

A Needs Assessment Study of LBT Women: The Relationship Between Sexual Orientation/Gender Identity, Health-Seeking Behaviors, and Perceived Quality of Care Issues

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ABSTRACT: This study reports the results of an extensive needs assessment survey conducted under the auspices of the Lesbian Services Program (LSP) at Whitman-Walker Clinic with approximately 700 lesbian, bisexual, and transgendered (LBT) women in the greater metropolitan Washington DC area. The survey collected information to: (1) describe the population served by the LSP catchment area; and (2) learn about respondents' health concerns and needs, care-seeking practices, perceptions of risk, and access to care. Respondents provided information about their: (1) self-identified sexual orientation (SO) and gender identity (GI); (2) significant physical and mental health concerns; (3) health care and disease prevention practices; and (4) SO/GI-related concerns including selection of health care providers, confidentiality and decision to "come out" to health care providers, and perceived effect of SO/GI on quality of health care. Preliminary results indicate that some respondents have significant concerns about the impact of their SO/GI on their health care. In addition, many respondents report they have failed to seek health care, partly in response to concerns about institutionalized homophobia from the health care community.

KEY WORDS: *Health surveys, needs assessment, gay and lesbian issues*

INTRODUCTION AND SURVEY PURPOSE

What are lesbian/WPW¹ and transgendered health needs? These communities and organizations that serve them are in need of information to answer this and other questions, and develop an action plan for future services. The Institute of Medicine (IOM), in a groundbreaking 1999 report², issued a call for research on lesbian health, especially regarding access to care. Although the IOM report holds promise as a spur to future health research, a few recent research studies strongly suggest that lesbians confront painful barriers when they seek care, and may delay or forgo seeking care as a result.

According to a recent report, lesbians access to health care³ is fraught with barriers that are both structural and financial, and require overcoming significant personal and cultural⁴ barriers.

Specifically, research studies show that many lesbians tend to avoid or delay regular health screening examinations, including routine breast cancer screenings and pap smears^{5 6 7}. These delays, often related to past negative experiences with homophobic health care providers⁸ (including

Assessment and Directions for the Future. Potential barriers presented by managed care systems: Lack of partner insurance benefits, more difficulty to choose a "lesbian-friendly provider," less ability to benefit from family focused care. It has also been estimated that from 12.3 to 27 percent of lesbians lack health insurance.

⁵ Haynes S.G. *Are lesbians at high risk of breast cancer?* Proceedings of the 14th National Lesbian and Gay Health Foundation Conference: 1992 July 10, Los Angeles CA.

⁶ O'Hanlan K.A. *Lesbians in Health Research Scientific Meeting: Recruitment and Retention of Women in Clinical*

Studies. Presentation to the Office on Women's Health, National Institutes of Health) 1993 July 10 Washington, DC. U.S. Department of Health and Human Services: NIH Publication No 95-3756.

⁷ Biddle B.S. *Health Status Indicators for Washington Area Lesbians and Bisexual women: A report on the Lesbian Health Clinics First Year.* (1993). Washington DC. Whitman Walker Clinic

⁸ Well-documented in the medical literature and in our own surveys in the Washington, DC metropolitan area. See

¹ "WPW" connotes "women who partner with women."

² Institute of Medicine. *Lesbian Health: Current Assessment and Directions for the Future.* Washington, DC: National Academy Press. (1999).

³ Defined as the timely use of personal health services to achieve the best possible health outcomes IOM 1993. *Access to Health Care in America.* Washington, DC: National Academy Press. (1993).

⁴ Institute of Medicine. *Lesbian Health: Current*

patronizing treatment, intimidation, attempts to change the patient's sexual orientation (SO), hostility, breach of confidentiality, invasive and inappropriate personal questioning, neglect, denial of care, undue roughness in the physical exam, and sexual assault), may place lesbians at risk for increased morbidity and mortality that comes from delayed diagnosis and treatment.

Finally, assumptions of heterosexuality and routine questions regarding birth control and male partners leave lesbians with the choice of either disclosing their SO or remaining closeted. If a lesbian chooses not to disclose her SO, she not only has to live with the discomfort of being dishonest about such a fundamental aspect of her life, but she may be putting herself at increased health risk by withholding information that may have a bearing on her health conditions, health care needs, or risks.

The Lesbian Services Program (LSP) of Whitman-Walker Clinic, Washington, D.C, administered and conducted a needs assessment survey to better understand lesbian, bisexual and transgendered (LBT) women, specifically, their health care needs and concerns, care-seeking practices, and access to care. The survey questions were designed to collect information about respondents who are likely to be in the catchment area served by LSP, including demographic information, SO and gender identity (GI), and significant physical and mental health problems and concerns. LSP also wanted to learn about respondents' health screening practices and delay in seeking care, as well as the relationship between respondents' decision to disclose their SO and the quality of health care they have received.

METHODOLOGY

Survey Development and Pretesting. The needs assessment survey was designed to solicit information about respondents' health needs and concerns, care-seeking patterns, and perceptions of LSP. Survey items were developed after examining

other lesbian health surveys and consulting key informants knowledgeable about LBT identity and health-related issues, including social workers, community activists, and health care professionals. Some open-ended items were included to elicit detailed, personal and subjective information about participants' health care concerns and experiences. Qualitative information elicited from open-ended items was evaluated to substantiate or increase understanding of survey findings.

The survey was pretested with 30 volunteers who were representative of LBT persons in the greater metropolitan Washington DC area. Appropriate modifications were made upon survey pretesting results, especially regarding item wording, formatting, and item order. The survey was also translated into Spanish for administration with native Spanish-speaking respondents.

Community Outreach and Advertising.

Presentations about the needs assessment were made at several LSP organizational meetings, including rap groups and Clinic sessions. The leadership of 34 community-based GLBT organizations with constituencies in distinct segments of the GLBT community within the greater metropolitan Washington DC community also agreed to distribute the survey. These organizations included religious, political action, employee groups/company, activist, ethnic, social, health, for Latino/as, African-American, Pacific Islander, etc. groups, minority/youth, professional groups, advocacy, women's, city- and community-based political action and social groups.

"Palm cards," 8 ½ x 11 colored posters, and ten 11 x 17 "point of sale" displays with tear-offs were distributed community-wide, featuring information about the survey. In addition, announcements about the survey were included with four periodicals, including those geared toward the GLBT community. The circulation of all four periodicals is the entire Washington D.C. metropolitan center.

Women were invited to call LSP offices to speak to the project intern. Because we wanted to reach women not already linked to LSP, a "snowballing" technique was implemented to identify survey respondents. A total of 3500 surveys, with postage paid envelopes, were printed. Data collected began in late August, 1999 and closed after two months on October 31, 1999.

Bradford, above and Denenberg, R. *Invisible women. Lesbians and Health.* Health PAC Bulletin 992. 22(1), 14-21. Stevens P.E., and Hall J.M. *Stigma, health beliefs and experiences with health care in lesbian women.*

Image: Journal of Nursing Scholarship. (1988). 20(2), 69-73. Stevens P.E., and Hall J.M. *Abusive healthcare interactions experienced by lesbians: A case of institutional violence in the treatment of women.*

Response to the Victimization of Women and Children. (1990). 13(3), 23-7.

Survey Distribution and Community Response.⁹ Pink-covered surveys were distributed at lesbian bars and events to women who are likely to be “strangers” who are less familiar with LSP services. 129 surveys were returned out of approximately 1000 distributed surveys, a response rate of approximately 13 percent. 14 percent of women over 40 returned pink surveys, whereas 28 percent of women under 40 returned them. There was little difference between African American and White women’s responses (18 vs. 21 percent, respectively), but 30 percent (n= 27) of Latinas were reached this way.

Purple-covered surveys were distributed to current LSP clients, individuals included within the LSP mailing list, persons included on other organizations’ mailing lists, and to persons requesting the survey by phone. This effort resulted in the return of 471 completed surveys out of approximately 2500 distributed surveys, a response rate of approximately 19 percent.

Data Entry, Analysis, and Coding Conventions. Simple frequencies and cross tabulations were calculated using EPIINFO, a free survey-entry and data analysis program developed by the CDC. Some variability was due to our interpretation of certain blank fields as either a “blank” or a “no” response. All data is subject to future final verification. All respondents who indicated they were heterosexual and who reported not having had a female partner within the last five years were discarded, as were respondents residing outside the catchment area (two cities and four counties) of interest.

Study Limitations. Study limitations include the fact that the survey sample was not drawn randomly, and therefore, survey results cannot be extrapolated to the greater population. Second, survey information was self-reported with no possibility of independent verification of the data. Inaccuracies in self-reporting is not uncommon for survey respondents, who might over- or underestimate their utilization of screening and other health services. Thus, study implications should be interpreted accordingly.

Analysis of certain subgroups, such as Native American women and Asian/Pacific Islander women, was not possible due to their small numbers in the

⁹ Almost 10 percent (60 surveys) were uncoded (either the cover was removed or did not exist). 5 percent of surveys had no age data; no race data on 2.7 percent.

sample. Subgroup analysis on Latina respondents should be interpreted with caution because of their small numbers.

SURVEY SAMPLE CHARACTERISTICS

Race, Ethnicity, and Educational Level of Respondents. The racial/ethnic composition of sample respondents was reasonably consistent with that of the overall Washington, D.C., metropolitan area. Of the 660 survey respondents, 71 percent were white, 22 percent African American, 5 percent Latina, 2 percent Asian or Asian Pacific Islander, and 4 percent are Native American. The majority (60 percent) was 30-49 years old, with respondents almost evenly divided between women aged under 40 and women aged 40 and over. Respondents are highly educated; nearly half have graduate or professional degrees. Residence of respondents was almost evenly divided between Maryland, DC, and Virginia.

Health Insurance and Income. Almost 90 percent of respondents have health insurance, and their income generally reflects the relatively high income of the area. Nine percent are currently uninsured, much lower than the rates in DC, MD and VA (17 percent DC; 16.6 percent MD; 14.1 percent VA¹⁰). The reported median annual household income of respondents is in the range of \$50,000 and \$74,999. Thirteen percent make less than \$16,825 as individuals, living at approximately 200 percent of the poverty level¹¹. Approximately nine percent make less than \$20,300 as a household, living at approximately 200 percent of the poverty level¹².

Family Status. Slightly more than half of respondents are partnered with women, 30 percent are single, 2 percent are partnered with a man. Sixty-four (N=64) percent reported they were currently in a mutually monogamous relationship. In addition, 79 percent do not have children. Eighteen (N=18) percent have one or more children, almost 60 percent of whom are raising their children. An interesting finding for LSP program planners is that 17 percent

¹⁰ U.S. Census: Health Insurance Coverage: 1998 - State Uninsured Rates.

¹¹ \$8,240- 1999’s Federal Poverty Guidelines.

¹² Although we do not know the size of these households, 1999’s Federal Poverty Guidelines cite \$11,060 for a family of two.

would like to have their first child or additional children in the future.

SURVEY RESULTS

Sexual Orientation (SO) and Gender Identity (GI). Respondents generally self-identified as both “female” and “lesbian,” although there was diversity relative to self-labels and reported behaviors. Fifteen percent identified as “bisexual” or “women who partner with women.” The majority of respondents report they are “out” in all or some situations, but almost five percent may be considered “closeted,” only coming out to self/partner and some others.

- ❖ 96 percent identified their GI as “female;” more than one percent identified their gender as either “male” or “transgendered.”
- ❖ The majority (69 percent) identified as “lesbian.” Among other labels, 8 percent identified as “bisexual,” and 7 percent as “woman who partners with women.”
- ❖ African American women were more than twice as likely as any other sub-group (race or age) to use the term “woman who partners with women.”

Whether and how a woman chooses to label her SO or identify as “lesbian,” “bisexual,” or “queer” may refer to her sociopolitical identity, current desire or attraction, current or past same sex sexual behavior, all three, or some combination of other factors not listed here. Although 69 percent of respondents identified as lesbian, 9 percent reported having sexual relations with men within the prior year, and 21 percent reported having sexual relations with men within the prior five years. These findings suggest that labels do *not* necessarily correspond to sexual behavior. Thus, it may be more relevant for health providers and educators to focus on sexual behavior, rather than identity labels.

Physical Health Problems. Women’s most frequently reported they have or have ever had the following health problems: primary medical needs, asthma and allergies, arthritis and joint pain, menstruation problems, weight concerns, vaginal infections and breast lumps. There are few differences among women’s major health problems by demographic subgroup (age or race). Primary medical care, asthma/allergies, arthritis/joint pain, and menstruation problems were the most frequently reported reasons for respondents seeing a health care provider within the year prior to survey completion. Almost half of all women under 40 years of age have

(or have had) menstruation problems. In addition, 38 percent of respondents report having a weight problem; African Americans ranked weight as their most common health problem.

Physical Health Concerns. Respondents were asked to report their health concerns, and identified weight issues, breast cancer, breast lumps and cervical cancer as the most significant concerns for all demographic subgroups, regardless of age or race. Interestingly, concerns respondents identified frequently did not necessarily translate to actual mortality risk. The leading causes of death for all women nationally are (in rank order): diseases of the heart, lung cancer, cerebrovascular disease; breast cancer; and accidents.¹³ Additional findings include:

- ❖ Arthritis/joint pain was the number one concern reported in the 40 and over group, and the number two concern for both white and black women.
- ❖ Respondents from most age and racial groups ranked breast cancer among their top three health concerns; nearly one third are concerned about breast cancer.
- ❖ 21 percent of African-American respondents are concerned about HIV/AIDS, more than any other racial/ethnic group.
- ❖ African Americans ranked weight as their number one health concern.

Mental Health Problems. Depression and anxiety were the top mental health problems reported by all subgroups. Forty-three (N=43) percent report suffering from depression within the past year, 49 percent of whom indicated they had experienced more than 2 weeks feeling “sad, blue or depressed” within the previous year. These figures indicate much higher proportions of depression than the nationwide figure of 25 percent of women who reportedly experience severe depression in a year. Only about one-fifth of these women will get the treatment they need.¹⁴ By contrast, one-third of survey respondents sought care from a health care provider for depression, the most common reason reported for seeing a mental health provider.

More than one-third reported having suffered from anxiety within the past year, while 34 percent had experienced anxiety or panic attacks during the same period. Many refrained from seeking

¹³ National Center for Health Statistics. (1998). U.S. Centers for Disease Control.

¹⁴ American Psychological Association website.

professional care or support from friends and family and may experience their mental health problems in isolation.

Substance Use. Eighty percent reported they use alcohol; 25 percent reported smoking cigarettes; 25 percent smoking marijuana; and 4-6 percent reported using other illegal drugs. The survey did not collect information about the frequency of use of these substances or efforts to enter recovery programs. In addition, the items regarding frequency and duration of substance usage were ineffective and could not be used to yield useful data.

Screening and Disease Prevention Practices. Fully half of all respondents reported they had *not* asked health care providers how to take better care of their health. However, a higher proportion of African-American women reported asking about screening tests than any other subgroup. In general, however, respondents vary substantively regarding their completion of health screening procedure by sub-group as well as by procedure, as indicated by the following results:

- ❖ Nearly one-third of respondents under 40 reported not having a pelvic exam/pap smear within the prior year, although yearly screening is generally recommended. This rate is considerably higher than that for women nationally within this age group — 21 percent of whom did not have one within the prior year¹⁵.
- ❖ A positive finding was that 29 percent of respondents age 40 and over reported they did not have a pelvic exam/pap smear within the previous year compared to women nationally within this age group – about 38 percent of whom had not been screened for the same time period. Yearly screening is generally recommended for this age group.
- ❖ Almost half of all respondents reported they did not receive a clinical breast exam (CBE) during the prior year, although yearly screening is generally recommended. Respondents did worse than women did nationally – about 25 percent of whom did not have a CBE.
- ❖ Half of all respondents aged 40 and older had not had cholesterol screening in the last year, although periodic screening is recommended for all women aged 45-65.

- ❖ Forty percent of respondents aged 40 and older had not had blood pressure screening within the prior year, although periodic screening is recommended.

Delay in Seeking Care. Despite the fact that 92 percent of respondents are insured, almost one in three women said she delayed health care in the past year due to financial or insurance concerns, lack of provider, or lack of convenience. Almost one third reported they had delayed seeking health care within the past year because “it wasn’t convenient.” Convenience could mean time pressures, pressures in taking care of others, or not seeing one’s own health care as a priority.

Financial concerns also played a role in why some respondents delayed seeking health care. Twenty-one (N=21) percent reported they had delayed seeking health care within the previous year because they could not afford to obtain health care; another 15 percent delayed getting health care because they lacked health insurance when they needed health care. The next section describes other reasons respondents may delay seeking care.

Disclosure of Sexual Orientation (SO) to Providers. The majority of women (67 percent) have disclosed their SO to the health care provider they see most often; African American women (59 percent) were less likely to disclose their SO to providers than white women (70 percent). Most of these respondents feel disclosure has no impact on their quality of care.

The degree to which someone is “out” has a clear effect on the decision whether to disclose her SO to a health care provider. Nearly 80 percent of those who reported they are “out in all or out in almost all situations” also reported they are “out” to their providers; of those “out” in fewer situations, fewer than 40 percent reported they had disclosed to their health care provider.

More than half of those who have not disclosed their SO feel it is unimportant to share this information with their provider. However, a substantial minority reported concerns in this area. Fifteen (N=15) percent believe their SO has a negative impact on the quality of health care they have received. Another 30 percent feel uncomfortable disclosing to their provider and are worried about the consequences of disclosing their SO, including receiving poor care and lack of confidentiality.

More than half of respondents wrote comments expressing fear and frustration associated

¹⁵ BRFSS. (1998). U.S. Centers for Disease Control.

with frequent negative experiences relative to disclosure of their SO to current or former health care providers. These comments indicate clearly how problems in the clinician-patient relationship – distrust, fear and provider homophobia – can lead to avoidance and delay in obtaining care. The frequency and intensity of these comments suggest that the perception of homophobia from providers is a significant barrier to getting care.

“Alienation” appears to accurately describe these individuals’ degree of dissatisfaction with health care delivery. Alienation from the health care system for these respondents has resulted in avoidance of providers, delay in seeking care, disruptions in continuity of care, and/or inadequate trust between provider and client.

DISCUSSION AND STUDY IMPLICATIONS

Survey results indicate that respondents articulated many concerns about health care, which ironically enough, overlapped significantly with concerns articulated by the greater heterosexual population regarding access to health care, constancy of care, and a sense of being just a “number” in the health care system. However, it is apparent that an additional layer of concern exists for many respondents relative to their SO and/or GI and its impact on the quality of health care they receive. Interestingly, even though respondents to this survey were generally well-educated and financially independent, a minority still failed to access health care, at least in part because of their SO and/or GI.

Respondents also identified an array of women’s physical health issues as concerns, as well as actual problems for which they may or may not seek care. Despite the fact that 92 percent are insured, many respondents are still not obtaining critical screening services. Depression is a critical issue, and social support may be lacking for many who suffer from mental health problems.

Survey results also clearly reveal problems associated with barriers to health care access and lack of empowerment for at least some respondents. Respondents also reported a high degree of dissatisfaction with care, as well as concerns about sexism, racism, homophobia, and transphobia in the health care delivery setting. These concerns help to illustrate why some WPW may tend to avoid or delay care, and suggest a strong call to arms to educate both providers and consumers.

Concerns about not being treated respectfully by health care providers, or the fear they will encounter prejudice as a result of their SO and/or GI,

appear to prevent at least some respondents from obtaining routine health care and from pursuing screening practices that could prevent the onset of serious health conditions. Some WPWs may fail to disclose important personal information which could compromise their health care, impede their access to appropriate and reasonable health care opportunities, and place them at risk for severe health problems.

The findings indicate those women’s’ access to health care could be improved in a number of ways. Study participants have common negative experiences with the health care systems – many of which may be unique to the WPW population. Most WPWs clearly value having a provider to whom they feel comfortable disclosing their SO and/or GI who will use important personal information in a respectful and appropriate manner. Open-ended responses also stressed the value of continuity of care for lesbians and emphasized the need for health care providers who are able to provide sensitive gynecological services and mental health services and peer support for WPW. This problem is likely to be particularly acute for respondents who identify as “transgendered,” who may need specific kinds of reassurances that they will be treated sensitively and appropriately by health care providers.

The current climate for research on LBT women and their health issues is becoming increasingly receptive and should provide many avenues for future research. An important recommendation stemming from this study is that future surveys of the LBT community should have clearly delineated operationalizations of SO and GI, particularly for women of color, who may perceive “lesbian” to be a term reserved for white women who partner with women. This will help ensure greater representation of respondents within the LBT community. Future health care surveys of WPW evaluate how representative the study results described within this paper are to the greater LBT community. Ultimately, this study and other research activities should generate valuable information that will have significant implications for the quality of health care and the delivery of appropriate services for WPW.