therefore is not unique to lesbians. However, the qualitative data did show that women needed to feel comfortable with their HCPs, in a more general sense, to disclose their sexual orientation and other personal information. Evidently, comfort is one piece of the puzzle needed to understand lesbian women's overall experiences in healthcare settings.

On the surface, the quality of communication between patients and their HCPs did not appear to influence coming out, which contradicts previous research (Cant & Taket, 2006; Dardick & Grady, 1980; Eliason & Schope, 2001; Klitzman & Greenberg, 2002; White & Dull, 1998). However, upon reviewing the bivariate correlation between scores on the Approachability of Family Practice Consultations (AFPC; measuring comfort) and the Questionnaire on the Quality of Physician-Patient Interaction (QQPPI; measuring communication), these were just under the cutoff point for being considered 'too strongly' correlated to be combined in the statistical models (.80 and .75 for the Canadian and American samples, respectively). When QQPPI scores were substituted for scores on

the AFPC in both models, acceptable model fit was retained for both samples. This suggests that comfort and communication as measured in the current study were highly related constructs, with some overlap in meaning. By scrutinizing the two scales, one can see similarity in item content. For example, both scales included similar items focusing on lesbian patients' perceptions regarding: HCPs showing interest in their patients; HCPs understanding their patients; and patients being able to discuss health issues with their HCPs. Comfort and ease of communication between lesbian patients and their physicians seem to be intertwined – and perhaps one cannot be experienced without the other. Previous studies have consistently demonstrated the link between the quality of communication between the patient and her physician and better patient health outcomes (Beck et al., 2002; Stewart, 1995) – and the same applies to the current study.

Finally, trust and having an ongoing relationship with one's HCP were mentioned in women's narratives as promoting disclosure, similar to what has been reported in the published literature (Cant & Taket, 2006; Diamant et al., 2000; Fogel, 2005; Lehmann et al., 1998; Robertson, 1992), but were not present in the quantitative models. Perhaps too few items (i.e., no actual scales) were dedicated to measuring 'trust' and 'familiarity' to fully consider their respective influences on disclosure. In the qualitative data, some women explained how opportunities for disclosure were created through building trust, and when women became more familiar with their HCPs through establishing personal relationship, disclosure was seen as an important exchange of information to maintain authenticity.

### **Importance of Internal Versus External Facilitators of Disclosure**

This research aimed to begin to address the relative importance of internal versus external facilitators of lesbian women's coming out to their healthcare providers. It was

expected that external (healthcare environment, healthcare provider) as opposed to internal (patient-level) factors would be more influential in women's decisions to come out to their healthcare providers. This was confirmed in both samples. In the Canadian model, outness and education (patient-level factors) were less predictive of disclosure to HCPs than was having an LGBT-friendly provider. In the American model, having an LGBT-friendly provider was more powerful than outness, education, and internalized homophobia on disclosure. This promising finding points to the prominence of the provider's role in easing what can be a stressful transaction for lesbian women.

Beyond being the most influential predictor of disclosure, having an LGBT-friendly provider was also associated with internalized homophobia in a positive way. Through their support of LGBT communities, this new finding suggests that HCPs can potentially diminish negative, internalized feelings lesbian women have about themselves. Because we know that internalized homophobia can lead to stunted identity development, access to fewer social supports (including connections to LGBT communities), and poorer self-esteem and mental health (Herek, Cogan, Gillis, & Glunt, 1998; Igartua, Gill, & Montoro, 2003; McGregor, Carver, Antoni, Weiss, Yount, & Ironson, 2003), this finding lends insight into the ways minority stressors, including negative perceptions about the self, can be mitigated by healthcare professionals.

### **Support for Minority Stress Theory**

Minority Stress theory (DiPlacido, 1998) attempts to explain how holding sexual minority status, such as claiming a lesbian identity, adds additional stressors that are not present for heterosexual women. In describing the stressors that are uniquely relevant to the lives of lesbian women, DiPlacido (1998) makes a distinction between those that are internal and those that are external. External stressors surface in our everyday

interactions with people and systems, whereas, internal stressors, though often influenced by social experiences, are dealt with internally. The findings from this study support the distinction made by DiPlacido between external and internal minority stressors, and offers concrete examples of each type.

Firstly, the qualitative data showed how outside forces, including experiences of homophobia and heterosexism from HCPs, can influence disclosure. Women who had negative past interactions with HCPs who were prejudiced against lesbians had reservations about both coming out and seeking healthcare in the future. It was common for lesbian women to report experiences of heterosexism, where HCPs assumed that all of their patients were heterosexual. In particular, participants bemoaned the phrasing of certain questions because these made assumptions about women's sexuality, especially the routinely asked 'are you sexually active, and if so, what kind of birth control are you using?' and, 'is there a chance you could be pregnant?'. These are far from being new complaints – lesbians have been reporting the same, uncomfortable experiences for decades (e.g., Barbara et al., 2001; Hitchcock & Wilson, 1992; Mathieson, 1998; Robertson, 1992; Simkin, 1993; Stevens & Hall, 1988). Heterocentrism from HCPs either pushed lesbians to the point of disclosure, or it tucked them back into the closet. Some women were fed up with having to reason their way out of prescriptions for birth control, while others feared how an HCP who made assumptions about their sexuality would respond to a non-heterosexual woman. Regardless of the outcome, it was clear that negotiating what was already considered to be a stressful decision to come out was made even more difficult in the presence of heterocentrism. Lesbian health researchers have commented on the persistence of homophobia and heterosexism in healthcare settings at both individual and institutional levels (IOM, 2011). The current study's

findings parallel those of previous work, and show how external stressors particularly can impact disclosure as well as lesbian women's overall access to quality healthcare services (Barbara et al., 2001; Bjorkman & Malterud, 2007; Cant & Taket, 2006; DeHart, 2008; Edwards & van Roekel, 2009; Eliason & Schope, 2001; Fogel, 2005; Geddes, 1994; Mathieson, 1998; Mulligan & Heath, 2007).

Secondly, internal stressors were important to understanding disclosure and engagement in preventative health behaviours. In the American model, greater global outness and lower internalized homophobia facilitated disclosure. In the Canadian model, both outness and internalized homophobia had a place: outness, through its direct connection to disclosure, and internalized homophobia, through its inverse relationship to outness. In conjunction with stressors, Minority Stress theory suggests that buffers also exist (DiPlacido, 1998). In the models, buffers included affiliating oneself with feminist principles and having an LGBT-positive provider. These are important findings because they contribute not only to our understanding of what supports or does not support disclosure and healthcare seeking, but further, suggest possibilities for lessening the impact of sexual identity stigma in lesbian women's everyday lives.

### **Terminology, Fluidity, and Diversity in 'Lesbian Women's' Experiences**

Throughout this document and up until this point, I have used the term 'lesbian' with the assumption that all who were involved in this project – including my committee members and participants – would adopt the same, undefined, uncontested operational definition. Specifically, when I designed this study and envisioned the sample, I aimed to recruit women who had sexual or other forms of intimacy exclusively with other women. I assumed that the title of the study and the inclusion criteria reflected this requirement. Despite the request for women who self-identified as lesbian, a subset of respondents felt



more comfortable with other labels (e.g., queer, gay, bisexual) or no labels at all.

Looking at the behavioural measure of sexual orientation, most reported that their current sexual experiences were exclusively with other women. However, a subset of each sample reported sexual experiences with both men and women – these participants were excluded from all analyses due to best practice recommendations of separating lesbian from bisexual women in research to consider possible disparities in experiences (e.g., Durso & Meyer, 2013; IOM, 2011; Tjekpema, 2008).

The terms sexual minorities have used to self-identify have drastically changed over the decades to coincide with public discourse and perception regarding alternative sexualities (e.g., from invert, to homosexual, to gay and lesbian; IOM, 2011). For example, many women today – particularly those from younger generations (Glauser, 2012) – prefer ‘queer’<sup>7</sup> to ‘lesbian’, such that ‘queer’ is considered by some as a less limiting, more inclusive umbrella term representative of both sexual and gender minority people. Women seemed to have their own subjective interpretations of the term ‘lesbian’, and for the subset of lesbian or other-identified sexual minority women in the current study who reported sexual experiences with both men and women, these did not correspond with how researchers, including myself, have (unofficially or officially) operationalized this term. These findings suggest that, beyond the term ‘lesbian’, sexual minority women draw upon other contemporary vernacular to describe themselves. Additionally, we cannot assume that the meaning of these terms is equivalent across women, or even within a person’s lexicon over time (Diamond, 2000; Rust, 1992, 1993).

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<sup>7</sup> The term ‘queer’ was historically used as offensive slang to describe anyone who deviated from heterosexuality.

There is evidence to suggest that regardless of sexual orientation, women are apt to show changes – or fluidity – in their sexual orientation across the lifespan (Diamond, 2000). The concept of sexual fluidity was empirically investigated by psychologist Lisa Diamond (2000), and defined as follows: “...longitudinal changes in sexual identity, attractions, and behaviour as well as contemporaneous inconsistencies among these domains.” (p. 241). Diamond was among the first to follow adolescent and young adult women across several years in an effort to study fluidity (see Diamond, 1998, 2000, 2005). Her research supports the contention that sexuality is fluid in women, such that there is often discordance between one or more of identity, attraction, and behaviours over time. Diamond (2000; and others, see Rust, 1992) reports that it is common for lesbian women, for example, to be attracted to both sexes, and that these nonexclusive attractions have the potential to create inconsistencies among the triad domains of sexual orientation. It was not my intention to examine sexual minority women’s identity development over the life course; still, Diamond’s research is relevant in that it helps shed light on the reasons for mismatch in identity and behaviour for a subset of respondents, even at one point in time. Her work has implications for the dichotomous categorization of women who have sex with women only/women who have sex with both men and women used in the current study. This categorization may have been accurate when data collection occurred; however, since then, and if followed longitudinally, the same women may not fall into these same two categories, and there is the potential for more overlap than distinction between these groups (Rust, 1992). Although it was beyond the current study’s scope to explore the experiences of women who were bisexually active, I am dedicated to spending time with this data at a later point, to further our understandings of diversity within sexual minority women’s communities.

Lisa Diamond's work confirms the importance of researchers assessing multiple dimensions of sexual orientation, at various points in time, and to view these domains as complicated webs of connectivity and disjoint if our goal is to better understand the experiences of women who represent diverse 'lesbian' and other sexual minority communities. For healthcare providers, this means being aware that the terms and meanings women ascribe to are varied, and may or may not change over time to coincide with a shift in attractions and/or behaviours. Therefore, there is a need for HCPs to revisit their patients' preferred language around sexual identity, as well as any changes in meaning and behaviour, at regular intervals (GLMA, 2006). This recommendation applies to a physician's practice with all women, heterosexual and sexual minority alike, as women as a group have a stronger propensity for fluidity in the triad components of sexual orientation.

### **Strengths of the Current Study**

There are several strengths to the current study's design. A critique of previous research was the inclusion of small, convenience samples of women. Through the application of a diversified recruitment strategy plan, the current study's samples were large ( $N > 200$  for each country), and included women from multiple convenience samples (e.g., various personal networks, social and political groups, and geographically isolated readers of the popular publication *Lesbian Connection*). This is an improvement over previous studies and is a major strength of this research.

The participation of women from across Canada and the United States allowed for comparisons between these two countries, as well as a consideration of socio-political differences that had only been previously hinted at in the literature. Therefore, this study offers a unique look at how context can have an impact on lesbian women's experiences

of access to healthcare providers, their coming out to these individuals, and their adherence to preventative health standards.

The successful recruitment of a large number of women allowed for the use of a sophisticated multivariate data analysis technique, namely, path analysis. Virtually only a handful of quantitative studies had moved beyond univariate or bivariate methods to investigate lesbians' experiences with disclosure and healthcare seeking. Through path analysis, this study offered one interpretation of the 'bigger picture' of factors influencing both disclosure and healthcare seeking for Canadian and American lesbian women. Even fewer studies had attempted to extend and/or replicate the findings of existing research. By combining validated path models from Canadian researchers Bergeron and Senn (2003) and Steele et al. (2006), the current study makes an important contribution to the research through demonstrating stability in these frameworks across country and time.

Kline (2005) explains how techniques falling under the family of structural equation modeling – including path analysis – should not be employed unless the scales used to measure key variables are reliable and valid. Therefore, I borrowed all measures in the current study from previous research, and these had been reported as psychometrically sound (and comparatively, found to be reliable in the present study). Most quantitative studies focusing on disclosure in healthcare settings have used newly constructed instruments, meanwhile failing to report reliability and validity. Measurement issues continue to be a problem in the general LGBT health literature, and hinder the advancement of this area (IOM, 1999, 2011). This study's use of reliable and valid measures allows for comparability of findings across studies, as well as the possibility for replicability.

The present research was informed by theory. Past studies have tended to lack a solid rationale for focusing on certain aspects relevant to lesbian women's experiences of health and healthcare while ignoring others. I made decisions regarding what to include and what to exclude based on my review and understanding of two frameworks: Personal Risking (Hitchcock & Wilson, 1992) and Minority Stress theory (DiPlacido, 1998). A recent report released by the Institute of Medicine on the health of LGBT populations (IOM, 2011) pushed for health researchers to consider Minority Stress theory, to guide both research and practice. My work confirms the centrality of experiences of minority stress in understanding lesbian's reservations about disclosure, as well as their overall access to LGBT-positive primary healthcare services.

A final strength of the current study was its mixed-methods approach. The use of both quantitative and qualitative elements allowed for a detailed analysis of lesbian women's coming out experiences with their physicians. Women's narratives provided a rich supplement to the quantitative data, further illuminating the complexities involved in the decision-making process of coming out. The quantitative data alone could not have explained why or when women consider disclosure to be relevant to their encounters with their physicians, how heterosexism and homophobia interfere with whether they feel supported by their HCPs, or how some women simply make it their policy to disclose always – or never. Only through women's willingness to generously share personal experiences and insights was a closer examination of context made possible.

### **Limitations of the Current Study and Directions for Future Research**

Despite this study's strengths, the methods of recruitment resulted in limitations. Firstly, while large and inclusive of multiple convenience samples, the nature of these samples must be critiqued. Along with most of the studies reviewed in this document, the

current study employed a non-random sampling strategy to achieve adequate sample size, therefore results are not representative of Canadian and American lesbian populations. The IOM (2011) report calls for additional large-scale research that employs random sampling strategies so that results can be generalized to LGBT populations, meanwhile recognizing the challenges intrinsic to this design as they relate to these particular populations, such as the need for oversampling to reach sufficient  $N$  as well capture diversity in terms of race, class, ability, etc. Few studies have been able to do so, with the exception being the research focusing on disparities between sexual minorities and heterosexual people, where researchers have typically used archival data to investigate inequity. The goal of the present study, however, was to offer a specific, lesbian-centered approach to our understanding of an issue uniquely relevant to sexual minority women: disclosure as it relates to healthcare seeking. This study's goal was not to compare the experiences of heterosexual women to those of lesbians, within the context of a previously designed study which at best inquired about sexual orientation but from that point forward placed lesbian women at the periphery. As I have argued elsewhere (St. Pierre, 2012), convenience sampling is not inherently 'bad' or lesser in quality than probability sampling when used to study specific aspects of LGBT health. As the 1999 version of the IOM report on lesbian health explained, all sampling strategies carry inherent challenges, and depending on the researcher's intentions, convenience sampling can be an appropriate and useful way of collecting information on a very specific topic. However, there remains the limitation of being unable to generalize the results of the current study to the broader population of lesbian women who represent diversity in race, class, ability, and geographic location (urban and rural).

Similar to the majority of other studies in the field, lesbian women participants in the current study were privileged on all dimensions of race, class, ability, and geographic location, such that they tended to be White, middle-class, healthy and able-bodied, urban dwellers. The few studies considering minority women's experiences of disclosure and healthcare seeking suggest additional ways in which safety and access can be compromised (Brotman et al., 2002; Stevens, 1994). Based on her qualitative research with a diverse sample of lesbian women, Stevens (1994) best explains how intersections between gender, sexual orientation, ability, class, etc. can influence health and healthcare for women:

Participants frequently used the term “vulnerable” when describing how they felt in health care environments. They further communicated the experience of “compounded” vulnerability. That is, their sense of unprotectedness seemed to be added to in geometric proportion with each identity that did not match the male, heterosexual, Euro-American, middle-class, able-bodied norm. From their perspective, exposure to adversity in health care was doubled and redoubled not only because they were lesbian, but because they were women, persons of color, low-income earners, and/or persons who suffered from chronic health conditions: (p. 220).

As demonstrated by this study's qualitative findings, rural life also complicates the lives of lesbians, such that women experience fears regarding coming out to others and the unwanted sharing of this information within one's small community. Furthermore, the isolation that accompanies rural life can equate to fewer choices in terms of healthcare providers (Brotman et al., 2002; Tiemann et al., 1998). For the most part, the current study's findings speak to the experiences of privileged lesbian women living in Canada and the USA who report being on average in ‘good’ health; these women may experience more ease with decisions regarding disclosure as well as the ‘best’ access to healthcare compared to their minority counterparts. As Brotman and her colleagues (2002) summarize, “...what becomes important to understand is that people who experience

privilege...may find it easier to engage with health care practitioners about their sexual orientation and expect to be heard and understood (and when not understood, change their practitioners) than those with little privilege.” (p. 19). Therefore, the models in the current study represent the processes relevant to lesbian women who experience significant privilege.

What needs to be present for women who experience less privilege to seek healthcare first and disclose later may be different and also more complex than the models tested and validated here. There was a small number of women respondents in the current study who were excluded because they did not have a healthcare provider; these women were at a greater disadvantage in that they tended to report: lower incomes, no health insurance (American sample), being less open about their sexual orientation (American sample), and participating in preventative health standards less frequently than women who had HCPs. At the very core, these women’s experiences were qualitatively different from lesbians who were middle or upper class and had opportunities to disclose simply by having a physician. Models of healthcare seeking for these women would likely include income/class as a central predictor, with health insurance playing a role for American women. Also underrepresented in the current study were lesbian women of color, who may experience multiple layers of inequity in terms of healthcare access (IOM, 2011; Stevens, 1998). Physician cultural competency as it relates to working with diverse racial and ethnic communities may be just as important or even more so than having an LGBT-friendly provider for women of color. The above is meant to suggest that alternate models of healthcare seeking and disclosure are possible, and that the development of any model is influenced by the characteristics of the women participants recruited into the study.



All this to say that the homogeneity of lesbian samples in this and other studies continues to be a serious limitation to the advancement of knowledge about the diversity within these communities, particularly, how various aspects of self and identity can enter a healthcare encounter and have an impact on access. Oversampling in conjunction with more targeted recruitment strategies may be a solution to overcoming sampling bias, though it is clear that researchers including me continue to struggle with issues of representation, despite their best efforts.

Although the final sample sizes obtained for the current study would be considered 'large' and adequate for the path analysis models tested, I failed to reach the target goal of 600 participants total (300 per country). Recruitment efforts spanned nearly one year, and the sample I started working with was well over 700; however, about 300 participants were excluded on the basis of incomplete surveys, reporting behaviours inconsistent with lesbianism, and not having a healthcare provider. Future researchers conducting analyses requiring large samples should be aware that regardless of sampling strategy, prolonged recruitment and an even greater diversified recruitment plan might need to occur to obtain a sufficient number of participants. Furthermore, careful data monitoring throughout the data collection period may prove helpful in determining whether additional efforts are needed to reach one's target *N*.

As previously mentioned, all measures used in this research relied upon scales developed and validated in previous studies. Yet, I was unable to use the modified version of the Disclosure Questionnaire due to low reliabilities for the newly constructed subscales. It was clear that I was trying to use this measure in a way that it was not intended to be used. Perhaps had the newly created subscales held together well, the disclosure and healthcare seeking models might have performed differently.

Additionally, some of the factors investigated in the current study may not have surfaced in either model because the chosen MDQ only briefly measured them (e.g., safety of the healthcare environment, represented by one item from the MDQ). However, due to the scarcity of validated measures in the field, I had few options to choose from. The continued development of reliable and valid measures that are grounded in diverse lesbian women's experiences is key to capturing encounters with healthcare professionals and comparing findings across studies.

As previously discussed, longitudinal research by Lisa Diamond complicates the study of lesbian identity by demonstrating how women's sexuality is capable of changing over time. The current study looked at lesbian women's identity and sexual behaviours at one point in time. Yet, women's sexuality has been described as fluid, and the three components of sexual orientation may not be congruent at any one point in time (e.g., in the current study, some women identified as lesbian but reported continued sexual experiences with men). Therefore, it would be important for future researchers to at minimum consider fluidity in women's sexuality to help make sense of their data. Because identity is one component of sexual orientation central to disclosure, longitudinal research would help clarify how fluidity can have an impact on women's experiences with healthcare professionals, and whether this fluidity alters the relevance of disclosure.

A final limitation of the current study was its focus on only one perspective when two (or more) are involved in a typical healthcare encounter: the patient, her healthcare provider, and other office/clinic staff. This study tells us about the disclosure and healthcare seeking experiences of lesbian patients, specifically, what happens from a woman patient's perspective. This study does not tell us anything about what happens from a healthcare provider's standpoint, for example, how close would their perception of

patient interactions be to matching the picture presented by lesbian women? To what extent do HCPs consider themselves to be LGBT-friendly? And what role, if any, do HCPs see themselves playing in facilitating disclosure for their lesbian patients? As healthcare encounters are fundamentally social interactions between patients and their providers, future research should attempt to investigate these dynamic exchanges by triangulating data from the multiple sources involved.

### **Recommendations for Primary Healthcare Providers**

Recommendations for primary healthcare providers are offered in an attempt to pull together select findings from the current study, which may be the best suited to improving primary care for lesbian patients. These recommendations were informed by previous suggestions for enhancing care, specifically: Simkin (1993), the GLMA (2006) Guidelines for Care of Lesbian, Gay, Bisexual, and Transgender Patients; the Healthy People 2010 Companion Documents for Lesbian, Gay, Bisexual, and Transgender (LGBT) Health (Healthy People, 2010); the Institute of Medicine report on The Health Of Lesbian, Gay, Bisexual, and Transgender People (IOM, 2011); and the American Medical Association's Patient Sexual Health History: What You Need to Know to Help video (AMA, 2008).

#### **Knowing about the impact of minority stress on health/healthcare seeking.**

Lesbian women experience daily stressors that are unique to their status as sexual minority women (DiPlacido, 1998). When entering healthcare situations, women carry these stressors with them; these in turn affect aspects of their interactions with their HCPs, including their overall willingness to seek healthcare and later, whether or not they decide to disclose their sexual orientation. Internalized homophobia and making decisions about who to disclose to and when are two internal stressors that were important

to understanding disclosure and healthcare seeking in the current study. External stressors, such as women anticipating or actually experiencing homophobia and heterosexism from HCPs, were also notable barriers to disclosure and seeking services when needed.

HCPs need to be aware of what researchers now know: minority stressors create inequities in experiences of both health and access to services for lesbian women and other sexual minorities (IOM, 2011). Consequently, disparity is best understood through the lens of marginalization of LGBT communities, rather than from an individual biomedically-based deficit approach. The positive findings from the present study suggest that some HCPs are familiar with minority stressors and their impact – and in fact, HCPs may play a role in diminishing women’s negative internalized beliefs about themselves. In this way, HCPs can have a profound influence on women’s experiences through boosting positive beliefs about being a lesbian. Furthermore, by leaving hostility toward LGBT people and assumptions of heterosexuality out of their practice, HCPs can minimally ensure that they are not contributing toward minority stressors, and perhaps ideally reduce these in lesbian women’s lives.

**Expanding LGBT-friendly provider directory listings.** As theorized by Hitchcock and Wilson (1992), prior to seeking healthcare services, women engage in self-protective strategies to keep themselves safe from hostile healthcare providers. Essentially, lesbian women want to avoid encountering external stressors – or the potential of exacerbating internal stressors – so they sometimes seek recommendations for lesbian-sensitive HCPs from others in the community. As a form of outreach to lesbian communities, lesbian-sensitive HCPs may want to consider advertising themselves as such (GLMA, 2006). Having access to a list of LGBT-friendly providers

and services in one's region could improve women's overall healthcare seeking experiences from the start. The GLMA website has a worldwide provider directory – HCPs can sign up to indicate that they are LGBT-friendly, and patients can search the provider directory for sensitive HCPs in their area. In Canada, Rainbow Health Ontario (RHO) has a similar program. For lesbians who do not belong to extensive networks/communities of women, online provider directories could be an important locator tool.

**Creating LGBT-friendly environments.** A promising finding of the current study was that some women did have access to LGBT-friendly providers. In fact, an equal proportion of women (about 40%) from each sample selected 'completely true' to the statement that their physicians were LGBT-friendly. LGBT-friendly HCPs influenced their patients' lives in three positive ways: they promoted disclosure, were associated with lowering internalized homophobia, and increasing overall patient comfort. Women provided so many examples of how providers and the environments they worked in could be enhanced to be 'LGBT-friendly'. In line with the GLMA's (2006) recommendations for creating a welcoming and safe environment for LGBT patients, these were:

- Including information specific to LGBT people, e.g., in brochures;
- Posting symbols recognized by LGBT communities (e.g., rainbow flag, black triangle, double woman symbol);
- Posting a zero-discrimination policy that includes sexual orientation and gender identity (as well as other forms of diversity);
- Demonstrating up-to-date knowledge on/experience with LGBT patients; and
- Fostering inclusivity (e.g., affirming attitudes; inclusive language).

It is clear that spaces conducive to lesbian disclosure are ones that are LGBT-friendly. It is also clear that there are many ways a healthcare provider and the environment they operate within can be and are being LGBT-friendly. It is likely that becoming ‘LGBT-friendly’ is a process, a work in progress that is constantly evolving as new resources become available, illuminating a specific need to consider how LGBT populations fare in all aspects of mental and physical health (e.g., IOM, 2011).

Fostering inclusivity is at the core of the above listed examples of what makes an environment ‘LGBT-friendly’. Essentially, lesbian women want their HCPs to carve out room for alternative sexualities in their beliefs, knowledge, and practice. Physicians who demonstrate strong communication skills can promote inclusivity in their interactions with patients. Based on the GLMA’s (2006) recommendations for creating inclusive environments for LGBT people, the American Medical Association released a video aimed at improving physicians’ ability to collect a comprehensive sexual health history (AMA, 2008). This excellent teaching tool shows strategies for garnering important personal information from patients in a comfortable way by asking assumption-free questions and by providing context for asking such questions. The video starts by imploring physicians to first set the stage for patients in terms of detailing privacy and confidentiality, keeping their judgments in check, and explaining the relevance of collecting personal information on behavioural practices and sexual identity. As we know from the current study’s findings as well as from previous research, perceiving a good reason to disclose is imperative to encouraging coming out for women in the healthcare sphere. Explaining the reasons for obtaining information on sexual history (e.g., to have a more complete picture of the patient, their health risks, and how their identity and sexual behaviours are related to their overall health) could increase patients’

perceptions of the relevance of disclosure, particularly for lesbians who do not consider coming out to be pertinent in any healthcare situation. The AMA recommends that physicians ask their patients what terms they prefer to describe their sexual identity, and encourages HCPs to ask follow-up questions if they are unsure of the meaning of certain terms. The AMA further suggests that physicians use gender-neutral terms like “partner” or “significant other” with patients when assessing relationship status.

As described by the AMA (2008) video, taking a comprehensive sexual health history involves a focus on sexual behaviours both past and present, by asking questions such as: ‘Are your current sexual partners men, women, or both?’ and ‘In the past, have your sexual partners been men, women, or both?’ The GLMA’s (2006) guidelines include a sample intake form reflecting the use of inclusive language, which can be adapted by physicians and used in their practices (p. 15-19). Additionally, all women’s (not just lesbians’) identities, behaviours, and practices should be discussed on a regular basis, given the fluidity of women’s sexuality (GLMA). Through implementing these guidelines, physicians can elicit patient information on multiple dimensions of sexual orientation, as well as show by asking in a sensitive way that this information is relevant to understanding all women’s health.

**Training and professional development opportunities with focus on LGBT individuals.** Of course, the development of LGBT-friendly positive beliefs, knowledge, and practices cannot be harvested through simply reading guidelines and watching brief video clips. This process necessarily involves post-secondary training and continued opportunities for professional development for all healthcare providers (GLMA, 2006). In a recent study by Obedin-Maliver and colleagues (2011), the deans of medical schools in Canada and the United States were surveyed to establish the length and breadth of

content with focus on LGBT communities taught as part of curricula (note that LGBT people were lumped together, and intersections between gender, sexual orientation, race, etc. were not considered). It was found that a median of five hours total was devoted to LGBT health (pre-clinical). Although the majority of the schools (97%) trained their students to ask about sexual behaviours, a smaller proportion taught the difference between behaviour and self-identity (72%). The span of LGBT content varied widely across schools; however, commonly, HIV/AIDS and STIs were more often discussed than were non-disease topics (e.g., coming out, a minority stressor). A small percentage of deans rated their program as ‘good’ or ‘very good’ in terms of coverage of LGBT content (about 24%). Mimicking the above findings, a just released study with specific focus on lesbian patients and their health revealed that 78% of practicing obstetrician-gynecologists in the province of Ontario ( $N = 271$ ) reported a paucity of training in medical school (Abdessamad, Yudin, Tarasoff, Radford, & Ross, 2013). Authors from both studies compared their findings to earlier work, suggesting that diversity training with LGBT-focus for medical students has expanded over the years. Yet, as Obedin-Maliver et al. state, physician education with focus on LGBT health considerations is still inadequate in both length and scope: “It is possible that students are taught to initiate sensitive conversations but lack training to continue them in meaningful ways.” (p. 976). For example, lack of resources, such as the availability of experts in LGBT-health, continues to be a barrier to providing adequate training (Obedin-Maliver et al.).

A few women in the current study described receiving excellent LGBT-friendly healthcare through LGBT-specific community health centers and other organizations aimed at serving sexual and gender minorities. Effective service delivery models of LGBT culturally competent care exist in both Canada and the United States, for example,



Fenway Health in Boston, Massachusetts, and Sherbourne Health Centre (SHC) in Toronto, Ontario. Both Fenway Health and SHC offer a holistic approach to health, delivering physical, mental, and social health services to thousands of LGBT individuals every year. Requiring that medical students complete clinical hours devoted to working with LGBT clients at such centers could foster praxis and perhaps even encourage much needed expertise in LGBT health. In terms of continued professional development for physicians, in Canada, provincially funded programs such as Rainbow Health Ontario offer Continued Medical Education clinical sessions that meet criteria for accreditation by The College of Family Physicians of Canada. Training and professional development opportunities, however, are generally offered in metropolitan areas; unless physicians are willing to take their expertise to smaller urban or rural areas, lesbian women living in these communities will continue to experience more restricted access to LGBT-friendly healthcare institutions and by extension, physicians. The World Wide Web, which is accessible by all, offers a host of resources for healthcare professionals who wish to become more efficient at providing LGBT-sensitive healthcare (see resources section of GLMA, 2006). Only through exposure to additional and continued education will medical students and physicians alike become more aware of the existence of LGBT populations and our unique health and healthcare needs.

**Knowing about the benefits of disclosure.** Disclosure of sexual orientation by lesbian women to their healthcare providers allows physicians to more accurately assess their patients' sexual history and risks, and to tailor their treatment plans accordingly. In addition to providing a more detailed sketch of a woman's background and experiences, disclosure also leads to concrete health benefits for lesbian patients themselves. HCPs need to be aware that coming out can increase preventative health behaviours in lesbian

patients, such as eating healthily, engaging in regular exercise, avoiding smoking and drinking excessive consumption, and regular healthcare use. These findings are particularly encouraging in light of previous research, some of which have suggested that obesity, smoking, excessive drinking, and avoidance of healthcare seeking are especially problematic in lesbian communities (IOM, 2011). HCPs need to be aware that disclosure – followed by an affirmative response to this information – may prompt a discussion about these topics and subsequently, promote more positive global health and well-being in lesbian communities.

## **Conclusions**

Lesbian women's decisions regarding the disclosure of their sexual orientation to healthcare providers and their subsequent engagement in preventative health behaviours are influenced by a myriad of factors, both internal and external to them as patients. In this context, the experiences of Canadian and American lesbians are both similar and different. Lesbians tend to be more willing to come out to their physicians when their perceptions regarding whether or not the reason for their healthcare visit is relevant to their sexual identity, and this is true for women from both countries. Canadian and American lesbians experience minority stressors, such as internalized negative beliefs about themselves, concerns about being publically out, and heterosexism and homophobia from their healthcare providers; all of these either directly or indirectly have an impact on disclosure. Internalized homophobia, though, seems to play a more significant role in American lesbians' readiness to come out to their physicians, likely due to living in a more homophobic cultural climate. However, both Canadian and American lesbians also encounter buffers to minority stress, including support through feminist community and access to physicians who are LGBT-friendly. And finally, women from both countries

experience tangible benefits once they come out to their physicians, such as engagement in positive health behaviours, for example, eating healthily, exercising, and avoiding heavy alcohol use, as well as regular healthcare seeking.

Throughout this project, from design, to analyses, to making meaning of complex quantitative and qualitative data, I have contemplated the question of who is responsible for ensuring disclosure. When I first proposed this research project I focused on healthcare providers as the primary party responsible for eliciting this information from their lesbian patients. However, through the dissertation process I have come to realize that disclosure is best understood as a shared responsibility, negotiated within the dynamic interface of patients and their healthcare providers. By assuming shared responsibility – physicians by being savvy in asking rather than concluding their patient’s sexual orientation as heterosexual, and continuing this conversation in a knowledgeable and sensitive way; and patients in their willingness to respond to the caring physicians who ask – both medical and LGBT communities can benefit from our increased visibility, in addition to an integrated understanding of all women’s experiences of health and healthcare.

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## APPENDICES

### Appendix A: Demographics and Descriptives

Some questions adapted from Bergeron (1999) and US Census Bureau.

Please note: All measures are presented here in paper copy format; instruction wording will be modified to accommodate online survey administration.

The following questions ask about your background. Please indicate your response by circling the most relevant option, or writing in your response, where requested.

1-What is your age? \_\_\_\_\_

2-Are you currently living in:

1. Canada (**if selected, please go to question #3**)
2. United States (**if selected, please go to question #4**)

3-If you are living in Canada, what province/territory do you currently live in?

1. British Columbia
2. Alberta
3. Saskatchewan
4. Manitoba
5. Ontario
6. Quebec
7. New Brunswick
8. Nova Scotia
9. Prince Edward Island
10. Newfoundland and Labrador
11. Yukon
12. Northwest Territories
13. Nunavut

**\*\*If you answered question #3, please skip to question #5.**

4-If you are living in the United States, what state do you currently live in? \_\_\_\_\_

**\*\*If you answered question #4, please skip to question #6.**

5-If you live in Canada, which of these best describes your background (choose one or more)?

1. White/European
2. Black/African/Caribbean
3. Latin/South American
4. East Asian/Chinese/Japanese
5. South Asian/Indian/Pakistani
6. Aboriginal/First Nations

7. Arab/Middle Eastern
8. Other (please specify): \_\_\_\_\_

**\*\*If you answered question #5, please skip to question #7.**

6-If you live in the United States, which of these best describes your background (choose one or more)?

1. Hispanic or Latina
2. American Indian or Alaska Native
3. Asian
4. Black or African American
5. Native Hawaiian or Other Pacific Islander
6. White
7. Other (please specify): \_\_\_\_\_

7-What is the approximate population of the community you live in? \_\_\_\_\_

8-What is the highest level of education you have completed?

1. elementary school
2. some high school
3. completed high school
4. some college/university
5. college degree
6. university degree
7. some graduate school
8. master's degree
9. doctoral degree
10. professional degree

9-What is your annual household income before taxes?

1. under \$10,000
2. \$10,000-\$19,999
3. \$20,000-\$29,999
4. \$30,000-\$39,999
5. \$40,000-\$49,999
6. \$50,000-\$79,999
7. \$80,000 or more

10-What are your current living arrangements?

1. living with parent(s)/sibling(s)
2. living alone
3. living with roommate(s) (nonsexual)
4. living with partner
5. living with dependent children
6. living with partner and dependent children
7. other (please specify): \_\_\_\_\_

11-Do you self-identify as (choose the MOST relevant):

1. asexual
2. bisexual
3. gay
4. heterosexual
5. lesbian
6. queer
7. two-spirited
8. unsure
9. other (please specify): \_\_\_\_\_

12-How long have you self-identified in this way (indicate # of years)?: \_\_\_\_\_

13-Are you currently in an intimate romantic and/or sexual relationship?

1. yes (**if selected, please go to question #14**)
2. no (**if selected, please skip to #16**)

14-If you are currently in an intimate romantic and/or sexual relationship, is your partner...?

1. a woman
2. a man
3. other (please specify): \_\_\_\_\_

15-If you are in an intimate romantic and/or sexual relationship, how long have you been involved with your current partner (# of months)? \_\_\_\_\_

16-What is your marital status?

1. single
2. common-law
3. civil partnership
4. married
5. other (please specify): \_\_\_\_\_

17-How many children do you have? \_\_\_\_ (**if 0, please skip to question #19**)

18-If you have children, how old is your youngest child? \_\_\_\_\_

19-Since you have been sexually active have your sexual experiences been (circle only ONE response)...:

1. exclusively with women
2. exclusively with men
3. with both men and women
4. at first only with women now only with men
5. at first only with men now only with women
6. at first only with women now with both men and women
7. at first only with men now with both men and women
8. I am not sexually active

20-Where did you hear about the study?

1. a friend/acquaintance/colleague
2. social networking site (e.g., Facebook)
3. electronic listserv
4. organization/group
5. gay or lesbian publication
6. other (please specify): \_\_\_\_\_



## APPENDIX B

### Appendix B: Health Information and Descriptives

Adapted from Bergeron (1999), Fogel (2001), US Census Bureau, and Statistics Canada.

The following group of questions is about your health and about the type of healthcare provider you see. Please circle the response option that best matches your situation.

1-Overall, how would you rate your current health?

1	2	3	4	5
Poor	Fair	Good	Very good	Excellent

2-How would you rate your current health when compared to other women your age?

1	2	3	4	5
Poor	Fair	Good	Very good	Excellent

3-How would you rate your health now compared to your health five years ago?

1	2	3	4	5
A lot less healthy now	A little less healthy now	About the same	A little more healthy now	A lot more healthy now

4-Do you have a chronic disease (e.g., diabetes, asthma, HIV)?

1. yes (please specify): \_\_\_\_\_
2. no

5-**In the past year**, have you had a healthcare provider (a professional a person sees most often for their healthcare needs, e.g., when they get sick, when they need a health exam, etc.)?

1. yes (**if selected, please skip to question #7**)
2. no (**if selected, please go to question #6**)

6-Why haven't you had a healthcare provider (a professional a person sees most often for their healthcare needs, e.g., when they get sick, when they need a health exam, etc.) in the past year (select all that apply)?

1. relocation (e.g., moving to a new community)
2. financial (e.g., costs associated with receiving medical care)
3. accessibility (e.g., no services available in community, services are too far away)
4. other (please specify): \_\_\_\_\_

**\*\*If you answered question #6, please skip to question #8.**

7-Who do you see **most often for your healthcare needs** (when you get sick, when you need a health exam, etc.)?

1. physician
2. naturopath
3. gynecologist
4. midwife
5. nurse practitioner
6. other (please specify): \_\_\_\_\_

8-Do you have a prescription drug plan/health insurance that helps cover your medical expenses (e.g., prescription medication)?

1. yes
2. no

**\*\*If you selected yes and live in the United States, please go to question #9.**

**\*\*If you selected yes and live in Canada, please skip to question #10.**

**\*\*If you selected no, please skip to the next section.**

9-If you live in the United States and have a prescription drug plan/health insurance, what type of plan do you have (select all that apply)?

1. private insurance, through...
  - a. employment
  - b. direct purchase
2. government insurance, through...
  - a. Medicare
  - b. Medicaid
  - c. Military healthcare

**\*\*If you answered question #9, please skip to question #11.**

10-If you live in Canada and have a prescription drug plan/health insurance, what type of plan do you have (select all that apply)?

1. private insurance, through...
  - a. employment
  - b. direct purchase
3. public/government insurance, through a provincial drug plan

**\*\*If you answered question #10, please go to question #11.**

11-Of the following, which benefits are covered by your health insurance plan (select all that apply)?

1. Medical
2. Dental
3. Vision
4. Professional services (e.g., chiropractic, mental health, etc.)
5. Other (please specify): \_\_\_\_\_



## APPENDIX C

### Appendix C: Disclosure Questionnaire

Adapted from Fogel (2001, 2005).

Imagine the following scenario: For school or work related reasons you have to move to a new community. This means that you also have to start seeing a new healthcare provider (a professional you see when you get sick, when you need a health exam, etc.).

Given the situations below, how likely would you be to tell your **new healthcare provider** your sexual orientation?

When you read LGBT, it means lesbian, gay, bisexual, and transgendered.

Please place an X in the box that best describes your response to each statement.

	extremely unlikely to tell	somewhat unlikely to tell	a little unlikely to tell	neither likely nor unlikely to tell	a little likely to tell	somewhat likely to tell	very likely to tell
1. If my new healthcare provider treats me like everyone else, then I would be							
2. If my new healthcare provider is sensitive to LGBT issues, then I would be							
3. If my new healthcare provider is the same gender as me, then I would be							
4. If my new healthcare provider and I belong to the same ethnic group, then I would be							
5. If my new healthcare provider is LGB or T, then I would be							
6. If my new healthcare provider does not seem to listen to me, then I would be							
7. If my new healthcare provider asked my sexual orientation, then I would be							
8. If my new healthcare provider has an abrupt or abrasive manner, then I would be							
9. If my new healthcare provider seems interested in me and my care, then I would be							
10. If I heard my new healthcare provider or his/her staff make negative comments about LGBT people, then I would be							
11. If my new healthcare provider has experience treating LGBT clients, then I would be							
12. If it is obvious that my new healthcare provider is LGBT friendly, then I would be							

	extremely unlikely to tell	somewhat unlikely to tell	a little unlikely to tell	neither likely nor unlikely to tell	a little likely to tell	somewhat likely to tell	very likely to tell
13. If I have seen my new healthcare provider many times, then I would be							
14. If I trust my new healthcare provider, then I would be							
15. If I feel my new healthcare provider needs to know as much as possible about me, then I would be							
16. If I have health insurance that causes me to change healthcare providers often, then I would be							
17. If my sexual behaviors put me at risk for HIV or other sexually transmitted diseases, then I would be							
18. If I have not come out to many friends or family members, then I would be							
19. If I want my partner (even if I don't have one now) involved in my healthcare decisions, then I would be							
20. If other people such as my new healthcare provider's office staff will have access to my personal information, then I would be							
21. If my sexual orientation is written in my medical record, then I would be							
22. If I need to have a test (such as a pap test or rectal exam), then I would be							
23. If I am in need of serious medical care (such as surgery), then I would be							
24. If my new healthcare provider's office reading material is mostly religion-based, then I would be							
25. If there is a symbol such as a rainbow flag or HIV ribbon displayed in my new healthcare provider's office, then I would be							
26. If the questions on the medical forms assume that everyone is heterosexual, then I would be							
27. If a LGBT friend recommended my new healthcare provider, then I would be							
28. If I have a poor relationship with my new healthcare provider, then I would be							
29. If I am likely to see my new healthcare provider in a social setting, then I would be							
30. If the last healthcare provider I told my sexual orientation to reacted negatively, then I would be							

## APPENDIX D

### Appendix D: Modified Disclosure Questionnaire

Adapted from Fogel (2001, 2005).

To what extent have you experienced the situations below?

Healthcare provider means the professional you see most often for your healthcare needs (when you get sick, when you need a health exam, etc.).

When you read LGBT, it means lesbian, gay, bisexual, and transgendered.

Please place an X in the box that best describes your response to each statement.

	completely untrue	mostly untrue	somewhat untrue	neutral	somewhat true	mostly true	completely true
1. My healthcare provider treats me like everyone else.							
2. My healthcare provider is sensitive to LGBT issues.							
*3. My healthcare provider does not seem to listen to me.							
4. My healthcare provider asks about my sexual orientation.							
*5. My healthcare provider has an abrupt or abrasive manner.							
6. My healthcare provider seems interested in me and my care.							
*7. In the past I've heard my healthcare provider or his/her staff making negative comments about LGBT people.							
8. My healthcare provider has experience treating LGBT clients.							
9. My healthcare provider is LGBT friendly.							
10. I have seen my healthcare provider many times.							
11. I trust my healthcare provider.							
12. I feel my healthcare provider needs to know as much as possible about me.							
*13. I have circumstances that cause me to change healthcare providers often (e.g., health insurance, work relocation).							
14. My sexual behaviors put me at risk for HIV or other sexually transmitted diseases.							
*15. I have not come out to many friends or family members.							
16. I want my partner (even if I don't have one now) involved in my healthcare decisions.							
*17. Other people such as my healthcare provider's office staff have access to my personal information.							
*18. As far as I can tell, my sexual orientation is written in my medical record.							
*19. My healthcare provider's office reading material is mostly religion-based.							

20. There is a symbol such as a rainbow flag or HIV ribbon displayed in my healthcare provider's office.							
*21. The questions on medical forms in my healthcare provider's office assume that everyone is heterosexual.							
22. A LGBT friend recommended my healthcare provider to me.							
*23. I have a poor relationship with my healthcare provider.							
24. I am likely to see my healthcare provider in a social setting.							
*25. In the past, the healthcare provider(s) I told my sexual orientation to reacted negatively.							
26. My sexual orientation is relevant to my healthcare.							
27. My healthcare provider includes my partner (or would if I had a partner) in health related decision-making.							
28. My healthcare provider has social justice values (e.g., he or she cares about social issues related to human rights and equality).							

Please provide information on the following:

29. My healthcare provider is the same gender as me.

untrue	true	don't know
--------	------	------------

30. My healthcare provider and I belong to the same ethnic group.

untrue	true	don't know
--------	------	------------

31. My healthcare provider is LGB or T.

untrue	true	don't know
--------	------	------------

*Note.* \*Represents items that will be reverse coded.

## APPENDIX E

### Appendix E: Attitudes Toward Feminism and the Women's Movement Scale

Fassinger (1994).

For each of the following questions circle the letters that correspond to your own feelings or attitudes.		strongly disagree	disagree	neutral	agree	strongly agree
1.	The leaders of the women's movement may be extreme, but they have the right idea.	SD	D	N	A	SA
2.	There are better ways for women to fight for equality than through the women's movement.	SD	D	N	A	SA
3.	More people would favour the women's movement if they knew more about it.	SD	D	N	A	SA
4.	The women's movement has positively influenced relationships between women and men.	SD	D	N	A	SA
5.	The women's movement is too radical and extreme in its use.	SD	D	N	A	SA
6.	The women's movement has made important gains in equal rights and political power for women.	SD	D	N	A	SA
7.	Feminists are too visionary for a practical world.	SD	D	N	A	SA
8.	Feminist principles should be adopted everywhere.	SD	D	N	A	SA
9.	Feminists are a menace to this nation and this world.	SD	D	N	A	SA
10.	I am overjoyed that women's liberation is finally happening in this country.	SD	D	N	A	SA

## APPENDIX F

### Appendix F: Lesbian Internalized Homophobia Scale

Szymanski and Chung (2001).

For each of the following questions <u>circle</u> the letters that correspond to your own feelings or attitudes.		strongly disagree	moderately disagree	slightly disagree	neutral	slightly agree	moderately agree	strongly agree
1.	Many of my friends are lesbians.	SD	MD	SLD	N	SLA	MA	SA
2.	I try not to give signs that I am a lesbian. I am careful about the way I dress, the jewelry I wear, the places, people and events I talk about.	SD	MD	SLD	N	SLA	MA	SA
3.	Just as in other species, female homosexuality is a natural expression of sexuality in human women.	SD	MD	SLD	N	SLA	MA	SA
4.	I can't stand lesbians who are too "butch". They make lesbians as a group look bad.	SD	MD	SLD	N	SLA	MA	SA
5.	Attending lesbian events and organizations is important to me.	SD	MD	SLD	N	SLA	MA	SA
6.	I hate myself for being attracted to other women.	SD	MD	SLD	N	SLA	MA	SA
7.	I believe female homosexuality is a sin.	SD	MD	SLD	N	SLA	MA	SA
8.	I am comfortable being an "out" lesbian. I want others to know and see me as a lesbian.	SD	MD	SLD	N	SLA	MA	SA
9.	I feel comfortable with the diversity of the women who make up the lesbian community.	SD	MD	SLD	N	SLA	MA	SA
10.	I have respect and admiration for other lesbians.	SD	MD	SLD	N	SLA	MA	SA
11.	I feel isolated and separate from other lesbians.	SD	MD	SLD	N	SLA	MA	SA
12.	I wouldn't mind if my boss knew that I was a lesbian.	SD	MD	SLD	N	SLA	MA	SA
13.	If some lesbians would change and be more acceptable to the larger society, lesbians as a group would not have to deal with so much negativity and discrimination.	SD	MD	SLD	N	SLA	MA	SA
14.	I am proud to be a lesbian.	SD	MD	SLD	N	SLA	MA	SA
15.	I am not worried about anyone finding out I am a lesbian.	SD	MD	SLD	N	SLA	MA	SA
16.	When interacting with members of the lesbian community, I often feel different and alone, like I don't fit in.	SD	MD	SLD	N	SLA	MA	SA
17.	Female homosexuality is an acceptable lifestyle.	SD	MD	SLD	N	SLA	MA	SA
18.	I feel bad for acting on my lesbian desires.	SD	MD	SLD	N	SLA	MA	SA
19.	I feel comfortable talking to my heterosexual friends about my everyday home life with my lesbian partner/lover or my everyday activities with lesbian friends.	SD	MD	SLD	N	SLA	MA	SA
20.	Having lesbian friends is important to me.	SD	MD	SLD	N	SLA	MA	SA
21.	I am familiar with lesbian books and/or magazines.	SD	MD	SLD	N	SLA	MA	SA
22.	Being a part of the lesbian community is important to me.	SD	MD	SLD	N	SLA	MA	SA
23.	As a lesbian, I am lovable and deserving of respect.	SD	MD	SLD	N	SLA	MA	SA
24.	It is important for me to conceal the fact that I am a lesbian from my family.	SD	MD	SLD	N	SLA	MA	SA
25.	I feel comfortable talking about homosexuality in public.	SD	MD	SLD	N	SLA	MA	SA
26.	I live in fear that someone will find out that I am a lesbian.	SD	MD	SLD	N	SLA	MA	SA
27.	If I could change my sexual orientation and become heterosexual, I would.	SD	MD	SLD	N	SLA	MA	SA

28.	I do not feel the need to be on guard, lie, or hide my lesbianism to others.	SD	MD	SLD	N	SLA	MA	SA
For each of the following questions <u>circle</u> the letters that correspond to your own feelings or attitudes.		Strongly disagree	Moderately disagree	Slightly disagree	Neutral	Slightly agree	Moderately agree	Strongly agree
29.	I feel comfortable joining a lesbian social group, lesbian sports team, or lesbian organization.	SD	MD	SLD	N	SLA	MA	SA
30.	When speaking of my lesbian lover/partner to a straight person I change the pronouns so that the others will think I am involved with a man rather than a woman.	SD	MD	SLD	N	SLA	MA	SA
31.	Being a lesbian makes my future look bleak and hopeless.	SD	MD	SLD	N	SLA	MA	SA
32.	Children should be taught that being gay is a normal and healthy way for people to be.	SD	MD	SLD	N	SLA	MA	SA
33.	My feelings toward other lesbians are often negative.	SD	MD	SLD	N	SLA	MA	SA
34.	If my peers knew of my lesbianism, I am afraid that many would not want to be friends with me.	SD	MD	SLD	N	SLA	MA	SA
35.	I feel comfortable being a lesbian.	SD	MD	SLD	N	SLA	MA	SA
36.	Social situations with other lesbians make me feel uncomfortable.	SD	MD	SLD	N	SLA	MA	SA
37.	I wish some lesbians wouldn't "flaunt" their lesbianism. They only do it for shock value and it doesn't accomplish anything positive.	SD	MD	SLD	N	SLA	MA	SA
38.	I don't feel disappointed in myself for being a lesbian.	SD	MD	SLD	N	SLA	MA	SA
39.	I am familiar with lesbian movies and/or music.	SD	MD	SLD	N	SLA	MA	SA
40.	I am aware of the history concerning the development of lesbian communities and/or the lesbian/gay rights movement.	SD	MD	SLD	N	SLA	MA	SA
41.	I act as if my lesbian lovers are merely my friends.	SD	MD	SLD	N	SLA	MA	SA
42.	Lesbian lifestyles are a viable and legitimate way of life for women.	SD	MD	SLD	N	SLA	MA	SA
43.	I feel comfortable discussing my lesbianism with my family.	SD	MD	SLD	N	SLA	MA	SA
44.	I don't like to be seen in public with lesbians who look "too butch" or are "too out" because others will think that I am a lesbian.	SD	MD	SLD	N	SLA	MA	SA
45.	I could <b>not</b> confront a straight friend or acquaintance if she or he made a homophobic or heterosexist statement to me.	SD	MD	SLD	N	SLA	MA	SA
46.	I am familiar with lesbian music festivals and conferences.	SD	MD	SLD	N	SLA	MA	SA
47.	When speaking of my lover/partner to a straight person, I use neutral pronouns so the sex of the person is vague.	SD	MD	SLD	N	SLA	MA	SA
48.	Lesbian couples should be allowed to adopt children the same as heterosexual couples.	SD	MD	SLD	N	SLA	MA	SA
49.	Lesbians are too aggressive.	SD	MD	SLD	N	SLA	MA	SA
50.	I frequently make negative comments about other lesbians.	SD	MD	SLD	N	SLA	MA	SA
51.	Growing up in a lesbian family is detrimental for children.	SD	MD	SLD	N	SLA	MA	SA
52.	I am familiar with community resources for lesbians (bookstores, support groups, bars, etc.).	SD	MD	SLD	N	SLA	MA	SA

## APPENDIX G

### Appendix G: Outness Inventory

Mohr & Fassinger (2000)

Use the following rating scale to indicate how open you are about your sexual orientation to the people listed below. Try to respond to all of the items, but select “0” if some of them do not apply to you.

1=person definitely does NOT know about your sexual orientation status

2=person might know about your sexual orientation status, but it is NEVER talked about

3=person probably knows about your sexual orientation status, but it is NEVER talked about

4=person probably knows about your sexual orientation status, but it is RARELY talked about

5=person definitely knows about your sexual orientation status, but it is RARELY talked about

6=person definitely knows about your sexual orientation status, and it is SOMETIMES talked about

7=person definitely knows about your sexual orientation status, and it is OPENLY talked about

0=not applicable to your situation; there is no such person or group of people in your life

1. mother	1	2	3	4	5	6	7	0
2. father	1	2	3	4	5	6	7	0
3. siblings (sisters, brothers)	1	2	3	4	5	6	7	0
4. extended family/relatives	1	2	3	4	5	6	7	0
5. my <u>new</u> straight friends	1	2	3	4	5	6	7	0
6. my work peers	1	2	3	4	5	6	7	0
7. my work supervisor(s)	1	2	3	4	5	6	7	0
8. members of my religious community (e.g., church, temple)	1	2	3	4	5	6	7	0
9. leaders of my religious community (e.g., church, temple)	1	2	3	4	5	6	7	0
10. strangers, new acquaintances	1	2	3	4	5	6	7	0
11. my <u>old</u> heterosexual friends	1	2	3	4	5	6	7	0



## APPENDIX H

### Appendix H: Approachability of Family Practice Consultations

Adapted from Hackett & Jacobson (1995)

For each of the following questions circle the letter(s) in the box that corresponds to your own feelings or attitudes.		strongly disagree	disagree	neutral	agree	strongly agree
Your healthcare provider is the professional you see most often for your healthcare needs (when you get sick, when you need a health exam, etc.).						
1.	I raise all of the issues that I want to with my healthcare provider.	SD	D	N	A	SA
2.	Being with my healthcare provider is not stressful.	SD	D	N	A	SA
3.	My healthcare provider understands me as a person.	SD	D	N	A	SA
4.	I do not worry about going to see my healthcare provider.	SD	D	N	A	SA
5.	My healthcare provider takes a real interest in me.	SD	D	N	A	SA
6.	I do not worry about getting test results from my healthcare provider.	SD	D	N	A	SA
7.	My healthcare provider understands all of the health problems I have.	SD	D	N	A	SA
8.	Going to my healthcare provider is always stressful.	SD	D	N	A	SA
9.	I do not worry about making an appointment to see my healthcare provider.	SD	D	N	A	SA

## APPENDIX I

### Appendix I: Questionnaire on the Quality of Physician-Patient Interaction

Adapted from Bieber et al. (2010)

The following are a series of statements and assertions concerning a typical consultation with your healthcare provider, including decisions and results. Please indicate to what extent you agree or disagree with these statements.

Your healthcare provider is the professional you see most often for your healthcare needs (when you get sick, when you need a health exam, etc.).

	I do not agree	I partly agree	I agree	I strongly agree	I fully agree
1. My healthcare provider seems to be genuinely interested in my problems.					
2. My healthcare provider gives me detailed information about available treatment options.					
3. I feel I could trust my healthcare provider with my private problems.					
4. My healthcare provider and I make all treatment decisions together.					
5. My healthcare provider's explanations are easy to understand.					
6. My healthcare provider spends sufficient time on my consultation.					
7. My healthcare provider speaks to me in detail about the risks and side effects of the proposed treatment.					
8. My healthcare provider understands my needs and problems and takes them seriously.					
9. My healthcare provider does all he/she can to put me at ease.					
10. My healthcare provider asks about how my health-related issues affect my everyday life.					
11. My healthcare provider gives me enough time to talk about all my problems.					
12. My healthcare provider respects the fact that I may have a different opinion regarding treatment.					
13. My healthcare provider gives me a thorough examination.					
14. My healthcare provider gives me detailed information about my health-related issues.					



## APPENDIX K

### Appendix K: Perceived Adherence Scale

Adapted from Bergeron (1999)

The following is a list of different things that people may do as part of their lifestyle. Recommended frequencies vary for the different behaviours. For example, you should eat healthy daily, do breast self-exams monthly, and get physicals yearly. The response category “as often as suggested” means that you follow the recommended guidelines for that particular behaviour. For each of the examples please indicate (by circling your answer) how often you do each of the behaviours.

Type of behaviour	never	rarely	sometimes	frequently	as often as suggested
take vitamins	1	2	3	4	5
take herbs for your health	1	2	3	4	5
exercise regularly	1	2	3	4	5
eat healthy foods	1	2	3	4	5
avoid unhealthy foods	1	2	3	4	5
get plenty of sleep	1	2	3	4	5
*avoid smoking cigarettes	1	2	3	4	5
*avoid drinking excessive amounts of alcohol	1	2	3	4	5
*avoid taking illegal drugs (e.g., Marijuana or “pot”)	1	2	3	4	5
do breast self-exams	1	2	3	4	5
go for a physical exam	1	2	3	4	5
have cholesterol checked	1	2	3	4	5
have blood pressure checked	1	2	3	4	5
have a mammogram	1	2	3	4	5
have a Pap test	1	2	3	4	5
have a clinical breast exam	1	2	3	4	5
*see my primary healthcare provider when I need to	1	2	3	4	5

*Note.* \* represents additions to the scale.

## APPENDIX L

### Appendix L: Recruitment Letter

**ARE YOU A LESBIAN?**

**ARE YOU 16 YEARS OR OLDER?**

**DO YOU CURRENTLY LIVE IN CANADA OR THE UNITED STATES?**

If yes, then please consider participating in an exciting online study to find out more about lesbians' experiences with healthcare professionals. If you participate you will have the chance to win 1 of 5 \$100 cash prizes!

My name is Melissa St. Pierre and I am a lesbian Doctoral Candidate in the Applied Social Psychology program at the University of Windsor in Windsor, Ontario, Canada. For the past five years I have been committed to doing research which provides an understanding of the unique and diverse realities we live as lesbian women. This project is my PhD dissertation research. I am supervised by Dr. Charlene Senn, who is also a lesbian. I am interested in the experiences of lesbians who live in Canada or the United States and their triumphs and challenges while navigating the healthcare environment. This study will add to the relatively little information we know about our important health and healthcare needs as lesbians.

If you know other lesbians who are 16 years or older and who live in Canada or the United States, feel free to pass this email along to them!

Do you have questions? Or would you prefer to fill out a paper copy of the survey? Feel free to contact me at [stpier4@uwindsor.ca](mailto:stpier4@uwindsor.ca) or at 519-253-3000 ext. 4703 with questions or to request that a paper copy of the survey be mailed to you.

Ready to complete the survey? Click here to go to the website, or copy and paste the link into your browser!

Thank you for your time!  
Melissa St. Pierre

## APPENDIX M

### Appendix M: Consent Form



### Consent to Participate in Research

Title of Study: An Online Study of Lesbians' Experiences with Healthcare Professionals

You are asked to participate in an online research study conducted by Melissa St. Pierre, Doctoral Candidate in Applied Social Psychology at the University of Windsor in Windsor, Ontario, Canada. Dr. Charlene Senn, Professor from the Department of Psychology, is supervising this research.

If you have any questions or concerns about the research, please feel to contact me, Melissa ([stpier4@uwindsor.ca](mailto:stpier4@uwindsor.ca) or 519-253-3000 ext. 4703), or my supervisor, Dr. Senn (519-253-3000 ext. 2255).

#### PURPOSE OF THE STUDY

The purpose of the study is to learn more about the healthcare experiences of lesbian women living in Canada and the United States.

#### Who can participate:

You are invited to participate if you:

1. Self-identify as a lesbian.
2. Are 16 years or older.
3. Currently live in Canada or the United States.

#### PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

Read through this consent form and decide whether or not you would like to participate in this study. To participate, go to the survey by clicking on the link provided below.

Once you go to the survey, you will be presented with a series of questions that will ask about your experiences in healthcare settings.

First, you will be asked to provide some background information about yourself. Next, you will be asked to complete questions inquiring about your health, your social attitudes,

healthseeking behaviours, and your experiences with healthcare providers (both positive and negative).

Once you complete the survey (or if you decide not to participate), you will be directed to more information on the study, as well as a list of resources on lesbian health. The survey will take approximately 30 minutes to complete.

#### POTENTIAL RISKS AND DISCOMFORTS

Any request for information about your experiences with healthcare professionals has the potential to bring up memories of the best and worst experiences you have had. Reflecting on these experiences can bring up a range of emotions. If after you complete the survey you feel you would benefit from talking more about these experiences, we have provided a range of resources for you to consult.

#### POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

There are no direct benefits to you from participating in this research. However, results from this study will be used to help understand the healthcare experiences of lesbians living in Canada and the United States. By participating in this study, your responses will contribute to what is known about lesbians' health and healthcare needs.

#### PAYMENT FOR PARTICIPATION

There is no payment for participating in this study, however, to thank you for your help, you are invited to enter into a draw for 1 of 5 \$100 cash prizes. Once you complete the study, you will be provided with an area where you can enter your contact information if you would like to be included into the draw. Your contact information will **NOT** be linked to your survey responses in any way. Following the completion of the study (no later than fall 2012), I will notify the five winners of the draw, and a cheque for \$100 will be mailed to them in the currency of their country of residence.

#### CONFIDENTIALITY

Your participation in this study is completely voluntary and your responses will remain anonymous. Your answers cannot be matched to your identity or location and will be released only as summaries grouped with other people's responses. Information about the computer and Internet service provider you are using will not be collected. Your survey responses are entered into a non-identifiable data file with other people's responses. If you choose to enter your contact information into the draw, this information will not be linked to your survey responses, will be kept in a password protected file on a secure server in Canada, and will be destroyed once the draw has been awarded.

## PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw prior to submitting your survey, without consequences of any kind. Any research study benefits from having as much complete information as possible from participants. However, if you are uncomfortable about answering any question you may refuse to answer a question by skipping it, or you can change your mind and leave the study at any time without consequences. To leave the study, simply close the web browser window.

Closing your browser does not withdraw your answers to that point. To withdraw your data you must do so prior to submitting your survey by clicking the “Withdraw Data” button. Once you have submitted your survey, however, it is no longer possible to withdraw your data.

## FEEDBACK OF THE RESULTS OF THIS STUDY TO THE SUBJECTS

A summary of the results of this study will be available on the web by the end of 2012.

Web address: [www.uwindsor.ca/reb](http://www.uwindsor.ca/reb)

Date when results are available: no later than December 31, 2012

## SUBSEQUENT USE OF DATA

This data may be used in subsequent studies. This data may be used by the researcher for subsequent publications but will not deviate from the purpose described earlier. The information collected may be used to further examine the experiences of lesbians with healthcare professionals and within healthcare environments.

## RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time **prior to submitting your survey** and discontinue participation without penalty. If you have questions regarding your rights as a research subject, contact: Research Ethics Coordinator, University of Windsor, Windsor, Ontario N9B 3P4; Telephone: 519-253-3000, ext. 3948; e-mail: [ethics@uwindsor.ca](mailto:ethics@uwindsor.ca)

## SIGNATURE OF RESEARCH SUBJECT/LEGAL REPRESENTATIVE

I understand the information provided for the study **An Online Study of Lesbians’ Experiences with Healthcare Professionals** as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study.

Please print this consent form for your records.

**I agree to participate, please take me to the survey!**



## APPENDIX N

### Appendix N: Resource Letter

Thank you so much for participating in the Online Study of Lesbian's Experiences with Healthcare Professionals! Your contribution to the research will help us gain a better understanding of lesbian women's unique health and healthcare needs.

One of the ways in which our health as lesbians differs from the health of our heterosexual sisters is that many of us have to make stressful decisions about whether or not to disclose our sexual orientation to other people, including our healthcare providers. Even though we know that coming out can be difficult and stressful, we also know through the research that has been done so far that when we do come out to supportive healthcare professionals, we often experience positive benefits from our disclosure, such as a more tailored approach to our health. However, the responsibility to come out shouldn't lie solely in our hands as patients – our healthcare providers should help us do so in any way that they can!

My goal in conducting this research was to better understand what kinds of things influence our coming out to healthcare providers so that medical professionals are better informed on this important topic. Previous research suggests that our own background characteristics (e.g., how out we are to friends, family, and coworkers), the healthcare environment (e.g., do we think it's safe to come out?), our healthcare provider (e.g., are they sensitive to what it's like to be a lesbian?), and the kind of relationship we have with our providers (e.g., can we easily communicate with our providers?) all have an impact on whether or not we decide to come out. Through this research I hope to be able to bring healthcare professionals up to date about the things that they can effectively do to make their practice more welcoming and supportive, so that we can feel comfortable enough to come out, and in turn, receive the care that we deserve.

In conducting this research, I also wanted to consider the similarities and differences in the coming out experiences of American and Canadian lesbian women. There are many differences between the two countries, for example, same-sex marriage is available in all parts of Canada, but not the United States. A comparison between the two countries may tell us more about how political climate has an impact on the experiences we have with healthcare professionals.

It is not always easy to participate in this kind of research because the questions can bring up unpleasant memories of past experiences. If you've experienced discomfort as a result of participating in this study, please consider contacting one of the specialized services listed below. For your own information, I've also included a list of resources on lesbian health; feel free to consult these for further information about our health and healthcare needs.

### **GLBT NATIONAL HELP CENTER**

The Gay, Lesbian, Bisexual and Transgender National Hotline provides telephone and email peer-counseling, as well as factual information and local resources for cities and towns across the United States. All services are free and confidential.

**Website:** <http://www.glbtnationalhelpcenter.org/>

**Phone (toll-free):** 1-888-843-4564

**Talkline for Youth (toll-free):** 1-800-246-7743

**Email:** [glhn@GLBTNationalHelpCenter.org](mailto:glhn@GLBTNationalHelpCenter.org)

The GLBT National Help Center also maintain the largest resource database of its kind in the world, with over 18,000 listings. The database contains information on social and support groups, as well as gay-friendly religious organizations, sports leagues, student groups, publications, and more. Also included: information on GLBT-friendly businesses including lawyers, doctors and various counseling professionals. Consult the database for organizations in your area!

**Website:** <http://www.glbtnearme.org/>

### **LESBIANSTD.COM**

Provides information and resources regarding sexual health and sexually transmitted diseases in women who have sex with women.

**Website:** [www.lesbianstd.com](http://www.lesbianstd.com)

### **THE GAY AND LESBIAN MEDICAL ASSOCIATION**

GLMA is working to bring about equality in healthcare for LGBT people. When LGBT people go to see a doctor or other healthcare provider, the care we receive should be as good as anyone else would receive and LGBT healthcare professionals should not be discriminated against in our work. Provide some information and referral services to LGBT patients.

**Website:** [www.glma.org](http://www.glma.org)

### **CENTERS FOR DISEASE CONTROL AND PREVENTION (CDC)**

Section on lesbian, gay, bisexual, and transgender health, includes information on cancer, STDs, HIV/AIDS, smoking and tobacco use, obesity, etc. Also includes information on national LGBT health clinics.

**CDC Website on LGBT health:** [www.cdc.gov/lgbthealth/](http://www.cdc.gov/lgbthealth/)

### **MAUTNER PROJECT**

The Mautner Project, The National Lesbian Health Organization, improves the health of lesbians, bisexual and transgender women who partner with women (WPW) and their families. The Mautner Project educates lesbians about their health and trains health-care providers about their lesbian patients, providing tools and insights on how to achieve better health outcomes for lesbians.

**Website:** <http://www.mautnerproject.org/>

### **THE NATIONAL WOMEN'S HEALTH INFORMATION CENTRE, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES OFFICE ON WOMEN'S HEALTH**

Comprehensive, general information on women and girls' health, including a helpline where women can ask questions and get in touch with important resources.

**Website:** [www.womenshealth.gov](http://www.womenshealth.gov)

**Phone (toll free):** 800-994-9662

### **NATIONAL COALITION FOR LGBT HEALTH**

The Coalition is committed to improving the health and well-being of lesbian, gay, bisexual, and transgender individuals through federal advocacy that is focused on research, policy, education, and training.

**Website:** [www.lgbthealth.net](http://www.lgbthealth.net)

### **CANADIAN WOMEN'S HEALTH NETWORK (CWHN)**

The Canadian Women's Health Network (CWHN) was created in 1993 as a voluntary national organization to improve the health and lives of girls and women in Canada and the world by collecting, producing, distributing and sharing knowledge, ideas, education, information, resources, strategies and inspirations.

**Website:** <http://www.cwhn.ca>

**Phone (toll free):** 1-888-818-9172

**Email:** [cwhn@cwhn.ca](mailto:cwhn@cwhn.ca)

### **WOMENS HEALTH MATTERS**

Canadian source for reliable, evidence-based and up-to-date information on women's health and lifestyle issues. Most of the information on [womenshealthmatters.ca](http://womenshealthmatters.ca) is also available in French: [femmesensante.ca](http://femmesensante.ca). At [womenshealthmatters.ca](http://womenshealthmatters.ca), consumers will find the latest information, news and research findings on women's health, diseases and lifestyle trends. The site, which is updated several times a week, is backed by women's health experts at Women's College Hospital (Toronto).

**Website:** [www.womenshealthmatters.ca](http://www.womenshealthmatters.ca)

### **RAINBOW HEALTH ONTARIO**

The Rainbow Health Ontario website is designed to provide information to help both LGBT people and their health care providers become more aware of LGBT health issues. The website contains a resource database as well as a directory to locate sensitive healthcare professionals across Ontario.

**Website:** [www.RainbowHealthOntario.ca](http://www.RainbowHealthOntario.ca)

### **LESBIAN GAY BI YOUTH LINE**

The Lesbian Gay Bi Trans Youth Line is a toll-free, Ontario-wide peer-support phone line and internet chat service for lesbian, gay, bisexual, transgender, transsexual, intersex, 2-spirited, queer and questioning young people. Provides sex-positive, non-judgmental and confidential peer support through telephone listening, information and referral services, and through complementary outreach.

**Phone (toll-free): 1-800-268-9688**

### **CANADIAN RAINBOW HEALTH COALITION**

The Canadian Rainbow Health Coalition/Coalition santé arc-en-ciel Canada (CRHC/CSAC) is a national organization whose objective is to address the various health and wellness issues that people who have sexual and emotional relationships with people of the same gender, or a gender identity that does not conform to the identity assigned to them at birth, encounter. The organization provides a number of resources on issues relevant to lesbian health.

**Website:** <http://www.rainbowhealth.ca/>

**Phone (toll-free): 1-800-955-5129**

### **GAYCANADA**

Includes a directory for finding a range of region-specific resources, from alternative services to support groups.

**Website:** <http://www.gaycanada.com>

## **VITA AUCTORIS**

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