Cervical cancer screening behaviours of lesbian women: a review of the literature.
# Table of Contents:

Title page.................................................................ii

Acknowledgements......................................................iii

Declaration...............................................................iii

Table of contents........................................................iv

Abstract...........................................................................v

Introduction.................................................................6

Lesbian women's perceived barriers to cervical cancer screening...........8

Health promotion: the need for increased awareness............................10

The role of the nurse in facilitating expression of sexuality. .................13

Conclusion........................................................................14

Reference List....................................................................16
Abstract

Research into the health of lesbian women has been expanding internationally since the early 1990s. In Ireland, both health policy and research into the LGBT population tends to focus on HIV/AIDS, men’s sexual health clinics and mental health, resulting in a deficit into knowledge of lesbian women’s health status and behaviours. This study focuses on the case of cervical cancer screening behaviours of lesbian women in Ireland.

Findings from 10 international studies are contextualized to Ireland using health documents published by government agencies and departments. These studies are then compared to Gibbons et al. (2007), a piece of qualitative Irish research exploring the needs and experiences of the Irish healthcare system by 24 lesbian women.

Barriers to accessing healthcare are identified by lesbian women. The most common of these is heterosexism, which is prevalent in both international and Irish literature. Also discussed are: health promotion needs in this area and how the nurse can facilitate patients in the expression of sexuality.

Irish lesbian women demonstrate lower attendance rates for screening than their international counterparts, exacerbated by ambiguity in relation whether or not screening is actually needed by women who have sex with women. Recommendations including increasing training of nursing staff in LGBT health needs, health promotion strategies and cultural awareness is evident throughout these studies.

In conclusion, nurses have an opportunity to influence health behaviours and perception of risk among clients. The health needs of lesbian women are different than heterosexual women and nurses have a duty to recognize this, promote health and identify strategies to maintain wellness both in policy and in practice.
Introduction

This is a review of the current literature regarding cervical cancer screening behaviours in lesbian women. Concentrating on themes such as perceived barriers to screening, health promotion, the nurse’s role in promotion uptake of screening and facilitating patients to express their sexuality which is to the fore of international research. This review will apply international findings to Irish health documents.

There remains minimal research in the experiences of Irish lesbian women in relation to their health. Funding for LGBT health in Ireland tends to be directed toward HIV/AIDS issues, men’s sexual health clinics and Irish research tends to follow this trend (HSE 2009).

Cervical smear testing is just one initiative in which nurses play a vital role in health promotion. The National Health Promotion Strategy 2000-2005 (DoHC 2000) states that a philosophy of health promotion should permeate all aspects of healthcare. As such, health promotion is relevant to nurses and is a fundamental aspect of the provision of healthcare as per the Ottawa Charter for Health Promotion (World Health Organization 1986).

Due to the relatively small word count in this literature review, cervical cancer screening of lesbian women will be focused on. Guidelines state that women between the ages of 25-44 should obtain a smear test every three years, women aged 45-60 every five years and that two normal results must be obtained three years apart before moving to five year intervals (National Cancer Screening Service 2011). Limited figures exist regarding screening behaviours in Irish lesbian women suggest that they are 30% less likely than lesbian women in the UK or USA to be regularly screened for cervical cancer (Gibbons et al. 2007, Clark et al. 2009, HSE 2009, Fish 2010). Internationally, recommended intervals between testing vary, which may appear to worsen Irish statistics. Delayed screening may lead to more advanced diagnosis, and contribute to greater overall morbidity and mortality (Clark et al. 2009).
There remains a lack of national health policy specific to lesbian women in comparison to the general population. *A Plan for Women’s Health* (DoHC 1997) was the first Irish health document published which highlighted lesbian health as a concern. *Implementing Equality for Lesbians, Gays and Bisexuals* (Equality Authority 2002), included specific recommendations for health in the LGBT community and barriers to implementing these are examined by the National Economic and Social Forum (NESF) in *Equality Policies for Gay, Lesbian and Bisexual People: Implementation Issues* (2003). The Gay and Lesbian Equality Network (GLEN) and the Department of Justice, Equality and Law Reform are currently working in tandem to support the implementation NESF recommendations in government departments, including the Department of Health and Children.

The literature suggests that barriers to healthcare exist in the form of inadvertent heterosexist assumptions, an ambiguity in relation to lesbian health issues and a fear of discrimination as a result of sexual identity. Although specific figures of Ireland’s LGBT population do not exist, the Central Statistics Office (2012) estimate the number is around 8%. Therefore statistically, one in every twelve people the nurse encounters will be lesbian, gay, bisexual or transgender.

All nurses will encounter LGBT clients and families and as such cultural awareness, inclusiveness and effective communication should form the basis of all nursing interactions. Awareness of sexuality underpins nursing assessment and care planning (Roper *et al*. 2000).

Primary research papers were obtained using online databases such as CINAHL, Pubmed, Academic Search Complete, Ovid and PsychINFO. Irish health publications and government policies were also included in this literature search to contextualize the topic. Search words generated included: cervical cancer screening, smear test, lesbian health issues, disclosure, expressing sexuality and barriers to healthcare. Studies included both qualitative and quantitative. A number of studies were available pertaining to health behaviours (such as rates of smoking, figures on alcohol intake, rates of obesity) but few to health screening behaviours in relation to cervical cancer. Although helpful in determining
perceptions of health and wellness in lesbian women, all were not included in this review due to the limited word count.

For the purpose of this review, the term ‘lesbian’ will refer to women who engage in sexual contact with other women, whose primary sexual attraction is to women and those who self-identify as women. This is consistent with how lesbian women are represented in Irish health policy documents (HSE 2009)- see Table One. However, it is important for healthcare providers to note that although a person may identify as a lesbian, only 20% will have had exclusively same-sex contact in their lifetime.

Barriers to cervical cancer screening, facilitating sexuality and the nurse’s role in promotion of health among lesbian women will be discussed as core themes by critiquing international literature and applying it to an Irish context.

Lesbian women’s perceived barriers to cervical cancer screening

Cervical cancer screening is offered to women in Ireland between the ages of 25-60 by ‘CervicalCheck’, as part of the National Cancer Screening Service. The aim of this service is to detect changes in cervical cells before they become cancerous. Nurses are among healthcare professionals who perform smear tests (The National Cancer Screening Service 2011). Although uptake is high- 80% each year since commencing in 2008, research suggests that lesbian women in Ireland face barriers in accessing cervical screening (Gibbons et al. 2007, HSE 2009).

This theme aims to explore barriers to cervical cancer screening identified by lesbian women in international research and use Irish health publications to contextualize this issue to cervical cancer screening in Ireland.

A qualitative study of the experiences of 43 LGB individuals (n= 24 lesbians) in the North-West of Ireland by Gibbons et al. (2007) assessed experiences of gynecological health screening in an Irish context. 50% of the women interviewed had not obtained a smear test in the ten years prior to the study. Those that had had a smear test all described it as a negative experience. Four women cited the
reason for this being the doctor or nurse performing the smear test presuming that they were heterosexual. This research suggests that lesbian screening rates in Ireland are lower than those internationally, however the small sample size could have affected this. Although difficult to ascertain validity and reliability in a study such as this (Polit & Hungler 1991), the findings were first supplied to participants prior to publication, with each participant satisfied that their opinions were accurate and not taken out of context.

Tracey et al. (2010) published a cross-sectional survey of the cervical cancer screening habits of 225 self-identified lesbians in the USA that were obtained via an online questionnaire. Results showed that 31% (64 women) were 'non-routine screeners', meaning that they had failed to obtain a smear test in the 24 months before completing the survey. 22 women had never presented for a smear test. Non-routine screeners perceived more barriers than those who screened routinely. However, 59 participants in the study stated that they had in delayed seeking healthcare due to fear of discrimination as a result of their sexual orientation, consistent with behaviours of women in Gibbons et al.’s study.

A qualitative study of health screening behaviours of American women aged 40-75 was conducted by Clark et al. (2009) using data from the 2003-2005 Cancer Screening Project for Women. This study compared unmarried women of all sexual identities. Of the 630 individuals surveyed 34% (n= 213) identified as lesbian or bisexual. In contrast to Tracey et al. (2010), partner gender did not affect on-schedule cervical screening behaviours. Lesbian and bisexual women were more likely to have had on-schedule cervical screening than the heterosexual women studied (84.2% vs. 75.1%). However, they did find that of the lesbian of bisexual women studied, those who had delayed or changed their screening location due to their sexual orientation were less likely to report being on-schedule for screening.

Clark et al. (2009) and Tracey et al. (2010) state the need for nurses to facilitate open discussion of one’s sexual identity. Tracey et al. concluded that women who are facilitated to disclose their sexual identity to their healthcare provider are twice as likely to attend for cervical screening, which was consistent with views of Irish lesbian women included in Gibbons et al. qualitative discussion.
Review of international research would appear to suggest that cervical cancer screening rates are improving in lesbian women, but that lesbian women are less likely to present for smear tests at the recommended times (Price et al. 1996, Tracey et al. 2010, Clark et al. 2009, Matthews et al. 2004). Limited Irish research suggests this may be a result of uncertainty regarding lesbian women’s need to obtain screening.

**Health promotion: the need for increased awareness**

Research published by GLEN suggests that healthcare practitioners may believe that lesbian or bisexual women may not need cervical smear testing as regularly as their heterosexual counterparts (Allen 2008). However, research has proven that guidelines should be no different for women of any sexuality (Matthews et al. 2004), a fact that appears to remain ambiguous among both lesbian women and a number of members of the healthcare community (Gibbons et al. 2007).

This theme aims to explore barriers in health promotion perceived by lesbian women, in particular to cervical cancer screening.

Gibbons et al. (2007) found that individuals participating in their study often felt that health promotional materials were not relevant to them, due to the underlying assumption of heterosexual sexual activity. However, research suggests that up to 80% of lesbian women have had sexual activity with at least one man, and emphasizes that this should be taken into account by healthcare providers when interacting with lesbian clients (Marrazzo et al. 2001). Of 248 lesbian women included in this study by Marrazzo et al., lesbian women who had never engaged in sexual contact with a man were less likely to have received a smear test in the past, and this was due to the belief that it was unnecessary.

Polek and Hardie (2010) complied information of health risk perception of 96 self-identified lesbian women following a descriptive correlational survey in the USA. They used participant’s knowledge of Human Papillomavirus (HPV) and cervical cancer to assess these women’s perception of risk. 30% of the women surveyed did not identify HPV as a cancer risk, and the same figure did not know that HPV
could be spread by female-to-female sexual contact. Both of these statements have been proven not to be true (National Cancer Screening Service 2011). In an Irish context, this is consistent with findings of Gibbons et al. (2007) whose study showed that 25% of participants surveyed understood that lesbians were at less risk of developing cervical cancer than heterosexual women, and 30% referred to a lack of knowledge of gynecological cancer risks both among lesbian women and demonstrated in previous encounters with healthcare staff.

A study by Fish (2010) drawing on qualitative data collected via online survey of the experiences of 5,909 lesbian women in the UK addressed the need for promoting awareness of cervical cancer. They identified a need for consistent, clear health information in regard to their health needs so that they could make informed decisions. They identified ignorance and confusion regarding sexual health information and in particular with regard to screening behaviours for gynecological cancers. They described the absence of information for lesbian health in healthcare settings as a barrier to knowledge, and an excluding factor in accessing healthcare.

This lack of lesbian specific health information in healthcare settings is a theme that was present throughout the literature (Seaver et al. 2008, HSE 2009, Fish 2010).

There is evidence to suggest that screening in lesbian women increases with age. It is theorized that reaching an age where breast cancer screening is commenced serves as a ‘cue to action’ for lesbian women. This was demonstrated by Tracey et al. (2010) where the mean age of women who screening in adherence to cancer guidelines was 43 years, as opposed to women who did not, who had a mean age of 37. This is consistent with findings of Matthews et al. (2004) who aimed to examine cervical cancer screening behaviours using similar demographic samples of heterosexual (n= 279) and lesbian (n= 550) women to control economic, educational and geographical variables. They found that screening rates in these groups were inversely proportionally to one another, with heterosexual women demonstrated highest rates amongst their younger cohort (women of child-bearing age) and tapering off with age. The opposite is true of lesbian women and it is theorized that this is due to greater encouragement by healthcare providers for
older lesbian women to receive smear tests, consistent with the ‘cue to action’ theory proposed by Tracey et al. Irish evidence of this is not currently available, however this may provide two target sub-groups for health promotion strategies in further research.

All nurses have a role to play in health promotion, and an issue present in all literature reviewed is the need for cultural awareness on behalf of nurses and the need for increased awareness of their lesbian clients (Polek & Hardie 2010). The HSE (2009) outline the need for training among healthcare staff of LGBT issues, with particular emphasis on the need for increasing awareness of the needs of LGB clients. This is consistent with findings of a report published by GLEN (Allen 2008), and if implemented would respond well to recommendations made by lesbian women in the literature studied in this review.

The nurse in facilitating the expression of sexuality

Sexuality is deemed a vital component of the nursing process in terms of assessment and care planning (Roper et al. 2000). However, to be fully understood in a holistic way, sexuality (as with all other Activities of Living) should be understood with respect to factors that may impact them. These factors may be: biological, psychological, sociocultural, environmental and politico-economic. Research demonstrates that lesbian women prefer a more holistic model of care where their sexuality may modify their health needs (Seaver et al. 2008), and the impact of their sexuality on many aspects of their life is taken into account, as described by Roper et al. (2000).

An issue common throughout the literature is that of ‘heterosexuality’ the socially and culturally embedded assumption that all people are heterosexual. Participants in Gibbons et al.’s study felt that constantly being faced with the issue of “assumed straightness” led to a sense of invisibility and a feeling of exclusion from healthcare services. A quantitative study of information obtained from 17 women and 10 men through interviews by Rondahl et al. (2006) described several accounts of assumed heterosexuality in interactions with nursing staff. Participants felt that having to refute a basic assumption that they were heterosexual impeded and obstructed communication regarding their health. A quantitative study of 2269
LGB people in New Zealand by Neville and Henrickson (2006) supported these findings. They distributed a 133-item questionnaire composed of close-ended questions. This study demonstrated that 83.2% \((n=842)\) of women surveyed stated that their healthcare provider ‘always’ or ‘usually’ presumed them to be heterosexual. Neville & Henrickson conclude that nurses have a responsibility to provide opportunities for disclosure of sexual identity, which is supported by other authors, such as Brogan (1997) anecdotally, and Gibbons et al. (2007) qualitatively.

Analysis of a seven-point Likert scale of the importance of their healthcare provider’s attitude regarding their sexuality by Neville & Henrickson (2006) resulted in women deeming this ‘important’ \((n=1,014)\). 35.4% \((n=571)\) individuals stated that their healthcare provider’s receptive attitude positively influenced their care. A qualitative, descriptive study of 17 men and 10 women in Sweden found that the majority of informants described feeling insecure about disclosing their sexuality to staff (Rondahl et al. 2004). However, they also felt that it was important to them to do so, so as not to impede communication. They found that the majority of nursing staff reacted positively to their sexuality. Participants felt that nurse’s reacting in a friendly, interested and caring manner to their disclosure was important, and was the most desired reaction.

At this time in Ireland, facilitating disclosure and expression of sexuality appears to be intertwined (Gibbons et al. 2007). Qualitative research by Seaver et al. (2008) of 22 lesbian women suggests that a non-judgemental attitude and strong communication skills on the part of a healthcare provider is the most important factor in accessing healthcare as a lesbian woman. This is consistent with Rondahl et al. (2004). Difficulties in disclosure of sexual identity to healthcare services is likely to result in inappropriate care, and by assuming all patients are heterosexual, nurses may be inadvertently perpetuating the invisibility of LGBT people in healthcare (HSE 2009).
Conclusion

The purpose of this literature review has been to explore cervical cancer screening behaviours in lesbian women. International research suggested main themes such as barriers perceived to screening, the need for health promotion campaigns in this area and effective nurse-patient communication regarding sexuality. This was mainly consistent with experiences of lesbian women in the single piece of Irish research applicable to this study by Gibbons et al. (2007). Issues such as heterosexist assumptions, fear of discrimination and uncertainty about how to broach the topic of sexual identity with healthcare providers is present throughout the literature.

There is very little Irish research into lesbian attitudes towards their health and perceptions of healthcare in Ireland. There is a gap in research focusing on this issue. Research taking into account barriers encountered, knowledge of lesbians own health beliefs and behaviours in Ireland would enhance what is already known about the health of lesbian women internationally.

Ascertaining accurate demographic information regarding the amount of LGBT individuals in Ireland would benefit further research as larger samples could be obtained, ensuring representative data and validity of research.

Without data relating to LGBT individuals actual encounters of health care in Ireland it is difficult to influence policy, both locally and to direct research funding toward this issue nationally. It is evident that an open, respectful attitude is needed on the part of nurses and that it is necessary to be informed of the presence of LGBT clients and their needs. LGBT individuals also have a responsibility to be informed of their individual health needs. Nursing staff should be aware of the importance an individuals sexual identity may hold for them, and the multifaceted implications of being gay in modern Irish society.

In conclusion, there is a need for increased understanding of the sociocultural, economic and political situation that exists for gay people in Ireland on the part of nurses. Nurses must understand the way in which this influences, or may influence
their client’s health. Awareness of the diversity of their client population is the key theme that underpins the literature included in this review.
Reference List


Table 1. Definitions of sexual identity in the context of Irish healthcare.

<table>
<thead>
<tr>
<th>Sexual Identity</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lesbian</td>
<td>A woman whose primary emotional and sexual attraction is to other women. This term often refers to women who are same sex attracted, rather than women who have sex with other women but do not self-identify as lesbian. While many women identify as gay, the term lesbian is commonly used to describe same sex attracted women.</td>
</tr>
<tr>
<td>Gay</td>
<td>A man whose primary emotional and sexual attraction is to other men. This term often refers to men who are same sex attracted, rather than men who have sex with men but do not self-identify as gay.</td>
</tr>
<tr>
<td>Bisexual</td>
<td>A person who is sexually and emotionally attracted to people of both sexes.</td>
</tr>
<tr>
<td>Transgender</td>
<td>Transgender is an inclusive, umbrella term used to describe the diversity of gender identities and gender expressions. The term can be used to describe all people who do not conform to the common, traditionally-held views of gender roles and gender presentations, including transsexual people.</td>
</tr>
<tr>
<td>Transexual</td>
<td>Transsexualism describes where a person has been assigned one gender on the basis of their sex at birth, but identifies as belonging to the opposite gender. A main feature of transsexualism is significant discomfort and distress due to the transsexual person’s conviction that their body, as it is, does not reflect who they feel they really are, accompanied by a persistent desire to live permanently as a member of the opposite sex. The progression from living publicly and presenting as a man to living and presenting as a woman, or vice-versa is referred to as “transition”. The medical term and diagnosis for transsexualism is gender identity disorder.</td>
</tr>
</tbody>
</table>

Source adapted from Health Service Executive (2009) ‘LGBT Health: Towards meeting the healthcare needs of lesbian, gay, bisexual and transgender people’. Dublin: Stationary Office.