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ORIGINAL ARTICLE

Lesbian women's experiences with health care: A qualitative study

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Abstract

Background. Although the social situation for gay, lesbian, and bisexual people has improved over the last decades, lesbian women still face unique challenges when seeking healthcare services. *Objectives.* To explore lesbian women's healthcare experiences specifically related to sexual orientation to achieve knowledge which can contribute to increased quality of healthcare for lesbian women. *Methods.* Qualitative study based on written stories, with recruitment, information, and data sampling over the internet. Data consisted of 128 anonymously written answers to a web-based, open-ended questionnaire from a convenience sample of self-identified lesbian women. Data were analysed with systematic text condensation. Interpretation of findings was supported by theories of heteronormativity. *Main outcome measures.* Patients' histories of experiences where a lesbian orientation was significant, when seeing a doctor or another healthcare professional. *Results*. Analysis presented three different aspects of healthcare professionals' abilities, regarded as essential by our lesbian participants. First, the perspective of *awareness* was addressed – is the healthcare professional able to think of and facilitate the disclosure of a lesbian orientation? Second, histories pointed to the *attitudes* towards homosexuality – does the healthcare professional acknowledge and respect the lesbian orientation? Third, the impact of specific and adequate *medical knowledge* was emphasized – does the healthcare professional know enough about the specific health concerns of lesbian women? *Conclusion*. To obtain quality care for lesbian women, the healthcare professional needs a persistent awareness that not all patients are heterosexual, an open attitude towards a lesbian orientation, and specific knowledge of lesbian health issues. The dimensions of awareness, attitude, and knowledge are interconnected, and a positive direction on all three dimensions appears to be a necessary prerequisite.

Key Words: *Attitude of health personnel, family practice, health services accessibility, homosexuality, female, minority health, prejudice, self-disclosure*

Over the last years questions and assumptions as to whether lesbian women are prone to certain diseases or health complaints have been forwarded. Lesbian women as a group may suffer from certain health complaints to a greater extent than do exclusively heterosexual women or the general female population [1], probably due to the effects of marginalization. Examples are mental problems such as anxiety disorders and depression [2], and a higher consumption of alcohol, drugs, and nicotine [3–5]. Research has tried to map out the distributions of risks for diseases [6] especially the risk for breast cancer [7], but existing studies of the actual disease prevalence leave inconclusive information [8].

Although lesbian women's social situation has been improved in the last decades, their health and utilization of healthcare services are still affected by the effects of marginalization.

- Healthcare professionals need a persistent awareness that not all patients are heterosexual, an accepting attitude towards female homosexuality, and knowledge of specific lesbian health issues, in order to offer quality healthcare for this group of patients.

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Studies investigating lesbian women's healthcare utilization point towards higher utilization, as in mental healthcare services, as well as lower utilization, such as in general practice [9,10]. Some studies indicate that lesbian women do not to follow the recommendations for screening programs like cervical cytology tests and mammograms to the same extent as heterosexual women [11]. Other research focuses on the patient's disclosure of a lesbian orientation to the healthcare provider, indicating that most lesbian patients wish to tell the healthcare provider about their sexual orientation, and that disclosure implies improved quality of care [12].

Hence, lesbian women may still face some unique challenges when seeking healthcare services. Existing research indicates that experiences of being a lesbian, whether openly declared or passing as heterosexual, have strong bearings on lesbian women's use of healthcare services. We therefore accomplished a study in which lesbian women's healthcare experiences were explored, focusing on aspects specifically related to sexual orientation, aiming for knowledge which can contribute to quality care.

Material and methods

Qualitative data about healthcare experiences were obtained as written answers to a web-based, open-ended questionnaire. The study also included a specific question about coping, which will be separately reported in another article. The study was approved by the Regional Committees for Research Ethics in Norway and the Norwegian Data Inspectorate.

The recruitment process was extensive, searching for self-identified lesbian participants. We placed click ads on Norway's most important gay website, on the websites of the Norwegian gay/lesbian support organization and gay pride festivals, and on a web-based, publicly accessible network for research on homosexuality. There were interviews on national radio, in the capital newspaper, and in the web edition of Norway's largest gay/lesbian magazine.

A publicly accessible website with the internet address http://www.lesbiskhelse.net was open from May to December 2007, presenting information on the study, its purpose and design, on anonymity and consent, and on the researchers. Anonymity was ensured by automatic deletion of the IP address of the informant's computer, and the informants were encouraged not to use any names. No password or personal identification was asked for.

The questionnaire started by asking the participant to testify that she was a woman 18 years or older, that she considered herself a lesbian, and that she had read the information and accepted that what she wrote would be used for research purposes. Then followed the two open-ended research questions, to which answers could be up to 500 words long. The question about healthcare experiences was designed like this:

> *Describe a concrete experience – good, bad or neutral – that you have had because you are lesbian, when seeing your doctor or another healthcare professional.*

We asked for experiences with any kind of healthcare professional. Most of the histories specified the profession involved. The majority dealt with general practitioners, but there were also encounters with midwives, nurses, psychiatrists, psychologists, physical therapists, and homeopaths. The last part consisted of demographic background data.

When the material was saturated, that is when incoming responses presented themes already sufficiently dealt with in previous contributions, the website was terminated. At that time we had received 121 responses with a total of 128 histories concerning encounters with healthcare professionals.

Demographic specification of the sample is presented in Table I. The typical participant was born in Norway, in her twenties, partnered, childless, well educated, working, and living in a big city.

The histories were transferred to NVIVO7 and analysed with systematic text condensation [13,14] by both authors in cooperation towards generalized descriptions and concepts reflecting how lesbian women are being met by healthcare professionals in Norway. Analysis was data-driven, although supported by theories of *heteronormativity* for additional understanding to be reached. Heteronormativity denotes how the social life of Western culture is constructed on the assumption that all people are heterosexual, assuming the heterosexual nuclear family norm to be natural and universal, and thereby making homosexuality socially invisible and second class [15].

Results

Analysis presented three different aspects of healthcare professionals' abilities, regarded as essential by our lesbian participants. First, the perspective of *awareness* was addressed – is the healthcare professional able to think of and facilitate the disclosure of a lesbian orientation? Second, histories pointed to the *attitudes* towards homosexuality – does the healthcare professional acknowledge and respect the lesbian orientation? Third, the impact of specific and adequate *medical knowledge* was emphasized – does the healthcare professional know enough about the specific health concerns of lesbian women?

Table I. Demographic specification of the study sample.

Variable	Category	Population: Sample (%)	Population: General female population (%)
Age			
	18–19	5	3
	20–29	39	16
	30–39	29	18
	40–49	9	18
	50–59	13	16
	60 and older	2	29
	Missing	2	–
Education			
	Primary school	2	32
	Secondary school	26	41
	Bachelor's	44	23
	Master's	23	4
	Missing	6	–
Employment			
	Unemployed[1]	2	2,5
	Homemaker	2	
	Employed/ self-employed[1]	64	68
	Retired, welfare	5	30
	Education, military[2]	20	35
	Missing	6	
Marital status			
	Girlfriend	20	
	Registered partner	20	0.1
	Hetero married	0	46
	Cohabitant[3]	30	17
	Single	26	
	Other	2	
	Missing	2	
Children			
	No	69	12
	Yes, young	16	
	Yes, adult	12	
	Missing	2	
Residence[3]			
	Rural	8	21
	Small town	20	33
	Medium town	20	14
	Big city	51	32
	Missing	2	–
Birthplace[3]			
	Norway	87	92
	Western countries	7	4
	Other countries	4	4
	Missing	2	

Notes: Comparable numbers for the total Norwegian female population aged 18 and older are given when appropriate. Exceptions: [1]Women aged 15–74; [2]Women aged 19–24; [3]The general population of both men and women.

Awareness

A number of histories demonstrated how the healthcare professional apparently took for granted that the patient was heterosexual. The woman would then have to choose to actively intervene and inform the professional about her lesbian orientation, or passively pass as heterosexual. A student in her twenties shared her experience:

> *This is not a history about discrimination, nor is it offensive. It is merely about a preconception among doctors and about always having to explain and emphasize being different. (62)*

Many informants had felt forced to disclose, often when in a vulnerable situation such as for example during a pelvic examination, because the doctor insisted on an explanation when he found incoherent the combination of a sexually active life, no contraception, and no possibility of pregnancy. Some participants had been given medical information aimed at heterosexual activities; others had received prescriptions for contraceptives or had had pregnancy tests taken, even after revealing a longstanding lesbian orientation. A few participants did not see the need to inform their healthcare professionals about their lesbian orientation; other histories displayed a lack of confidence in the health authorities, or a reluctance to disclose out of embarrassment.

There were also quite a number of positive histories, and many informants had had almost only favourable experiences with their doctors. These women were happy to be acknowledged as lesbians and at the same time be regarded as ordinary patients, making communication with their healthcare professionals relaxed and open. Some informants liked the way the doctor had not made any comments about their sexual orientation; others appreciated their healthcare professionals' explicit support. Some said that the healthcare professional had valued the information because it could have an impact on further treatment. An urban woman in her forties wrote:

> *I have told my present regular GP and it has never been made into something special, and that is nice and comfortable. (5)*

Attitude

A large number of the histories described consultations where the doctor had been perceived by the participant as uncomfortable, prejudiced, or overtly condescending after their disclosure. Some doctors had become brutal during examinations; a few had become overwhelmingly engaged in the lesbian orientation. Other doctors seemed to think that being lesbian equals being depressed, or that the lesbian orientation was the cause of all illnesses and complaints the patient presented. According to a mother of grown children living in the countryside:

No matter what I wanted to bring up; migraine, hot flushes, fatigue, anaemia; she switched to saying that being lesbian had to be very hard…. I changed doctors. (36)

A group of participants told of experiences with fundamental, negative consequences while undergoing psychotherapy. There were reports of psychotherapists stating that a same-sex orientation is pathological. Other therapists said it was the cause of their mental problem, trying to "heal" or "solve" it. A few therapists had terminated the treatment abruptly after disclosure. A highly educated woman said:

I stopped after half a year without having come any further in the understanding of why I had an eating disorder, and without coming closer to any solution. I was just even thinner and sicker. (154)

There were a number of histories regarding significantly positive meetings with professionals. These histories demonstrated how the healthcare professional can give support during the coming out process, help the patient accept herself as a lesbian, provide comfort when her lover or partner leaves or dies, or how the patient can be backed up when having a rough time as an open lesbian in the community. A mother working on a switchboard said:

I saw my GP during a difficult period in my private life, among other things the breakdown of a relationship with a male partner, and starting a relationship with a girl. I want to praise my GP for an open attitude and understanding. It was important for me to feel accepted and he was very open about the issue. (158)

Some histories came from participants who had mental problems or were drug abusers attributed to problems with their lesbian orientation. Their healthcare professionals had been able to notice the patients' lesbian orientation and had then been markedly open and accepting about it, facilitating self-acceptance and strength in the participant.

Medical knowledge

A number of histories revealed that healthcare professionals may have problems informing lesbian patients about sexually transmittable diseases. Several participants had been told that screening for cervical cancer (Pap smear) is not needed for lesbian patients. Another group of participants had been told that the lesbian orientation was merely a phase when young; that these emotions would disappear with time and the woman would eventually become heterosexual. These women described how they were left with uncertainty and unanswered questions. As this student in a medium-sized city reported:

I tell the doctor that I have a genital yeast infection that I can't get rid of … I say that my partner is a girl and ask if she needs to use the treatment. The doctor is taken aback for a moment, before she says: "I don't know…. If she touches you…." It didn't really give me a clear answer, but didn't dare to ask more. (14)

Nevertheless, other histories demonstrated that healthcare professionals may have excellent knowledge of specific health concerns in lesbian women. Some participants had received helpful information about safer sex and sexual transmission of diseases between women; others had been asked relevant questions when consulting for genitourinary complaints. One or two participants had seen their GPs because of physical symptoms, and the GPs had understood that the underlying cause was anxiety around an emerging lesbian orientation. A registered partner in her thirties stated:

I was very physically ill without understanding that it was because I was mentally exhausted…. The doctor that I came to understood quickly that my physical illness was caused by something other than a virus, and she gave me a close and good follow-up. She was actually the first one to put into words emotions and difficult things linked to identity. (38)

Discussion

This study has demonstrated negative and positive consequences of healthcare professionals' awareness of the existence of lesbian women among their patients, the impact of healthcare professional attitude towards homosexuality, and how lack or possession of adequate medical knowledge affects the treatment lesbian patients receive. Below, we discuss the strengths and limitations of the study design and the impact of our findings.

Study strength and limitations

We received a large number of histories, describing different situations with several types of healthcare professionals, and with varying outcome. There were so many aspects accounted for in the histories, as well as repetitions of themes, that we consider the material to be saturated and to represent a broad range of healthcare experiences among lesbian women.

The lesbian orientation of the researchers, as well as our professional backgrounds as GPs, has certainly influenced the interpretation of the findings and the choice of theoretical frames for the understanding of the results. Our personal knowledge of situations like

the ones our participants describe has enabled us to recognize the extensive impact of heteronormativity.

We used a web-based design for recruitment and sampling to obtain a large number of participants and to reach women from all parts of Norway as well as non-organized lesbians, resulting in a convenience sample of self-identified lesbian women. Close to 80% of Norwegian households have internet access [16], and the general educational level in the population is high [17]. The issue of representativity is challenging when studying lesbian women [18]. Neither the total number of women identifying as lesbians nor the characteristics of this population are known entities. A diverse sample is important for the findings to be valid for a broad range of lesbian women. Our sample seems to be complex enough to be representative of lesbian women at large in Norway today, although with a bias towards partnered and educated women.

Quality care for lesbian patients

The significance of provider awareness, attitude, and knowledge for the quality of healthcare for lesbians is known from before [19,20]. Our study contributes to existing evidence by presenting a broad range of ways these issues can be enacted positively or negatively, but perhaps even more by indicating how the three dimensions of awareness, attitude, and knowledge are interconnected. A positive direction on all three dimensions appears to be a necessary prerequisite for quality care for lesbian women. Below, we elaborate the foundation of such an interpretation, supported by theories of *heteronormativit*y [15].

Within this theoretical framework, the awareness called for by our participants becomes more than the mere reception of factual information about a lesbian orientation when the patient chooses to disclose. It becomes an issue of identity and dignity. The social situation for gay, lesbian, and bisexual people has improved radically over the last decades in Western society. There is less formal prejudice, being "out" as a homosexual is less dangerous, and legal rights have improved [21]. Nevertheless, recent research demonstrates that the issue of disclosure is fundamental in lesbian women's encounters with healthcare professionals [22]. Disclosure is perceived to imply risk; risk of condemnation of the self, risk of impaired communication, of inferior healthcare [23]. Lesbian patients usually want to be in a position to choose whether to disclose or pass as heterosexuals after an assessment of the situation, weighing the risk of prejudice versus her need for the information to be known [24]. Thus, we see how lesbians themselves link awareness, or the atmosphere concerning disclosure, to the doctor's attitude [19]. So, the conclusion of our study is supported by findings of prior research: that awareness cannot be separated from attitude.

Existing research indicates that healthcare professionals often neglect the issue of sexual diversity among their patients, and many report low levels of knowledge [25]. Mere tolerance rather than respect seems to dominate [26]. Doctors report that they feel uncomfortable dealing with sexual health matters of lesbian patients and other marginalized groups [27], and that a lack of knowledge of the lifestyles and sexual practices of lesbians implies a barrier to communication [28]. Many healthcare professionals in our study apparently did not know that all women, regardless of sexual orientation, are recommended regular screening for cervical cancer, and they were perceived as unaware that STDs may transmit sexually between women, although less easily. A few of our histories call attention to the belief that homosexuality is pathology, demonstrating how outdated and erroneous "knowledge" [29] may have a deep negative impact on treatment, which has also been indicated by others [30]. In addition, our data point to a lack of knowledge about coming-out depressions and internalized homophobia, which may lead to incorrect diagnosis and treatment.

Our study demonstrates how the lesbian orientation and the issue of disclosure as related to healthcare are handled differently by individual patients. The doctor needs to map out the significance of the lesbian orientation in each case in order to communicate with and treat the patient well; similar to how we briefly map out every patient that comes to the clinic. Furthermore, our findings may be transferred to patients representing other marginalized groups. That all complaints are attributed to the special trait of the patient is not specific for the marginalization experienced by lesbian women; "she is depressed because she is lesbian" equals "he has knee pain because he is obese" [31], or "it is all associated with her chronic fatigue syndrome" [32]. Furthermore, doctors may be ignorant of issues specific to the group or condition, such as the call for specific nutritional advice from an obese patient [31], which illuminates that a positive attitude cannot always make up for a lack of knowledge.

Implications

Doctors should be informed about the implications of heteronormativity, and be attentive to the significance and vulnerability of disclosure. Consultation techniques should be supplemented with habits of always using gender-neutral language and meeting new patients with a positive mind towards the question of sexual orientation. Medical knowledge about lesbian women should include gynaecological and sexual health issues, but above all the effects of marginalisation on health, well-being, and identity.

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