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OUR HEALTH MATTERS:
PROMOTING THE HEALTH OF SEXUAL MINORITY WOMEN
IN THE NEW MEDIA LANDSCAPE

A Thesis

Presented to
the Faculty of Social Sciences
University of Denver

In Partial Fulfillment
of the Requirements for the Degree
Master of Arts

by

Brenda Kane

November 2010

Advisor: Adrienne Russell

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Title: OUR HEALTH MATTERS: PROMOTING THE HEALTH OF SEXUAL
MINORITY WOMEN IN THE NEW MEDIA LANDSCAPE

Advisor: Adrienne Russell

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Abstract

The shifts occurring in the mediascape and the field of public health offer new opportunities for promoting the health and wellness of sexual minority women. As a population that has historically been underserved by the healthcare system, sexual minority women face multiple barriers to achieving positive health outcomes. They are often less likely to access preventive healthcare services and more likely to engage in risky behaviors that are detrimental to health than heterosexual women. Despite the significant health disparities among sexual minority women, studying this population has not been a priority in health research and there is little research-based evidence to guide patient-provider communication or health interventions. Public health and LGBT advocates have called for further health research on sexual minority women, funding and advocacy to promote their health, and education for healthcare providers on how to provide preventive health services in a way that is sensitive to the unique needs of this population. This research project is situated at the intersections of new media, gender studies, and health communication. A non-probability study of sexual minority women in the U.S. was conducted in order to plan and implement a Web-based health communication campaign in Colorado that encourages preventive health practices among sexual minority women. This paper assesses the ways in which new media can best be leveraged to improve the health outcomes of this population.

Acknowledgements

Thank you to every person that dedicated your voice to this project.

I dedicate this work to you.

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INTRODUCTION

New media hold great potential for addressing the health care needs of underserved minority populations in their ability to forge community networks, facilitate access to health information, and redefine health narratives. The lesbian community in the U.S., a population whose health care status and needs have been largely ignored in women's health research and the mainstream health care system at large, has begun to benefit from these innovations in health communication, particularly in terms of sharing research online with health care providers, policymakers, and the public. The paradigmatic shifts occurring in both the public health sector and the overall mediascape are creating new spaces for the lesbian community to reimagine multiple aspects of their identities, including their physical health and psychosocial well-being. Online communication technologies, such as webcasts, blogs, wikis, virtual reality interfaces, interactive platforms, and social networking websites offer new possibilities for understanding health issues relevant to the lesbian community. They also challenge traditional health modalities inscribed by Western medicine and the U.S. health care system, decentralize health information, and create new spaces for alternative options, including preventive, behavioral, and holistic health care. This phenomenon of emergent alternative health options online is best understood within a conceptual framework that is interdisciplinary, drawing from various schools of thought, including new media studies, public health, gender studies, and cyberfeminist theory. Further research and health

interventions at the interstices of these fields can extend the benefits of greater accessibility and choice to the lesbian community.

This research paper explores the intersection of public health, identity politics, and digital communication technology and proposes communication strategies that can strengthen the lesbian community in the United States. Part one of this paper is a textual analysis of scholarly work and media that address the unique implications of both identity politics and technology as they pertain to the health and wellness of the lesbian community. The first chapter, *Health Disparities Among Sexual Minority Women*, outlines the major barriers to receiving quality healthcare that face sexual minority women (SMW), including lesbians, and sets the stage for a public health intervention directed at this population. The second chapter, *The Health Status and Needs of Lesbians in the U.S.*, addresses the ways in which self-identification as a sexual minority affects risk factors for specific diseases and health conditions and also health outcomes. The third chapter, *Cultural Influences and Existing Health Initiatives*, is an analysis how lesbian culture can be expressed through the use of digital communication technology in ways that promote health and wellness. In particular, it examines the ways in which cyberfeminist theory can inform the production of digital lesbian cultural artifacts and describes grassroots health initiatives that have already produced high-technology works to promote lesbian health. The fourth chapter, *Upstream Strategies for Health Promotion*, describes large-scale efforts that have been made to promote SMW's health, including research, funding, political action, and media advocacy, including digital interventions. The fifth chapter, *Promoting Health in the New Media Landscape*, explores the ways in which innovations in communication technologies are changing the

public's understanding of health information and how it is accessed. It also proposes new directions for the promotion of lesbian health within the context of digitally mediated healthcare.

Part two of this paper outlines original research investigating issues of access to healthcare, overall health and wellbeing, and use of digital media tools among SMW in the U.S. It explores the potential for digitally mediated health interventions directed at SMW through an analysis of findings from an online study. The first chapter, *Research Methods*, is an overview of the study, including rationale for the research methods employed and strengths and limitations of the study. The second chapter, *Study Findings*, reveals comprehensive information about the study's participants, including their demographics, health and wellness status, and patterns accessing technology, health information, and health services. Findings from this study, particularly an analysis of the behaviors and attitudes of the study sample, were used to inform a health communication campaign directed at sexual minority women. The final chapter, *Our Health Matters Campaign*, highlights the strengths and challenges of using Web-based technology to promote lesbian health and describes the sustainable, community-based website that was developed based upon findings from the study. The study sample is thought to represent a segment of the target audience, which is sexual minority women living in Colorado.

The findings from the formative evaluation were used to develop and design the Our Health Matters website in ways that will best engage the target audience. The planning of this digital component ran parallel to the various stages of research and analysis. The Our Health Matters website is a user-driven website that will promote the health of the SMW community in Colorado. It will house relevant research, provide

online and community-based health resources, and generate dialogue among community members, healthcare providers, researchers, and policymakers. Our Health Matters will be a Drupal-based website with user-friendly modules, making it more sustainable, accessible, and community-oriented than traditional static websites. It will be participatory and interactive, providing user membership, blog updates with commenting capabilities, and dynamic community calendar features. In many ways, it will be co-created with the community of SMW in Colorado. The further development of the website will be an ongoing process that is continuously informed by the community. User-generated content and community dialogue will further refine the website as a health resource for the community. The Our Health Matters website represents a growing body of public health work that is informed by theoretical insights, makes use of technology, and intervenes with sexual minority communities to promote health and wellness.

CHAPTER ONE: HEALTH DISPARITIES AMONG SEXUAL MINORITY WOMEN

Overview of Lesbian and SMW Health Disparities

Research has indicated that self-identified lesbians and other sexual minority women (SMW), or those who define themselves as bisexual, gay, or transgendered, may be at higher risk for poorer health outcomes than heterosexual women. (Solarz 1999) There is mounting evidence that attributes this higher risk to differential rates of health behaviors (Bradford et al 1994; Burnett et al 1999; Deevy 1990; Polena et al 1994; Powers et al 2001; Roberts & Sorensen 1999; Trippet & Bain 1992; Valanis et al 2000; White & Dull 1997) and also socioeconomic and cultural barriers to accessing and using appropriate healthcare. (Bradford et al. 1994; Bybee & Roeder 1990; Cochran & Mays 2001; Lehmann et al 1998; Mathews et al 1986; Randall 1989; Stevens & Hall 1988) Health issues that affect heterosexual, bisexual, and lesbian women, as well as transgender individuals, are thought to be largely similar, and SMW, including lesbians, possess no unique biological predisposition to any disease. (Solarz 1999) However, lesbians are characterized by any one or a combination of factors that differentiate them from heterosexual and bisexual women, including identification with a specific sexual minority community, sexual partnering behaviors, and affectional preferences. These factors are thought to be the root of differences in accessing and using healthcare, practicing health behaviors, making health decisions, and achieving overall health outcomes. (Shankle 2006; Solarz 1999)

Recent research demonstrates the breadth of health epidemics facing women, including cardiovascular disease, breast cancer, and cervical cancer (Centers for Disease Control and Prevention 2010; Kerr & Mathy 2007) and some studies have shown that lesbians are at increased risk for these diseases, as well as increased risk of mortality from these diseases. (Gay and Lesbian Medical Association 2010; Kerr & Mathy 2007) Many attribute these outcomes to a lack of protective factors, lower rates of preventive health behaviors, including the Papanicolaou screening test, breast self-examinations, and mammograms, and also a host of behavioral health issues unique to the lesbian community, such as a prevalence of heavy drinking. (Kerr & Mathy 2007; Shankle 2006) Studies also cite disparities among lesbians, such as not having access to and making use of quality healthcare, as being a hindrance to good health. According to the Office of Women's Health of the U.S. Department of Health and Human Services, lesbians face unique challenges within the healthcare system and also frequently avoid preventive care and treatment for disease, which can cause poor mental and physical health. (U.S. Department of Health and Human Services 2006) However, literature review of lesbian health studies and generalizability of the health status of lesbians in the U.S. have been difficult. Historically, studies on lesbian and other SMW's health have been contradictory and sometimes reveal few differences between lesbian, bisexual, and heterosexual women in undergoing preventive health care behaviors and the ensuing health outcomes. (Aaron, Markovic, Danielson, Honnold, Janosky, & Schmidt 2001; Kerr & Mathy 2007; Koh 2000) Disparate findings and lack of consensus among researchers have indicated a critical need for more research dedicated to lesbian health and a standard measurement of sexual orientation. (Kerr & Mathy 2007) While more research is

needed, what little is known about lesbian and SMW's health points to a variety of physical and mental health issues that are related both in obvious and also more subtle ways to sexual orientation and gender identity. Studies exploring these relationships, coupled with a cogent measure of sexual orientation, are beginning to emerge, but further investigation is necessary in order to develop evidence-based public health interventions that target this community.

Lesbian and SMW Community Profile and Segmentation

Lesbian health issues are inextricably linked to the unique culture and social norms of the lesbian community. Therefore, in order to fully understand which health issues pertain to lesbians specifically, it is imperative to first clearly delineate the lesbian population and differentiate it from the larger SMW community. In order to do so, a valid measure for determining a lesbian sexual orientation must be selected. There are different schools of thought as to which measurement techniques should be implemented when studying sexual orientation, and behavioral definitions of sexual orientation have frequently been confounded with self-identification measurements. (Diaz, Vlahov, Greenberg, Cuevas, & Garfien 2003; Kerr & Mathy 2007) Different labels for sexual minority women are used in literature on lesbian health because of the diversity of labels, identities, and sexual behaviors integrated into research. (Laumann et al. 1994) Sometimes sexual orientation is measured behaviorally and women who report having sex with women (WSW) are included in one group, regardless of identity variance. (e.g. Marrazzo, Koutsky, Kiviat, Kuypers, & Stine 2001) The strength of this approach is that it does not assume sexual behavior based solely upon identity. However, this method

imposes sexual labels onto women based strictly on their behaviors and fails to factor in the strong cultural, behavioral, and relational influence of lesbian identity. (Kerr & Mathy 2006) Other times, sexual orientation is measured as self-reported identity and behavior is assumed to follow reported sexual identity, with heterosexual women having sex with men and lesbians having sex with women. In these studies, lesbians are often compared to heterosexual women and bisexual women are either excluded altogether (e.g. Aaron et al 2001) or collapsed into the same study population as lesbians. (e.g. Mays et al 2002) While sexual behavior cannot be determined strictly by self-reported sexual orientation, the strength of this approach is that it recognizes that a lesbian identity entails more than simply sexual behavior. Rather, measuring sexual orientation by self-report identity validates a complex psychosocial identity encompassing social norms and behaviors that both directly and indirectly influence health outcomes.

Disparate findings due to non-standardized measurement techniques within SMW's health research highlight the need for researchers to clearly outline how and why they choose to measure sexual orientation. A closer examination of within group differences, including how sexual identity and behavior may factor into risk differently for lesbians versus bisexuals or other sexual minority women, such as transgender individuals is needed. (Kerr & Mathy 2006) Furthermore, differences in cultural background, race and ethnicity, age, physical ability, and geographical location should also be taken into consideration, as these factors can affect the choices and challenges associated with labeling oneself. For example, older women may sometimes prefer to identify as "gay" or "lesbian," while younger women may prefer to identify as "dyke" or "queer," historically derogatory terms that have since been reclaimed by the LGBT

community as an act of empowerment. They may also reject labels altogether as they perceive them as a form of submission to male-dominated societal norms. (Shankle 2006) In contrast, SMW of color may sometimes reject self-identification as a sexual minority because they are already part of a minority population and may feel that claiming another minority label would compound the oppression they already experience. (Mays et al 2002)

For the purposes of this paper, a lesbian is defined as a woman who self-identifies as a lesbian and it is assumed that her emotional, social, and sexual feelings and relationships to be primarily with women. A bisexual woman is defined as a woman that self-identifies as bisexual and it is assumed that her emotional, social, and sexual feelings and relationships are with both women and men. The term “sexual minority women” (SMW) is used to refer generally to lesbian, gay, bisexual, and queer women. In its general application, the term is less sensitive to self-identification as it typically includes female-to-male transgender individuals that identify as men. For this paper, the term includes everyone that self-identifies as sexual minority women regardless of gender identity (biological women versus transgender women). While the primary focus of this paper is on the lesbian community living in the U.S. with special attention paid to the lesbian community of Colorado, the literature and media review, textual analysis, and investigative research also take into consideration other SMW. Bisexual women are included because they share some of the same sexual, emotional, and relational connections with women as lesbians, although to varying degrees. Female-to-male transgender people (FTMs) or transmen are taken into consideration because, while they may or may not prefer women as sexual, emotional, and relational partners, they have

lived in a female body at some point in time and also identify as queer. They may also have identified previously as lesbians or bisexual women before transitioning, the process of changing one's gender. To a lesser extent, the experiences of male-to-female transgendered individuals (MTFs) self-identifying as lesbians and bisexuals are also taken into consideration. The reasoning for an expansive definition of the SMW population is that bisexual women and transgender individuals are likely experience some of the same cultural norms, oppression, and stigmatization as lesbians, both on a societal level and while accessing health care. Situating lesbian health research within the larger context of health issues relevant to SMW assists in more clearly defining the health concerns most pertinent to self-identified lesbians, and also describes the larger community of women and transmen of which lesbians are a part.

Conceptually defining the different segments of the sexual minority population, particularly the SMW population, and developing methods to identify members has been a challenge in health research. However, most research studies assessing sexual orientation can do so by simply adding a single question, either concerning sexual attraction, sexual behavior, or sexual orientation identity. As these questions are not equally important in all studies, they must be considered in the context of the study. (Meyer & Northridge 2007) The measurement of sexual orientation identity may be particularly important when the results are to be used for prevention efforts directed at a particular segment of the population. This is because individuals who identify as lesbian, for example, have been more easily targeted with prevention efforts than women who have sex with women (WSW) that hold no sexual minority identity. Nevertheless, few health studies have focused on lesbians as a category separate from bisexual women and

have, instead, combined the two groups under the unproven assumption that these two groups of women are more similar than different. (Shankle 2006) However, some research trends have emerged that have begun to differentiate these populations. (Diamant et al 2000; Koh 2000) For example, compared to bisexual women, lesbians have been found to be more likely to be in a partnered relationship, and less likely to have ever contracted a sexually-transmitted infection. Also, while bisexual women have been found to be more likely to have undergone cholesterol screening, lesbians have been found to be more likely to have performed breast self-examinations. (Kerr & Mathy 2006) Further differentiation between lesbian, bisexual, and transgendered sexual minorities should be a priority when considering the overall health needs of sexual minority women.

Estimates as to the size of the lesbian population in the U.S. are problematic, but from a public health perspective, it is important to consider the number of individuals in this target population in order to best address their health concerns and allocate resources. The number of lesbians living in the U.S. has not been well documented and varies depending on whether researchers defined lesbian by identity or behavior, and whether bisexual women were included in the research. However, estimates range from 1.3 percent to 8.6 percent of the total U.S. population. (Shankle 2006) It is important for public health and demographic researchers to continue to work toward enumerating this population in order to assess the public health implications and to develop programming that addresses relevant health behaviors and diseases among lesbian women. Additionally, audience segmentation by age, race and ethnicity, socioeconomic status, and geography is key to understanding variance within the population and creating public

health interventions. In Colorado, for example, studies assessing qualities of the LGBT community have primarily revolved around purposive sampling and qualitative analysis. Researchers have not yet conducted large-scale probability studies in order to quantify the LGBT population in Colorado. However, estimates based on the U.S. Census and other sources suggest that more than 186,000 LGBT individuals live in Colorado, including 12,000 transgender people and that gay and lesbian couples live in 62 of Colorado's 64 counties. In 2010, the One Colorado Education Fund polled 4,619 LGBT Coloradans, 29 percent of which self-identified as lesbian, and determined various characteristics of lesbian respondents, including aspects related to health, work, spirituality, and social support. The study also found that the Denver Metro area has a significantly higher percentage of gay men and fewer lesbians and bisexuals than other regions of the state. (One Colorado 2010)

Transgender men and women have unique life experiences that influence their health risks and probability of accessing the healthcare system or engaging in preventive health behaviors. Since sexual orientation has been found to operate independently of gender identity, (Norsigian 1998) transgender people may or may not identify with the lesbian or bisexual community. However, some male-to-female (MTF) transgender women identify as lesbian or bisexual, and some female-to-male (FTM) transgender men have held a lesbian or bisexual female identity before transitioning. (Norsigian 1998) MTF transgender women that identify as lesbian or bisexual women have unique health risks, including estrogen replacement therapy, which puts them at greater risk for contracting certain cancers. FTM transgender men that previously identified as lesbian or bisexual females have many similar risks as female sexual minorities in addition to risks

unique to transmen, including testosterone replacement therapy and a greater risk of substance abuse and mental health issues due to increased stigmatization, including from other SMW. Additionally, while transgender people generally access care for gender related health reasons, including hormone replacement therapy, sexual reassignment surgery, and mandatory psychological evaluations, there still exist many barriers to healthcare for transgender people compared to other populations. (Harcourt 2006) The perspectives of MTF and FTM transgender individuals provide rare insights into SMW health research that have not been investigated extensively. Furthermore, transgender health issues bring to light the fact that sexual orientation and gender identity are often fluid rather than static self-identifiers that develop across a lifetime. More health research across the lifespan of the SMW population is needed, as sexual orientation and gender identity development can be an ongoing process that begins in early adolescence and lasts late into adulthood.

Barriers to Healthcare Facing Lesbians and SMW

Receiving preventive healthcare services, such as getting regular health check ups and preventive screening tests, are among the most important things women can do to maintain their health (Norsigian 1998) and yet, research has found that lesbians are less likely than heterosexual women to receive such care, particularly annual pap smears and clinical breast examinations. (Cochran et al. 2001; Diamant et al. 2000; Kerr & Mathy 2006) Recent studies have shown that while both lesbian and bisexual women indicate relatively high rates of lifetime preventive health behaviors, these same women report lower rates of recent preventive health behaviors when compared to heterosexual women,

indicating that they are not currently engaging in routine preventive health behaviors. (Kerr & Mathy 2006) It has also been found that lesbians, but not bisexual women, are less likely than heterosexual women to have received annual pap smears and clinical breast examinations. Furthermore, lesbian women of color and younger lesbians are even less likely to have engaged in these behaviors, which points to health disparities, even within the SMW population. (Kerr & Mathy 2006) Some studies indicate that lesbians are at increased risk for breast and cervical cancers and are also at increased risk of mortality of these diseases, and suggest that lower rates of preventive health behaviors and later detection of these diseases are to blame. (Gay and Lesbian Medical Association 2010) This suggests that if lesbian women were to engage in preventive health behaviors more regularly, particularly preventive health screenings, these diseases could either be prevented or detected earlier, resulting in a better prognosis and lower mortality rates. (Kerr & Mathy 2006)

Researchers have postulated that the primary factor accounting for lesbian health disparities is the community's lack of engagement in preventive health behaviors, particularly accessing the healthcare system for preventive care and communicating openly with healthcare providers. This supposition has influenced lesbian-oriented health communication campaigns, the majority of which have emphasized breast cancer awareness. For example, both the Mautner Project and Lesbian Community Cancer Project support health within the lesbian community by providing breast cancer awareness and prevention education. Interestingly, while lesbians report lower rates of engagement with preventive healthcare services, some research shows that lesbians are more likely than bisexual women to conduct breast self-examinations. (Wells et al. 2006)

Lesbians may be more aware of self-exams due to the ongoing health communication campaigns targeted at the lesbian community that emphasize the importance of early detection. (Shankle 2006) These campaigns have been motivated by the belief that lesbians are at greater risk for breast cancer. However, there is not sufficient empirical evidence to support these claims. (Lesbian Health and Research Center 2009) Regardless of whether lesbians are at higher risk for breast cancer, women identifying as lesbians may very well have participated in community events, read lesbian centered magazines, or socialized with other lesbians and have been exposed to these messages. This is one explanation for why lesbians have a higher rate of conducting breast self-exams. Bisexual women may not have been exposed to these messages as much, possibly because they have traditionally been stigmatized within the lesbian community.

There exist many social factors that make access to quality healthcare difficult for lesbian women. Research indicates that cultural components of the lesbian community, such as increased high-risk behaviors and decreased protective factors, put women at greater risk for some health problems. Additionally, lesbians face systemic barriers to health, including inequitable healthcare coverage and culturally incompetent healthcare providers that are not sensitive to lesbian issues. Furthermore, when lesbians do access healthcare, they are often not upfront about their sexual orientation due to fear of stigmatization. Behavioral health researchers have speculated that a primary reason that lesbian women face health disparities that heterosexual women do not is that provider-patient communication has been impeded by a lack of sensitivity, awareness, and overall cultural competence on the part of healthcare providers. Even though the American Psychiatric Association removed homosexuality from the Diagnostic and Statistical

Manual of Mental Disorders in 1973, lesbians continue to face discrimination from both physical and mental health providers. Many studies indicate that sexual minority patients frequently encounter negative reactions from physical and mental healthcare providers, ranging from disgust, to titillation, to denial of the existence or validity of a lesbian identity. Stereotyping, biases, discrimination, and ignorance on the part of providers can result in adverse provider-patient interactions that greatly diminish the health and wellbeing of the lesbian community at large.

Cultural competence among healthcare providers, or their ability to interact effectively with people of different cultures, is becoming recognized as a critical component to achieving positive health outcomes within different minority populations, including the SMW population. Cultural competence among healthcare providers regarding SMW entails their ability to understand specific health issues, risks, protective factors, and cultural components of this community. A better understanding of the health status and needs of SMW assists healthcare providers in communicating and effectively interacting with lesbians, bisexual women, and transgender individuals. In order to improve their cultural competence, healthcare providers must begin to develop an awareness of their own cultural worldview, including their attitudes toward cultural differences and any biases or prejudices they may have toward sexual minorities. In addition to having an awareness of and knowledge about health issues that pertain to SMW, healthcare providers must also develop a skill set that will address these issues. LGBT health advocates and organizations, such as the Gay and Lesbian Medical Association, have developed tools that assist healthcare providers in developing their

cultural competence by providing knowledge about the SMW community and also pointers on how to most effectively interact with segments of the population.

There is growing evidence that that lesbian and bisexual women are much less likely than heterosexual women to access healthcare. (Solarz 1999) One reason that lesbian and bisexual women may be disinclined to access healthcare is that there are few healthcare settings culturally competent enough to deal with their health issues. (Harcourt 2006) The knowledge and skills necessary to adequately serve this population are lacking, mostly because little research-based information exists to guide the practices of healthcare providers. Studies have shown that heterosexist norms guide the clinical practice of many healthcare providers. Sixty percent of the lesbians in the Michigan Lesbian Health Survey and 27 percent in the National Lesbian Health Care Survey reported experiences in which health care workers assumed they were heterosexual. (Shankle 2006) In a recent health study of lesbians and bisexual women, less than 10 percent of the women claimed they have ever been asked their sexual orientation by a physician and, of the women that have ever disclosed their sexual orientation, 30 percent reported receiving a negative reaction from their healthcare provider. (Mravack 2006) Lesbians may already fear rejection, humiliation, and discrimination if they disclose their orientation. Lack of knowledge on the part of healthcare providers may confirm lesbians' perception that healthcare providers are not sensitive to their needs. It may also prevent them from ever disclosing their identity to healthcare providers and even seeking healthcare in the future.

Several studies indicate that the majority of lesbians do not disclose their sexual orientation to physicians when they seek medical care. (Bybee & Roeder 1990) Due to

the real and perceived stigmatization of SMW, lesbians may choose not to be open about their sexual identity when communicating with healthcare providers. When they do choose to disclose their sexual identity, healthcare providers may not be savvy to the healthcare needs of the lesbian population, either due to ignorance or bias. There is mounting evidence, however, that disclosure of sexual orientation among SMW results in better overall health outcomes. Disclosure increases patient-provider communication and facilitates discussion about preventive health behaviors and other lifestyle choices. Women that disclose their sexual orientation are more likely to be open to discussing other health issues and, consequently, more likely to engage in preventive health behaviors than those women that do not disclose their orientation. (White 1997)

Even though cultural competence is increasing among providers, continuous education about diverse populations and skill building is necessary. LGBT health advocates have called for clinical guidelines to help facilitate improved dialogue about the health needs of SMW within various healthcare settings. Positive patient-provider relationships and communication have shown to result in positive outcomes, including patient satisfaction and improved emotional and physical health outcomes, decision-making, and compliance. Aspects of provider-patient interactions that are linked to positive outcomes include information-giving, affective behavior, discussing psychosocial content, information exchange, and patient-centered behavior and decision-making, such as responding to a patient's ideas. (Aaron 2001) Furthermore, research suggests that female physicians engage more often in communication behaviors linked to positive outcomes, particularly patient satisfaction among women. Whether the implications of physician behaviors apply to the health outcomes of SMW specifically is

largely unknown. However, the available studies on SMW in primary care settings show that most lesbians prefer female family doctors and have difficulty communicating with providers and disclosing their sexual orientation to providers. (Cochran & Mays 1998; White & Dull 1997) These findings suggest that lesbian women could greatly benefit from positive provider-patient interactions that address the psychosocial components that influence their health and encourage patient-driven decision-making.

Institutionalized homophobia within the healthcare system and communication barriers contribute to specific physical, mental, and behavioral health problems within the lesbian community. Lesbians have historically been the target of prejudice and discrimination, not only due to their sexual orientation, but in some cases, also due to their race and gender. (Solarz 1999) In a multisite, longitudinal health study, 56 percent of white lesbians and 33 percent of black lesbians reported discrimination on the basis of sexual orientation, 85 percent of the black women reported further discrimination based on race, and 89 percent of the women also reported having experienced gender discrimination in their lives. (Solarz 1999) Cultural incompetence within healthcare stems from broader societal homophobia, including inequitable civil rights and disparities in health insurance coverage and household incomes, all of which create significant barriers to quality care for lesbians. A primary reason that lesbians sometimes neglect medical screening is that in the U.S., there is a lack of health insurance that offers health benefits for same-sex domestic partners. Additionally, most employers do not provide health insurance coverage to gay and lesbian partners of employees. Employees that do receive health coverage for their lesbian partners must pay federal income taxes on the value of the insurance. (Shankle 2006) The legalization of same-sex marriage and

granting same-sex partner coverage would allow lesbians to benefit more frequently from preventive health care and medical treatment for disease and would likely increase the likelihood of them seeking care.

Regardless of the reasons that lesbians do not seek out healthcare or receive quality care, the resulting mental and physical health challenges within the community are often related to their lack of preventive care measures. Many efforts have been made to address the health issues that are perceived to be the most urgent, including breast cancer awareness campaigns and studies on alcohol use within the lesbian community. However, many important health issues have been overlooked and misperceptions about the risk of experiencing certain health problems run rampant, not only among healthcare professionals, but within the lesbian community, as well. Further understanding the complexities of the impact of lesbian identity on health status will help to inform future health communication campaigns and provider education efforts.

CHAPTER TWO: THE HEALTH STATUS OF LESBIANS IN THE U.S.

Lesbian Health Status Overview

There is some empirical evidence to support the belief that lesbians are at higher risk for certain health problems. At the same time, there are also widely held assumptions of greater risk and misconceptions about certain lesbian health issues. (Solarz 1999) Both of these factors have important implications for the health-seeking behavior and health outcomes of lesbians other SMW. While lesbian health research was a narrowly focused field of study in the 1990s, it has since expanded with increased funding to include numerous lesbian health and wellness topics, such as cardiovascular disease, reproductive cancers, intimate partner violence, sexually transmitted infections, alcohol and tobacco use, and mental health issues. It is becoming evident that while lesbians face the same health problems as heterosexual women, lesbians are sometimes at greater risk for some of these problems due to stresses from stigmatization and marginalization, and differences in health behaviors, and in the way they interact with the healthcare system. (Solarz 1999) Lesbians also face developmental challenges across the lifespan associated with their sexual orientation, such as coming out, societal attitudes, family rejection, and internalized homophobia. They may react and manage these differences in ways that affect their health. Furthermore, ethnic minority women face the additional challenge of integrating their sexual and racial identities. Therefore, it is virtually impossible to separate lesbian health issues from the cultural, social, and political influences that affect the lesbian community. An understanding of the

overlapping health and psychosocial factors becomes important when taking a public health approach to lesbian health. Effective health communication strategies and public health interventions that promote lesbian health and wellbeing should be designed with these components in mind.

Cardiovascular Disease and Lung Cancer

Cardiovascular disease, including coronary heart disease and cerebrovascular disease, is the leading cause of mortality among women living in the U.S., causing more than half of all deaths in the U.S. (CDC 2010; WHO 2010) Research has identified risk and protective factors for cardiovascular disease and some studies indicate that the prevalence of these factors vary between lesbians and heterosexual women. (Shankle 2006) Self-reported behaviors and health status among self-identified lesbians were compared to a probability sample of women from the general population and modifiable risk factors for cardiovascular disease were greater among lesbians. (Aaron et al. 2001) Lesbians may be at increased risk due to factors such as higher rates of alcohol abuse, smoking, and obesity compared to heterosexual women. Studies also show that lesbians have a higher body mass overall and are generally less concerned about weight issues than heterosexual women. (Roberts et al. 1999) The Women's Health Institute reports that body mass index differs significantly between lifetime lesbians and heterosexual women, with a greater proportion of lifetime lesbians having a BMI of more than twenty-seven. (Valanis et al. 2000)

Lung cancer is the most frequent cause of cancer death for women and almost eighty percent of lung cancer deaths in women are due to smoking. (CDC 2010)

Smoking can also cause cancer of the larynx, mouth, throat, esophagus, bladder, kidney, pancreas, cervix, and stomach, and also acute myeloid leukemia. (CDC 2010) Although smoking prevalence data among lesbians and bisexual women are limited, available data have consistently shown that smoking rates among lesbian and bisexual women are higher than those in the general population. (Shankle 2006) Only eight studies on smoking rates among lesbians were conducted between 1987 and 2000. The majority of these studies determined sexual orientation through self-identification and used probability or convenience sampling. Overall, the respondents tended to be white, in their thirties, and college educated, and reported smoking rates ranging from 11 to 50 percent. More recent studies have assessed the smoking prevalence and patterns of cigarette smoking among lesbians and bisexual women, as well as the risk factors associated with these populations. Current published estimates of prevalence of cigarette smoking among lesbians range from 20 to 30 percent and 12 percent among bisexual women. (Bradford 1994) Data also indicate lesbians may have a higher rate of lifetime exposure to tobacco. (Gruskin et al. 2001) Data from the Women's Health Institute indicate lesbians are twice as likely as heterosexual women to be heavy smokers and while almost half of heterosexual women report never smoking, only a third of lifetime lesbians reported never smoking. (Shankle 2006)

Risk factors that contribute to a higher prevalence of smoking within lesbian and bisexual populations include depression, negative body image, marketing and advertising directed at the LGBT community, different gender norms, abuse of other substances, and smoking behavior of significant others. (Shankle 2006) Smoking is often more culturally acceptable among lesbian women than heterosexual women since gender roles that are

less clearly defined among lesbians make smoking, a traditionally masculine habit, more readily tolerated. Lesbians are also less likely to obtain medical care and, therefore, may receive less tobacco-cessation education and counseling. (Shankle 2006) Further research is needed on the reasons as to why lesbians smoke more than the general population, and also on the barriers to quitting, including those unique to lesbians and those shared with all women. Limited access to quality healthcare and a lack of culturally appropriate tobacco cessation programs and materials may be contributing factors that should be investigated further.

Breast Cancer, Gynecologic Cancers, and STDs

The most common form of cancer in women in the United States is breast cancer (CDC 2010) and significant attention has been paid to the potential for increased risk of breast cancer among lesbians. (Solarz 1999) Studies on cancer among lesbians have attempted to assess the differences in risk factors and prevalence of those risk factors, and also the differences in the way that healthcare is received. Some studies also show that lesbian women perceive their risk of breast cancer to be substantially higher than their actual calculated lifetime risk of breast cancer. Whether or not lesbians are at higher risk of breast cancer than heterosexual women, some studies have found that there is a common perception in the lesbian community that they are. Also, health communication campaigns directed at the lesbian community have focused on messages about breast cancer and often take precedence over other preventive health messages. Although the actual prevalence of breast cancer among lesbians is not known, some theorize that lesbians may be at increased risk of breast and other cancers due to diminished protective

factors and increased risk factors, including higher rates of smoking, increased body mass, poor diet, higher alcohol intake, and differential rates of hormone exposure associated with less use of oral contraceptives and a lower likelihood of bearing children. (Solarz 1999; Shankle 2006) However, there are no epidemiological studies supporting the assertion that lesbians are at increased risk for breast or other cancers. Some studies have focused on the attitudes of lesbians regarding health and treatment for disease. For example, in one study comparing heterosexual women and lesbians with a diagnosis of early stage breast cancer, several of the reactions among lesbians were different than those of the heterosexual women. For example, lesbians reported less concern about their appearance than did heterosexual women in terms of mastectomies and chemotherapy, particularly when they were in intimate relationships. This finding seems to support claims that lesbian culture places less emphasis than heterosexual culture on the importance of physical appearance and that in lesbian relationships, emotional closeness is valued more than sex. (Kerr & Mathy 2006) Lesbians were also found to employ more adaptive forms of coping compared to heterosexual women, including emotional support from friends, positive reframing, and venting of their feelings. This study attributes this difference primarily to the virtue of lesbians belonging to a minority group, and speculates that lesbians have adopted coping mechanisms over time due to challenging situations associated with their sexual orientation.

Cervical cancer is the ninth most deadly cancer for women in the U.S. (CDC 2010) and cervical cancer risk is generally associated with heterosexual behavior, including multiple male sexual partners, unprotected intercourse, and the presence of the human papillomavirus (HPV), a common sexually transmitted infectious virus. While

lesbians are at less risk for cervical cancer than heterosexual women, the vast majority of lesbians or 90 percent report having had heterosexual intercourse in their lifetime and approximately one-third report recent heterosexual contact. (Bybee & Roeder 1990; White 1997) Furthermore, cervical neoplasia, which is associated with HPV infection, has been detected in lesbians that report no sexual encounters with men in their lifetime and genital warts have been detected in lesbians, including those with no history of having sex with men.

The Papanicolaou test is the most important screening tool used to diagnose and prevent the development of invasive cervical cancer and yet, data suggest that lesbians may have routine testing less frequently than is recommended. For example, 23 percent of respondents in the National Lesbian Health Care Study reported their last Pap test was more than two years ago and other studies indicate lesbians without prior male sexual partners may be even less likely to have Pap tests. (Bradford & Ryan 1988; Marrazzo et al. 1996) Conditions that contribute to less frequent screening among lesbians include a lower perception of risk and also barriers to healthcare, including heteronormative health care practices. For example, primary care for women tends to be organized around reproductive health needs. Also, public funding for women's health has been centered on issues that are less salient for lesbians than heterosexual women, such as family planning and prenatal care. In many clinical environments, intake forms, educational materials, insurance information, and interviews that include questions about health history assume that patients are heterosexually active. Since there is a lower rate of regular Pap tests among lesbians than heterosexual and also bisexual women, it is more difficult to detect cervical cancer at early stages in lesbians. Some studies indicate the risk of developing

ovarian and endometrial cancer is higher in lesbians than heterosexual and bisexual women because they lack both preventive healthcare and the protective factors of pregnancy, abortion, and contraception. Lesbians are much less likely than heterosexual women to report having biological children and only 34 percent of lifetime lesbians report ever having ever been pregnant compared to 90 percent of heterosexual women. (Mravack 2006) Furthermore, only 17 percent of lesbians between the ages of 25 and 36 report having used oral contraceptives, compared to approximately one-third of heterosexual women within this same age range.

Sexually transmitted infections have become an epidemic in the U.S. with numerous negative outcomes for women, including cervical cancer, chronic pelvic pain, infertility, and ectopic pregnancy. Despite the belief among many lesbians and their providers that they are not at risk of contracting sexually transmitted infections, there is some research-based information that contradicts these beliefs. (Mravack 2006) For example, HPV is the most common sexually transmitted infection in the U.S. and women who have sex only with other women can get HPV. (Atlanta Lesbian Health Initiative 2010) However, traditional gynecological examinations focus on and respond to heterosexual behavior and tend to overlook the risks of female-to-female contraction of sexually transmitted infections. Counseling for women about sexually transmitted diseases traditionally assumes sex with male partners, and self-disclosed lesbians are often perceived to have a lower risk of contracting sexually transmitted disease or acquiring certain types of cancer despite evidence to the contrary.

Mental Health Issues

Anxiety disorders and depression, which are the most common mental health issues for women, are also prevalent within the lesbian population. However, the causes of mental health issues tend to differ between lesbians and heterosexual women. Lesbians frequently report experiencing social ostracism, internalized homophobia, legal discrimination, and lack of social support systems, which are all factors that adversely affect mental health. For women discovering their sexual identities or claiming a sexual minority identity, coming to accept themselves often signifies experiencing dissonance in their lives on many levels. Lesbians frequently report anxiety and depression, often internalize the negative societal attitudes that are directed toward sexual minorities, and have a high rate of suicidal ideation. (Gruskin et al. 2006) In a 1994 health study of 2,345 lesbian and bisexual women, more than half of the respondents reported that they had suicidal thoughts and 18 percent had attempted suicide. (Solarz 1999) Unfortunately, even as sexual minority clients seek counseling two to four times more frequently than their heterosexual counterparts, studies have indicated that sexual minorities consistently experience prejudice, disapproval, and ignorance from mental health professionals. However, mental health issues associated with sexual orientation have gained greater prominence in U.S. culture recently. Lesbian individuals face a multitude of challenges, but also increasing rights and opportunities as they explore and proclaim their sexual identity. In order to achieve positive outcomes, mental health practitioners working with lesbian clients should identify any homophobia they may have, be culturally sensitive to the realities of multiple oppressions, and be prepared to help lesbian clients develop healthy relationships with themselves and with their partners.

Lesbians often report experiencing minority stress, the perceived pressure of negative life events and associated stigma resulting from discrimination based on sexual orientation. (Gruskin et al. 2001) The stress that lesbians experience related to the difficulties of living in a homophobic society is hypothesized to play a major role in lesbian health issues. Stress among lesbians may result from many factors, including the burden of concealing one's lesbian identity from family, coworkers, and friends, being the target of violence and other hate crimes, or being denied the same rights as heterosexual women, such as marriage, partner visitation rights in the hospital, and making healthcare decisions for an ill partner. The repeated, chronic stress that lesbians often experience has definite mental health repercussions and also physiological costs, including increased allostatic load and heightened neural response. The ensuing health problems associated with stress include elevated blood pressure, which can lead to hypertension, and also elevated cortisol, which can cause increased abdominal fat, atherosclerosis, calcium loss from bone, muscular weakening, and cognitive impairment. The precise health effects of stress on lesbians have not been examined systematically, but it has been hypothesized that lesbians sustain negative effects similar to racial or ethnic minorities and individuals of lower socioeconomic status (SES) that experience discrimination. (Solarz 1999) Studies have found that black individuals reporting internalized experiences of discrimination have higher blood pressure than both white individuals and also other black individuals that do not internalize discrimination and rather dealt with their stress with a social support system or other resource. (Solarz 1999) Findings also suggest that individuals of lower SES are more likely to encounter negative life events and have fewer social and psychological resources for coping with stress. It

has been hypothesized that lesbians who are members of racial or ethnic minority groups or are of a lower SES may be most affected by stress as racism and financial stressors may compound the negative effects of homophobia.

Violence

Violence against lesbians, including hate crimes, gay bashing, domestic violence, and sexual assault, greatly undermines the health and wellbeing of the lesbian community. The rates of physical abuse, sexual abuse, and incest among lesbians are not significantly different from reports of all women (Bradford et al. 1994). However, the nature of violence against SMW women may have different undertones, including societal homophobia. Antigay crimes account for 11 percent of hate crimes in the U.S. and are the third largest category of violent crimes following racial hate crimes and crimes based on religion. More than half of the lesbian respondents in both the National Lesbian Health Care Survey and also the Michigan Lesbian Health Survey reported having been verbally attacked and five to eight percent reported being physically attacked for being a lesbian. (Bradford & Ryan 1994; Bybee & Roeder 1990) Most studies of lesbians report experiences of sexual abuse similar to heterosexual women. The rate of sexual abuse among lesbians is approximately 38 percent, which is comparable to rates reported in studies of the general population of women. This disputes the notion that women become lesbians as a result of sexual abuse or incest. However, there is a higher probability in lesbian relationships than heterosexual relationships that more than one partner will have experienced sexual abuse. Furthermore, studies report that nearly 70 percent of lesbians in treatment for alcohol abuse disorders report childhood sexual

abuse, indicating a need for culturally sensitive therapies that address co-occurring mental health issues.

Intimate partner violence is a significant problem that hinders the health and wellbeing of women and studies indicate that the prevalence and severity of domestic violence between women is comparable to those of heterosexual relationships. However, lesbians may encounter challenges when seeking help, including the pervasive denial among social service professionals that domestic violence exists among women. Lesbians may be resistant to reporting incidents because of a lack of understanding by law enforcement professionals. Women's shelters are also frequently resistant to openly and sensitively dealing with lesbian domestic violence. Despite calls to action to develop lesbian-specific domestic violence interventions, healthcare service providers have done little to address lesbian battering. Many lesbian health advocates attribute the lack of services available addressing lesbian partner violence to an overarching heterosexual bias among providers that fails to validate a lesbian identity or recognize lesbian relationships. Traditionally, there has been reluctance among mental health practitioners to even admit that domestic violence between women occurs. Violence in lesbian relationships challenges conventional gender norms and feminist notions of domestic violence that attribute violence to male socialization and privilege. Some theorize that domestic violence among women can be attributed to internalized homophobia or self-hatred and also substance abuse problems. Findings suggest that it is inadequate to use a heterosexual framework for domestic violence to assist lesbian couples. Lesbian health advocates call for more expansive treatment modalities that recognize domestic violence

among women and also provide appropriate and affirming counseling, safe spaces for the victims, and lesbian friendly treatment options for the perpetrators.

Alcohol and Drug Abuse

Research has indicated that lesbians tend to drink alcohol more heavily than heterosexual women. In order to cope with mental and emotional challenges resulting from their stigmatized identity, lesbians often turn to the use of alcohol and other substances. Lesbians report using alcohol and other substances to in order to self-medicate depression and cope with minority stress. (Gruskin et al. 2006) Higher rates of alcohol consumption and abuse can be attributed to the high levels of stress lesbians experience due to marginalization and discrimination in society. Some studies indicate a link between workplace harassment and increased alcohol consumption and others have found that perceived stress among lesbians is positively correlated with frequency of drinking to intoxication. (Shankle 2006) Research shows that lesbians often engage with their community in bars, that lesbians who frequent bars are more likely to drink, and that lesbians generally drink more than their heterosexual counterparts. (Aaron et al. 2001; Cochran et al. 2000; Diamant et al. 2000; Drabble et al. 2005) Furthermore, the National Alcohol Research Center found that women who identify as lesbian or bisexual are more likely to report problems with alcohol. (Drabble & Trocki 2005) Lesbians are less likely to abstain from alcohol (Diamant et al. 2000) and are more likely to experience alcohol problems, negative consequences due to their drinking, and alcohol dependence than heterosexual women. (Cochran et al. 1988; Drabble et al. 2005) The health tradeoffs of regular alcohol use include increased risk of digestive problems, hypertension, pancreas

disease, cancer, anxiety, and depression. Regular excessive alcohol use is also associated with aggressive and violent behavior, accidents and injury, financial and work problems, and relationship difficulties. (WHO 2010)

The lesbian bar has been a cornerstone of lesbian culture since the 1920s and remains an important social space for lesbians even today. Many lesbians frequent lesbian bars in order to meet a wide range of needs. Consistently, lesbians' motivations for frequenting lesbian bars include socializing, relaxing, spending time with friends, and enhancing conversation. (Gruskin et al. 2001) Lesbians often experience acceptance and social support at lesbian bars and for some lesbians, bars are the only spaces in which they can be completely open about their identity. The positive outcomes of frequenting the lesbian bar include finding extended community, having a support network, feeling safe, developing a sexual identity, and socializing with fellow community members. (Gruskin et al. 2001) Lesbian bars have become culturally agreed upon staging areas for the fulfillment of different psychosocial needs, particularly developing a lesbian identity and establishing social support networks. Even though there is a range of positive reasons for lesbians to socialize at bars, being a part of bar culture also puts lesbians at greater risk for different health and safety problems, including legal consequences, work impairment, and behavior incongruent with their image of themselves or their values. Historically, lesbians have also experienced harassment and violence at lesbian bars.

Drug use and addiction are also issues that affect the health and wellness of the lesbian community and are sometimes perpetuated by bar culture. Some studies indicate that lesbians are more likely than women in the general population to abuse certain illicit substances. In a subsample of lesbians that took the National Household Survey on Drug

Abuse, lesbians were more than four times as likely as women in the total sample to have used marijuana in the past year. Overall prevalence rates for past-year cocaine use was relatively low, only seven percent among lesbians, but this is still more than twice the rate among the total sample. In a multisite study, lesbians were more than twice as likely to indicate that they had gotten help for substance abuse problems at least once in the past and that the majority of lesbians that were abstainers were likely in recovery from substance-related problems. (Hughes 1997) Research used data from large national population-based databases to compare women with same-sex partners with those with only male partners and found a substantially higher rate of substance dependency among women with same-sex partners. However, it cannot be assumed that these women identified as lesbian since this study did not include questions about self-identity. Overall, findings from studies on lesbians and substance abuse suggest that sexual minority status and chemical dependency are strongly correlated. Furthermore, lesbians that engage in heavy drinking and frequent lesbian bars are more likely to have other substance abuse issues.

Despite the negative consequences associated with frequenting lesbian bars, consuming alcohol, and using illicit substances, recent studies confirm that lesbian bars remain an integral social space for lesbians that meet their needs for social connection. When considering the impact of alcohol and other drugs on the health and wellbeing of lesbians, it is necessary to take into consideration the psychosocial importance of the lesbian bar, the connection between minority stress and alcohol and drug use, and the inevitable health and wellbeing tradeoffs of frequenting bars. Knowledge about the link between alcohol and drug abuse and the stress caused by societal marginalization can

better inform the design of effective interventions directed at the lesbian community. Furthermore, treatment centers may require education in order to provide lesbian-friendly treatment options as any hostility and homophobia will most likely fuel the shame and guilt that often at the root of chemical dependency. Finally, given the extent to which lesbians are relationship-oriented, lesbians looking to quit or cut down on drinking or stop using drugs may also require partner and peer support in order to experience a successful recovery.

There is some evidence that many lesbians do not know about non-drinking community alternatives to the bar, such as book readings or performance art. (Gruskin et al. 2006) Some studies suggest that public health social marketing campaigns should highlight alternatives to bars within the lesbian community. These campaigns could work to reimagine the lesbian bar in ways that are not centered on alcohol consumption, but rather, healthy alternatives that support socializing while maintaining cultural significance. Since it is unlikely that these alternatives will completely replace bars, it is also important for public health and LGBT advocates to work with bar owners to conduct education on alcohol abuse. It may also be feasible to encourage bar owners to expand their offerings and services in an economically viable way, so that their business is not solely dependent on the purchase of alcohol. Some lesbian bars and lounges are beginning to follow this trend by serving a wider variety of non-alcoholic and coffee drinks, hiring lesbian musicians and performance artists, exhibiting the work of local lesbian artists, serving food, and providing access to the Internet. By collaborating with public health advocates, lesbian bar owners can cultivate community in ways that provide healthy alternatives to drinking, encourage access to technology and local

culture, and facilitate social support and networking. The lesbian bar may also be a central domain in which to engage lesbians to facilitate health discourse.

CHAPTER THREE: CULTURAL INFLUENCES AND EXISTING INITIATIVES

The Impact of Community on Health

The culture of the lesbian community influences the behaviors, beliefs, and attitudes that affect the health outcomes of lesbians. Studies have shown that holding a lesbian identity may actually predict certain health behaviors, particularly in terms of involvement with the community and experiences with the healthcare system. (Shankle 2006) Identifying with the lesbian community may prove to influence women's decisions regarding diet and exercise, smoking, alcohol and substance use, personal relationships, and physical and mental health care seeking behavior. (Kerr & Mathy 2007) Lesbians may be exposed to the health messages of state and local health departments that are targeted specifically at this community, and they may also experience social support from community members that encourage positive health behaviors. Conversely, certain elements of lesbian culture and the broader LGBT culture may adversely affect the health outcomes of lesbians, particularly the bar culture, misconceptions about health risks among lesbians and their providers, and less tangible social forces such as internalized homophobia, rejection of heteronormative culture, fear of stigmatization, and shame. These cultural influences can impede the adoption of preventive health behaviors. Understanding the nature of the lesbian community as a whole and also the diversity within the community is needed to accurately assess the health needs of lesbians.

There are a variety of factors that are thought to be protective of lesbian health, including well-developed social support systems and involvement in the lesbian community. While lesbians do not differ from heterosexual women in the amount of social support they receive, it is evident that they draw this support from different sources. (Kerr & Mathy 2006) Lesbians frequently have a tenuous relationship with their families of origin and rejection and disapproval from family members may be major stressors in their lives. However, when families are approving and supportive, this can be a significant protective factor. Often, lesbians are part of “families of choice,” composed of close friends, particularly members of the lesbian community. While lesbians in the National Lesbian Healthcare Study reported high levels of stress, most reported that they relied on the lesbian community and on lesbian and gay male friends for support and socialization and reported overall satisfaction with their lives. (Bradford & Ryan 1994) Furthermore, lesbians are often more likely than heterosexual women to report they have obtained support from friends when coping with illness. While the length of lesbian relationships has been shown to be significantly shorter than heterosexual relationships, studies show that lesbians value emotional support, sometimes over physical intimacy, in their romantic relationships. (Kerr & Mathy 2006) In fact, lesbian relationships are instrumental in lesbian identity formation because, unlike gay men, lesbians are more likely to come out as a lesbian within the context of a relationship. This can sometimes be detrimental to lesbian relationships, particularly when lesbians find themselves intensely involved with another woman or living with a partner before completely coming to terms with their sexuality. Other times, positive and meaningful same-sex

relationships may contribute to self-acceptance and healthy development among lesbians, particularly in closeted or geographically isolated couples.

Lesbian Cultural Influences

Much like other minority communities, the lesbian community has struggled to define itself and to perpetuate a meaningful identity on the fringes of mainstream society. Lesbians living in the U.S. have defined their culture in a variety of fashions and share a “herstory” that encompasses a wide range of cultural components, including dress, food, music, literature, spirituality, sports, dwellings, relationships, sexuality, theory, and health. Lesbians have a rich history of using the arts and different forms of storytelling to sustain their subculture and preserve their communal and individual wellbeing. Lesbian autobiographical narratives, performance, and film have been central aspects of identity formation and community solidarity. Lesbian cultural artifacts, including short stories, poems, critical theory, artwork, cartoons, photography, music, and new media, have become increasingly visible over time, and illustrate the lives, social milieu, ideas, and visions of lesbians past and present. Cultural leaders in the community have created definitive works, including groundbreaking pieces like the *Well of Loneliness* by Radclyffe Hall, photographs by JEB, the cartoon series “Dykes to Watch Out For” by Alison Bechdel, music by Kay Gardner and Sue Fink, and political essays and creative writing by Audre Lorde, Elsa Gidlow, Lee Lynch, Pat Parker, and Valerie Miner. Over time, lesbians have developed their culture underground and, increasingly, with openness and pride. Within the past two decades, lesbian culture has been appropriated more and more by mainstream media, including magazines, radio, and television, which has had the

effect of both normalizing a historically marginalized identity, and also stereotyping and oversimplifying a community that is full of complexity and diversity.

Health and wellness issues have been addressed both directly and indirectly by different forms of lesbian cultural production, including music, publications, films, and new media, including websites, blogs, and forums. While lesbian identity has been expressed on the Web, the few cultural artifacts that specifically address the health needs of lesbians and promote their health and wellbeing are rare. However, the cyberfeminist movement, which has been active over the past two decade, has facilitated the articulation of feminist and women's issues online, including lesbian and SMW identity performance and politics, and offers helpful insights into the potential for lesbian health promotion on the Web. The cyberfeminist project is also very much in line with the manner in which the lesbian community has expressed its identity, in that it is both highly informed by critical theory, and also complemented by politically charged, artistic cultural works. Aligning lesbian health promotion with feminist and queer theory, high technology, and creative production makes this public health initiative very much a cyberfeminist endeavor.

Approaching lesbian health from a cyberfeminist theoretical lens contextualizes lesbian health and wellness media within a larger body of cyberfeminist work, which has evolved concurrently with new media, particularly the Internet. Since the early 1990s, cyberfeminist theory and practice have addressed issues such as lesbian identity, the relationship between the body and technology (Haraway 1991), the cyberpotential for feminists to leverage digital technologies for personal and political purposes (Stone 1992), the expression of non-dichotomous, hybrid identities (Guertin 2003), and the

creative application of theory. (Wilding 2009) The work of cyberfeminist scholars and artists is useful for informing new health communication narratives, particularly as they relate to lesbian identity. It also highlights the need for tangible, theoretically engaged, high-technology work that benefits the lesbian community.

Central to cyberfeminism is the topic of disembodiment or consciousness without physical form, particularly as it relates to the gap between cybernetic identities and women's lived realities. (Muri 2003) Therefore, when theorizing about digital applications of public health initiatives, it is important to consider the ways in which disembodied online practices can either impede or promote the physical and mental health of the lesbian community and other SMW. Many cyberfeminists affirm that digital culture liberates users from the physiological markers of identity, opening up spaces for cybernetic imaginings that refute hegemonic notions of gender roles. (Haraway 1991) They envision virtual communities in which subjects are constructed through the collective imaginary, thus allowing great freedom of identity expression. Cyberfeminist theorists have explored the liberatory potential of technology, deconstructing narratives of domination and control in high technology culture (Braidotti 1996), and exploring the potential for social space and identity performance in the virtual world. (VNS Matrix 2009) Cyberfeminism often illustrates optimistically the ways in which women can be empowered by technology as a liberating force that defies patriarchal power and traditional gender and sexuality norms. It explores how notions of femininity and masculinity are in transition and the ways in which technology will be the impetus for a new cultural ideology to emerge. (Plant 2007) Many cyberfeminist theorists envision the Web an emancipative space in which queer identities can thrive, as they believe that

disembodiment challenges nature-based, body-centered feminisms and patriarchal notions of sexuality and the body. (Haraway 1991)

Even as prominent cyberfeminists laud the unification of the body and the machine, many other feminist theorists have problematized the portrayal of the Web as a utopian space that defies rigid gender definitions and oppressive power dynamics. These critics are particularly worried about cyberfeminism's neglect of women's physical bodies and lived realities and argue that digital culture can potentially replicate the existing social order of material culture. (Muri 2003) A central argument amongst these theorists is that the Internet is a privileged space in which primarily white, educated, upper to middle class women participate. (Wilding 2009) They also assert that cyberfeminism must not only be interested in theory, but also, the engaged practice of artistic and technological production. (Old Boys Network 1997) They characterize the conjunction of digital communication technology and identity politics as abstract and detached, contending that even as identities have become more complex in cyberspace, they have also become more fragmented as minds and consciousness are detached from physical bodies. (Stone 1992) Even as "technosocial" individuals and virtual communities are essential to the cyberfeminist movement, physical bodies invariably dictate experience. Cyberfeminists struggle to understand the ways in which gender equality can be imagined online, even as issues of power and access exist on the physical level. (Stone 1992) The new imaginative possibilities for thinking about embodiment and identity within the human-technology interface must be tempered with a considerable amount of caution. (Wolmark 1999) While this view of identity and technology is more pessimistic, it also explores subversive uses of new communication technologies,

particularly as they can facilitate the work of a transnational movement to infiltrate the networks of power and communication. (subRosa 2005) As women and their communities around the globe are impacted by technology, cyberfeminists simultaneously resist and benefit from the power of these new technologies to develop contestational strategies and form activist networks and coalitions. (subRosa 2005)

The paradox of cyberculture outlined by cyberfeminist theorists is that even as bodies seem to matter less and less, particularly online, bodies have also never been more significant, especially in terms of identity politics. This tension is useful, however, when considering the ways in which digital technologies can be leveraged to promote the physical wellbeing of the lesbian community. The simultaneous emphasis on women's lived reality and also rejection of body-centered identity within cyberfeminist theory can inform narratives of lesbian physical health and psychological wellbeing. Furthermore, the cyberfeminist emphasis on practical work will help navigate from theory into practice, and circumvent any potential obstacles as it merges with the fields of public health and health communication. It is from this theoretical foundation upon which new research and digital structures that matter to lesbian health will be built.

Existing SMW Health Programs, Initiatives, and Resources

The health resources available to lesbian individuals for health information exist as localized, community-based programs and also online, either as subdomains of mainstream or federally funded health websites or as specialized websites of agencies dedicated to LGBT health generally or lesbian health specifically. Lesbian health information on large mainstream or federal websites, such as that of the Center for

Disease Control and Prevention, the World Health Organization, or the Department of Health and Human Services, tends to lack depth, often encompassing only a page of text, and is generally given less weight than other more prominent, male-centered LGBT issues, such as HIV/AIDS in the gay male population. While information on websites geared toward lesbians are mostly not as dynamic or interactive as mainstream health websites, the health information available on these websites is both more comprehensive and specific. These resources are also associated with culturally relevant community organizations that support lesbian health research, provide direct health care services, promote health education within the community, and offer health-oriented social support. They also offer new possibilities for engaging the community in ways that are not geographically restricted, such as making health information and health assessments accessible to individuals with Internet anywhere in the U.S. and hosting interactive forums and lectures online. Such virtual communities increase the density of the lesbian community and also the potential for interaction.

Grassroots organizations addressing lesbian and other SMW health that target community members began to emerge two decades ago and have evolved to include web presence. In 1990, Susan Hester founded The Mautner Project in Washington D.C. in memory of her partner Mary-Helen Mautner, who died of breast cancer in 1989. The impetus for the work of the Mautner Project was that sexual minority women are less inclined to seek preventive health care due to discrimination and homophobia. By educating the community and their health care providers and providing tools and insights, the organization strives to achieve better health outcomes for lesbians. The Mautner Project aims to improve the health of lesbians, bisexual women, and transgender women

who partner with women and their families. The organization provides direct services to individuals with cancer and other life-threatening illnesses and offers various support and wellness groups for grieving a loss, smoking cessation, and nutrition. The Mautner Project also educates health care providers, policymakers, the press, and the general public about the needs and concerns of lesbian, bisexual, and transgender clients. In coalition with other health organizations, the Mautner Projects conducts primary research about sexual minority women's health and advocate at national, state, and local levels for public and private sector research on lesbian health and inclusion in mainstream health initiatives. Programming at organization has expanded over time to encompass a variety of lesbian health issues relevant to different segments of the community and different key players. For example, the Spirit Health Education (S.H.E.) Circle is a national, holistic health education program focused on African-American women who partner with women and addresses the influences of culture and sexuality on health. Also, the Mautner Project's "Removing the Barriers to Accessing Health Care for Lesbians" is the first and only training program for physicians and other healthcare professionals on the health needs of lesbians.

The Mautner Project's website brings the benefit of local, community-based education to a national level where lesbians in the U.S. can access health information online and learn about how to more effectively communicate with providers. While the original intent of the Mautner Project was to address cancer education and treatment resources in the lesbian community, the organization now takes on a variety of health issues in the community, which is reflected in their website. The Health Info section of the website provides information on barriers to care, risks, symptoms, and treatment for a

wide range of health issues affecting lesbians, including cancer, heart disease, and mental health problems, as well as recommendations for preventing illness, living a healthy life, and talking to health care providers. The website also provides member-driven email support groups for breast cancer survivors, caregivers, and those grieving a loss of a partner. The Mautner Project has developed video-based trainings that are available online and, to celebrate its 20th anniversary, the organization recently posted a video highlighting their programs and milestones. Interactive elements of the website include a daily health poll, social networking, and the use of AidMaker, software that allows users to make charitable donations to the organization when they shop online. There is also a current events section with relevant local and national news affecting sexual minority women and a Mautner Project newsletter with information on programs, events, and health tips.

The Lesbian Community Cancer Project is another lesbian focused, grassroots organization that is specifically geared toward cancer education and treatment. It was founded in 1990 with the goal of making the medical establishment more sensitive and responsive to women generally and lesbians in particular and also to educate women about making informed health decisions. In 2007, the Lesbian Community Cancer Project merged with the Howard Brown Health Center in order to take advantage of the strengths of both organizations and to work on programmatic initiatives together. The current mission of the program is to promote the health and wellbeing of lesbian, bisexual, and queer women and transgender individuals through advocacy, research, culturally competent medical care, health programming, and education on lesbian health topics. The Lesbian Community Cancer Project primarily provides direct services,

including prevention, screenings, treatments, and emphasizes accessible and appropriate care. Howard Brown sees thousands of lesbian and queer women annually and provides them with a variety of mental health and medical services. The program accepts many types of insurances, but also provides a sliding scale and free screenings to ensure that money is not a barrier to women's health. Currently, the organization's website is geared toward the Chicago community, promoting local events, fundraisers, and services. However, the website is under construction and will soon feature a new section on health information for sexual minority women, similar to that of the Mautner Project, which will bring the innovative work of the organization to SMW nationally. The website is also launching a social media campaign on breast cancer awareness, "Story of a Boob," and the organization is requesting women to send in stories about what they do to keep their breasts healthy and any experiences they have had with healthcare providers and their breasts.

The Lesbian Health and Research Center (LHRC) began as a grassroots initiative and is currently the only lesbian-focused health and research organization that is housed within a world premier health institution, the University of California, San Francisco School of Medicine. The center works to facilitate research on the lesbian community and to close the gap in lesbian health disparities. The focus of LHRC is to help community members find healthcare providers, improve dialogue with providers, and also answer health questions. The organization also works with the healthcare community and policymakers to advance further research that will inform policy. In 2006, LHRC released an educational video online, "Lesbian Health Care," featuring professor Patricia Robertson, MD, from the Department of Obstetrics, Gynecology, and

Reproductive Sciences at UCSF. The video was part of a monthly series of talks on contemporary issues in women's health that is archived online by the UCSF Center for Gender Equity. The video addresses the unique health issues facing lesbians, including cultural and societal forces. Specific health topics that are included are the reproductive options for lesbians and end of life issues for lesbians. The video series provides opportunities for outreach, networking, and education, both on campus and online with its interactive features, including a live question and answer session via email.

The Atlanta Lesbian Health Initiative (ALHI) is a non-profit agency that was founded in 1996 by a small group of women to provide education, advocacy, support, and access to care to the lesbian community. ALHI is the only agency in the southeast devoted exclusively to the health of lesbians, their partners, and their families. While the agency's initial focus was on cancer support, it has since expanded to include prevention education and health promotion. In 2007, the ALHI Lesbian Health Fund was established with contributions from local businesses in order to provide programming, including health screenings and assessments, health education, support groups, and health-oriented social functions. The primary function of the health fund is to provide underinsured and uninsured lesbians access to essential health screenings, including pap smears and mammograms. ALHI's signature health education program, Carpe Boobem, has educated more than 5,000 women on self-examination, clinical breast exams, and mammograms. ALHI runs a variety of support groups, including those for women diagnosed with cancer and other illnesses. In order to address domestic violence within the lesbian community, ALHI runs support groups for both victims of domestic violence and also batterers. Their state certified batterer intervention program assists lesbian

batterers to make changes in the way they relate to their partners, and work toward breaking the cycle of violence. The agency also provides social opportunities and has formed an alliance with Atlanta's 25 year-old lesbian network, Fourth Tuesday, and its tradition of social networking dinners on the 4th Tuesday of every month. The organization views social support and networking opportunities as essential to developing and maintaining good mental health for members of the lesbian community.

The ALHI website features are perhaps the most cutting edge, interactive, and user-friendly of all lesbian health websites. In addition to promoting local programming and services, the website offers accessible information that is relevant to lesbians living anywhere in the U.S. The website provides a provider search engine with which lesbians can find a lesbian friendly health care provider in their area by city, name, or specialty. Other features that are useful for lesbians seeking health information regardless of geographical location are the ALHI news features and referrals to online resources by health topic. One of ALHI's latest developments, the Lifestyle Link, is an online health assessment designed to help lesbians review their current health-related behaviors and provide personalized feedback on how to maintain a healthy lifestyle through diet, exercise, and regular visits to health care providers. Upon completion of the assessment, users receive a customized report with recommendations on how to develop and maintain a healthy lifestyle. The report emphasizes that the health assessment is not intended to be a substitute for medical advice and encourages women to speak with their health care providers about specific health concerns. Additionally, the Lifestyle Link report refers visitors to the ALHI Health Resource Center for information on relevant health topics and resources in their local area.

Unmet Communication Needs

While the lesbian community has been inundated with messages about breast cancer, the need for community-focused education about other preventive health measures have been largely overlooked. Misperceptions are prevalent regarding lesbian and bisexual health, both among medical professionals and the lesbian community itself. Despite emerging research on lesbian health and an influx of community-based grassroots and digitally mediated health interventions, insufficient attention has been paid to the integration of lesbian health and digital technology. By merging the insights of scholars from multiple disciplines, including cyberfeminism, public health, and new media, it is possible to make theoretical links in order to understand how lesbian health disparities can be mitigated with the use of digital technologies and emergent health communication strategies. Cyber health communication strategies for this community have the capacity to open up new avenues for access to healthcare information and resources. The innovative concept digital lesbian health media requires more research in order to investigate current digital applications that are relevant, critique their aesthetic and functional viability, and apply them to different segments of the lesbian community. This body of work will fill the gap in research located at the intersections of multiple fields, and will inform future theory and practice.

CHAPTER FOUR: UPSTREAM STRATEGIES FOR HEALTH PROMOTION

Overview of Upstream Strategies

Upstream strategies to advance lesbian and other SMW's health attempt to make systemic changes in the practice of healthcare, the allocation of resources, and the formation of public opinion by influencing key players and important decision-makers on local and federal levels. Public health advocates have worked to advance evidence-based health prevention and intervention efforts within societal contexts that often marginalize and stigmatize lesbian and other SMW's health issues. Recently, major federal health institutions, including the Center for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH) have received demands to eliminate research and prevention efforts related to sexual orientation or sexual behavior, indicating research and advocacy priorities are often driven more by ideology than by science. (Shankle 2006)

After the publication of the Institute of Medicine report on lesbian health in 1999, it became evident that there is a dearth of information about lesbian and SMW's health and that there is a need for further research on SMW and a clear delineation of the effects of behavior and identity. While the Healthy People 2010 initiative made the groundbreaking decision to include health objectives addressing sexual orientation in 10 of the 28 prevention focus areas for the U.S., data are not currently being collected to track these objectives. Furthermore, the document fails to address health disparities in LGBT populations and ignores transgender populations altogether. (Harcourt 2006)

Important projects being undertaken by public health researchers, advocates, and LGBT

community members alike include funding health research, advancing different forms of health promotion, including media advocacy, and advocating for policy change.

SMW Health Research

Lesbian, bisexual, and transgender health research emerged as a burgeoning body of work in the early 1990s. Up until that point, discrimination and abuse against lesbians and other SMW had been clearly documented, but the impact on physical and mental health remained in need of study. Also, the health theories that had informed public health initiatives were based primarily on men's bodies and experiences and, to a lesser extent, those of heterosexual women. Furthermore, the health studies of women in particular had failed to differentiate lesbians and bisexuals as subgroups or to take into consideration transgender individuals. (Solarz 1999) Even as women's health as a field of study has become more central to dominant health discourses over time, the health concerns of the lesbian community have not been investigated comprehensively. (Harcourt 2006) Nevertheless, some health studies over the past two decades have focused on lesbians as a minority population, and have addressed the health disparities not only among men and women, but also among heterosexual women and lesbians. (Solarz 1999) Other studies have focused on the unique health needs of female-to-male transgender patients and their access to care for hormone treatment and sexual reassignment surgery. (Harcourt 2006) LGBT community members themselves have organized politically to gain funding for federally funded research initiatives, which are critical for identifying their specific health needs. Such research is necessary for providing data that will justify the funding of further studies and addressing prominent

issues, such as the identification of SMW in healthcare, the health risks unique to these subgroups, and homophobia and stigmatization. Backing for more comprehensive research is critical for understanding what risk and protective factors shape the physical and mental health of SMW.

While much is known about certain health topics relevant to the LGBT community, such as HIV/AIDS among gay and bisexual men, little is known about the lesbian population. In one study, it was found that literature focusing on LGBT health comprised only one-tenth of a percent of all indexed articles in MEDLINE from 1980-1999, and that 56 percent of those articles focused on HIV and STDs among gay and bisexual men. Gay men and MTFs have received more attention from the healthcare community, as well as funding for research and public health campaigns, primarily because of the prevalence of HIV/AIDS within this community as a top public health concern. (Harcourt 2006) Lesbian health issues were brought to the forefront for the first time with a publication based on findings from a study funded by the National Institutes of Health (NIH) Office of Research on Women's Health and recommendations from a 1997 conference held by the Institute of Medicine Committee on Lesbian Health Research Priorities. The volume, *Lesbian Health: Current Assessment and Directions for the Future*, directed attention for the first time to the study of lesbian health issues. It recommends viable methods for conducting studies of lesbians, and identifies barriers that hinder such research. The reasons for conducting research include the need to gain knowledge to improve the health status of lesbians and to confirm beliefs and counter misconceptions about the health risks of lesbians. (Solarz 1999) The scope of such studies must consider both the individual and also the political perspectives of integrating

lesbian identity politics into healthcare, including the concerns of medical professionals, system-wide challenges, political pressures, and attitudes within the lesbian community. Major barriers to conducting research include inconsistencies in the way sexual orientation is defined, the lack of appropriate control groups or longitudinal data across the lifespan of lesbians, and legislative failure to recognize lesbian health issues. (Solarz 1999) Nevertheless, there are many potential benefits of such comprehensive research, including standardized methods for asking about sexual orientation in primary care settings without violating privacy, exchanging information among researchers, and disseminating findings to the public.

Studies since the publication of *Lesbian Health*, researchers have examined the challenges unique to the study of lesbian health and also bisexual and transgender health, and have attempted to understand the perceptions of these populations and their providers in order to assess the health disparities of these subgroups. A salient issue within these studies is the lack of cultural competence amongst providers and the resulting avoidance of healthcare by SMW because of difficulties communicating with providers. (White 1997) Studies of perceptions among SMW regarding their health show that respondents who are “out” to their primary care providers are more likely to seek health and preventive care and are more comfortable discussing personal topics. Contemporary studies reveal that SMW perceive alternative practitioners as more culturally sensitive and easier to communicate with than traditional medical providers. (White 1997) In general, research on SMW’s health emphasizes the need to recognize discrimination against SMW patients in healthcare and recommends guidelines for providing quality healthcare to these patients. Medical doctors need stronger skills communicating with

SMW, so that important medical and psychosocial information can be shared. Just as the IOM Committee on Lesbian Health Research Priorities identified challenges to conducting lesbian health research, so too do the majority of the studies that have been conducted in the field. They identify homophobia within the medical profession and also lack of funding as major challenges to SMW's health research. They emphasize the need for the SMW community to identify themselves and for activists and advocates to find researchers willing to devote funds and labor to research projects.

There are several research issues that make data collection on LGBT health topics challenging. One of the greatest challenges to representative sampling in lesbian health research is generalizability. (Harcourt 2006) Due to the relatively small size and large diversity of the lesbian community, with sexual orientation and gender identity cutting across all racial, ethnic, and socioeconomic backgrounds, it is difficult to define this population. (Harcourt 2006) It is also difficult to measure the health issues of LGBT populations, as most population-based survey studies lack methods to assess sexual orientation and gender identity. In lieu of large-scale, federal data collection and probability sampling, researchers studying lesbian health have implemented alternative sampling methods, including targeted advertising and snowball sampling techniques. While these research methods may increase the possibility of selection and volunteer biases, they are often necessary to recruit LGBT study populations.

There is no consensus on how to generate questions that capture sexual orientation, and in order to determine the sexual orientation of respondents, studies have used self-identified orientation, reports of the sex of the respondents' sexual partners, and the gender to whom the respondent is attracted. Due to the lack of consensus on how to

define sexual orientation, it is imperative to specify how and why sexual orientation and gender identity is measured when conducting LGBT health research. Until standardized measures of orientation and identity are validated for large-scale measurements of the health status of LGBT populations, researchers must rely upon smaller descriptive, qualitative studies. These studies can be helpful for collecting information on demographic and cultural components to inform the creation of questions and topics for future larger-scale projects. Since little is known about the health status of different LGBT populations, multiple research methods are appropriate.

These gaps in research can also be addressed by ensuring routine LBTQ inclusion in large-scale demographic data gathering. There has been a movement in LGBT health research to encourage all researchers to collect sexual orientation and gender identity data in addition to other demographic data as part of their research protocols. Given the U.S. Census Bureau's successful use of a single "choose all" item to collect race and ethnicity data, the Lesbian Health and Research Center recommends including the following question to access both sexual orientation and gender identity via self-report: *Do you consider yourself to be one or more of the following: straight, gay, lesbian, bisexual, or transgender?* This question presents challenges, such as breach of privacy, particularly when respondents are required to verbalize their identity over the telephone, but is a valid option, particularly for more anonymous mail-in or Internet studies. While LGBT organizations and public health researchers have advocated to include sexual orientation and gender identity questions for decades, it was only recently that large federal and state health surveys started to include questions related to sexual behavior and same-gender sexuality that support analysis of different segments of the LGBT population.

Unfortunately, it was the AIDS epidemic that finally called for information on patterns of sexual behavior in the U.S. population in order to design and implement programs to curb the epidemic. Funding was made available to draw samples of the general population that would allow prevalence estimates of same-gender sexual contact. Without such broad reaching sampling, lesbian health research would be limited to small, non-probability samples that limit the generalizability of findings. Continued resources, both financial and scientific, are necessary to sustain lesbian health research and facilitate the analysis of health issues of sexual minority populations on a large scale. Probability sampling provides reliable information about health behaviors and risks among lesbians that can be used in the design and implementation of health education and disease prevention efforts.

Traditionally, the cross-sectional population survey has been the default methodology in public health research. However, in more recent years, there has been growing interest in developing new research techniques to investigate public health topics, including qualitative methodology and high-technology approaches. While large-scale quantitative measures are most appropriate for health issues that are well documented, qualitative measures are more appropriate for describing health issues of populations of which little is known. In the field of public health, qualitative methodology has generally been viewed as unrigorous and unsuitable for answering key questions. However, qualitative data-gathering techniques have been part of health research, including clinical case studies, field observation, and other ethnographic techniques. It is a valid approach for investigating different cultures and relating social practices and processes to health experiences and outcomes. Furthermore, the Internet

and its resources have become a new arena for the refinement and enhancement of public health research questions and field methods, including qualitative research. In fact, gay men, who have shown to be frequent users of the Internet, were one of the first populations to be involved in Internet health research. New possibilities for investigating lesbian and SMW's health with innovative research methodologies, including non-probability and qualitative research online should be explored further.

For the most part, findings from lesbian health research, both online and off, have been directed toward healthcare providers, rather than the lesbian community itself. For example, professional organizations like the Gay and Lesbian Medical Association provide research-based guidelines on how to best treat sexual minorities. Founded in 1981, GLMA is the world's largest and oldest association of LGBT health care professionals and has become a leader in public policy and advocacy related to LGBT health. The organization works to dispel myths among providers about LGBT health issues and to ensure equality in healthcare for lesbian, gay, bisexual, and transgender individuals. The organization educates providers on a broad range of LGBT health issues, including breast and cervical cancer, hepatitis, mental health, substance abuse, tobacco use, depression, and access to care. The organization's approximately 1,000 members live in the U.S. and several other countries and include physicians, medical students, nurses, physician assistants, researchers, psychotherapists and other health professional from a broad range of medical specialties.

Fundraising and Advocacy

Given that health research is critical to furthering the lesbian health agenda, LGBT health advocates have sought funding from a variety of sources, including corporate sponsorship and government grants. Corporations have increasingly sponsored cultural events and provided direct donations to national and local nonprofit organizations in order to fortify relationships with LGBT consumers. They have also funded research exploring how to best reach LGBT markets and target LGBT consumers with intimate knowledge of the cultural subtleties of segments of the community. (Burnett et al. 1999) Some LGBT advocates have perceived inclusion of the LGBT community in the economic marketplace as progress toward social acceptance. However, some public health advocates have criticized advertising, sponsorship, and promotions from corporations whose products negatively affect the health of the community. For example, alcohol and tobacco corporations have increasingly targeted LGBT communities with specialized marketing, even though there is mounting evidence suggesting that the LGBT community is disproportionately impacted by tobacco, alcohol, and drug-related health problems. (Drabble & Trocki 2005) LGBT media, community organizations, and leaders are in a position to critically consider the social and health impact of corporate funding, balance the interests of corporate sponsors with their consumers, and adopt policies that affirm the value of LGBT health over profit-making.

Public health focused counterads are a valuable tool for counteracting misinformation and irresponsible promotion of risk behaviors by corporations sponsoring LGBT media and cultural events. Counteradvertising has been an effective strategy for challenging industry manipulation and cultural norms that enable risky behavior and has

proven successful in influencing healthy behavior change. For example, LGBT health advocacy groups have successfully used counteradvertising strategies to reduce tobacco consumption. Community-based campaigns have reduced point-of-sale tobacco advertising among stores in LGBT neighborhoods and placed counterads in LGBT media venues with positive outcomes. (Drabble & Trocki 2005) Counterads contextualize health problems and generate support for change in policy. In addition to counteradvertising, other forms of social marketing, systematic applications of marketing to achieve positive health outcomes, can be employed to disseminate health messages into specific segments of the LGBT community, including the lesbian community.

Foundations also play an important role in advancing lesbian health by funding LGBT health research, initiatives, advocacy, and other efforts to influence policy change and social justice for the LGBT community. Progressive and mainstream foundations must more readily fund organizations engaged in media advocacy and health policy change to defuse anti-gay messages and policies. Conservative foundations have successfully promoted an agenda that depicts the LGBT as a threat to the general population through the funding of right-wing think tanks, media, and political groups. Public health professionals recommend the adoption of written guidelines for ethical funding on the part of LGBT media and community-based organizations as a solution to misrepresentation of LGBT health issues. While funding for LGBT health initiatives has been scarce, community-based organizations committed to the equity of marginalized groups and addressing health disparities have seen positive outcomes. The only fund in the world solely dedicated to the unique health needs of lesbians is the Lesbian Health Fund, which supports research addressing the diversity of sexual minority women's

communities and health promotion for lesbian and bisexual women. The mission of the LHF program is to address the misinformation and homophobia among healthcare providers and the lack of scientific data on lesbian health needs that often result in inadequate medical care for lesbians. LHF strives to support a wide range of medical research that addresses lesbian health issues and also the education of healthcare providers on lesbian health and cultural sensitivity.

Public health and LGBT advocates must work together to forge policies that protect the health and wellbeing of the LGBT community at large and the lesbian community specifically. While lesbians, bisexuals, and transgender individuals have made great progress in winning and securing equal rights, the community must still make strides toward fully closing the gap in LGBT healthcare. There are still major challenges to address, including reduced access to employer-provided health insurance, stress from harassment and discrimination, and lack of cultural competency in the healthcare system. Studies continue to generate evidence of the public health impact of these disparities, but lack of funding to more fully understand the health status and needs of lesbians compounds these problems. More research-based information is needed to direct the healthcare providers that serve the community and also the health communication campaigns targeted at the community. LGBT allies and public health advocates are encouraging policymakers to seek ways to increase access to healthcare for LGBT individuals, provide culturally appropriate care, and conduct more health research on LGBT issues and populations.

Media Advocacy

Mainstream media, LGBT media, and the Internet offer important opportunities to promote lesbian public health. The media are powerful mechanisms for advancing public health in LGBT communities, but can also be sources of misleading messages about health, sexuality, and risky behavior. Public health researchers, practitioners, and policy advocates have a shared responsibility to promote LGBT health and increase awareness of previously underrepresented segments of the community, including the lesbian community, through various media outlets. Advances in technology, such as digitally mediated health communication campaigns, are beginning to open new avenues for public health promotion and have the potential to benefit the overall health and wellness of the lesbian community.

Mainstream media sources have expanded to include a wide range of alternative communication and LGBT media venues, including newspapers, radio, television, and advertising. The rate at which LGBT issues are covered by mainstream media sources is at an all time high. An analysis of five decades of reporting on gays and lesbians in two major weekly news magazines found that coverage on LGBT issues, including health and mental health topics, grew from two articles in the 1940s to 151 in the 1990s. However, it also reported persistent problems with fairness and accuracy in reporting on LGBT issues, including a disproportionate focus on pathology and also stereotypical and negative portrayals of the LGBT community. Furthermore, lesbians and communities of color are greatly underrepresented with coverage disproportionately focusing on gay white men. A prime example of disproportionate mainstream coverage of the health of the LGBT community is the AIDS epidemic, which received significant coverage in the

1980s, the majority of which linked AIDS/HIV to stereotypical depictions of promiscuous gay men. Often with the complicity of mainstream media, the AIDS epidemic has been used as a pretext to advance anti-gay public opinion and policy rather than public health solutions. Until all segments of the LGBT community are represented objectively in mainstream media, LGBT people will continue to face stigmatization. While objectivity in reporting on LGBT issues has improved over time, reporting is still often skewed by oversimplification, generalization, and prejudice.

Members of the LGBT community, their allies, and public health advocates have worked to advance LGBT disease prevention and health policy messages and challenged mainstream media to improve accuracy and sensitivity in reporting. Informing and influencing the media is necessary in order to change public perceptions about the LGBT community and also to effect policy and practice related to LGBT health issues. Many organizations, including grassroots advocacy groups, health coalitions, and nonprofits, have been formed in order to advocate for LGBT communities and educate the media on LGBT issues, including GLAAD, the AIDS Coalition to Unleash Power (ACT UP), and the Human Rights Campaign. Advocates have proposed “fair practices” in reporting that they hope will be adopted by journalists. These include responding to derogatory comments and unfounded allegations against the LGBT community by questioning sources, insisting upon evidence, and applying the same rigorous standards in their coverage of LGBT subjects as they would for other important social and health issues. Increased accurate media coverage of LGBT issues, campaigns, and events will mobilize public awareness and promote the health and wellbeing of lesbians. Media advocacy can support accurate, sensitive, and fair reporting of LGBT issues, shape the political and

social environments affecting LGBT communities, and apply pressure to effect policy change.

The LGBT community, like other marginalized groups, has created its own alternative media sources for addressing political and social concerns that have been overlooked or distorted by mainstream media. Since there have been significant barriers to broadcasting LGBT issues in mainstream media, particularly broadcast media, LGBT print media has become the primary vehicle for communicating about the lives and interests of sexual minorities. Unlike mainstream corporate organizations, LGBT media have been created by and embedded within the LGBT community and are reflective of issues pertinent to LGBT people, including health and wellness topics. Over the past 50 years, numerous LGBT publications have emerged that voice to diverse segments of the LGBT community. Since socializing in the LGBT community has centered largely around the bar scene, one of the first LGBT media formats was the “bar rag,” a cheaply produced periodical that promoted bar activities and also included some editorial content and sometimes paid personal ads. Bar rags have traditionally served as makeshift community directories that outline LGBT community activities and organizations and connect community members in safe, LGBT-friendly environments. While the size and scope of LGBT media have expanded to include local community papers and, to a lesser extent, radio and other electronic media, these earlier LGBT media were not representative of the diversity of the entire LGBT community and tended to privilege the perspectives of white gay men.

In the 1970s and 1980s a broader range of LGBT media began to emerge that was more inclusive of different segments of the community, such as sexual minority women

and people of color. Population-specific publications for lesbians, bisexuals, transgender people evolved and generally emphasized political and social change. They also began to address key health issues and provided health information that was largely ignored by mainstream media, including safer sex practices, treatment for diseases, and lesbian health issues. In the mid-1990s, a new generation of less radical and more commercial LGBT publications emerged, including *The Advocate*, *Out*, *Genre*, and *10 Percent* for men, and *Square Peg*, which is now out of print, and *Deneuve*, which is now *Curve*, for women. This new genre of publications grew by attracting mainstream advertisers that perceived the LGBT community to be a profitable niche market with considerable disposable income. This category of less radical publications can also be thought to include more general, yet liberal minded, gay-friendly publications, including *The Village Voice* and *LA Weekly*. The driving force behind these publications has been to attract advertisers rather than delivering timely information. Many LGBT health advocates have criticized the motivation behind these publications, particularly as they tend to depend upon advertising from the tobacco and alcohol industries, which perpetuate the norm of substance use within the community. LGBT media sources are an optimal venue for communicating public health messages, but at the same time, there are several potential barriers, including editorial practices and policies that may reject strong public health content for fear of offending potential advertisers.

Increasingly, LGBT media have expanded to include both entertainment oriented and technologically advanced channels, including cable broadcasting, radio, and electronic media, such as podcasts and websites. LGBT public health advocates have worked to include health messages into these avenues and also to develop and market

their own media, including videos, toolkits, and care guides for dissemination into mainstream and also population-specific audiences. LGBT entertainment media, including movies, television, and music have also received increased attention as a format for public health communication. While these media can be a source for purveying unhealthy norms, public health interventions can work to counteract these messages. There is a dearth of research on the influence of entertainment media on specific populations and the possibilities for infusing public health messages into LGBT entertainment have gone largely unexplored. Creative initiatives to leverage technology and entertainment could potentially augment LGBT health interventions and mobilize public awareness around LGBT health issues.

The Internet and the Web have provided new media formats and new forms of connectivity that further public health interventions targeted at LGBT communities, and have also equipped users to create and become part of media themselves. There is a growing number of public and private websites dedicated to addressing LGBT health issues and a burgeoning body of online resources that promote user participation. User-driven and interactive platforms provide innovative venues for members of the LGBT community to connect, share information, engage in discourse, and produce their own content. The expanded development and dissemination of high-quality, accessible Internet websites and alternative media can play a central role in advancing the health needs of the lesbian community. New media can be used as a sophisticated tool for increasing healthy and safe behaviors within the lesbian community and enhancing the visibility and communication options of lesbian public health organizations. The Web provides a nexus for grassroots organization and policy change advocacy, which is

crucial in a political environment that is either indifferent or hostile to lesbian public health services, research, and advocacy. A cogent example of the utilization of Web-based technology to organize, communicate, and signal a rallying point for diverse LGBT groups is the National Coalition for LGBT Health's website, which lists dozens of member organizations and circulates weekly summaries of news and announcements related to LGBT health to its electronic membership list. Web-based technologies are also useful for developing public health communication campaigns with hyper local content. Forums that are located online, but intended for residents of a well-defined local area can provide health information that encourages utilization of community resources and community building. Websites informed with statistical information on the health status and demographics of a particular residential population or segment of the population can address health concerns more effectively than generic mainstream websites.

CHAPTER FIVE: PROMOTING HEALTH IN THE NEW MEDIA LANDSCAPE

New Media and Lesbian Health Communication

Increasingly, health professionals, policy advocates and government officials are bringing the benefits of information technology to healthcare. In recent years, governments, hospitals, healthcare providers, and pharmaceutical manufacturers have placed a significant amount of medical information, data, and services online. More and more, physicians are encouraging patients to use email or web messaging instead of telephone calls or in-office visits for medical issues. Prescription drug and medical equipment manufacturers are making their products more readily available online. Healthcare consumers can now visit health department websites and compare performance data on healthcare providers and access health information on diseases, prevention, and treatment online. While LGBT health advocates have slowly begun to follow suit by providing health information, communication, and services online, the promise of LGBT e-health remains largely unfulfilled.

For segments of the lesbian population that are media-savvy, the Internet is a powerful communication tool with its ability to connect community members, increase visibility of pertinent issues, and create safe spaces to identify with a minority community. Nonprofits and small groups that have historically struggled to reach large numbers of LGBT individuals are now aided by the use of Web strategies and other forms of electronic media to organize and educate constituencies more effectively. Even

organizations that operate with minimal resources have reached larger audiences than would have been possible with newsletters and other traditional media. Web strategies have also increased communication between LGBT communities and health professionals. Government websites have presented little LGBT health information, but there are a few exceptions of sites that offer important resources. The Substance Abuse and Mental Health Service Administration, for example, provides an extensive section of information on LGBT substance abuse within its primary website. Some local health departments have LGBT-specific information on the Web, including the Seattle and King County Public Health Department. The websites of grassroots organizations and lesbian activist groups have arguably had more of a dramatic impact on lesbian health by offering important resources online that are community oriented.

The commercial sector has also begun to offer consumer-friendly information about health topics affecting the LGBT community with websites that offer daily news updates, archived articles, and concise information responding to medical questions submitted by medical professionals. However, it is often more difficult to find quality, reliable health information on commercial sites compared to government or nonprofit sites since the main objective of these websites is not necessarily the wellness of the community, but rather, to promote a product and make a profit. Gayhealth.com is an example of a website that presents balanced LGBT health information in a user-friendly format. However, it has struggled to generate a stable base of revenues and exemplifies the limitations and economic fragilities of such an enterprise. It is nevertheless a rare example of an online resource that provides quality information about a wide range of LGBT health topics and offers hope for future health-focused LGBT businesses online.

While the LGBT community has taken advantage of the Internet, quickly and creatively establishing a significant presence on the Web, the lesbian community has been slower to adopt new technology to promote its causes. The majority of community-based organizations using new media to conduct online outreach are geared toward gay men and focus primarily on HIV/AIDS prevention and safer sex practices. While the Internet affords greatly increased access to health information and resources, there have been varied results of Internet access for the health of LGBT people, as there are barriers to its efficacy. For example, there are many competing messages on the Web that undermine public health agendas. Also, the digital divide is still a reality for many lesbians without access to computers, personal communication devices, or the Internet and digitally mediated health interventions will most likely neglect this segment of the population. Issues of access must be further addressed, particularly among lesbians living outside of urban areas and lower-income lesbians.

The Web also offers potential solutions to research barriers, including activism to garner public and private funding, ongoing conferences, and the broad dissemination of information about SMW's health to providers, researchers, policymakers, and the public. The Internet and the use of innovative technologies has become key to activism and information sharing. Anticipating the political and scholarly potential of the Internet even in 1990s, *Lesbian Health* suggests that contemporary technology and the Internet should be used to conduct lesbian health research. Recommendations include computer-assisted interviews for maximum disclosure and large-scale probability surveys, as well as the establishment of a clearinghouse of research online. Even before the full potential of Web 2.0 had been explored, lesbian health researchers turned to the Internet as a

solution to the various challenges of funding, accessibility, and confidentiality characteristic of the study of lesbian health. While a few lesbian health websites have been established since the publication of these studies, none have completely harnessed the power of Web 2.0 or fully taken advantage of interactive features, social media, or other new media tools, such as blogs, wikis, web videos, and webcasts. However, the fields of public health, health communication, and healthcare in general have begun to fully embrace the potential of the digital technology. Therefore, there exist numerous cogent examples of the convergence of digital media and health communication upon which new lesbian health media and cyber strategies can be modeled.

Innovations in communication technology and media have begun to change the face of public health, particularly in terms of the ways in which health information is shared. Public health researchers and new media developers are beginning to examine the implications of changes that are underway in the mediascape on health communication, including the shift from expert-controlled messaging to consumer-initiated and interactive communication. (Gomez 2009) New media are playing a pivotal role in transitioning the ways in which the public engages with healthcare. For example, health websites are growing four times as fast as the Internet overall, and 61 percent of Internet users now seek health information online. (Gomez 2009) Avenues of access and education are beginning to emerge for populations previously underserved by the mainstream healthcare system. For example, AIDS.gov has recently launched a comprehensive new media literacy campaign that also connects different communities with education and resources. Web technologies such as webcasts, social networking, blogs, and microblogs like Twitter allow providers and consumers alike to address

healthcare topics, raise awareness, educate interested parties, make calls to action, create instant focus groups, and increase the positive share of voices surrounding the topic. (Parker & Thornson 2008) WebMD embodies some of the potential for digitally mediated health interventions with interactive, self-administered health screens, educational slide shows and videos, and a host of health information resources. While the full potential of new lesbian health media has not yet been explored, other minority populations, such as Latinos, Blacks, and women of color have begun to harness the Web for the purpose of community-based health promotion and lessons can be learned from these projects, as well.

The Web affords different levels of engagement for public health discourse, from grassroots to governmental participation. The emergence of digital communication technologies and health communication are complementary in many ways. For example, public health initiatives seek to increase access, improve the quality of healthcare, and reduce costs, and new media is increasingly accessible, interactive, and low-cost. New uses for digital technology include educating health providers and patients through interactive media, facilitating collaboration among health researchers and providers, and extending the traditional flow of health information to reach patients that want to share in decisions about their care. Such applications of digital technology include health blogs, online health screenings, virtual doctors, medical encyclopedias, virtual worlds, texting, and webcasts. Health communication, marketing, and media have become important for non-profits, health advocacy organizations, industry leaders, and individuals alike for garnering support and advocacy. This cultural shift presents opportunities and challenges, such as mobilizing mass communication to empower individuals to adopt

healthy behaviors, directing policymakers to important health issues, and framing those health issues for public discourse. These concepts can be applied to lesbian health communication in terms of understanding how to harness new media in ways that improve individual health and the healthcare delivery system at large.

Recent research has shown that the Internet has changed how the general public approaches their health and wellbeing as many consumers are using the Web as their first source for health information. However, no such studies thus far have addressed the lesbian community's health information consumption. Nevertheless, the ideas of many new media scholars can be applied to lesbian health media. For example, the role technology plays in health communication has been examined in depth, particularly in terms of how new media can improve health literacy and communication between providers and their patients. Digital technology has been shown to serve as the most practical and efficient form of distributing health-related information. (Parker & Thornson 2008) Emerging research in cyber-health technology has also taken into consideration ethnic and racial disparities in healthcare utilization and addresses the need to develop new technological methods or “cyber strategies” for closing these gaps. (Gibbons 2007) Some studies exemplify the ways in which new media technologies can be leveraged to communicate and intervene with specific populations in order to improve their health, and demonstrate the strengths of digital media in comparison to print media and face-to-face intervention, which are both more resource intensive and sometimes less effective. (Brendyen and Kraft 2008) Other studies have examined the Web behavior of specific populations seeking advice related to health and interpersonal relationships online, and have shown that many Internet users access health websites to ask questions

related to romantic relationships and sexual health. (Suzuki & Calzo 2004) Even though these studies have not directly addressed sexual orientation or gender identity, the methods used can be applied to lesbian or other SMW individuals, as they may exhibit similar online behaviors, such as anonymous advice seeking, and benefit from similar health intervention and communication strategies.

The most recent publications on new media health promotion have presented innovative ideas for reaching out to underserved communities in ways that resonate with cultural values and norms regarding health. For example, public health advocates have recognized the importance of personal narratives and storytelling in public health interventions and also the potential for new media tools to promote health and prevent disease. Personal narratives through any medium can promote community building, healing, and tribal identity. Digital storytelling, such as public health videos, streaming lectures, and testimonials online, help to decentralize written text for health promotion and disease prevention. The practice is an important health communication method, but also a community building and healing tool. While providing facts and information assists with educating the community, storytelling creates a visceral experience that makes learning more memorable. A cogent example is The Positive Project, which is a nonprofit endeavor to use the stories of people infected with HIV/AIDS to raise awareness, reduce stigma, promote prevention, encourage testing, and enhance care. The organization's website, ThePositiveProject.org, hosts the largest collection of HIV+ video testimonials in the world and represents digital storytelling from people of all walks of life. As of yet, no such project has been attempted to reach out to the lesbian community regarding health issues. However, digital storytelling is an innovative, participatory

public health intervention within the lesbian population that is relevant to the community's tradition of cultural identity development through storytelling and performance. There is a need for further investigation into the implications of digital storytelling on lesbian health, particularly projects that examine the attitudes of lesbians regarding testimonial and narrative health promotion and also the efficacy of such works to enhance the health and wellness of lesbians. Furthermore, digital storytelling, which encompasses a wide array of digital narrative strategies, has great potential for increasing digital literacy and closing the digital divide among lesbians by involving community members in the production of digital testimonial videos.

In tandem with the benefits of rapidly developing communication technology, there are also a host of challenges for the public and also health professionals. A major challenge is that it is virtually impossible to keep up with the constant infiltration of research findings that are published, disseminated, and reported online. The creation and availability of new health information and services is ahead of the means for the public to make use of that knowledge. While the science of informatics can assist in the presentation of health information online, the translation of that knowledge in terms of the significance and reliability for different communities is lacking. As there is greater access to portals, reviews, and authoritative advice, decision makers will need assistance in translating this knowledge to help them make the most appropriate health decisions. Another challenge is the appropriate implementation and equitable distribution of these technologies, which is crucial in order to achieve widely pervasive health outcomes. Not only must the needs of the people making the health decisions be taken into consideration, but products of technology must also be available in forms that are

congruent with these needs in order to achieve the best results possible. Different formats and points of entry may be suitable for different populations, including websites, email, text messaging, podcasts, streaming video, and social networking. The development of innovative tools in partnership with health consumers may be necessary if tools already in existence cannot meet certain health needs. Certainly, communities can be empowered when their needs are linked to the appropriate tools or they are enabled to participate in the development of new tools.

Other challenges related to e-health communication include the digital divide or the gap between health consumers with effective access to digital technology and those with limited or no access at all, competing health messages online, and forces beyond technology that influence health. The digital divide encompasses both the imbalance in physical access to technology, such as computers, PDAs, cellular phones, and the Internet, and also digital literacy, including the resources and skills to participate in e-health communication. However, telemedicine has made great advances in addressing the digital divide, including the ability to instantaneously and remotely notify authorities in rural areas of outbreaks, leveraging social networks for support or aid in health promotion, and electronically securing advice and support in ways that are complementary to personal contact. Another challenge to the effectiveness of digitally mediated health communication is the negative influence of new media, which has the potential to diffuse health promotion campaigns and encourage unhealthy decisions, such as tobacco use, unhealthy diets, risky sexual behavior, and excessive alcohol consumption. Finally, health is influenced not only by the personal decisions that people make, but also, by external factors, including the environment, society, the dominant

culture, and social interactions. Therefore, there are significant limitations to how far cyber strategies can go to improve public health. Nevertheless, new media health communication efforts can be fortified by the social sciences in order to understand how public health efforts can be most effective in crafting messages that support healthy behaviors. Despite the significant challenges presented by digital health communication opportunities, wireless technology and the Internet have great utility for informing and serving populations, including the lesbian community, where there is limited access to professionals and other resources. (Parker & Thorson 2008)

Even while most cyber-health theories and strategies do not directly address the lesbian community, they do take into consideration similar issues concerning healthcare disparities, communication barriers, and the overall impact that new media have on the larger healthcare system, including providers, insurance companies, and healthcare policies. They also suggest the development and promotion of new media solutions, which can be tailored to meet the needs of the lesbian community. While little has been done in the way of implementing digital interventions in the lesbian community to promote healthy behavior changes or facilitate access to health information, studies conducted with different populations provide examples of cyber strategies that can be emulated. At the heart of health promotion is communication and the underlying assumption that people will respond to improved access to health information in order to make better-informed decisions regarding their health. Access to health information is not limited to clinics and hospitals and by increasing availability of health information online, rapid advances in communication technology have the potential to significantly enhance the practice of health care, address inequities in people's access to health

information and services, and empower individuals and communities to take charge of their health and wellbeing. Greater equity and increased opportunities to access information, advice, and support through electronic means can lead to high-quality care and improved public health.

Conclusion

As a minority population, the lesbian community has faced healthcare disparities, such as difficulty accessing healthcare and a lack of culturally competent providers, which have not been addressed comprehensively in either health studies or public health communication campaigns. Nevertheless, the changing face of the mediascape, as it integrates digital technologies and becomes more user-generated and participatory, offers new opportunities for the lesbian community to seek out health information and for information on lesbian health to be accessed by healthcare providers. While recent studies have attempted to measure the effectiveness of digital technologies in supporting the public's access to healthcare information, no such study has been directed specifically toward the lesbian community. In order for these new avenues to be most effective, more research is needed, not only on current applications of digital technology for population-specific health communication, but also, on the healthcare needs relevant to the lesbian community. A study situated at the intersections of lesbian and queer identity politics, public health, and new media is necessary in order to fully grasp the implications of this technocultural phenomenon. This information will benefit the lesbian community, their providers, and researchers wishing to understand the best methods for communicating health topics to minority populations. New media strategies for promoting lesbian health

can be informed by various schools of thought, including cyberfeminism, queer theory, women's studies, public health, alternative health, and new media studies. The convergence of these fields will inform both research and practice related to lesbian health.

Advances in technology can empower individuals in their interactions with the healthcare system and enable health professionals to better meet the needs of their clients. This is significant for lesbian health because the implementation of new health information technology can facilitate the development of communication tools that meet the health needs of lesbians and facilitate communication among providers about SMW health issues. "Digital medicine" is an extremely new phenomenon that has begun to change the face of healthcare service delivery and health information. The new media landscape is merging with health communication in a way that is remaking healthcare and reinventing health narratives in the U.S. and around the world. Further research is needed to understand the potential and also the limitations of digital media to enhance healthcare. The lesbian community must explore the political, social, and ethical factors, and also the racial, ethnic, and economic disparities presented by online healthcare. The community must address important issues related to e-health, including accessibility for disabled and low-income women, limitations to technology utilization on public, private, and non-profit websites, health literacy, language barriers, sponsorship, conflicts of interest, and distrust of information online. The relationship between e-health utilization and attitudes about healthcare within the lesbian community should be a top priority in lesbian health research.

CHAPTER SIX: RESEARCH METHODS

Study Overview

The intent of this study was to assess the health status of adult SMW living in the U.S. and also their patterns of accessing health information, health services and different forms of digital technology. It investigated both individual and group characteristics and behaviors, including perceptions, identity, motivation, beliefs, and practices. The relationship between health risk, current preventive health behaviors, and minority sexual identity was assessed in order to develop a health intervention that accurately targets and supports the lesbian community in Colorado. Subjects were recruited on Facebook and other online social networks to take a Web-based survey on their health, wellness, and access to healthcare and technology. This study sought to identify health and wellness trends, particularly preventive health care behaviors, among self-identified lesbians, bisexual women, and transgendered individuals. The self-report surveys were administered online using an anonymous survey tool at SurveyMonkey.com. The survey questions addressed physical health, mental and emotional health, sexual orientation, gender identity, preventive health, and experiences, attitudes, behaviors, and beliefs in regard to healthcare, technology, and new media. The anonymous survey data were used to formulate a descriptive and qualitative analysis of emerging health patterns among the lesbian community and also to assess the community's use of health-related new media. The surveys were then used to inform the development of a health communication campaign, Our Health Matters. The campaign is intended to benefit a wide range of

SMW, both in Colorado and in other U.S. states, but is geared specifically toward self-identified lesbian women in Colorado. The main component of the Our Health Matters campaign is the website, OurHealthMatters.us, which will serve as a hyperlocal portal of health information, education, resources, and social networking for lesbians in Colorado. This health intervention may serve as a model upon which a more broadly disseminated campaign or other local campaigns can be modeled.

Research Questions

The primary objective of this research project was to investigate the current healthcare status and needs of the lesbian and other SMW population in the U.S. in order to develop new media strategies that will engage this community at the local level, provide education and resources, and ultimately, build a healthier community. In order to achieve this goal, the study sought answers to the following questions: *How can new media and online communication technologies best be leveraged to meet the healthcare needs of the lesbian community in Colorado? How can comprehensive online information services empower lesbian individuals to make healthy lifestyle choices, such as accessing healthcare or taking preventive or self-care measures? In what ways are the needs of the lesbian community going unmet and what are the contributing factors? How can new media strategies support grassroots engagement to promote policy advocacy and build social environments that are supportive of lesbian health issues? How can health communication work to rearticulate lesbian identities in new, culturally relevant spaces online?*

Survey Sampling Considerations

When weighing the methodological options for this research, it was important to take into consideration the importance of sampling in health research among SMW, particularly since past biased samples have been detrimental to the wellbeing of the LGBT community. For example, the medical profession initially came to consider homosexuality a mental disorder based on “evidence” from biased survey sampling of gay inmates in mental hospitals and prisons. Another example of bias in research is the recruitment of gays and lesbians from bars for studies of alcohol abuse, which could be purposive for understanding the subgroup of gays and lesbians at high risk for substance abuse, but cannot determine the prevalence of substance abuse in the general population of gays and lesbians. Just as poor sampling can create significant problems for the health of lesbian community, so too can sound sampling design can be advantageous to the community by furthering the health and civil rights of lesbians. For example, it was an experiment with a non-probability sample that first successfully challenged the medical model of homosexuality as psychopathology. (Meyer & Northridge 2007) While only probability sampling allows for making generalizations from the sample to the broader population, there have been numerous other important experimental, non-probability study designs used to study the LGBT community. Non-probability sampling is often preferred due to the challenges of identifying difficult-to-reach populations and also the high cost of probability designs and is appropriate for drawing a specific sample appropriate to the research question. (Meyer & Northridge 2007) At the same time, probability sampling of the lesbian population can serve public health by providing statistically defensible information to have a general understanding of the health

behaviors and needs of lesbians. Including questions about sexual orientation and gender identity in national health-related population studies, such as the National Health Interview Survey, is a priority for lesbian health. Taking these insights into consideration, this study opted for an approach that employed non-probability, convenience sampling.

It is important to examine the complex relationship between sexual identity and preventive health behaviors and the underlying mechanisms that guide this relationship. Ignoring self-reported sexual orientation reduces a valid identity tied intimately to community, networks, and relationships, to a function of sexual behavior. It has been the lack of differentiation between lesbian, bisexual, and heterosexual women in health studies that has resulted in inconclusive reporting. Furthermore, studies have not used terminology that is sensitive to the particularities of the LGBT community, especially its younger generations. For example, self-identifiers such as “queer” and even “gay” for sexual minority women are prevalent in the lesbian community, but have not been used as part of research questions in lesbian health research. For these reasons, subjects in this study were given the option to identify as either *lesbian*, *gay*, *bisexual*, *queer*, *straight*, or *other* with a specification required.

Research Methods

This study used a mixed method approach, applying purposive, snowball, and convenience sampling procedures to ensure a large and diverse sample from which to identify important issues of lesbian health and technology. This non-probability sampling method facilitated research of individuals from the SMW population in the U.S.

that have access to digital technology. Lesbians and other sexual minority women were recruited online, which meant all subjects had access to a computer and the Internet. As the purpose of the study was to reach as many individuals as possible, snowball sampling was selected as a variation in lieu of other systematic inclusion and exclusion criteria, such as quota sampling. This way, participants were able to refer others they knew to the study and more subjects were recruited. This study was purposive in that it intentionally recruited sexual minority women online in order to assess quantifiable measurements related to health status and access to health care and technology. Additionally, qualitative, interview or open comment questions were included in the survey in order to explore the depth and richness of experience within this population in a way that simple quantitative survey questions could not. This allowed further development of the variables identified in the quantifiable survey questions. Selecting particular cases of the targeted population based on answers to the open comment questions facilitated a deeper understanding of issues of central importance to lesbian health.

To a certain extent, the web-based surveys depended on respondent-driven or networked “link-tracing” sampling, in which links or connections between subjects were used to obtain the sample. Generally, this design is used as a method of sampling hidden or difficult-to-reach populations and is often used to make estimates about the social network connecting the population. This study used respondent-driven sampling in that respondents were selected from the social network of existing members of the sample. While the original respondents or “seeds” were recruited with advertisements online, other respondents were recruited using a chain-referral procedure from the seeds on Facebook, Twitter, and email distribution lists.

Study Design

The web-based surveys were created using Survey Monkey's design software and were conducted confidentially online and at a subdomain of SurveyMonkey.com. The surveys consisted of 40 multiple-choice and open comment questions, which were divided into four categories: *Demographic Information*, *Identity and Wellbeing*, *Health and Wellness*, and *Health Information and Technology*. The first page of the survey was an informed consent form detailing the purpose of the study, the risks and benefits involved with participation, and a consent statement that verified participants understood the information and were at least 18 years old. Only adults were recruited so that parental permission did not have to be obtained and also because it was assumed that adults would have more experience with the healthcare system. By clicking the "Continue" button participants consented to participate in the study and were also directed to the first section of the survey, *Demographic Information*. The questions in this section asked the subjects' biological sex, gender identification, sexual orientation, age, ethnicity, relationship status, education, income, place of residence, and method for accessing the survey. The *Identity and Wellbeing* questions asked about how open or "out" the subjects were about their sexual identity in different contexts and the impact their identity has had on their wellbeing. The *Health and Wellness* questions asked about the subject's physical, mental, and emotional health. Finally, *The Health Information and Technology* questions asked about decisions subjects have made that affect their health, such as receiving different types of care, finding health information, and using technology.

The survey was designed in such a way that allowed subjects to determine their level of anonymity and degree of participation with different elements of the study. The informed consent page assured that any potentially identifying information would be kept confidential and that the study was completely voluntary. Since the study was voluntary, it was necessary to make every question on the survey voluntary, as well. In other words, for each question, participants were given multiple-choice options for their answers and also an option of not answering the question. Therefore, in the data analysis that follows, the term “respondents” refers to those participants that elected to answer a particular question and not the entire sample. The participants were also encouraged to share information above and beyond what was afforded by selecting a simple multiple-choice answer. There were comment boxes after many of the multiple-choice questions in which participants were invited to share their thoughts on the topic with prompts, such as: *If you'd like, please comment briefly on the circumstances and how the incident(s) affected your life.* Additionally, each section of the survey had a subheading that described the nature of the questions of that section and also included the text: *Please add any additional comments in the blank boxes. Your opinion matters!* The final page of the survey gave participants the option of either entering their email address in order to enter a \$100 Spa Finder drawing or opting out. By clicking the “Enter” button on the final page, participants submitted their completed surveys. They were also directed to OurHealthMatters.us, which was under construction during the study, but still provided resources, including LGBT-friendly health websites, including that of the Lesbian Health and Research Center. Visiting the website also presented an opportunity to sign up for

the Our Health Matters newsletter, which will be electronically distributed on a monthly basis as part of the Our Health Matters health communication campaign.

Recruitment Efforts

The intent of the study was to recruit adult self-identified lesbian women and, to a smaller extent, self-identified bisexual women and transgendered individuals living in the U.S. Efforts were made to recruit as many subjects from Colorado as possible, as the primary objective of the health campaign is to serve the health needs of Coloradans. The study also attempted to target subjects from various socioeconomic and ethnic backgrounds. It attempted to reflect the ethnic diversity of the U.S. in general and Colorado specifically. Subjects initially learned about the survey via ads on the online social networking website Facebook. The ads targeted self-identified lesbians, bisexual women, and transgender individuals in Colorado and also nationally with criteria set using Facebook's filtration mechanism. One of the criteria was that the subjects either lived in Colorado or another U.S. state, as one ad targeted people in Colorado and one ad targeted people in the U.S. Additional criteria were that subjects were at least 18 years old, identified as female or transgender, and expressed an interest in the LGBT community on their profiles. Facebook requires that at least one profile interest is selected upon creation of an ad, so as many as possible relevant interests were selected, including LGBT, gay and lesbian rights, women's health, and so on. Subjects were directed to the survey via the Facebook ads, which were linked to the web page that displayed the informed consent form on SurveyMonkey.com. Participants were also

recruited by emails on LGBT listservs that were redistributed virally, posts of participants on Facebook and Twitter, and by word of mouth.

The duration of the study was two months, beginning August 1, 2010 when the surveys and ads went live and ending October 1st, 2010 when both were taken offline. The ads were given adjustments intermittently, such as updating images or wording, in order to continue to receive attention from Facebook users. Each participant was involved in the study for approximately 20 minutes, which was the estimated time it takes to complete the survey. While the subjects were not be compensated or paid for their participation, as an incentive to participate, they were given the option of entering a drawing to win \$100 from Spa Finder, a wellness oriented business that offers services such as massages, spa treatments, and health education. All subjects were enrolled in the study on a volunteer basis and the surveys were submitted confidentially online using Survey Monkey's anonymous survey tool. While there is an option on Survey Monkey to limit one survey per IP address, this function was not used, so as to maintain privacy and also to allow more than one subject to use the same computer. The demographic information that was collected was age, gender, sexual orientation, ethnicity, relationship status, income, education, and city. To ensure anonymous responses, the respondents' IP addresses were not stored in the survey results. Respondents became less anonymous if they elected to be enrolled in the drawing or sign up for the newsletter since email addresses were collected from these participants. For the drawing, one email address was selected randomly and sent an electronic gift card and all other email addresses were destroyed. The email addresses of participants that signed up for the monthly newsletter will be used by the web administrator strictly for electronically distributing the

newsletter. All survey data were stored on SurveyMonkey.com, a secure site that tracks subjects anonymously with unique identifiers.

Risks and Benefits

The first page of the survey consisted of an informed consent form that detailed the purpose, risks, and benefits of participating in the study. The subjects were at no more than minimal risk or not greater than those ordinarily encountered in daily life and all participants were willing to disclose their sexual orientation and gender identity confidentially online. The only information that could potentially identify the subjects was anonymous demographic information, and the chance that subjects could be identified by their demographic information was remote. No names were collected, which greatly minimized any potential negative social ramifications due to the disclosure of the subjects' sexual orientation or gender identity, such as homophobia, harassment, loss of employment or social standing, or hate crimes. This also greatly minimized any resulting negative psychological or emotional problems, such as depression, guilt, and fear. However, a potential risk to the subjects' psychological wellbeing was that answering the survey questions about identity, sexual orientation, discrimination, and prejudice could potentially conjure up negative emotions, such as a depressed or anxious mood. Since the end result of the study was to produce an online public health intervention for the subjects and similar populations, this provided psychological and emotional support. Subjects were informed of this project, as well as other local LGBT health resources upon completion of the survey.

There were many benefits the subjects could have gained from participating in this study, including health education and a sense of empowerment from helping to inform an online resource that will benefit their community. The subjects may also have experienced positive psychological and social effects as a result of being supported in an area of their lives where there was little or none before. Upon completion of the survey, subjects were given information about the health website to which they were contributing, as well as other online resources, such as LGBT-friendly mental and physical health websites and support forums. Finally, the subjects were offered an incentive for participating in the survey, which was an opportunity to enter a drawing to win \$100 from Spa Finder. This proved to be an effective motivator for participants and also increased the volume of respondents once it was advertised on Facebook. Initially, the ads did not advertise the drawing, but once it was, the number of impression and clicks on the ads increased dramatically.

Strengths and Limitations of the Study

Strengths of this study include the use of qualitative research components, purposive snowball sampling online, and the inclusion of a wide range of demographic questions. The open-ended questions engaged with participants to create innovative research strategies and share their experiences. They evoked shared knowledge on the topic of SMW health as participants provided significant resources in terms of insights, ideas, experience, theories, and research needs. The snowball sampling approach was another strength because it assisted with the recruitment of a larger study sample than would have been possible without this technique. By identifying subjects that met the

criteria for inclusion in the study and then having them recommend others that also meet the criteria, it is very likely that the study was able to generate a larger sample, including otherwise inaccessible or difficult to reach subjects. Another strength of the study is that it assessed a variety of factors that may play a role in the relationship between sexual identity and preventive health behaviors, including socioeconomic status, educational attainment, race, and ethnicity. Differences in socioeconomic status can influence preventive health behavior in terms of ability to access healthcare and educational attainment may determine the level of knowledge of the need for preventive health behaviors. Other factors, including access to healthcare, past experiences, and lifestyle components, including smoking, drinking, and physical activity, were assessed, as these factors may be related to the level of disclosure to healthcare providers and may influence a variety of preventive health behaviors.

There were some methodological limitations that prevented clearer conclusions about the relationships postulated in this study. For example, there were sample design limitations, particularly the significant limitations to generalizability from any convenience sample to the population of interest. This convenience sample included only a relatively small group of respondents with an already established presence online, which prevents generalization of the broader population of lesbian women. The sample is representative of the larger SMW population in limited ways necessary for research, but generalizations cannot be made about the larger SMW population. This lack of representativeness makes non-probability sampling significantly less useful when describing larger populations. Unfortunately, public health has already been underserved by the lack of statistically defensible information describing the health behaviors and

needs of the lesbian community. For this reason, it is particularly important to advocate publicly for the inclusion of questions about sexual orientation on large-scale public health and census surveys in the future.

Another limitation of this study is that since the participants opted into the study voluntarily, it is possible that they were somewhat more comfortable discussing and disclosing aspects of their health and sexuality than other segments of the SMW population. They were also already “out” about their sexual identity to a certain degree because they were all affiliated with a lesbian-focused social network or self-identified as a sexual minority online. Also, since the study was reliant on self-report health behaviors, it is possible that respondents may have provided more socially acceptable responses. The study may have also introduced a self-selection bias in that those who became aware of the survey either as part of the LGBT community online or via a LGBT email distribution list and then consented to participate in the survey may have been demographically or otherwise distinct from those who did not have a LGBT presence online or refused the survey. For example, the fact that the primary recruitment effort occurred on Facebook, a website that originally began as a collegiate networking site, could have presented a bias in terms of educational attainment of the subjects. Finally, the study was limited because the measures used were original measures that have not been previously validated in a SMW sample.

Due to the limitations of the sample, there were some inevitable ensuing biases, such as self-selection bias, which affected the study results.

Finally, there were strengths and limitations inherent in the use of Web-based surveys as the primary source material for this study. Web-based non-probability

sampling is a cost-effective and convenient mode for reaching a narrowly defined, special population. The approach defines the respondent population by virtue of web access and, additionally, the online social networking recruitment efforts attracts subjects that are affiliated with the SMW community, including expressed interest in SMW issues on Facebook, membership of a LGBT-focused listserv, and social connections with other self-identified sexual minorities. One benefit of web-based surveys is that they permit a level of administrative control, such as skip patterns, edit checks, and automated data analysis, which are not possible in non-computerized modes, such as conventional mail. There are also many possibilities for incorporating multimedia technologies into web surveys, which have gone largely unexplored in most survey research applications. The functionality of Survey Monkey permitted easy survey design and analysis. Rerouting subjects to the Our Health Matters website augmented the health communication intervention in that this connected subjects immediately to the health campaign and encouraged continued commitment and engagement by providing a Facebook “like” link and an option to sign up for the monthly newsletter. While web-based data collection is convenient and cheaper than other methods of survey sampling, such as mail or telephone surveys, it may not always be desirable to rely exclusively on web-based data. Unless the target group is limited to Internet users, there is potential for coverage bias in the sample. A more defensible approach would be to conduct a dual-frame design in which web-based data collection is used to gather data from web-accessible members of the target group, and another approach is used to reach others. This could be a good opportunity for respondent-driven or snowball sampling in which respondents that take the survey online are given the option of informing their social network of the surveys. They could

direct them to access the survey online or print copies of the survey for those that do not have access to the Internet.

CHAPTER SEVEN: STUDY FINDINGS

Participant Demographic Information

A total of 470 participants, including self-identified lesbians, bisexuals, and other sexual minorities answered questions on the survey and 427 participants (90.9%) completed the entire survey. The youngest and also the most frequent age cited by respondents was eighteen (10.9%) and the oldest respondent was seventy-two. The majority of the respondents were between eighteen and twenty-nine (61.48%), with approximately one-third (32%) identifying themselves as between thirty and forty-nine and the smallest age group represented being fifty and older (6.5%). The participant sample was dispersed geographically across the U.S. and surveys were submitted from 44 states, as well as Washington, D.C. and Canada. Many of the surveys came from Colorado (11%), California (10%), Texas (6%), Pennsylvania (5%), and Arizona (5%), representing approximately 37% of all respondents. Respondents were most frequently from Colorado, which is attributable to the advertising that targeted this population. Fifty participants were from Colorado with 35 living in the greater Denver and Boulder metropolitan areas, including Denver, Aurora, Littleton, Wheat Ridge, Thornton, Lafayette, and Boulder. Fifteen respondents reported living in smaller, rural and mountain towns across the state, including Fort Collins, Greeley, Loveland, Grand Junction, Durango, Fountain, Monument, Calhan, and Dillon. While Colorado's rural population constitutes only 13.7% of the general population, (USDA 2010) the rural residents in the Colorado sample constitute 30% of the total Colorado sample. These

urban and rural distributions signify a need to develop health interventions relevant to populations that are geographically dispersed across that state with special attention paid to rural residents with fewer local resources.

In terms of the race and ethnicity of the respondents, 83.9% identified as White, 10.5% identified as Black or African American, 9% identified as American Indian or Alaska Native, 7.9% identified as Hispanic or Latino, 1.1% identified as Asian, and 1.1% identified as Native Hawaiian or Other Pacific Islander. A small percentage (4.9%) of the subjects identified as “other” with a specification and while most racial and ethnic self-identifiers like *mixed*, *Multiracial/Creole*, and *everything* referred to a multiracial identity, others were more blatantly resistant to the idea of race or ethnicity as a classification with commentary like *I don't believe race is a real thing and human*. Since subjects were allowed to select more than one identifier, it is difficult to determine whether or not the sample is reflective of the general U.S. population. While the percentage of American Indians or Alaska Natives is higher than the general U.S. population, this may be a factor of participants selecting this option in addition to another race or ethnicity. The two largest minority groups, Black or African American and Hispanic or Latino, are the same in the general population as in the sample, although there are differences in proportion. In the sample from Colorado, 89.8% identified as White and 22% identified as Hispanic or Latino, which is proportionately reflective of the two largest racial groups in Colorado. Most minorities groups were also comparable to the general Colorado population in terms of proportion. However, there were no Black or African American respondents in Colorado despite the fact that this group constitutes 4.4% of the population in Colorado. (USDA 2010) These findings indicate a need for

further outreach to racial minority populations, especially Black or African American SMW, within the LGBTQ community.

In the total sample, 440 subjects identified as female, 20 as male, and 6 as “other” with a specification, including self-identifiers alluding to intersexuality, like *hermaphrodite* and *intersexed*, and transgenderism, like *transgender (female to male)* and *Not sure how to answer this, born male, had gender reassignment many years ago*. These unique self-identifiers point to the role that intersexuality and transgenderism play in lesbian and other sexual minority identity development. Some self-identifiers like *irrelevant* and *genderqueer* were defiant toward the notion of a dichotomous definition of biological sex and chose not to distinguish between biology and gender identity. Of the total 466 respondents that answered the sexual orientation question, 456 (97.9%) were sexual minorities. The majority of all respondents (53.8%) self-identified as lesbian or gay, as did the majority of both biological females (53.9%) and transgender females (66.7%). Of all participants, 45.9% identified as lesbian, 31.1% as bisexual, 7.9% as gay, 7.9% as queer, 2.1% as straight, and 4.9% chose unique sexual orientation identifiers. Of those respondents that selected a unique identifier, over 60% chose to identify as *pansexual*, which is characterized by romantic and sexual attraction toward people, regardless of their biological sex or gender identity. Other responses included *dyke*, *2 on the Kinsey scale*, and *homoflexible*, reflecting the humor and creativity that sexual minorities often apply to the serious issue of their sexual orientation. It is not clear why a very small percentage of respondents identifying as straight chose to take a survey targeted at the LGBT community, but based on qualitative responses that were given,

they appear to be LGBT advocates and may represent a valuable community of allies and may include transgender individuals that identify as straight.

In terms of gender identification, 416 of all participants that responded to the gender question and 95% of self-identified biological females identified as female. Twenty subjects identified as male, 4 as female-to-male transgender, 3 as male-to-female transgender, and 24 as “other” with a specification. Of the 24 subjects identifying their gender as either male or transgender (female-to-male), one-third were biological females. Of the 3 male-to-female transgender subjects, 100% identified as biologically male and also as either lesbian or bisexual. While these individuals are a small minority, constituting less than 1% of the total subject population, these responses indicate a need to be inclusive of transgender SMW women that are biologically male. The great majority of those choosing unique gender identifications opted for terms similar to genderqueer with responses like *queer*, *genderqueer*, *genderbender*, *gender fluid*, and *gender variant*, indicating a preference among sexual minorities to refute traditional notions of masculinity and femininity. Possessing a dual gender identity was apparent in some identifiers like *Androygne* and *male & female* and sometimes had a spiritual undertone in identifiers like *Two Spirit* and *male soul in female body*. Confusion and indecision surrounding gender identity was also evident in comments like *None really fit since I'm Hermaphrodite. Mostly male with female*, and *Androgynous - leaning more towards female, but I don't identify as female*. Overall, gender identification appears to be an empowering act among sexual minorities and was articulated quite literally through self-identifiers like *I am proud of being a woman, but I do not feel as though I am a man*

or a woman, and whatever I want to be! Even as this population resists classification to a large extent, self-identification is a powerful tool that is wielded with enthusiasm.

In general, participants were college educated, earned less than \$24,000 per year, and were in a committed relationship. Of the entire sample, 47.2% had graduated from college, 20.6% had attended graduate school, 15% had received some college education, 4.5% had graduated from high school or received a GED, and 2.4% reported another educational status, such as *Still in high school with plans to attend a 4 year college and graduate school* or *trade school and advanced ed.* Despite the significant educational achievements of the participants, the majority of them (59.9%) reported earning less than \$24,000 per year, 26.9% reported earning \$25,000 to \$49,999, 7.4% reported earning \$50,000 to \$74,999, and only 6.1% reported earning more than \$75,000. While it cannot be determined from the data, the discrepancy between high educational achievement and relatively low income level could be attributable to participants being enrolled in school and not working full time. These findings, however, support assertions that sexual minorities tend to be overeducated and underemployed. The fact that Facebook began as a social network among collegiate students may present another self-selection bias in that many of the respondents use Facebook in order to connect to college peers. It could not be determined if participants were from single income households or if they cohabitated. However, the majority of participants (50.8%) reported being either in a monogamous relationship, married, or partnered. Further research should be conducted to determine the rate of cohabitating sexual minority women and the affect on their overall health and wellbeing.

There was some variance in educational achievement, income level, and relationship status among sexual minority women by sexual orientation. For example, the majority of self-identified lesbians (50.7%) reported having attended some college, but not having received a degree, which is more the twice the rate of those having attended college and not having graduated in the total sample. Also, the majority of lesbians (56%) reported being either in a monogamous relationship, married, or partnered, which is a slightly higher rate than that of the total sample population. There was no significant difference between lesbians and the total sample in terms of income level, as 53.3% of lesbians reported earning less than \$24,000, which is only slightly less than the rate among the total sample. Among bisexual women, 44.4% reported attending some college, which is similar to the rate among lesbians. Unlike within the total sample or among lesbians, the rate of single bisexual women who were either never married or were divorced (39.3%) was almost equal to the rate of bisexual women that were either in a monogamous relationship, married, or partnered (40.7%). The greatest discrepancy among bisexual women was that 72.1% reported earning less than \$24,000, which is significantly higher than the rate among the total sample and among lesbians. Further studies should be conducted to determine the significance of the variances among lesbians and bisexual women in relationship to different social statuses, including education, employment, and relationship, particularly as they relate to overall health. Exploration of protective factors, particularly the high rate of lesbians being in a committed relationship and the overall high rate of educated sexual minority women, could potentially inform public health initiatives working to counteract risk factors among these populations.

Participants reported learning about the survey from Facebook ads, email, friends and colleagues, and other social networking methods, including links and posts of friends on Facebook and tweets on Twitter. In the total sample, the majority of participants (85.5%) reported learning about the survey from a Facebook ad, 10.9% from a friend or colleague, 2.6% from another social networking source, and 1.1% from an email. Interestingly, in the Colorado sample, only 68% of the participants reported learning about the survey from a Facebook ad, and 26%, nearly double the percentage of the total sample, from a friend or colleague, 4% from an alternate social networking source, and 2% from email. These findings indicate that Facebook ads are a successful method for recruiting research subjects and that they encourage participants to refer their friends on the same platform and also other social networking platforms. It is unclear why participants in Colorado had a greater rate of referrals from friends and colleagues and it cannot be determined if these referrals were in person and word of mouth or were indeed email or other social networking method referrals. It is evident that social networking was effective in distributing the message virally about taking the survey and generating snowball sampling to recruit a larger convenience sample. Community outreach strategies could be used in the future to further engage the community, particularly those members that do not participate on Facebook or other social networking websites, in order to encourage participation in online research. Distribution of brochures or fliers in LGBT venues, such as community centers and clubs, could potentially garner more attention from sexual minority women that are not as inclined to participate socially online.

Overall, the majority of the participants were young, white, lower-income sexual minority women that identified as lesbian or bisexual, tended to be in committed relationships, and were either in college or had already attained a college degree. This population represents a younger generation that could potentially influence the future health status of sexual minority women with the use of technology and social networking. Learning about the health behaviors of these women will be important in the planning and development of public health interventions targeted at sexual minority women in the future. It is clear from the prevalence of peer referrals in this study that the Web is a rich environment in which to generate discussion and recommendations about sexual minority health. While these women may be at a technological advantage compared to some of their peers and possibly older generations, they have the capacity to influence segments of their community that have little or no access to Web-based technology. They may also be positive role models for women that do have access to technology, but are questioning their sexual orientation or SMW that are not comfortable being out about their identity online. Innovative Web-based health interventions should be further developed with the use of different digital media to strategically target younger generations of sexual minority women because they will be future leaders in the community.

Identity and Wellbeing

The second portion of the survey was intended to assess for the ways in which a sexual minority identity influences different psychosocial aspects of an individual's wellbeing. Since self-acceptance and a social support system are crucial to the overall wellbeing of sexual minorities, subjects were asked how "out" or open they were about

their sexual orientation and gender identity to different people in their lives, including healthcare providers. The majority of sexual minorities were out to all the people in their lives, including friends, family, coworkers, acquaintances, and healthcare providers. The people to which respondents most frequently reported being out were friends (97.9%), followed by Facebook and other online friends (89.4%), family (84.8%), and coworkers or classmates (77.9%), indicating that the sample had a strong overall support system that was accepting of their identities. Participants less frequently reported being out to people with whom they were not very familiar, including strangers in public (57.5%) and acquaintances at bars and clubs (57%). The majority of participants were out to both their physical and mental healthcare providers, including their doctors or primary care providers (61.4%) and their therapists or counselors (50.1%). Only 24.8% of respondents reported being out to alternative medicine practitioners (24.8%). This may be due to the fact that the participants do not access this type of care very frequently, especially since they are out to most people in their lives. Fifty respondents or 11.5% of sexual minorities reported being out in different contexts and provided additional commentary, suggesting many of them were out to everyone. Some comments illustrated unique experiences related to coming or being out in different work settings, such as schools -- *I am a teacher and am out to my students* – churches -- *I am also out to people at my church* – the military -- *I'm following the 'don't ask don't tell policy* – and hospitals – *supervised a medical student just so I could see if he asked (sexual orientation) and then corrected him and told him to teach his classmates*. The Internet has special significance for the ways sexual minorities negotiate their “outness,” as was addressed by comments like *I blog about gender, sexuality, and relationship stuff, so complete strangers all over know*.

The participants were asked what types of discrimination and homophobia they have faced due to being out about their sexual orientation or gender identity. Most frequently, respondents reported having experienced verbal abuse (62%) and loss of friends (54.1%). Participants frequently reported coming out during high school when they first became aware of their sexual orientation and often experienced difficulties coming to terms not only with their sexual identity, but other aspects, including religion and ethnicity, as evident in this comment:

I've been spit at and called names. All of that's stopped since graduating high school, and college is a lot more open. But every time the right wing uber Christians come to campus and say that all of the fags and Jews are going to hell, I end up full of self-hatred and doubt.

Even though the majority of participants reported being out online, some reported gay bashing and slurs online with comments like:

I've gotten comments online but just from homophobes I didn't know... I've been called a fat lezzi online. It made me cry.

Other common experiences of discrimination included disownment or rejection by family members (35.7%), loss of social standing or reputation (26.6%), and job discrimination or loss of employment (21%). Being rejected by family members was prevalent among the participants, as reflected in comments such as this one:

When I was 20 and came out to my mother, she kicked me out of her house and I had to live in homeless shelters for a while until I could get on my feet and get my own apartment. Thankfully, over the past few years after having a long talk with her, she has come around and is a lot more accepting of me.

Nearly one-fourth of respondents (23.5%) reported self-hatred or internalized homophobia, which indicates a considerable need to address self-esteem and self-acceptance among sexual minority women, even when they have social support systems. In addition to facing barriers, respondents also indicated that sometimes it was necessary

to remain closeted to benefit their wellbeing, which can potentially perpetuate feelings of internalized homophobia. For example, one respondent reported:

I was denied health insurance by a few places in Kansas. I'm going to have to NOT give out my preferred gender status to get health insurance.

Sometimes, a sexual minority woman's job can force her or her partner to remain in the closet, and reinforce negative feelings she has about her identity, as reported by another respondent:

The "Don't Ask Don't Tell" act that forces my current partner to being "straight." Because of that, she has to hide an entire half of her life.

While experiencing physical violence as a result of their identity was not as common among participants, more than one-sixth (14.7%) reported having experienced some form of physical abuse or hate crime, particularly when they were younger, and some incidents were extremely violent. One respondent reported:

When I was in high school, I was a victim of gay bashing. I was stereotyped by people full of hate. I was beaten and had a knife to my throat. I'm lucky to be alive this day. I still have flashbacks of this. It has to stop!!!!!!

Homophobia was found to negatively impact the physical and emotional wellbeing and safety of some respondents, such as this one:

I was tortured and abused in school for being a lesbian and was also called a slut regularly because of my love for other women. I was hit and kicked frequently, because they didn't want to be associated with a "dyke". It's funny, because I am rather feminine.

A portion of respondents reported discrimination within the healthcare system and at work in ways that affect health, including being denied health insurance for them or their partner (13.3%), being denied other work benefits (8.2%), and being denied

visitation rights in the hospital (6.5%). Some respondents addressed these barriers, describing experiences of being denied coverage:

I have been unable to get health insurance for years due to my low income and preexisting mental health conditions, and my partner's company not having partner insurance.

Other respondents reported being denied visitation rights:

Dealt with my partner not being allowed in with me when at the emergency room at Denver Health, despite being together legally, and having our partnership documented with doctor. This happened twice before I dealt with it.

Participants also reported instances of discrimination in their general experiences with the healthcare system, even when they worked within it. One respondent working within the healthcare system experienced job discrimination:

After coming out, my current funding was ending and I was told there weren't any more jobs that I qualified for in my department. Shortly after I left, they hired someone to do EXACTLY what I had been doing. Luckily, I was able to get another job- in a different department of the hospital. I was shocked and appalled that in a HOSPITAL - where care is provided to ALL walks of life, I would be discriminated against.

Another respondent was denied visitation rights at the hospital where she worked as a nurse:

A MD who I worked with daily told me I did not have to visit my partner while she was in hospital for uterine cancer. Admissions refused to put me as next of kin or take info from me. I would not have been allowed to visit at all if I had not worn my scrubs and hospital ID tag when I came before and after shifts (outside of visiting hours) under the doctor's radar.

Despite experiences of discrimination and challenges navigating the healthcare system, this group of sexual minority women indicated that it is important to overcome barriers such as homophobia, discrimination, and systemic inequities in order to receive quality healthcare. The survey asked about the importance of being out to healthcare providers and also about how comfortable the participants were about being out about

their sexual orientation and sexual identity to healthcare providers. The vast majority of participants (88%) indicated that they thought it was important for LGBT people to be out to their doctors, primary care providers, and other medical providers. A large majority (80.3%) also indicated that they felt comfortable discussing their sexual orientation and gender identity with these same healthcare providers. An even greater percentage of participants (95%) indicated that they thought it was important to be out to their therapists, counselors, and other mental health providers and 92.2% indicated that they would feel comfortable discussing their sexual orientation and gender identity with these same mental health professionals.

When asked if they thought it was important for LGBT people to be out to their doctors, primary care providers, and other medical providers, many respondents saw the benefit of being out, but also felt ambivalent about their own comfort level due to a fear of discrimination, as expressed in comments such as these:

I'm undecided. On one hand, yes, because there should be information provided specific to the GLBT community regarding safe sex and other health issues... but I think it is risky. Discrimination in healthcare based on a provider's "values" is a really scary thought.

Yes, because it affects our access to healthcare. BUT...I have found that healthcare is very heterosexist. I have a very hard time coming out to my doctors, especially my OBGYN.

Perhaps not surprisingly, 95.7% of respondents reported feeling comfortable discussing their sexual orientation and gender identity with family, friends, and acquaintances to whom they were out. Interestingly, they also indicated that they felt comfortable discussing various health and wellness issues with these same people, including physical health (92%), behavioral health like exercise, diet, sex life, drinking, and smoking (82.9%), and mental health (81.5%). These rates were only slightly lower

than the rates of respondents indicating that they felt comfortable discussing with doctors, primary care providers, and other medical providers the same issues: physical health (97.3%), behavioral health (87%), and mental health (85.6%). These findings suggest that when discussing health issues, speaking to someone to whom they are out is important for sexual minorities in terms of feeling comfortable.

Participants were also asked about barriers to healthcare that they have experienced, including health insurance coverage. The majority of respondents (73.3%) reported having some form of health insurance, including private insurance from an employer (36.9%), public health insurance like Medicaid or Medicare (15.8%), an individual policy (10%), or some other form of coverage (10.6%), including coverage from Tricare, the Veteran's Administration, a parent's insurance plan, and the Indian Health Services. One respondent reported: *I never had it until my partner got a new job that allows same sex insurance.* More than one-fourth of respondents reported both that they did not have any health insurance coverage (26.7%) and also that lack of health insurance prevented them from receiving the best care possible (28.9%). A large proportion of the respondents reported one or more barriers to receiving the best care possible, including lack of a LGBT-friendly or culturally competent healthcare provider (26.3%), mental health issues like depression and anxiety or substance abuse problems (20%), not knowing what questions to ask providers (15.6%), fear of discrimination (14.1%), not being satisfied with their current care (13.9%), not receiving holistic healthcare (13.2%), and not knowing where to receive care (12%). The main barriers that participants commented on were the cost of healthcare services and also the lack of cultural competency among healthcare providers, as illustrated by this comment:

Number one is being poor and general lack of universal health care in U.S. Even with that, though, culturally incompetent health care providers make every visit a struggle: it should be a routine part of medical education.

Work environments that are not accepting of homosexuality, including the military, which employed a large proportion of the respondents, present unique challenges to receiving different types of health services:

Being out precludes obtaining mental health services and any sort of substance abuse (services.) I could see this being a problem for many.

In response to the barriers to receiving quality healthcare, some respondents shared the ways in which they have adapted to challenges to health and wellbeing couple, including a lack of healthcare services:

I am my best care provider. I use only affordable methods that focus on healing and prevention and not disease and illness.

It was clear from both the data and the commentary of some respondents that discrimination affected the wellbeing of participants on many different levels and often in complex ways. It was sometimes detrimental to their mental health, finances, and family, as illustrated in one comment:

My children were removed from my custody because I was honest about my sexuality. I spent a great deal of time and money in the legal system to maintain a very basic level of contact and visitation with my children. I would not wish such an experience on anyone. I ended up in Bankruptcy Chapter 7 as a result of the financial drain. My children bore the most harm from this though.

The participants reported a wide range of both subtle and overt discrimination that impacted their wellbeing, and they were often unclear about the exact ramifications of those experiences:

It's impossible to calculate. Lost career opportunities, lost friends, physical violence, emotional/psychological violence. It's been a challenge.

While there was a sense that participants were often overwhelmed by the experiences of being a sexual minority, there was also an undercurrent of pride and optimism and a desire to take good care of themselves:

It's impossible to know the full extent of how homophobia has shaped my life. It seems to me though that the more I keep my chin up and respect myself, the more respect I command from others.

Health and Wellness

Findings from this study suggest that discrimination has directly affected the wellbeing of sexual minority respondents. The current health and wellness status of the SMW sample was explored in more depth in the third portion of the survey, which asked specific questions about these topics. In general, the participants reported overall good health, involvement in preventive health measures, an interest in maintaining a healthy lifestyle, and a relatively high degree of life enjoyment, particularly in terms of being open and connected and feeling compassion for others. The majority of respondents rated their overall health as good (59%) and nearly a one-fourth of respondents (24.2%) rated their health as fair. A small portion (11.3%) rated their health as excellent, but an even small portion (5.5%) rated their health as poor. Participants were asked which of any of a host of physical, mental, and emotional complaints they experience on a regular basis. The most frequent physical complaint among participants was fatigue or low energy (71.7%), which was followed by tension or stiffness (65.9%). The most frequent mental and emotional complaint was depression or lack of interest (59.2%), which was followed by sleep disorders (65.9%), including difficulties falling or staying asleep.

The participants were asked to select from a list of activities which self-care and preventive health measures they take. The majority of participants reported keeping a

healthy diet and (58.7%) and staying physically active (53.4%). However, the most frequently reported self-care and preventive health measures were abstaining from alcohol or drinking in moderation (77.4%) and abstaining from smoking (63.9%). Many of the comments related to self-care and preventive health measures indicated a strong belief in the efficacy of alternative health practices, including yoga, reiki, massage, herbal supplements, energy work, and acupuncture. Other popular self-care and preventive health measures included taking vitamins and nutritional supplements regularly, accessing mental health services, including attending therapy sessions and taking medications, and finding solace in spirituality and religion.

Interestingly, while abstaining from alcohol or drinking in moderation was the number one self-care measure, the majority of participants (52.1%) also reported drinking more than three alcoholic drinks in one day in the past three months, which is above the moderate daily drinking guidelines for healthy women. (WHO 2010) This indicates that sexual minority women perceive to be drinking moderately even when they are not, and that the population could possibly benefit from health education surrounding moderate drinking guidelines. Nevertheless, when asked how many alcoholic drinks they have per week, respondents most frequently responded none (47.9%), followed closely by one to seven drinks (45.9%), which is within the moderate weekly drinking guidelines for healthy women. (WHO 2010) This may indicate that while sexual minority women may be at risk of binge drinking, their frequency of doing so is minimal. Only a small percentage of respondents (6.2%) reported having more than seven alcoholic drinks per week. In terms of tobacco and drug use, more than one-third of respondents (34.8%) identified themselves as current tobacco users and also more than one-third of

respondents (35.1%) reported current non-medical use of drugs, including marijuana, cocaine, and ecstasy. These findings indicate that the rate of alcohol, tobacco, and drug use is relatively high within this population and that health interventions targeting sexual minority women should address the health risks of substance abuse.

Since studies have indicated that stress due to sexual minority identification is a major factor in health problems for sexual minority women, the survey assessed for the presence of stress in the lives of subjects. When asked which aspects of their lives were stressful for them on a regular basis, the majority of respondents cited finances (69.4%) and family (53.8%). Life aspects that were stressful for a considerable portion of the respondents were work (46.2%), school (42.8%), their emotional well-being (41.1%), their health (37.3%), their significant relationship (34.4%), and coping with daily problems (31.8%). It cannot be determined from these data whether a sexual minority identity aggravates these different stressors, as they are common to the general population. However, given that many respondents reported experiencing stress on a regular basis due to numerous life factors, stress management and stress reduction strategies should be a critical component of any health education campaign or health intervention targeting this population.

Access to Health Information, Services, and Technology

In general, participants indicated a relatively high frequency of accessing healthcare with the majority accessing routine health care and more than a third accessing mental health and alternative health services. Participants reported receiving routine checkups from a medical doctor with the majority of respondents (58.6%) having

received one within the past year. Just over one-fifth of respondents (22.1%) reported receiving a routine checkup more than two years ago, 16.9% reported receiving one within one to two years ago, and very small percentage (2.4%) reported having never received a routine checkup. More than one-third of respondents (35%) reported accessing mental health care services within the past year and also indicated positive outcomes from these services with 42.9% reporting being either satisfied or extremely satisfied. More than one-third of respondents (37.1%) also reported having used alternative health services, such as acupuncture, chiropractic, massage therapy, and naturopathy, within the past year. They also reported positive outcomes from these alternative health therapies with 43.9% indicating they were either satisfied or extremely satisfied with the results of these services. These findings suggest that SMW with access to technology have a significant need for healthcare services and also indicate that this population is frequently accessing care.

In addition to reporting overall satisfaction with mental health and alternative health services, the majority of respondents (59%) reported feeling either satisfied or extremely satisfied with their experiences with their primary care providers. However, there were a variety of responses indicating mixed feelings about their experiences with medical providers. Many participants reported negative experiences with their primary care providers that may prevent them from seeking care in the future:

Automatically gendered my partner as "he" without asking. That kind of default thinking made me think twice about explaining the complexities of gender as I relate to it / my partners in the future and ultimately prompted my move.

I dislike doctors anyway; this one was (mildly, but annoyingly) incompetent. I will be looking for a midwife or nurse practitioner next time I want to receive healthcare.

Doctors these days tend to blame all issues on either weight or mental health without positive reinforcement for whatever gains you have been able to make.

I felt judged at my last physical because I hadn't been there in so long. It's hard to find a new doctor that you can feel comfortable with and trust.

Other participants reported more positive experiences with healthcare settings and primary care providers that were tolerant, accepting, or affirming:

Had to get a physical for nursing school. First time at the campus clinic. Not a perfect experience, but not the worst I've ever had. Some forms included a transgender option, which was nice to see, but no other visible signs of it being a welcoming place for LGBTQ folks.

My doctor has been my doctor since I was 12, and though she's never outted herself, she is very involved with outted homosexuals so at the very least, she's tolerant.

She's queer-friendly and practices preventative care. She's amazing.

A relatively large portion of respondents that commented on their experiences related that they preferred Eastern medicine or other alternative health services:

My first experience with a Western medicine doctor involved my partner not being allowed to accompany me in my first hospital experience. :(

I hate Western medicine. Unless I have a broken bone or need my appendix out-allopathic doctors largely cause more harm than good.

They did not diagnose the problem correctly...had to get alternative health care to get it right...

In general, participants indicated that they have access to digital technology and that they receive their health information both online and from healthcare providers.

When asked which communication tools they use, the most frequent response was Facebook or some other social networking website (99.1%). An overwhelming majority (96%) reported having access to a personal computer and the Internet (95.3%).

Respondents also reported using phones for texting (89.5%), YouTube or other video

websites (49.6%), Skype or other video communication (28.3%), PDAs (27.9%), and blogs (27.4%). When asked where they receive their health information, the most frequent response was from doctors or other healthcare providers (77.6%). The majority of respondents also indicated that they receive health information from friends and family (66.2%) and on health websites (54.3%). Additionally, respondents reported receiving health information online on daily news websites (23.6%), other blogs and websites (17.1%), Facebook and other social networking websites (15.5%), and YouTube and other online videos (8.6%).

When asked which health and wellness topics the participants would like to know more about, the most popular response, cited by 61% of respondents, was sex and sexuality topics and the second most popular topic, cited by 54.5% of respondents, was diet and nutrition. Other popular topics were mental health (49%), exercise (47.1%), alternative health (40.1%) and, to a lesser extent, preventive health (34%), health reform and policy (34%), and social support (32.5%). The vast majority of participants (70%) indicated that they would be either extremely likely (37.7%) or very likely (32.3%) to use a health and wellness website that offers free health assessments and quizzes, health videos, social networking, and forums for lesbian, bisexual, and transgender locals. One-fourth of participants (25.1%) indicated they would be somewhat likely, and 4.9% indicated they would be not at all likely to use such a website.

The open-ended responses related to this question revealed many important implications for the development of a new media health intervention or communication campaign for this community. In general, respondents highlighted the need for the website to provide accurate, reliable information, consider the opinions of its users, and

be accessible to SMW of all walks of life. The majority of respondents had positive reactions to the idea of this website, while others expressed some skepticism, particularly in terms of the relationship between social networking and health:

Another social networking site? Give me a break. But a forum for sharing information would be awesome.

One respondent indicated that she wouldn't be likely to use such a website since she didn't see a correlation between sexual identity and health, and also, there are more professional and reliable sources available already:

I don't use forums/social networking for health information. When I do go online for information, I read professional articles. Additionally, my sexuality has nothing to do with either my physical or mental health for me, so I wouldn't see the point of using a site like described above.

Another respondent described a negative experience she had already had on an LGBT website dedicated to health:

There is a website called Gays.com I joined though stopped using. It was very lackluster after a few weeks. The same loud n proud people trying to TEACH others how to behave. Bored people sitting at home, a few with raging mental illnesses they were proud to share in graphic detail. It seemed like sitting on a bus with the random luck of the draw, not an educated and controlled flow of information.

This feedback indicates that a strong connection between health and community must be emphasized in any campaign seeking to effect change in the SMW's community. It also suggests that perhaps less energy should be devoted to developing another social networking website, and more to developing reliable resources, recruiting the input of health professionals, and designing well-researched health information. There was further evidence that if users trusted the information on the website and enjoyed visiting it, the social networking aspect would occur on its own:

I would blast it all over Facebook and include a link in my blog as well. Depending on how much I like it, I might include a link on my website too. We need more for our community... Especially that we can send uneducated medical people to.

It was clear that user-driven dissemination of health information and content development was of interest to many respondents:

Sounds good. Keep the lesbian/trans/genderqueer content steady and visible and in return you'll get my participation in the polls/blogs.

For some, the idea of such a website seemed like a valuable opportunity to generate dialogue surrounding wellness topics and make community connections, including friendships and romantic relationships. This seemed to be of particular interest to respondents with disabilities or living in rural areas and older respondents:

Disabled folk are at an extreme disadvantage, as are older women and people who do not drink. I have met women in bookstores, in a bar, introduced by friends. Now I've been alone for over a decade due to working nights and having cancer growing and now trying to recover-where do I go with a cane and my oxygen tank? Steps are out, standing is out, drinking is out, even NOW and Wiccan gatherings are not accessible due to steps or on street parking where I cannot safely unload and reload my scooter. I would love a partner or even a few dates.

Respondents also emphasized a desire to have access to a resource that addresses new and relevant health topics: *Yes, as long as it WASN'T just HIV/AIDS plus drugs and alcohol abuse.* Some comments emphasized that there should be education available on how to communicate with healthcare providers:

I answered yes, that I would feel comfortable discussing issues with my medical providers, but it depends on how comfortable they make you feel. I've been lucky for the most part. But, I've had many experiences where I would convey I'm a lesbian and the provider would gloss over it or invalidate it by offering condoms, for instance. It's all about how a provider acknowledges you and the things you say.

Respondents emphasized that the website should be inclusive of different segments of the community and that it would be valuable to have a safe space online to discuss health topics:

I think trans stuff needs to be fully integrated and not an after thought. Also needs to be equally welcoming and informative for both FTMs and MTFs.

It would be nice to have a forum where one wouldn't be worried about "offending" someone or fearing that some crazy person would begin to stalk/harass/berate you because of your sexual identity.

Overall, participants responded positively to the idea of a website that addressed their health concerns, and some expressed enthusiasm:

Think this is actually a great idea for a site - a 'queer' vantage point would eliminate some of the more self-loathing heterosexist messaging to women in health magazines -- and could be funnier, less frustrating, and more positive.

Discussion

This study provides evidence that it is essential to acknowledge differences in health behaviors related to women's sexual identities in order to bring to light the relationships among sexual behavior, sexual identity, and preventive health behaviors. It also demonstrates that it is imperative to consider other demographic factors, including age, ethnicity, location, ability, and SES, because they influence these relationships. This study began to shed light upon the extent to which a lesbian identity or other SMW identity influences preventive health behaviors through various mechanisms, including educational attainment, access to care, social support, community involvement, and relationships with healthcare providers. This research is strong evidence that there is a great need for more research on lesbian and SMW health research, including community-based studies that highlight local patterns and health needs and also large-scale

probability studies that identify a larger SMW population in the U.S. Findings from this study can be used to inform health communication campaigns and interventions directed at the community.

CHAPTER EIGHT: *OUR HEALTH MATTERS* CAMPAIGN

Target Audience and Behavior Change

The primary goal of the Our Health Matters campaign is to use Web-based technology to educate lesbians and SMW in Colorado about the importance of self-care and preventive care. The main component of the campaign is the website, which will serve to develop community, facilitate health information sharing, and encourage SMW to access healthcare. The primary desired health outcome of the campaign is for lesbians in Colorado to take on preventive health measures, including accessing preventive care, such as regular health screenings, including the Pap test, breast examinations, and other preventive health screenings. However, given the barriers to healthcare indicated in survey findings, such as fear of stigmatization by providers and lack of health insurance, Our Health Matters also seeks to empower SMW in Colorado to take their health matters into their own hands by developing healthy behaviors, becoming more aware of health risks, and cultivating a healthy social network. Rather than striving to achieve just one specific behavior change within the lesbian community in Colorado, the Our Health Matters website will provide general empowerment tools. These tools will include a guide on how to develop effective communication with health care providers, health assessments to encourage risk reduction and the adoption of healthy behaviors, including exercise, healthy diet, receiving routine health examinations, and opportunities to establish positive, health oriented social networks and activities within the community.

Use of Diffusion of Innovations Theory

Our Health Matters is a digitally-mediated health communication campaign that is informed by the Diffusion of Innovations (DOI) theory as it relates to public health. DOI is a process through which an innovation, such as a new preventive health measure, is communicated through certain channels over time among members of a social system. (Rogers 1994) This theory is helpful for understanding the ways in which the importance of preventive health behaviors, such as seeking routine physical exams or accessing health information online, can be communicated among SMW in Colorado. DOI characterizes health communication as the creation and sharing of innovative ideas or new health messages by members of a particular population in order to reach a mutual understanding. (Rogers 1994) In this way, health communication is participatory and user-driven. From a DOI perspective, the innovation of Our Health Matters is the idea and practice of digitally-mediated preventive healthcare among SMW. The communication channel, which includes the *hardware* and *software* employed, is also in and of itself innovative. In DOI theory, the hardware is the tool that embodies the innovation and the software is the knowledge base for the tool. In the Our Health Matters campaign, the hardware includes the computers and Internet connection used by the target audience and the software or knowledge base includes both the technical knowledge necessary to develop a digitally-mediated health intervention and also the knowledge of the health status and needs of the target population. While new technology and new health messages may raise doubt, the information contained in the software component serves to reduce the uncertainty associated with the cause-effect relationship involved in achieving a desired health outcome. (Rogers 1994) For example, reliable

health information and data presented on a health website about topics, such as the connection between a strong social network and reduced stress, serves to reduce doubt among participants regarding the efficacy of certain preventive health behaviors.

Due to the newness of the idea being communicated and the channel through which it is being communicated, participants are thought to have varying degrees of comfort with the health message and different rates of adopting the health behavior. Since uncertainty among participants in the process of adoption is a characteristic of diffusion, it is useful when planning a health communication campaign to understand the different speeds of adoption among portions of a social system as described by DOI theory. The timeline associated with DOI is influenced by the *innovation-decision process*, a chronological process in which individuals become aware of an innovation, form an attitude or opinion, and either adopt or reject the innovation. If individuals choose to adopt the innovation, there is also a process of implementation and confirmation, in which participants try the health behavior and then experience positive outcomes related to that behavior. DOI theory defines five different groups of adopters related to the rate of adoption: *innovators*, *early adopters*, *early majority*, *late majority*, and *laggards*. In the case of Our Health Matters, the participants in the formative study can be thought to be the innovators because they are some of the first SMW to use Web-based technology in the adoption of preventive health measures, particularly health information seeking behavior. Assuming that Our Health Matters can rely on these innovators to participate in the campaign long-term, they will facilitate diffusion to other segments of the community, attracting early adopters, an early majority, and so forth. In DOI theory, it has also been argued that social networks play a crucial role in the

diffusion of innovations and that the widespread adoption of computer networks has led to more effective diffusion of innovations. (Andrews 1984) Therefore, social networking online and in person will play a critical role in the innovation-decision process among SMW.

In order to determine the potential of the Our Health Matters campaign to effect change, it helpful to evaluate it in terms of different DOI characteristics that affect the rate of adoption: *relative advantage*, *compatibility*, *complexity*, *trialability*, and *observability*. These characteristics are thought to be positively related to acceptance and adoption of the innovation. (Rogers 1994) The relative advantage and compatibility are strengths of Our Health Matters that will accelerate acceptance. The relative advantage of the campaign is that it offers health information in an innovative fashion by making use of digital technology to disseminate relevant health messages quickly and efficiently and build community at a local level. The campaign is compatible with the innovators and other potential adopters because it is consistent with their values, including leading a healthy lifestyle and being well-informed, and also their experiences and habits, including making use of social networking to share their knowledge. The complexity of the campaign may slow acceptance because it may be difficult to understand and use, particularly because the idea of preventive health among SMW encompasses a wide-range of behaviors, instead of simply one concrete behavior. The complexity is further heightened due to the high-tech aspect of the campaign, which may hinder certain portions of the population from participating. However, the campaign has strong trialability, or the degree to which the innovation may be tried on a limited basis, particularly because the formative research served as a trial run. This small-scale testing

reduces the risk of participants rejecting the innovation since future campaign efforts will be informed by feedback from the study. The observability or the perceived degree to which the results of innovating are visible to others and is positively related to acceptance cannot yet be fully determined. The majority of survey respondents in the formative evaluation indicated that they would be likely to use a website geared toward SMW in order to access health information. They also reported a high degree of interest in adopting preventive health behaviors. However, the actual impact of such a website on the health behaviors of this population has not yet been evaluated.

In addition to the characteristics that affect rate of adoption, it is also important to consider how reinvention, the ways in which the users will change or modify the innovation, will affect the process of adoption and implementation. Users will be encouraged to contribute their voices, engage in dialogue, and inform the content and structure of the website, thereby making the Web-based campaign one that is participatory and user-driven. In this way, the users have the potential to change and modify the innovation in ways that cannot necessarily be anticipated. A rare but cogent example of diffusion and reinvention in a health communication campaign targeting SMW is the Atlanta Lesbian Health Initiative (ALHI), which has successfully disseminated its prevention message throughout its local community using Web-based technology. While its initial focus was breast cancer support, its purpose has expanded to include general health and prevention education. The ALHI website's interactive and social networking features have facilitated reinvention by encouraging input and feedback from users. Our Health Matters can learn from such a project in applying DOI concepts.

Our Health Matters Website and Health Messages

The primary health message of Our Health Matters is that SMW in Colorado should adopt a healthy lifestyle that includes taking preventive health measures and engaging with community members to reinforce those behaviors. Depending on the reasons users access the website, it may play a role in encouraging SMW to access health care. If SMW access the website when they are seeking health information on a specific health condition, it may encourage them to access healthcare. If that is not possible, the website can provide health information in a culturally relevant way and provide alternatives to traditional care. The content of the website will address pertinent health issues that were raised in the formative research, including strategies for communicating with healthcare providers, stress reduction solutions, education about moderate alcohol intake, resources on substance abuse treatment and smoking cessation, information on alternative health and self-care techniques, and community activities that are not centered on bar culture. The website will use the Drupal platform to support sustainable, user-friendly development and encourage community members to be involved with development with its accessible modules. The website will have different levels of administration privileges, including content editing privileges for those that are most committed to the cause and also general membership that will include access to special features, such as a community calendar and personal health profiles. Technical features of the website will include a health blog with a complementary monthly e-newsletter, interactive elements like health polls and assessments with instant feedback, social networking feeds, dynamic images and posts, and eventually, more dynamic features, including digital video testimonials. In order to sustain the campaign long-term,

community members committed to the cause will be recruited to help maintain the website and develop content. Health professionals in the community will also be recruited to offer their professional insights and possibly advertise their services.

Since community is a critical component of the campaign, the website will strive to be as inclusive as possible and, therefore, the language used will reflect this inclusiveness. For this reason, the title of the campaign reflects ownership and community, and does not exclude bisexual women or transgender individuals. In some ways, the website will serve as a virtual health oriented community for SMW in Colorado. The study's online surveys assessing issues of access to healthcare, overall health and wellbeing, and use of digital media tools began the dialogue with this community. Commentary from the study has been taken into consideration in developing content, particularly concerning the needs specific to this community and the ways in which they have been either been met or ignored both online and off. The study began to generate dialogue with members of this community in order to gain an intimate understanding of their subjective experiences. Interpersonal communication will continue play a critical role in the dissemination of health messages in the campaign. Discourse will be encouraged on the website with the use of surveys, polls, blogs, membership, a calendar of community activities, and social networking components, including Facebook and Twitter feeds. In the future, digital storytelling may also play a role in the campaign with SMW being recruited to participate in health testimonial videos archived on the website. In this way, the health messages of the campaign may be co-created with the community. Additionally, aspects of social marketing and edutainment may be central to the campaign in that the website may begin to incorporate social

marketing strategies and health focused entertainment, such as videos, music, and stories, in order to support the cause of lesbian health promotion.

Conclusion

The changing nature of the mediascape and the ensuing influx of user-generated content signify a new era of healthcare consumption in which the SMW can be empowered to take their health into their own hands. The shift from users' passive consumption of health information online to their proactive engagement is of great importance to the SMW community, which has historically been left out of the traditional healthcare discourse, inscribed as it is with heteronormative notions that fail to consider the health needs of this population. New health communication strategies have great potential to serve the SMW community as an underserved minority population since they offer opportunities for discourse, community building, identity formation, and the creation of new health narratives. Further studies should be conducted to monitor and evaluate any gaps between theory and application. Public health initiatives geared toward SMW can be fortified by taking the various approaches employed in this project, including textual analysis, online surveying, and the development of an interactive health forum online. The formative research for the Our Health Matters campaign indicates that the majority of the health challenges that SMW face are rooted in social issues related to their sexual orientation, particularly in terms of the health impact of identifying with a minority community. Public health researchers must continue to investigate the impact of sexual identity on health risk and health prevention behaviors. Such findings are

necessary in order to develop interventions that accurately target and support diverse groups of women.

The new technocultural practices of online health communication, networking, and education can create new avenues for lesbians and other SMW to access health information and engage in critical dialogue. They also form spaces that can redefine the significance of health within the lesbian community and rewrite health narratives. Just as new media are redefining health communication, so too will new, digitally-mediated lesbian health initiatives redefine the meaning of healthcare and the ways in which it is accessed. These new practices challenge old healthcare paradigms that fail to address patients holistically or take into consideration the psychosocial components of health. New lesbian health narratives encompass non-traditional approaches to health, offering new healthcare options and modes of delivery that are not necessarily aligned with the current U.S. healthcare system, a hegemonic institution that has overlooked the variegated health needs of lesbian individuals. They also view health as encompassing physical, mental, and social wellbeing. Online communications facilitate new health narratives in the public imaginary, incorporating notions such as preventive and behavioral healthcare, as well as self-care and alternative therapies. The potential is great for the emergence of online lesbian health initiatives and more effective channels of health communication that will strengthen this population.

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APPENDIX

Our Health Matters Survey

1. What is your biological sex?
 - Female
 - Male
 - Other (please specify)

2. What is your gender identification?
 - Female
 - Male
 - Transgender (Female to Male)
 - Transgender (Male to Female)
 - Other (please specify)

3. Which of the following terms do you use most often to describe your sexual orientation?
 - Lesbian
 - Bisexual
 - Gay
 - Queer
 - Straight
 - Other (please specify)

4. What is your age?

5. Which one or more of the following would you say is your race or ethnicity?
 - American Indian or Alaska Native
 - Latino and/or Hispanic
 - Asian
 - White
 - Black or African American
 - Native Hawaiian or Other Pacific Islander
 - Other (please specify)

6. Which status best describes you?
 - Single / Never Married
 - Single / Divorced
 - In a Monogamous Relationship
 - In an Open / Polyamorous Relationship
 - Partnered / Married
 - Other (please specify)

7. What is the highest level of education you have completed?
 - Some High School
 - High School Graduate / GED

Some College
College Graduate
Graduate School / Postdoctoral
Other (please specify)

8. What is your annual income?

Less Than \$24,000
\$25,000 To \$49,999
\$50,000 To \$74,999
\$75,000 To \$99,999
\$100,000 +

9. In what city/town do you live?

10. How did you learn about this survey?

Facebook Ad
Email
Friend / Colleague
Business Card
Other (please specify)

11. To whom are you "out" about your sexual orientation and/or gender identity? Please check all that apply.

Friends
Family
Coworkers / Classmates
Acquaintances at Bar / Club
In Public / Strangers
Doctor / Primary Care Provider
Therapist / Counselor
Alternative Medicine Practitioner
Online Friends / Facebook
Other (please specify)

12. What types of discrimination and/or homophobia have you faced due to your sexual orientation and/or gender identity? Please check all that apply.

Loss of Friends
Loss of Social Standing / Reputation
Disowned / Rejected by Family Members
Gay Bashing / Slurs
Gay Bashing / Hate Crimes / Physical Violence
Job Discrimination / Loss of Employment
Denied Health Insurance for You or Your Partner
Denied Other Work Benefits
Denied Visitation Rights in Hospital
Self Hatred / Internalized Homophobia

13. Yes or No. Do you think it is important for LGBTQ individuals to be "out" to their doctors, primary care providers, and other medical providers?

14. Yes or No. Do you think it is important for LGBTQ individuals to be "out" to their therapists, counselors, and other mental health providers?

15. Yes or No. Would you feel comfortable discussing your physical health (routine exam, illness, injury, etc.) with:

A doctor / primary care provider?

Friends, family, acquaintances to whom you're "out"?

A therapist / counselor?

An alternative health provider (chiropractor, acupuncturist, etc.)?

16. Yes or No. Would you feel comfortable discussing your mental health (well-being, depression, anxiety, etc.) with:

A doctor / primary care provider?

Friends, family, acquaintances to whom you're "out"?

A therapist / counselor?

An alternative health provider (chiropractor, acupuncturist, etc.)?

17. Yes or No. Would you feel comfortable discussing your behavioral health (exercise, diet, sex life, drinking, smoking, etc.) with:

A doctor / primary care provider?

Friends, family, acquaintances to whom you're "out"?

A therapist / counselor?

An alternative health provider (chiropractor, acupuncturist, etc.)?

18. Yes or No. Would you feel comfortable discussing your sexual orientation and/or gender identity with:

A doctor / primary care provider?

Friends, family, acquaintances to whom you're "out"?

A therapist / counselor?

An alternative health provider (chiropractor, acupuncturist, etc.)?

19. What kind of health insurance or health care coverage do you currently have?

Private health insurance plan from employer or workplace

Other private health insurance (individual policy, self-insured)

Public (Medicaid or Medicare)

I don't have insurance

Other (please specify)

20. What, if anything, prevents you from receiving the best health care possible (getting the information and services you need)? Please check all that apply.

Nothing

Not "out" to my health care provider

- Lack of LGBTQ friendly provider
- Lack of culturally competent provider
- Lack of insurance
- Fear of discrimination
- Mental health issues (depression, anxiety, etc.)
- Substance use issues (alcoholism, drug addiction, etc.)
- Don't know where to receive care
- Don't know what questions to ask providers
- Not satisfied with my current quality of care
- Not receiving holistic/alternative health care

21. How would you rate your overall health?

- Excellent
- Good
- Fair
- Poor

22. Which of the following self-care and preventive health measures do you take?

Please select all that apply.

- Keep a healthy diet
- Stay physically active
- Maintain a healthy body weight
- Abstain from smoking
- Drink alcohol in moderation or abstain
- Take preventative medication, if applicable
- Do self breast exams
- Get regular physical exams
- Get regular pap smears
- Get screened for sexually transmitted infections
- See a chiropractor or massage therapist
- Meditate
- Other (please specify)

23. Physical State. Which of the following do you experience on a regular basis? Please select all that apply.

- Physical pain
- Tension or stiffness
- Fatigue or low energy
- Colds and flu
- Headaches
- Nausea or constipation
- Menstrual discomfort
- Allergies/skin rashes
- Dizziness/light-headedness
- Accidents/falling/tripping

24. Mental/Emotional State. Which of the following do you experience on a regular basis? Please select all that apply.

- Distress from physical pain
- Negative feelings about yourself
- Moodiness or temper
- Depression or lack of interest
- Being overly worried about small things
- Difficulty concentrating
- Vague fears or anxiety
- Restlessness
- Difficulty sleeping or falling asleep
- Recurring thoughts or dreams
- Other

25. Stress. Which of the following are stressful for you on a regular basis?

- Family
- Significant Relationship
- Health
- Finances
- Sex Life
- Work
- School
- General well-being
- Emotional well-being
- Coping with daily problems

26. Yes or No. Do you currently smoke or use any other form of tobacco?

27. When was the last time you had more than 3 alcoholic drinks in one day? (One drink is a 12 oz. beer, a 5 oz. glass of wine, or 1.5 oz. of liquor.)

- Never
- Within the past 3 months
- Not within the past 3 months

28. How many alcoholic drinks do you have per week? (One drink is a 12 oz. beer, a 5 oz. glass of wine, or 1.5 oz. of liquor.)

- None
- 1 to 7
- More than 7

29. Yes or No. In the past 12 months, have you used drugs (including marijuana, cocaine, ecstasy, etc.) other than those required for medical reasons?

30. Life Enjoyment. Which of the following do you experience on a regular basis? Please select all that apply.

- Openness to your "inner voice/feelings"

Presence of positive feelings about yourself
Interest in maintaining a healthy lifestyle (e.g., diet, fitness, etc)
Feeling of being open and aware or connected when relating to others
Confidence in your ability to deal with adversity
Compassion for, and acceptance of, others
Satisfaction with the level of recreation in your life
Feelings of joy or happiness
Satisfaction with your sex life
Time devoted to things you enjoy

31. When was the last time you visited a doctor for a routine checkup? A routine checkup is a general physical exam, not an exam for a specific injury, illness, or condition.

Within the past year (1-12 months ago)
Within the past two years (1-2 years ago)
Two or more years ago
Never

32. How satisfied were you with your most recent experience with that doctor / primary health care provider?

Very satisfied
Satisfied
Somewhat satisfied
Unsatisfied
Very unsatisfied
N/A

33. When was the last time you saw a counselor, therapist, or psychiatrist for counseling?

Within the past year (1-12 months ago)
Within the past two years (1-2 years ago)
Two or more years ago
Never

34. How satisfied have you been with the outcomes from this mental health care?

Very satisfied
Satisfied
Somewhat satisfied
Unsatisfied
Very unsatisfied
N/A

35. When was the last time you used alternative health care services (acupuncture, aromatherapy, chiropractic, massage therapy, naturopathy, herbalism, Chinese medicine, Ayurveda, meditation, hypnosis, etc.)?

Within the past year (1-12 months ago)

Within the past two years (1-2 years ago)
Two or more years ago
Never

36. How satisfied have you been with your health outcomes from these alternative health care practices?

Very satisfied
Satisfied
Somewhat satisfied
Unsatisfied
Very unsatisfied
N/A

37. Which of the following communication tools do you use? Please select all that apply.

Computer: Public / Friend's/ Work
Computer: Personal
Phone: Texting
Phone: Calls
Blackberry / iPhone / etc.
Internet
Facebook or Other Social Network
Blogs
You Tube or Other Video Site
Skype or Other Video Communication

38. Where do you receive your health information? Please check all that apply.

Friends / Family
Doctor / Primary Care Provider
Therapist / Counselor
Alternative Health Practitioner
Coworkers/Classmates
Books / Magazines / Newspaper
Acquaintances at Bar / Club
Online: Daily News Site
Online: Blogs / Websites
Online: Health Web Site
Online: Videos / YouTube
Online: Social Network / Facebook
Other (please specify)

39. What health and wellness topics would you like to know more about?

Illness and Disease
Diet and Nutrition
Exercise
Sex and Sexuality
Coming Out

Sexually Transmitted Infections
Mental Health
Preventive Health
Smoking
Alcohol
Drugs
Prescription Medications
Alternative Health
Social Support
Health Insurance
Health Care Providers
Health Reform / Policy
Other (please specify)

40. How likely would you be to use a health and wellness website that offers free health assessments and quizzes, health videos, social networking, and forums for lesbian, bisexual, and transgender locals?

Extremely likely
Very likely
Somewhat likely
Not at all likely