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Inclusion and exclusion in mid-life lesbians' experiences of the Pap test

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Lesbians are said to feel excluded by sexual health messages that presume heterosexuality, a finding linked to lower levels of Papanicolaou (Pap) testing. This paper discusses a small, focused qualitative study based in Calgary, Canada that illuminated mid-life lesbians' experiences and perceptions of Pap testing and health. Participants indicated that they felt compelled and invited to access Pap testing by an inclusive discourse – that of 'mid-life', a period associated with an increased need for body surveillance. They also reflected upon aging as an experience of liberation, increased confidence and a time when they could 'catch up' on health and sexuality issues denied them in their younger days. On the other hand, there was significant uncertainty about Pap testing, human papillomavirus (HPV), cervical cancer and what kind of sexual healthcare is necessary for lesbians, which was reinforced by physician messages suggesting a reduced need for Pap testing when lesbian sexual identity was disclosed. In approaching mid-life lesbian healthcare, we suggest that greater analytical attention should be paid to the ways in which lesbian women are included, as much as excluded, in dominant sexual health scripts particularly by health providers who need to attend to women's diverse experiences and needs.

Keywords: lesbian; Pap test; exclusion; Canada

Introduction

Recent analyses argue that lesbians are excluded from safer sex messages because dominant sexual scripts, or contemporary social and cultural discourses that influence lived experience and decision-making, assert that 'real' sex, and therefore 'real' risk, is defined by penile penetration (Power, McNair and Carr 2009, 70, 78–9; Richardson 2000, 37–8). Sexual health information that assumes heterosexuality may result in a 'social construction of immunity' for lesbian women (Richardson 2000, 34) who may perceive themselves to be at low risk for sexually transmitted infections (STIs), including human papillomavirus (HPV), the virus responsible for the majority of cervical cancers (Hyde et al. 2007; Power, McNair and Carr 2009; Powers, Bowen and White 2001). Richardson (2000) discussed ways in which lesbians are excluded from sexual health messages.

A recent study concluded that lesbians generally feel at low risk for STIs, including HPV, because they are excluded from dominant sexual scripts that inform the negotiation of safer sex practices (Power, McNair and Carr 2009, 67). This perception of exclusion

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contributes to lower Papanicolaou (Pap) test rates and later detection of cervical cancer (Diamant, Schuster and Lever 2000) in lesbians.¹ Given strong evidence that experiences of discrimination, unequal treatment and reduced access (Powers, Bowen and White 2001, 45), stigmatisation or fears of discrimination underpin lesbians' experiences with health providers (Bergeron and Senn 2003; Hudspith 1999; Mathieson 2007), it is entirely appropriate that 'exclusion' has emerged as a dominant analytical focus in lesbian health research (e.g. Mathieson 2007; Power, McNair and Carr 2009; Ramsay 1994; Richardson 2000).

In response to these findings, scholars have promoted inclusive, explicit and lesbian-specific healthcare approaches (Power, McNair and Carr 2009, 79; Hyde et al. 2007, 47). It is unclear what contemporary forms of inclusion in lesbian healthcare would entail. Inclusion in social policy is linked to engaging diverse, marginalised or underprivileged populations (Baldock 2007, 15–16). From the literature on education and social inclusion we find inclusion subsumed by other names, such as 'mainstreaming', 'integration' and 'normalization' (Thompkins and Deloney 1995). With regard to sexual minorities, scholars have advocated 'sexual citizenship' as a paradigm that offers belonging, inclusion, visibility, rights and justice (Daley 2006, 798). Epstein (2007, 11) proposed that an 'inclusion and difference paradigm' now dominates US healthcare policy, but that these reforms have unintended consequences:

By approaching health from the vantage point of categorical identity, they ignore other ways in which health risks are distributed in society. By valorizing certain categories of identity, they conceal others from view. By treating each of the recognized categories in a consistent fashion, they often ignore important differences across them. By focusing on groups, they obscure individual-level differences.

Conceptualisations of lesbian 'inclusion' therefore deserve attention and cannot be assumed to uncritically offer empowerment, belonging or personal satisfaction.

Attentive to calls for more inclusive approaches to sexual healthcare for lesbians, the purpose of this paper is to examine feelings of inclusion and exclusion expressed by a group of mid-life lesbians in Calgary, Canada, who recount their experiences with Pap testing. We hope to shed light on critical questions about how mid-life lesbian women's sexual healthcare needs can be made visible and distinct without fomenting stigma or motivating hegemonic assumptions about lesbian experiences and identities.

The objective of this study was to understand the experiences of mid-life (defined as 45–55 years of age) lesbian women in Calgary related to the Pap test in order to improve clinical practice. Participants' discussion of the Pap test experience yielded recommendations to improve practitioners' communication and clinical encounters with their lesbian patients as well as suggestions for creating a more welcoming clinical setting (Szewchuk and McIntyre 2010). In addition to discussing their clinical experiences, participants also provided a rich discussion on intersecting issues of sexuality, health risk and health-seeking behaviours that specifically related to their age group's experiences of inclusion and exclusion. It is these experiences that form the basis of our analysis in this paper.

Methodology

This research took place in Calgary, a city of about one million people and the largest city in Alberta. Alberta is one of Canada's western provinces, where the petroleum industry, tourism and agriculture produce an economy characterised by rapid growth and periodic downturns. One of the city's iconic celebrations is the Calgary Stampede, which highlights

the city's identification with rural-based, cowboy lifestyles; conversely, Calgary is also home to the second largest number of corporate head offices in Canada. Gay and lesbian communities in Calgary are increasingly visible, although public spaces dedicated to these groups come and go with the times, in line with the city's boom-bust nature. The city has a gay pride council, which supports an annual parade, dance and festival, a gay and lesbian travel agency and several gay and lesbian community service providers. In keeping with the region's cowboy culture, a gay rodeo is held annually. Yet among Canadian provinces, Alberta is politically conservative and is the least gay-friendly in terms of basic laws and protections. For instance, sexual orientation was not protected by Alberta's human rights legislation until October 2009 (Government of Alberta 2009).

The participants in this study were self-identified lesbian women, within the mid-life age range and living in Calgary, who had experienced at least one Pap test in Calgary. Because we were interested in the clinical experience of the test itself, we excluded women who had never had a Pap test, a group who might reveal different factors leading to Pap avoidance. In addition to these characteristics, participants were purposively selected on clinical risk factors known to be associated with needing a Pap test, i.e. biological motherhood and previous gynaecologic problems. Participants were elicited using email lists and social networks focusing on gay and lesbian people in mid-life, as well as announcements posted at a local lesbian bar. Additionally, flyers were distributed at a community organization that caters to Calgary's sexual minorities' community. Some participants were also recruited through snowball sampling.

Recruitment yielded seven eligible women, one of whom was slightly younger than our preferred age range, whose mean age was 48.7 (range 43–54) years. One participant was Asian, the rest were white. All women had some post-secondary education and two had completed master's degrees. All participants worked, one received government financial assistance for a temporary disability. Five women were partnered with women, one was married (same-sex marriage is legal in Canada) and one identified herself as single. One woman had children in a previous heterosexual marriage and six were nulliparous. Another woman had attempted conception through in-vitro fertilization.

Interview locations consisted of either the participant's home or a community location of her choice. Written informed consent was obtained from participants in accordance with the ethical protocol approved by the Conjoint Health Research Ethics Board of the University of Calgary. Semi-structured interviews, consisting of simple open-ended questions over the course of an hour, were conducted by the second author (AS) between October and December 2008. The research method was intended to generate dialogue about experiences that may have been overlooked or underexplored in large-scale, survey-based studies, not to produce generalisations applicable to a large population of lesbians.

Results were returned to participants in a focus group meeting and subsequently by way of a written report. Participants supported the results and expressed that they accurately reflected their experiences and perceptions. On the basis of our own review of the data and the response of participants to our results, we concluded that we had reached sufficient saturation with the seven interviews to comment on the clinical issues encountered by the women and their broader experiences within the healthcare system.

Nonetheless, the limitations of this study include the small sample of lesbian-identified women from a particular Canadian centre, who are also likely better educated than the general population of self-identified lesbians.

All interviews were audio-recorded and professionally transcribed, transcripts were then compared to audio-recordings for accuracy. Extensive field notes were prepared after each interview. Conventional qualitative analysis (Hsieh and Shannon 2005) was used to

code and interpret the interviews using NVivo 8 (QSR International 2009). All authors participated in transcript review and analysis. The following sections of the paper discuss interview results that illuminated experiences of exclusion as well as inclusion.

Results

Mid-life lesbians in this study described themselves as being part of an age group with greater health risks. They also reflected upon aging as an experience of liberation associated with increased confidence and the capacity to 'catch up' on health and sexuality knowledge that they found inaccessible in their younger days due to lack of available information and stigma against their sexual orientation. The women were generally proactive in seeking information, especially from the Internet, but also from friends, family and, to a lesser extent, health centres. Still, there was a significant amount of uncertainty and confusion about Pap testing, HPV, STIs, cervical cancer and the extent to which sexual healthcare was necessary for lesbian women. Participants had mixed experiences with physicians and with Pap testing in terms of communication and disclosure and in terms of being provided or denied Pap tests.

'I certainly never heard about it from my mother': coming of age before gay 'liberation'

Participants identified themselves as a generation that came from a different era when awareness of sexuality, health and healthcare was limited, especially for rural women. For example, Leila² explained the trajectory of her knowledge of Pap testing:

I certainly never heard about it from my mother ... I never heard about it from my friends ... I mean if they had told me when I was 15 that if I never had sex with a guy, I'd never have to have a Pap test, then I would never have had sex with a guy you know but they didn't seem to know those things in those days so now I have to have a Pap test every second year. (Leila, age 48)

Brenda, originally from rural Alberta, also described a sense of growing up in a different era, when people did not go to the doctor for every problem:

It's just, the way that we, we were brought up you know like if your arm was hanging from the socket you know Mom would sew it up and put it back in the socket. You know you're just built tough. (Brenda, age 49)

When they were younger, the women got their information about sexuality and sexual health from birth control centres and books or they did not have access to information:

No, [I] didn't even know anything about it [Pap test]. Unfortunately when I was younger none of it was explained to me. (Sheila, age 51)

The issue of access to information, likely faced by many heterosexual women as well, was particularly acute for lesbians. Some women were more explicit about how 'coming out' was affected by being from a different era, before 'gay pride' and before there were supportive arenas in which lesbian sexuality could be openly discussed:

I tried to come out in the '80s but it wasn't safe because, again, the way I was spoken to and stuff, I just thought I don't want to be ... so it was just easier to live a celibate life. ... I did have this circle say to me oh we've always known when I finally did say, by the way. They said well we've always known. ... I said well I didn't. (Sheila, age 51)

So if you do the math, those are people who were born in the '60s and like mid-50s to mid-60s and so those of us of that age who have come out, like just coming out was such a big thing, so getting some of that information, it's like, that's like the least of my concerns ... I didn't even

figure out for myself that I was lesbian until I was 33 so figuring out my safe lesbian health, was like a whole other galaxy and I was just discovering this little tiny universe here and so, yeah it was kind of limited in that way. (Sam, age 54)

Women thus distinguished themselves from younger women and from younger lesbians:

If you took like a lesbian in her twenty to thirty range right now and compared her body of knowledge about not just her own sexuality but just like all those things related to that, I'm like in kindergarten compared to that. (Sam, age 54)

In relaying how her own mother avoided Pap testing, Brenda suggested that an attitude of embarrassment and secrecy is associated with 'the old days', while contemporary attitudes of openness and assertiveness are important for detecting health problems. Besides distinguishing themselves from other lesbians based on their generation, the women in this study also spoke of new attitudes and behaviours important for mid-life women in general.

'As I got into my '30s I kept hearing more about Pap smears': mid-life surveillance and women's perceptions of Pap testing

Mid-life surveillance

The women in this group made statements about an increasing need for body surveillance in mid-life. Pap testing was often seen as part of this surveillance, along with mammograms and general awareness of health and well-being:

I know that at a certain age it's a good idea to have that checked. ... I got it [Pap test] the first year I was supposed to. I can't remember what year it was but I'm pretty sure I was in my late 30s, early 40s and as soon as I was supposed to ... and I come from a line of healthcare people and my sister was recommending that I go as soon as possible after 35 and get one. (Leila, age 48)

As you get older things just start breaking down. You're not, your body changes right so ... you know when that's all changing, you, the rest of your body has to be going through some changing too so I think you gotta keep on top of it. (Brenda, age 49)

Surveillance was associated with the body 'breaking down' and 'changing' in mid-life, and the need to pay more attention to health issues as a result. The women also associated mid-life Pap testing with breast cancer awareness, hormonal changes, menopause and other aspects of general health. Sam suggested that certain tests are necessary 'for a woman over 40' and that Pap testing was something she should do regularly:

I felt like the Pap smear was something that I should be doing annually and just add it to my list of now that I'm older okay ... these are these things you're supposed to get done, you know your blood pressure, your yearly mammogram. I got my cholesterol tested. (Sam, age 54)

In these statements, women asserted that Pap testing was something they were supposed to do as mid-life women. Below, we discuss the experience of seeking and receiving health information across the life course and the ways in which these women's lesbian identity played a role in these experiences as well as perceptions of risk.

In search of knowledge

An unexpected finding of this study was the extent to which mid-life lesbian women were actively seeking information and support, particularly via the Internet. All of the

participants mentioned that they used the Internet to access freely available information and some asserted that Internet research was a vital part of their healthcare strategy:

It's only in my older years that I'm finally understanding you know a little bit more and seeking the information too. . . . I wish I knew what I know now back then. I probably wouldn't have asked the question [about HPV to the doctor]. I would have just researched it by going on the Internet and finding out what is it all about and the fact that it's been around 4000 years. (Sheila, age 51)

If somebody tells me something or hears something, then I would go and do a search. At this point, I'm probably more likely to do it on the Internet. . . . It's much easier to do it from home so if that information is out there, it's nice if it can be made available. (Terri, age 47)

Women's efforts to find out more about health and sexuality in their mid-life years shows the extent of new desires to be experts about themselves and the extent to which they were excluded from expertise in the past. In some cases, women were explicit about the fact that their doctor would not always be their primary source of information:

It would always have been friends first, family second, um, and then my own research, ah, either through the Internet or at a library and then finally it would be the doctor and that's kind of a scary realization is that the doctor is down there at fourth [chuckle]. (Debbie, age 43)

The desire to seek information for oneself indicates a level of empowerment, but also revealed women's varying perceptions of their own risk in regards to sexual health, as we discuss in the following sections.

'I'm not just a regular woman': views on lesbian risk

While women perceived Pap screening as an important test for mid-life women, lesbian sexuality was associated with a set of unique health needs, including the perception of decreased sexual health 'risk'. Four of the seven participants stated that lesbian sex is safer than heterosexual sex and others questioned whether the Pap was important for lesbians. For example, Debbie explained that lesbian women were at lower sexual health risk because getting STIs were associated with penile contact:

I actually had a lot of assumptions about the fact that because I was a lesbian somehow lesbian sex is safer even though I was worried about Pap tests for the whole cancer aspect . . . when you're in high school, junior high your peers, at least my friends and I always thought that when you got a venereal disease it always came from the guy. It was always the guy's fault and so it was always the dirty penis thing so I think when you finally come out as a lesbian, you carry that assumption and you think you're safe now because you don't have that apparatus involved in your sexuality. (Debbie, age 43)

Brenda, like Debbie, indicated that she sometimes had conflicting thoughts about what all women need versus what is needed 'from a lesbian point of view':

I think that it should be mandatory once a year kind of thing. Not, not from a lesbian point of view like I just kind of shook it off too because I was in that same mindset of, oh really because I don't need birth control, I don't need a Pap, because I don't have any worry about becoming pregnant. (Brenda, age 49)

Kate had also thought that the Pap test was only necessary when sexually active with men:

It was just like a few days ago when I was telling my girlfriend about me doing this interview, that I actually even this week had a discussion about the Pap test and, and I said you know I don't even see why I need to have them anymore, because I haven't been with men and then she was the one that tell [sic] me about some virus, HPV virus or something like that, that, that I guess can stay in your body so that's why it's still important for me to have a Pap test. (Kate, age 49)

Despite perceptions of the safety of lesbian sex, a significant finding was that women also associated Pap testing with a woman's general well-being and mid-life body surveillance. In this regard, all participants were able to identify the Pap as looking for cancer, but HPV or STIs were rarely mentioned. Sam was one of the interviewees who most strongly expressed that Pap testing is for all women regardless of sexuality:

I just figure I categorize myself in with other women and so if, if they're at risk, I'm also at risk regardless of whether I've had sex with a man or not. Like I still have the same parts. ... Women in general they talk about getting their Pap smear done so you just as a woman you just sort of lump yourself in that group. I have never really designated my healthcare to be different although I suppose it could be but I have not like said oh I'm gay so therefore my needs are different than this larger group of women. (Sam, age 54)

Regardless of point of view on the need for a Pap test, lesbian identity was considered as unique from mid-life female identity. Sam still questioned whether her physician or 'the medical community' really 'knew' the true risks of lesbian women. Leila, who described a good relationship with her physician (who knew of her sexuality) stated: 'I know that [my doctor] thinks about my health in terms of a lesbian.' Leila was therefore one of the few women in the study who confidently stated, 'I'm not just a regular woman, I'm a lesbian.' Tension regarding beliefs of the needs of mid-life women versus the needs of lesbian women was exacerbated by information received from physicians. Several women had had physicians advise them against Pap testing for lesbian women (or for less frequent testing) as was the case for Terri:

I knew a fair amount about the, the HPV virus and stuff like that. I've never had sex with men so I mean that, when she [doctor] said that [I didn't need a Pap] I just kind of thought well it makes sense but I didn't really think much more about it. (Terri, age 47)

These experiences raised issues of empowerment as women 'came of age' at mid-life.

"You get to a point in your life where you're not afraid to talk about your health": paradoxes of disclosure and empowerment

Most of the women in this study described themselves as gaining courage, assertiveness and knowledge in mid-life. In the past, women identified difficulties speaking out, which stemmed from actual negative treatment by physicians, but also related to being from an era of relative silence and shame around lesbian sexuality. Growing older was associated with increased capacity to be assertive in health matters. For instance, Brenda made the powerful assertion, 'You get to a point in your life where you're not afraid to talk about your health.' This section explores some of the actions and experiences in clinical settings that follow or contradict a sense of courage and empowerment. For some, these capacities enabled them to speak up in the doctor's office or take independent action to address their health concerns, in particular in seeking Pap testing:

I didn't like the way that we were as a lesbian and not having heterosexual relations and things like that, how easy it seemed to be in the mindset of the doctor to brush you off and say no you don't need a Pap. You, why, why do you need one? You're, you're not having intercourse ... you talk to friends about that and they said no, you have to demand it. You know if you're a lesbian, you have to demand it and I go why should it make any difference? (Brenda, age 49)

I argued with my doctor every year to get this test when she sort of discouraged it. (Sam, age 54)

Terri, who has a master's degree in sociology and had fought for same-sex benefits in the workplace when few employers offered them, also found empowerment through aging

and education. She had described a 'rough' sexual health visit with a rural Albertan provider as a young woman. Years later, she reflected on this:

I think the knowledge of the potential abusive physicians by patients was probably pretty limited at the time, particularly limited at a place like [rural Albertan town] so it, it really would have been many years later before I would have thought about, um, how inappropriate this doctor was with, with me. (Terri, age 47)

Despite her history of self-advocacy, she repeatedly described her clinical encounters regarding Pap testing as 'really uncomfortable' and even upsetting in both a physical and psychological way. In terms of communication with her physician, she said:

I've had physicians who are pretty good communicators . . . I think it's a two-way thing and I'm not particularly communicative with physicians either. (Terri, age 47)

Thus growing confidence in their knowledge about their body and health needs did not always translate into openness or assertiveness with health professionals. Some women explained that either the atmosphere was too impersonal and potentially judgmental to talk openly or that their efforts at communication were shut down by health providers.

Sheila described trying to speak up about poor treatment from clinic staff on numerous occasions:

When I got shot down it's like just bear with it and every now and then I would speak up and get shot down again so I'd be quiet for a little bit longer but there's always something in me that always makes me have to speak up yet again. (Sheila, age 51)

Debbie described how she had to force herself to come out to her gynaecologist despite feeling anxious:

I would say it's quite anxiety-ridden when I knew I was going to have to go in and talk particularly to the gynaecologist about my lack of libido and such. I pretty well had come out to them during the first surgery because of course it was a question of are you pregnant or will you ever be pregnant and they insisted on doing a pregnancy test so I pretty well had to say look I'm a lesbian, I'm not pregnant. (Debbie, age 43)

These uncertainties and reluctances about disclosing sexuality illuminate a central tension in our participants' experiences: their growing confidence in knowledge about their bodies and the need for mid-life surveillance and assertiveness was often constrained in the interaction with the healthcare provider. Even though Brenda described having a positive relationship with her physician, she also indicated that she and her doctor had very little communication about sexual health and, thus, her doctor operated on assumptions about what lesbians do:

There was no assumption that well maybe we're bringing a third in and maybe it's a male, there was never anything asked. Would doctors ask that? Are they able to ask that kind of question? (Brenda, age 49)

Kate, who also described a 'pretty good' relationship with her doctor, said that there was 'generally no discussion' with her current doctor about Pap testing or sexual health and that her doctor had not asked her about her sexual history:

Nothing at all [about sexuality], which is actually what I thought was interesting because she didn't even, I mean she didn't even know that I, I mean for the longest time I think she just assumed I was straight like I said but never, ever has asked me anything about that ever. (Kate, age 49)

Women in this study affirmed the persistence of heterosexism in the medical system in that their health providers tended to assume they were straight (Mathieson 2007, 274). Some studies indicate that, overall, disclosing sexual orientation results in better

healthcare (Steele, Timmouth and Lu 2006), but this depends on whether the provider is appropriately informed about lesbian health needs. Indeed, some participants expressed a sense of 'relief' at being open with their provider. However, other studies suggest that 'Women report negative impacts of disclosure and inappropriate advice from providers as a direct result of disclosure' (Mathieson 2007, 277). For the women in this study who did come out, some had no noticeable shift in the course of care, questioning or treatment or experienced a series of assumptions on the part of physicians about lesbian needs and risks that resulted in inappropriate advice. Thus, while participants expressed a desire for more openness and communication with physicians, it is clear that disclosure must be accompanied by both acceptance and an awareness of women's true needs.

Discussion

The women in this study asserted that they are from a different era. Born between 1956 and 1967, they came of age in a time that is generally associated with social activism, the women's movement, radical and liberal feminism, civil rights and new levels of openness about sexuality and sex. In urban north American centres, a political movement for gay liberation emerged in the late-1960s (Efscoffier 1985, 122; Engel 2001; Jay and Young 1992), while in Canada, Smith (1999, 37, see also McLeod 1996) dates the emergence of a gay and lesbian movement based in major eastern cities such as Ottawa, Montreal and Toronto to 1971. Scholars suggest that, in Canada, lesbians were marginalised by both male dominance in the gay liberation movement and heterosexism in the women's movement (Smith 1999, 37–9). Lesbian sexuality and political activism did not become visible in Canada until the 1980s (Smith 1999, 39; Taylor and Rupp 1993).

In 1975–1985, when the women in this study were approximately 20 years old, lesbian women in rural Canada were not in a position to experience sexual liberation. It was, as participants suggested, a case of being marginalised in terms of information and awareness about lesbian sexuality, rights and health. While they may have missed out on a coming of age in their youth, this group of women approached mid-life at a time when women's health issues received unprecedented attention and care in the medical system and broader public health discourses. Weisman (1997, 179) writes of a paradigmatic shift in women's health taking place in the 1990s that drew attention to gender inequities in healthcare and to improving the health of women. The aims of the woman-centred healthcare movement were reflected in policy initiatives such as the US Breast and Cervical Cancer Mortality Prevention Act of 1990, which resulted in the launching of the US Centers for Disease Control's National Breast and Cervical Cancer Early Detection Program (Weisman 1997, 182). In Canada, the new emphasis on women's health, and in particular on the health concerns of mid-life women, was represented by the emergence of specialised clinics such as the Saskatchewan Women's Mid-life Health Centre and the Westcoast Clinic for Women's Midlife Health in Vancouver, based in a major urban centre in western Canada, which founded programs such as Pap and Mammogram Awareness Week.

Our participants' entering mid-life also corresponded to the rise of accessible information technologies permitting them to seek out health information for themselves and thus learn more about their own bodies. Importantly, it was not just media and public discourses that influenced women's thinking about Pap testing, it was also the perspectives of their friends, partners and family members and views posted on the Internet that invited mid-life lesbian women to take care of their health in particular ways. In a sense, women were experiencing more than just dominant sexual scripts – by taking account of the various experiences and perspectives of their friends and co-workers and the multifarious

views on the Internet they may have been compelled to pursue preventive health measures. Our participants more often associated Pap testing with cancer screening than with HPV, indicating the potency of an inclusive discourse that compels lesbian and non-lesbian women to take up Pap testing for general health and well-being.

Yet, as scholars of exclusion have pointed out, 'the terms of inclusion can be problematic, disempowering, or inequitable' (Hickey and de Toit 2007 as cited in Fangen 2010, 134) and propose that women lose, not gain, power over their health and bodies when they are targeted by powerful institutions such as the medical system, through which authoritative experts determine what they need. Coney (1991), Morgan (1998) and others are also critical of health discourses that pathologise a natural aging process in women. Yet Morgan admits that the 'medicalisation of women's health' is not necessarily experienced as disempowering. This was the case with participants in this study. A kind of 'medicalized agency' (96) emerged as participants described feelings of satisfaction and empowerment from being assertive about their health needs and insisting on action from healthcare providers. This was also apparent as they distinguished themselves from, in their views, both an older, more complacent generation of women who submitted to medicalised authority and from a younger generation of lesbian women who have had unconditional access to sexual health information in much more supportive socio-political conditions and thus have had less need to be assertive or demanding.

Nonetheless, our study also demonstrates the barriers to inclusive healthcare confronted by our participants. Mathieson (2007) writes, 'The empirical evidence from the USA, the UK and Canada overwhelmingly points to a history of discriminatory attitudes towards gays, lesbians, and bisexuals on the part of health care providers' (274). The women in our study were not generally subjected to discriminatory language or treatment from physicians to whom they came out. Rather, if they were out, they faced the risk of being told that they did not really need Pap testing and were made to feel as though they were inconveniencing the doctor by insisting on Pap testing, a qualitatively different kind of exclusion. Thus, physician actions and words that marked off lesbian health needs as less pressing and less necessary contradicted the sense that mid-life women are supposed to have Pap tests. Furthermore, the discourse of mid-life 'bodily breakdown' was for many of our participants the first time they had ever felt included in health promotion messages, which at the same time confounded beliefs about the decreased 'risks' of lesbian women. In this case, the medicalisation of mid-life, combined with increased access to previously inaccessible knowledge and views via the Internet was a compelling contradiction to experiences of exclusion related to a sense of being distinct from other women on the basis of sexuality alone. These contradictions likely play a role in decreased uptake of Pap testing by lesbians who share these experiences (Diamant, Schuster and Lever 2000).

This small focused study of mid-life lesbians indicates the effects and operation of inclusion as much as exclusion in dominant health scripts. The Pap experience emerged as a symbol of mid-life that is itself an inclusive and compelling health script, even though lesbian sexuality is excluded from health discourses. Yet inclusion comes with its own risks. For some women, the sense of being included in healthcare scripts by virtue of aging and of being female motivated actions that nevertheless led to experiences of exclusion in clinical settings. For others, the sense of having important, unique healthcare needs as lesbian women, partially motivated by broader mid-life health discourses, prompted participants to seek out information via the Internet to avoid awkward and potentially demeaning encounters with healthcare providers. These conflicting scripts challenge mid-life lesbians to understand and act on their mid-life health surveillance responsibilities and

speak to the need for healthcare providers to pay more attention to social locations such as age when examining lesbian health.

Conclusion

A history of exclusion means that lesbians may see themselves as absent from sexual health scripts, or they may already have strategies for reinterpreting general health messages 'from a lesbian point of view', as one of our interviewees said. In this study, perceptions of cancer risk, increased confidence in mid-life and the need for mid-life body surveillance invited and compelled women to pursue healthy actions. Without promoting what Taylor (2008, 525) has criticised as 'inclusion via assimilation', we suggest it is still important to recognise and leverage the assertion, 'I have the same parts', where it exists. However, in light of arguments that stress the medicalisation of mid-life women, it is essential to cast a critical eye to a politics of inclusion, as well as exclusion, to better understand the ways that lesbians are empowered and oppressed in competing and even contradictory ways, inside and outside the doctor's office.

Recent studies have suggested that if information about lesbian sexuality is not open and explicit in health promotion messages, lesbians assume the issues being discussed refer to heterosexual women (Power, McNair and Carr 2009, 76). In this study, women felt 'included' in the discourse of mid-life health, but often constrained or conflicted by how their lesbian identity influenced these needs. Our findings affirm Fangen's (2010) suggestion that exclusion is dynamic, complex and multidimensional because 'an individual lives his or her life in many different arenas' (133). Inclusion and exclusion, belonging and non-belonging, participation and non-participation can occur simultaneously (153). As has been pointed out before, just as 'the notion of gender as the most important category in women's experiences flattens out important differences' (Hankivsky 2007, 78), research into lesbian experiences should be wary of producing a 'categorical hegemony' (Friedman 1995, 4) based on lesbian identity alone (Kerker, Mostashari and Thorpe 2006). Epstein (2007, 10) has pointed out that attempts to address disadvantage and exclusion of vulnerable groups may end up exacerbating stigma or discrimination against them. What is clear in this study is that many of those who do choose to come out as 'lesbian' experience stereotypes about sexual behaviour and other health risks that contradict their true needs and ignore other identity labels such as 'mid-life woman'. Our findings show that no matter how explicit and open health messages are about lesbian sexuality, the quality of care from healthcare providers is critical in creating inclusion and must take into account the diversity of lesbian experiences and needs.

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Notes

1. It is important to note that women who have sex with women are advised to follow the same screening guidelines for cervical cancer as women who have sex with men. At the time of the study, Pap testing in Alberta was recommended for 'All women aged 18 and over who have had sexual intercourse' (Alberta Cervical Cancer Screening Working Group 2006), which could be interpreted as excluding women who self-identify as lesbian.
2. Pseudonyms are used to indicate the source of quotes.

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Résumé

Il est dit des lesbiennes qu'elles ne se sentent pas visées par les messages de santé sexuelle qui prennent pour acquise l'hétérosexualité, une situation liée à un taux de recours au frottis cervical plus faible parmi elles. Cet article décrit une étude qualitative modeste et ciblée, conduite à Calgary, au Canada, qui a apporté un éclairage sur les expériences et les perceptions de lesbiennes dans la quarantaine concernant le frottis cervical et la santé. Les participantes ont indiqué qu'elles se sentaient contraintes et incitées à avoir recours au frottis cervical par un discours non spécifique – celui de «la quarantaine», une période de la vie associée à la nécessité de plus en plus marquée de surveiller l'organisme. Elles ont également parlé du vieillissement comme d'une expérience de libération, d'une plus grande confiance en elles, et d'une période de leur vie où elles peuvent se «rattraper» sur des questions de santé et de sexualité, dont elles ont été privées dans leur jeune âge. D'un autre côté, elles ont exprimé des incertitudes significatives à propos du frottis cervical, du papillomavirus humain (HPV), du cancer du col de l'utérus et du type de soins de santé sexuelle dont elles ont besoin, ces incertitudes se renforçant avec les messages des médecins qui, dès l'instant où leur identité sexuelle est révélée, leur suggèrent une moindre nécessité du recours au frottis cervical. Notre approche des soins de santé pour les lesbiennes dans la quarantaine, nous amène à recommander la plus grande attention analytique aux modes d'inclusion et d'exclusion des lesbiennes, par les scripts de santé sexuelle dominants, en particulier de la part des prestataires de soins qui doivent être attentifs à la diversité des expériences et des besoins des femmes.

Resumen

Las lesbianas se quejan de que se sienten excluidas de los mensajes de salud sexual porque estos presuponen la heterosexualidad, lo que se ha vinculado a bajos niveles de la prueba citológica (Papanicolau) entre este colectivo. En este artículo analizamos un pequeño estudio cualitativo y centrado que se llevó a cabo en Calgary, Canadá, donde se reflejan las experiencias y percepciones de lesbianas en la edad madura con respecto a la prueba citológica y la salud. Las participantes indicaron que se sentían obligadas e invitadas a acceder a las pruebas citológicas por un discurso inclusivo que se refería a la “edad madura”, un periodo que se relaciona con una mayor necesidad de vigilancia corporal. También reflexionaron sobre la edad como una experiencia de liberación en la que aumentaba la confianza y un momento en que podían ponerse al día con cuestiones de salud y

sexualidad que se les había negado en su juventud. Por otra parte, existía una gran incertidumbre sobre la prueba citológica, el virus del papiloma humano (VPH), el cáncer cervical, y qué tipo de salud sexual es necesaria para las lesbianas. Esta incertidumbre se reforzaba por los mensajes de los médicos puesto que atribuían una menor necesidad a la prueba citológica cuando se revelaba la identidad sexual de las lesbianas. En el enfoque para la salud sexual de mujeres lesbianas en la edad madura, sugerimos que se preste mayor atención analítica al modo en que las mujeres lesbianas son incluidas, o excluidas, en los guiones dominantes de salud sexual, en particular por los profesionales de la salud que deben prestar atención a las diferentes experiencias y necesidades de las mujeres.