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## Exploring Healthcare Experiences of Lesbian, Gay, and Bisexual College Students Using Community-Based Participatory Research: A Dissertation

Caitlin M. Stover

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Exploring Healthcare Experiences of Lesbian, Gay, and Bisexual  
College Students Using Community-Based Participatory Research

A dissertation presented

by

Caitlin M. Stover

Submitted to the  
University of Massachusetts Worcester  
Graduate School of Nursing  
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*"Exploring Healthcare Experiences of Lesbian, Gay and Bisexual College Students  
Using Community-Based Participatory Research"*

A Dissertation Presented

By

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Dean/Professor  
University of Massachusetts Worcester  
Graduate School of Nursing

## Dedication

This dissertation is dedicated to my children, Nicole Elizabeth and Colin Scott.

May you learn and practice the skills of tolerance and acceptance towards all those who surround you.

## Acknowledgement

“The greatness of a community is most accurately measured by the compassionate actions of its members. A heart of grace, and a soul generated by love.” ~ Coretta Scott King

This dissertation is the culmination of many people’s efforts. My husband Scott provided me endless hours of encouragement and attention, as I re-read the same sentence looking for the perfect word, revised conceptual models for clarity, and agonized over edits. His belief in me gave me the strength to keep typing during the late hours of night, on beautiful summer days when I rather be poolside, and through tragic family loss. Thank you for being my best friend and cheerleader, beanpole!

Nicole and Colin, you have been patiently waiting for mom to finish school since 2005 when I started my Master’s degree. Thank you for understanding why I always carried something to read at swimming, hockey, dance and baseball. You have learned to make my iced coffee to perfection and complete a load of laundry without ruining the clothes. I hope you also have learned that dedication and perseverance, although difficult and lonely at times, leads to a fuller appreciation of self and others.

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## Abstract

Little is known about the healthcare experiences of lesbian, gay, and bisexual (LGB) young adults (ages 18-24) and even less is known about LGB college students (ages 18-24). Helping LGB college students effectively access appropriate, sensitive healthcare has the potential to reduce negative long-term health consequences. Therefore, the purpose of this study was to describe the healthcare experiences of LGB college students (ages 18-24) in the local college community using community-based participatory research (CBPR). Three online synchronous focus groups and one online individual interview were conducted with 19 LGB college students between January and February 2011. The focus groups were segmented into lesbian ( $n = 7$ ), gay ( $n = 7$ ), and female bisexual ( $n = 4$ ) groups. One male bisexual was interviewed individually. The mean age of the sample was 20.7 years ( $SD = 1.2$ , range = 19-24). The sample was predominately White non-Hispanic (85%).

Qualitative content analysis was used to describe the healthcare experiences of lesbian, gay, and bisexual college students in the local community. One overarching theme (not all the same), one main theme (comfort during the clinical encounter), three sub themes (personalizing the clinical encounter, deciding to disclose and social stigma, and seeking support of self-identified sexual orientation) and one preliminary sub theme (perceived confidentiality) emerged from the analysis. One major action emerged from the analysis and supported the development of the social network site (on Facebook) entitled: College Alliance Towards Community Health (CATCH). The mission of CATCH is to provide LGB college students in the local community with a comfortable forum to learn about various healthcare concerns of lesbian, gay, and bisexual college students. Additional implications for nursing practice and implications for further research in the LGB college community are addressed.

## Chapter One

### State of the Science

#### Introduction

Understanding the healthcare experiences of young adults in college is an important area of research. Current studies in the general population indicate that young adults have the lowest rate of insurance coverage, which leads to reduced healthcare access (Park, Paul, Adams, Brindis, & Irwin, 2006). Additionally, due to the various paths explored by young adults after adolescence (e.g., military, parenthood, marriage, college), there is no common entry point for young adults into the healthcare system (Park et al., 2006). In addition, programs of healthcare support for adolescents (e.g. parental, school-based, and governmental) rarely follow the individual into young adulthood (Mulye et al., 2009).

Little is known about the healthcare experiences of lesbian, gay, and bisexual (LGB) young adults (ages 18-24) and even less is known about LGB college students in this age span. What we do know about this age group is limited to studies combining adolescent (ages 13-24) and general adult populations (ages 19-99). Knowledge about the healthcare experiences of LGB college students must be extracted from studies conducted within the general student body or from studies focused on the greater lesbian, gay, bisexual, transgender, and queer community.

The reason to focus on the healthcare experiences of LGB college students is multifactorial. First, LGB individuals are at greater risk for depression (Diamont & Wold, 2003), anxiety (Bostwick, Boyd, Hughes, & McCabe, 2010), eating disorders (Austin et al., 2009), and suicidality (D'Augelli, 2002; Silenzio, Pena, Duberstein, Cerel, & Knox, 2007) compared to their heterosexual counterparts. Second, compared to heterosexual adults, LGB adults demonstrate

increased risk behaviors that include cigarette smoking (Remafedi, Jurek, & Oakes, 2008), alcohol use (Corliss et al., 2010), drug use (Corliss et al., 2010), and high-risk sexual activity (Rhodes, McCoy, Hergenrather, Omli, & DuRant, 2007). Studies show that many of these risk behaviors begin in late adolescence and early adulthood (Corliss et al., 2010; Remafedi et al., 2008; Silenzio et al., 2007) and may be amplified during the college years. Third, LGB young adults must deal with the burden of social stigma and societal disapproval associated with their sexual orientation (Meyer, 1995; Saewyc et al., 2006), which may contribute to their decision to delay seeking healthcare (Stein & Bonuck, 2001; van Dam, Koh, & Dibble, 2001). Lastly, few studies have explored the healthcare experience of the LGB young adult community, and specifically, the LGB college community. The American College Health Association [ACHA] National College Health Assessment [NCHA] (2009), reported that 82.3% ( $N = 34,208$ ) of college students are between the ages of 18 and 24 years (average age 22.15 years, SD 6.26 years) and approximately 5% of this group self-identified as LGB.

Helping LGB college students effectively access appropriate, sensitive healthcare has the potential to reduce negative long-term health consequences. Hence, the purpose of this study is to describe the healthcare experiences of LGB college students (ages 18-24) in the local college community, utilizing community-based participatory research (CBPR).

CBPR is a collaborative research approach that uses the expertise of community members and researchers at all levels of the research process (Israel, Eng, Schulz, & Parker, 2005). The outcomes of CBPR must have a direct benefit on the target community, and can be in the form of tailored health interventions or health-promoting policy advocacy (Israel, Eng et al., 2005; Olshansky et al., 2005) (see Chapter two for details).

The specific aims of this study are to:

1. Describe factors (e.g., healthcare system, patient, provider, clinical encounter) that influence the healthcare experiences of LGB college students (ages 18-24) in the local community.
2. Identify a mechanism of action to facilitate a positive healthcare experience for LGB college students (ages 18-24) in the local community.

### **Background and Significance**

Vulnerability is innate to all humans and is highly influenced by community, social, and environmental factors interacting in a temporal relationship (Aday, 2001). Membership in a vulnerable group indicates a susceptibility to physical, mental or social health problems based on “marginalized socio-cultural status, limited access to economic resources, or personal characteristics such as age and gender” (DeChasney, 2008, p. 4). Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine (2006) have expanded this definition to include “groups that have faced discrimination because of underlying differences in social status, which can lead to potential gaps in health or health care” (p. 2215). According to Aday (1994), discrimination can also occur because of personal characteristics, such as sexual orientation. Sexual orientation is a complex construct comprised of sexual attraction, sexual behavior, personal identity, romantic relationships, and community membership (Herek, Norton, Allen, & Sims, 2010). The lesbian, gay, bisexual, and transgender (LGBT) community is a sexual-minority group to which self-identified individuals belong. Membership in the LGB community is voluntary. This may make it difficult for a researcher to identify specific sub-groups of the LGB community, such as LGB college students, if the LGB individual does not actively or publically associate within the

community (Herek et al., 2010). Consequently, in the review of literature, certain citations reference the age group of young adults (ages 18-24) and not the specific desired sample of LGB college students, which has limited available data.

According to Gates' (2010) analysis of data from the General Social Survey (GSS), approximately nine percent of the US population identifies as lesbian or gay (1.7%), bisexual (1.1%) or reports having same-sex encounters (5.8%). In this sample of 1,773 adults (18 years and older), 7.2% of LGB respondents were between the ages of 18-30 (Gates, 2010).

In the Commonwealth of Massachusetts, where this CBPR study was conducted, the Massachusetts Behavioral Risk Factor Surveillance Survey (BRFSS) captured an estimate of the number of LGB young adults. Estimates based on data from the 2001-2006 BRFSS suggests that 13.5% ( $n = 128$ , 95% CI [8.90, 18.09]) of the adults who responded as being gay or lesbian ( $n = 949$ ) were between 18 and 24 years old (Massachusetts Department of Public Health [MDPH], 2008). Of the 366 adults identified as bisexual, 41.1% ( $n = 150$ ) were between 18 and 24 years of age (MDPH, 2008). Lower estimates were found in the 2007 Massachusetts Youth Risk Behavior Survey (MYRBS). Fifty-nine randomly selected public high schools in Massachusetts provided a sample of 3,131 students in grades 9 through 12. In this sample, 5.4% ( $n = 169$ ) of participants identified as LGB and an additional 3.8% ( $n = 119$ ) youth identify as having experienced same-sex contact (Massachusetts Department of Education, 2007). This lower estimate of LGB prevalence may be due to these participants being younger than 18 years of age and not having completed the sexual identity development process. It is unknown how many LGB students are enrolled in a college or university in the Commonwealth of Massachusetts.

Vulnerable populations are at risk for health disparities (DeChasney, 2008). According to Kilbourne et al. (2006), health disparities are "observed clinically and statistically significant



differences in health outcomes between socially distinct vulnerable and less vulnerable populations that are not explained by the effects of selection bias” (p. 2114). Health disparities derive from various sources including, but not limited to the health care system, the healthcare provider or the patient (Institute of Medicine [IOM], 2002). For example, lack of health insurance coverage, inconsistent use of healthcare services, negative provider attitude, lack of provider acceptance of patient characteristics, and client dissatisfaction with healthcare services are some factors known to cause health disparities in vulnerable groups (Jillson, 2002).

Health disparities are found in the LGB community. In a population based study, lesbians ( $n = 84$ , mean age 33.4 years) were more likely to be overweight (OR 2.69, 95% CI [1.40, 5.18],  $p < 0.05$ ) and obese (OR 2.47, [1.19, 5.09],  $p < 0.05$ ) compared to heterosexual women (Boehmmmer, Bowen & Bauer, 2007). Gays and lesbians ( $n = 1,645$ , ages 18-64 years, 29.7% between 18-33 years) were significantly less likely to have a regular healthcare provider (AOR 0.95, [0.73-1.24],  $p = 0.05$ ) and 3.68 times more likely ([2.78-4.88],  $p < 0.01$ ) to report an activity limitation caused by a disability (Conron, Mimiaga, & Landers, 2010).

Numerous risk behaviors that may lead to health disparities also exist in the LGB community. Female bisexual participants (ages 18-23) had a 2.4 greater risk (95% CI [2.11, 2.75],  $p < 0.05$ ) and lesbians had a 1.8 time greater risk ([1.36, 2.40],  $p < 0.05$ ) to use marijuana compared to heterosexual peers (Corliss, Rosario, Wypij, Wylie, Frazier, & Austin, 2010). Additionally, female bisexual participants had almost five times the risk (RR 4.94, [3.75, 6.51],  $p < 0.05$ ) and lesbians had greater than three times the risk (RR 3.18, [1.76, 5.76],  $p < 0.05$ ) of utilizing any illicit drug other than marijuana compared to heterosexual participants (Corliss et al., 2010). Male bisexual participants (ages 18-23) had a 1.44 risk ([1.01, 2.07],  $p < 0.05$ ) of using marijuana compared to heterosexual counterparts (Corliss et al., 2010).

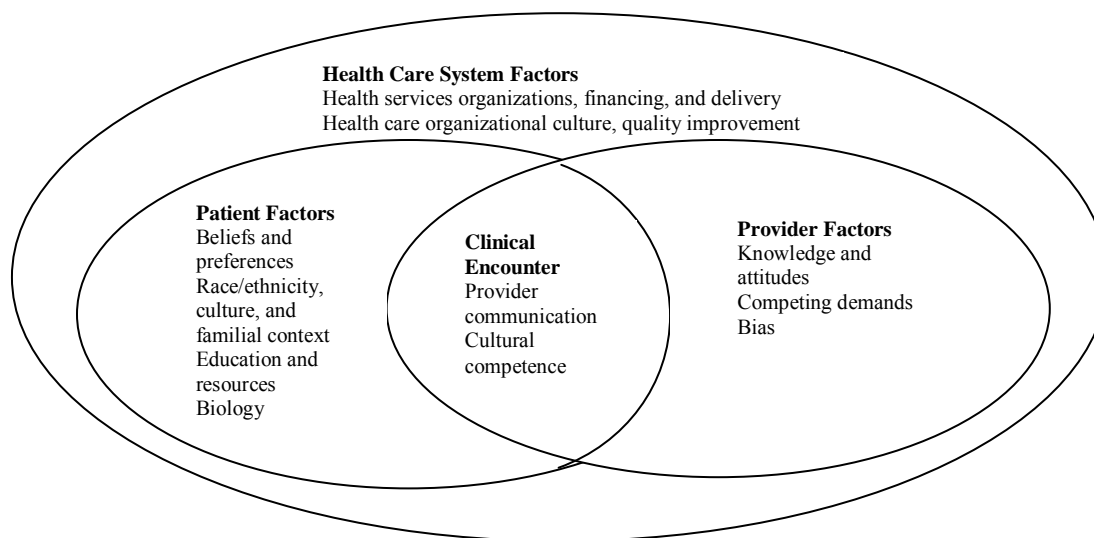
## Organizing Framework

Kilbourne et al. (2006) have developed a three-phase organizing framework to guide health disparities research from a health services (health systems) research perspective (see Figure 1). The use of this framework to structure the literature review complements the central principles of CBPR as researchers strive for action to benefit the group of interest (see Chapter Two for details).

Phase one of the framework detects the health disparity in a vulnerable group and identifies valid measurement of disparity and vulnerability. Phase two focuses on understanding the health disparity in a specific vulnerable population and identifying the “factors that explain the gaps in health and health care between vulnerable and less vulnerable groups” (Kilbourne et al., 2006, p. 2113). Phase three is a comprehensive step of developing, implementing, and evaluating interventions focused on eliminating or reducing health disparities in vulnerable populations.

This chapter will focus on phase two of the Kilbourne et al. (2006) research approach, which assesses underlying determinants of health disparities such as patient factors, provider factors, as well as the organization and delivery of healthcare at the practice or system level (see Figure 1). This framework will organize the literature review used to inform this CBPR study.

Figure 1. Origin of Healthcare Disparities



*Figure 1.* Understanding the origins of health and healthcare disparities from a health services research perspective: Key potential determinants of health disparities within the healthcare system, including individual, provider, and healthcare system factors. From “Advancing Health Disparities Research: A Conceptual Framework for Detecting, Understanding, and Reducing Disparities in Vulnerable Populations” by A.M. Kilbourne, G. Switzer, K. Hyman, M. Matoka, M.J. Fine, 2006, *American Journal of Public Health*, 96, p. 2116, Copyright (2006) by The Sheridan Press. Reprinted with permission.

### Factors Influencing the Healthcare Experiences of LGB Individuals

Descriptions of the healthcare experience of LGB college students are limited (Allen, Glick, Beach, & Naylor, 1998; Hoffman, Freemann, & Swann, 2009; Steele, Tinnmouth, & Lu, 2006; Stein & Bonuck, 2001). However, findings from studies with younger or older LGB samples are useful in identifying potential factors that may influence the healthcare experience of LGB college students. During the college years, the contextual influences that shape risky behavior, health outcomes, and access to care, may differ from other LGB sub-groups (Park et al., 2006). For example, LGB college students ( $n = 43$ ) were more likely to report threats or experience physical and sexual violence (AOR = 2.3; 95% CI [1.2-4.5],  $p < 0.05$ ), were less likely to report feeling safe on campus (AOR = 0.2; [0.1-0.6],  $p < 0.05$ ), and reported greater perceived stress ( $\beta = 1.0$ , SE = 0.4,  $p = 0.007$ ) compared to their heterosexual peers (Reed,

Prado, Matsumoto, Amaro, 2010). In turn, these variables (not feeling safe on campus, threats or experience of physical and sexual violence, and greater perceived stress) were also all significantly and positively associated with alcohol and other drug use and consequences among participants (Reed et al., 2010).

### **Healthcare system factors.**

The framework of Kilbourne et al. (2006) identifies various healthcare system factors, such as the healthcare organization, financing, delivery and organizational culture and quality improvement as possible influences in the health disparities of vulnerable populations. These healthcare system factors may influence an individual's utilization of healthcare services. As outlined by Anderson (1995), two main factors contribute to utilization of healthcare services, (a) healthcare providers must be made available to the individual, and (b) individuals must have the means (e.g. health insurance) and knowledge to access and make use of the services. A significant factor associated with utilization of healthcare in the LGB community is perceived confidentiality. This factor relies on organizational competency to employ federal Health Insurance Portability and Accountability Act (HIPAA) standards as well as convey the message of confidential care to the LGB individual seeking healthcare.

### ***Utilization of healthcare services.***

Little is known about the specific healthcare utilization patterns of LGB college students as many of the surveys target adults of all ages. Data from the 2000-2006 Behavioral Risk Surveillance System demonstrated differences in utilization of the healthcare system in the older LGB community (Buchmueller & Carpenter, 2010). Men in same-sex relationships ( $n = 2384$ ,  $M$  age 40.36) were more likely (OR 1.98, 95% CI [1.48, 2.64],  $p < 0.01$ ) to report unmet medical

needs, but they were also more likely (OR 1.36, [1.12, 1.65],  $p < 0.01$ ) to have a checkup within the past year compared to men in heterosexual relationships (Buchmueller & Carpenter, 2010). Additionally, 88% ( $n = 4633$ ) of males and females in same-sex relationships ( $N = 5265$ ,  $M$  age men = 40.36 and women 40.43) had health insurance, thus providing access to healthcare services (Buchmueller & Carpenter, 2010). However, compared to unmarried women in heterosexual relationships, females in same-sex relationships ( $n = 2881$ ) were more likely (OR 1.57, [1.27, 1.93],  $p < 0.01$ ) to report unmet medical needs and less likely (OR 0.76, [0.1, 0.86],  $p < 0.01$ ) to have had a check up in the last 12 months (Buchmueller & Carpenter, 2010). These females were also less likely (OR 0.74, [0.57, 0.97],  $p < 0.01$ ) to have a mammogram or Papanicolaou smear (Pap) test in the last three years (Buchmueller & Carpenter, 2010). These findings contradict previous results from Diamant, Wold, Spritzer, and Gelberg (2000), who found high percentages of preventative screening tests for lesbians. In their sample of 6,919 lesbians ( $Mdn$  age = 34), 71% ( $n = 4896$ ) received a Pap smear, and 83% ( $n = 334$ ) received a mammogram within the past two years (Diamant et al., 2000). This contradiction was not explained by sample demographics, but may be explained by the economic influences on healthcare services that occurred during the ten-year period between studies. Nevertheless, neither study reported data by age; therefore, transferability of these data to LGB young adults is uncertain.

### ***Confidentiality.***

Evidence is conflicting about the importance of confidentiality during a health visit for young adults. Maintaining confidentiality is important to healthcare providers. Pediatricians, ( $n = 48$ , 80%) report that they would not break provider-patient confidentiality by discussing their patient's sexual orientation with parents (East & Rayess, 1998). However, 65% of LGB

respondents ( $n = 98$ , ages 14-18) reported that their provider did not inform them during their visit about medical confidentiality, and 75% agreed that, if they had been aware of it, they would have engaged in a conversation about sexual orientation (Allen et al., 1998).

Furthermore, Ginsburg et al. (2002) conducted a four-stage mixed-method study with self-identified gay, lesbian, bisexual, and questioning youth between 14 and 23 years old to explore factors perceived to promote safety in the healthcare setting. Participants were recruited from one of three urban organizations providing support to the gay community. Stage I consisted of an exploratory focus group with eight expert participants. This group framed two research questions focused on characteristics of both the provider and the healthcare environment that promoted safety for the LGB young adult. Stage II used 14 focus groups to generate characteristics used as response options to the two research questions. In stage III, 94 different youth participants prioritized ( $1 = not\ at\ all\ important\ to\ me$  to  $5 = extremely\ important\ to\ me$ ) the top 34 responses from Stage II. During stage III, the healthcare environment characteristics of privacy and confidentiality had the second highest mean rating (4.72), falling just behind “the healthcare site, instruments, and provider are clean” [ $M = 4.75$ ] (Ginsburg et al., 2002, p. 411). Finally, in Stage IV, six focus groups were held to discuss the results of the survey. According to the results of these focus groups, the importance of privacy and confidentiality was discussed more than any other priority topic. Additionally, researchers noted that many of the survey items (e.g. professionalism, honesty, respect and sensitivity) generated further discussion about privacy and confidentiality by the study participants (Ginsburg et al., 2002).

Eight years later, Hoffman et al. (2009), replicated Ginsburg and colleagues (2002) study using an Internet-based version of the original survey of LGB youth (ages 13-21 years old,  $M = 16.9$ ;  $SD\ 2.2$ ). Mean-item scores for each provider and healthcare environment characteristic

were not reported (Hoffman et al., 2009). Statistical clustering created eight rank levels (1 = important to 8 = not important) with one to seven characteristics per rank. Again, privacy and confidentiality were ranked as high priority characteristics of the healthcare environment (level two of eight) by LGB youth (Hoffman et al., 2009). In contrast, in a sample of Los Angeles youth ( $N = 131$ ), only 18% identified that physician reassurance that sexual orientation would not be written in the chart as a method to improve sexual orientation discussions (Meckler et al., 2006). Therefore, confidentiality needs further exploration to understand the role it plays in the healthcare experience of LGB young adults.

### ***Healthcare availability.***

During young adulthood, the transition from pediatric-oriented to adult-oriented healthcare begins (McManus, Fox, O'Connor, Chapman, & MacKinnon, 2008; Reiss, Gibson, & Walker, 2005). Few studies focus on transitioning healthy young adults from pediatric-oriented care to adult-oriented care. However, studies that focus on moving chronically ill children to adult-oriented care have identified the following transitional barriers, (a) poor availability of adult services that were able to address the specific pediatric chronic health issue (Reiss & Gibson, 2002), (b) less expertise of adult-oriented practitioners to provide the transitioning young adult with developmentally appropriate care (Reiss & Gibson, 2002; Reiss et al., 2005), and (c) lack of adult provider competence (Reiss & Gibson, 2002), including issues around provider communication (Reiss et al., 2005). It is unclear if these barriers are also present for LGB college students who transition into adult-oriented care or college health service care and search for healthcare providers sensitive to their needs. Additionally, depending on the location of their healthcare provider (either at home or on campus), college students are challenged with

the coordination of healthcare services when their familiar healthcare provider is geographically unavailable.

*Available LGB-specific healthcare.*

Healthcare providers may use one or more mechanisms to promote a safe environment that demonstrates their acceptance of sexual minorities. Examples include posting relevant information in the waiting room and providing books, magazines, and pamphlets of interest to the LGB community (Gay Lesbian Medical Association, 2006). LGB-friendly symbols such as a pink triangle and rainbow flag may indicate sexual minority acceptance. Evaluation of these interventions has not been described in the literature; therefore, the effectiveness of such measures during a healthcare visit is unknown. Additional recommendations to improve healthcare provider competence include increasing provider cultural sensitivity and communication skills (Mayer, Bradford, Makadon, Goldhammer, & Landers, 2008; Mulligan & Heath, 2007). These solutions are challenging. A survey of curricula in United States internal medicine residencies reported that 79% of programs ( $n = 181$ ) spent three hours or less in their curricula covering gay-related material and 73% of programs ( $n = 167$ ) spent less than one hour of the curricula on lesbian-related material (McGarry, Clarke, Landau, Cyr, 2008). There are current initiatives within medical school student associations to increase the amount of curriculum time focused on LGB health-related issues (American Medical Student Association, 2010). In addition to United States medical schools, United States Schools of Public Health also have limited curricula in LGB-related health issues. A survey of 102 programs reported that 93 (91.2%) did not offer lesbian, gay, or bisexual content beyond that of HIV (Corliss, Shankle, & Moyer, 2007). Thus, the availability of LGB trained healthcare providers is limited. However,



Massachusetts is fortunate to have Fenway Community Health, located in Boston (MA), 40 miles away from the Worcester community where this study took place.

Fenway Community Health (The Fenway) in Boston, Massachusetts was founded with the mission to “enhance the physical and mental health of the local general community, with an emphasis on the provision of services for lesbian, gay, bisexual, and transgendered individuals” (Mayer, Mimiaga, VanDerwarker, Gladhammer, & Bradford, 2007, p. 691). The Fenway’s services of primary medical care, gynecological care, geriatric care, complementary and alternative therapies, and health promotion and screening programs are available to the LGBT community within and beyond Boston. In fact, a needs assessment in the City of Worcester indicated that almost half ( $N = 376$ , ages 12-80) of the LGBT sample received healthcare services outside of Worcester, with the majority going to The Fenway (Greater Worcester Community Foundation, 2006). Participants identified various reasons for accessing healthcare outside their local community. Examples included a perceived lack of lesbian-, gay-, and bisexual-friendly services in the Worcester area ( $n = 173$ , 46%) and selecting an agency based on reputation in servicing the LGB population [ $n = 170$ , 45%] (Greater Worcester Community Foundation, 2006). Additional reasons included receiving better quality services outside the Worcester area ( $n = 132$ , 35%), following through from a recommendation ( $n = 124$ , 33%), accessibility of healthcare site ( $n = 71$ , 19%), receiving more confidential care ( $n = 56$ , 15%) and cost ( $n = 34$ , 9%). Although youth (ages 12-24) made up 17% of the sample (Greater Worcester Community Foundation, 2006), there are no details describing the specific experience from the viewpoint of a young adult. Therefore, it is unknown what the healthcare experience of LGB college students in the Worcester community entails.

### ***Healthcare Access.***

Access to high quality, comprehensive healthcare is a goal for young adults (Society of Adolescent Medicine, 2004). In the recent past, young adults in the US between 18 and 24 years old were often uninsured and lacked a regular source of healthcare (Schwartz & Schwartz, 2010). When the Affordable Care Act of 2010 was passed, The US Department of Health and Human Services (2010a) projected that there were 29.5 million individuals between 18 and 25 years of age in the US. Of those individuals, 9.3 million were not eligible for dependent healthcare coverage (coverage provided through parental coverage). Among the remaining 20.2 million eligible for dependent coverage, 3.44 million young adults remained uninsured (US Department of Health and Human Services, 2010a).

Lack of insurance coverage limits access to healthcare. In fact, young adults without health insurance were 5.91 times more likely (95% CI [3.80, 9.18], no *p* value reported) to have difficulty accessing healthcare compared to youths with a provider and insurance (Benson, Garofalo, Hergenroder, & Murray, 2007). In this sample of LGB youth ( $n = 429$ , age range 16-24), those without a healthcare provider were 2.29 times more likely ([1.52, 3.45], no *p* value reported) than those with a provider to have trouble accessing healthcare. These findings are potentially problematic for the LGB college student without a healthcare provider. This is because important health education and screening tests may not occur for illnesses known to affect the LGB community disproportionately.

In the Commonwealth of Massachusetts, young adults (ages 18-25) made up 15.5% ( $N =$  approximately 987, 601) of the total population in 2006 (Henry J. Kaiser Family Foundation, n.d.). This estimate is congruent with a 2009 sample of Massachusetts adults ( $n = 3,041$ ) which

found that 14.8% were 18-25 years old (Long & Stockley, 2010). In this sample, young adults accounted for almost half (45%) of all uninsured persons (Long & Stockley, 2010) despite the existence of the Qualifying Student Health Insurance Program [QSHIP]. In 1989, Massachusetts instituted QSHIP for all full- and part- time college students in Massachusetts to provide access to comprehensive health insurance for young adults who may not be covered by their parents plan (The Commonwealth of Massachusetts Office of Health and Human Services, 2010). Essentially, QSHIP requires that full- and part-time college students purchase health insurance coverage or prove that they have comparable coverage through another means (i.e. parent or individual employer).

Recent legislative changes both locally (Chapter 58 of the Massachusetts Acts of 2006) and nationally (Affordable Care Act of 2010) make medical coverage more accessible to young adults. The Affordable Care Act of 2010 expanded dependent coverage through age 26 for married or unmarried dependents who do not have employer sponsored coverage (US Department of Health and Human Services, 2010b). However, beginning in 2014, this expanded dependent coverage will continue to be offered despite the availability of employer coverage, increasing the availability of health insurance coverage for young adults.

In Massachusetts, Chapter 58 was signed into law in April of 2006 (The Commonwealth of Massachusetts Department of Health and Human Services, 2006). Chapter 58 includes a Young Adult Plan, which offers young adults (19-26 years of age) who are not eligible for MassHealth (the Commonwealth's Medicaid plan) or employer health insurance plans, unsubsidized and low cost coverage through the Commonwealth Connector Program. The law also requires health insurers to allow young adults to stay on their parents' policies for up to two years after they are no longer dependent, or until their 26th birthday, whichever comes first. A

requirement of Chapter 58 is that all individuals carry minimum credible health insurance that is made available to them. This individual mandate carries a financial penalty on State income tax returns if not followed.

Navigating the laws and availability of health insurance may be a difficult task for some college students as they transition from pediatric- to adult- oriented providers and manage the fragmented healthcare involved with attending college. Additionally, LGB college students may have been terminated from their parental coverage due to family conflicts about their sexual identity. These conflicts may also influence the access to healthcare services with either current providers (i.e. pediatric-oriented providers) or transitioning services to adult-oriented providers.

### **Patient Factors**

The sociodemographic makeup of the LGB community varies in cultural, ethnic, racial, age, education, and income characteristics (Meyer, 2001). LGB individuals also have varying degrees to which they self-identify as either lesbian, gay, or bisexual, which is linked to their psychosexual development. In turn, there are varying degrees to which LGB individuals affiliate with the greater LGB community, their response to social stereotypes or prejudice, and their decision to disclose their sexual orientation (Meyer, 2001).

#### **Young adult development.**

Rumbaunt's (2004) analysis of data from the US Census 2000, provides a comprehensive description of young adults (ages 18-24 years). There were 27,117,388 young adults, made up of 48.9% female and 51.1% male. One out of seven young adults was an immigrant, 30 % had household incomes under the federal poverty level, 25% had not completed high school, 66.9% graduated high school and had some college, 7.9% had completed college, and 71% were in the labor force. A large majority of young adults continued to live in a parental household ( $n =$

24,271,071, 89.5%), while 1,994,167 (7.4%) lived in a college dorm, 274,204 (1%) were in the military, and 419,876 (3%) were in prison. In contrast, mid-decade data from the 2003-2006 Current Population Survey (CPS), found that of the 27,972,112 young adults (ages 18-24) sampled, only 49.7% lived at home with their parents and this percentage decreased as age increased (Rumbaunt & Komaie, 2007).

As adolescents transition into young adulthood, several developmental issues arise. All young adults encounter physiological and psychological changes while navigating the social stages of development. Over the past half century, demographic shifts in society (i.e., age of marriage, age of childbirth, moving out of the family home, and job stability) have led theorists to re-examine the developmental stages of young adults. In the past, young adulthood (ages 18-25) immediately followed adolescence with a goal of attaining various adult responsibilities (i.e., not living with parents, completing school, entering the workforce, marrying and having children). According to Arnett (2000), this stage is now more aptly called an emerging adulthood, where an individual gains freedom from his or her parents and other authorities, without yet enduring the full responsibilities of traditional adulthood. This new definition was supported in data from the US Census (2000), which found only 40.7% of young adults had reached none or one of these milestones, and only an additional 3% had achieved two or three of these milestones (Rumbaunt, 2004). The developmental tasks of emerging adults now include “accepting responsibility for one’s self and making independent decisions” (Arnett, 2000, p. 473). Exploration occurs in the areas of love, work, and worldview, thus allowing the individual to shape many aspects of his or her future.

During this period of emerging adulthood, individuals also experience the final stages of their sexual identity development. Sexual identity formation begins in late childhood with

feelings of sexual attraction (opposite- or same-sex attraction), continues through adolescence with sexual behavior (men who have sex with women, women who have sex with men, men who have sex with men, or women who have sex with women), and emerges as a sexual identity (heterosexual, gay, lesbian, or bisexual) during young adulthood (Bilodeau & Renn, 2005; Edwards & Brooks, 1999; Saewyc et al., 2004). The process of LGB sexual identity development is demonstrated by research studies with participants who reported having their first same-sex attraction between ages 10 and 14, followed by self-identification and possible disclosure between 15 and 18 years of age (Bilodeau & Renn, 2005; Lindley, Nicholson, Kerby, & Lu, 2003). LGB young adults have the added stress of developing a non-heterosexual sexual identity that may be fraught with disapproval from family, friends, and peers (Ryan, Huebner, Diaz, & Sanchez, 2009).

The process of negotiating healthy adult relationships, including those with healthcare providers, may be challenging for the young adult who is trying to hide his or her sexual preferences (Alexander & Schrauben, 2006). This “secret keeping” limits the ability of LGB individuals to (a) participate in LGB-specific resource programs, (b) receive support, and (c) access LGB-sensitive healthcare due to unresolved sexual identity confusion and fear of disclosure (Jillson, 2002). Consequently, in an attempt to cope with such difficulties, as the emerging adult in college becomes more independent (Arnett, 2000), risk behaviors associated with being LGB may be triggered (Alexander & Schrauben, 2006; Ryan, 2003).

### **Provider Factors**

According to Kilbourne et al. (2006), provider factors may contribute to health disparities in vulnerable populations. According to the Institute of Medicine (IOM, 2002), providers face

time and resource constraints, and occasionally encounter health concerns in which they lack knowledge. This knowledge deficit, or “uncertainty can „open the door“ for physicians” stereotypes and biases to affect their judgment of patients and interpretation of their presenting concerns” (IOM, 2002). The LGB community has identified that provider attitudes and characteristics influence their decision to disclose sexual orientation. Without the knowledge of an individual’s sexual orientation, important aspects of the patient’s health history may be missed (Neville & Henrickson, 2006).

### **Healthcare provider attitudes and characteristics.**

Although highly subjective, provider attitude is perceived as the therapeutic use of “silence, body gestures, words, and intonation” (van Dam et al., 2001, p. 17). When presented with three methods to ease sexual orientation disclosure to their healthcare provider, lesbians ( $n = 524$ ,  $M$  age = 40.01, SD 11.32) identified that written questions ( $n = 43$ , 78.2%), verbal questions ( $n = 37$ , 77.1%), and improving provider attitude ( $n = 20$ , 57.1%) were all viable methods (van Dam et al., 2001) that would encourage one to disclose to the provider. Specifically, lesbians ( $n = 20$ ) were 8.47 times more likely (95% CI [3.36, 21.35],  $p < 0.0005$ ) than heterosexual females to report that improving the healthcare provider’s attitude would increase the likelihood that they would disclose their sexual orientation (van Dam et al., 2001). Furthermore, lesbians and bisexuals who reported satisfaction with their healthcare provider were found to be 46% more likely ( $\beta$  0.54, [.384-.804],  $p < 0.002$ ) to disclose their sexual orientation (Polek, Hardey, & Crowley, 2008). Ultimately, sexual orientation and satisfaction with physician explained 30% of the variance in patient disclosure of sexual orientation to a healthcare provider (Polek et al., 2008).

In a sample of older LGB adults ( $n = 88$ ,  $M$  age 42), many significant relationships were found between provider characteristics and patient disclosure of sexual orientation (Eliason & Schope, 2001). Specifically, healthcare providers who exhibited personal warmth (chi square = 8.93,  $p < 0.006$ ), maintained close personal proximity during the healthcare interaction (chi square = 5.73,  $p < 0.03$ ), maintained eye contact (chi square = 10.56,  $p < 0.003$ ), used inclusive language (chi square = 7.51,  $p < 0.012$ ), had strong communication skills (chi square = 8.24,  $p < 0.008$ ), and were clinically knowledgeable (chi square = 5.73,  $p < 0.028$ ) were more likely to know their lesbian patient's sexual orientation (Eliason & Schope, 2001).

Few healthcare providers advertise themselves as LGB friendly, and, more often than not, the LGB young adult encounters a heterosexist attitude during his or her healthcare interaction (Mathieson, 1998). Heterosexism is the assumption that a "heterosexual orientation is natural and normal" (Perrin, 2002, p. 3). Herek (1984) defines heterosexism as an "ideological system that denies, denigrates, and stigmatizes any non-heterosexual form of behavior, identity, relationship, or community" (p. 4). Language is a major contributor to the concept of heterosexism, as many statements assume heterosexuality, thus setting a hierarchical relationship among the different sexual orientations (Dorland & Fischer, 2001; Herek, 2004). Examples of heterosexism encountered by LGB individuals include the use of (a) intake paperwork and insurance forms that do not provide the option of checking off sexual orientation or same-sex marriage, (b) specific pronouns such as "he" and "she" when the gender of the significant other has not been revealed, and (c) nouns such as wife and husband instead of partner when marriage relationships have not been disclosed (Dorland & Fischer, 2001; Mathieson, 1998; Nusbaum & Hamilton, 2002).



Discussing sexual orientation is an essential part of high-quality health care (Neville & Henrickson, 2006). However, only 17% (van Dam et al., 2001) to 30% (Stein & Bonuck, 2001) of healthcare providers ask about sexual orientation during a routine visit. In a sample of Israeli family providers ( $N = 99$ ), only one physician reported that he or she usually asked his or her patients' sexual orientation. In the same study, 34 physicians rarely asked, and 46 physicians never asked questions about sexual orientation (Dahan, Feldman, & Hermoni, 2008). A study in the United Kingdom suggested that almost half of a sample of adult general practitioners ( $N = 22$ ) reported that knowledge of their patient's homosexual or bisexual identity could pose a barrier to discussing issues related to sexual health due to personal awareness and general attitude towards same-sex relationships (Hincliff, Gott, Galena, 2005). East and Rayess (1998) reported that pediatricians worried about offending the patient ( $n = 22$ , 37%) and the patient's parent ( $n = 15$ , 25%). Additionally, 35% ( $n = 21$ ) did not know how to ask the questions, and 33% ( $n = 20$ ) reported that they did not know enough about the needs of the LGB population. These findings are possibly related to the fact that 47% ( $n = 28$ ) of pediatricians surveyed reported no formal training in LGB healthcare (East & Rayess, 1998). No studies were found describing the educational preparation of nurse practitioners or physician assistants in LGB evaluation and care. This is problematic because providers may not question patients about sexual identity issues, resulting in missed opportunities to address important health issues among LGB young adults (Neville & Henrickson, 2006).

In an Internet-based survey of lesbian, gay, bisexual, transgender, and questioning youth ( $M$  age 16.9 years,  $SD$  2.2), respondents identified the most important qualities of a healthcare provider. The seven provider characteristics found to be most important to youth included (a) medical competence, (b) honesty, (c) respect, (d) comforting, (e) nonjudgmental, (f) good

listening, and (g) treating homosexual youth the same as all other youth (Hoffman et al., 2009). Of note, these characteristics are not LGB-specific, but are priority characteristics also identified by heterosexual youth (Ginsburg et al., 1995). A general recommendation made about the healthcare facility included the ability to provide confidential care to minors, defined as those individuals under the age of 18 (Hoffman et al., 2009).

### **Clinical Encounter**

Potential underlying determinants of health disparities during the clinical encounter include patient-provider communication and cultural competence (Kilbourne et al., 2006). Strong patient-provider communication is essential to meet the healthcare needs of the LGB community, and requires the ability of both parties to discuss health issues related to sexuality and sexual orientation (Stein & Bonuck, 2001). A culturally competent healthcare provider is one who recognizes the unique health needs of the LGB community, including but not limited to disclosure of sexual orientation and forming a positive sexual identity (Mayer et al., 2008). A review of the literature demonstrates the importance of communication and cultural competence as central factors influencing the clinical encounter (Kilbourne et al., 2006).

#### **Disclosure of sexual orientation.**

The benefits of disclosing one's sexual orientation to a healthcare provider is not fully understood. LGB adults report that disclosure of sexual orientation to a healthcare provider can increase honesty and improve understanding (Stein & Bonuck, 2001), improve client-provider relationships (Mulligan & Heath, 2007; Williams-Barnard, Mendoza, & Shippee-Rice, 2001), and avoid unnecessary questions or procedures (Stein & Bonuck, 2001; Williams-Barnard et al., 2001). In a sample of 489 lesbians ( $M$  age =  $36 \pm 9.3$ ), disclosure of sexual orientation had a

moderate direct effect ( $r = 0.38, p < 0.05$ ) on regular use of healthcare services (Steele et al., 2006). Additionally, men who have sex with men ( $M$  age = 28) who disclosed their sexual orientation to their healthcare provider were 2.1 times as likely (adjusted OR, 2.10; 95% CI [1.01-4.38]) to receive a HIV screening test compared to those men who have sex with men who did not disclose (Bernstein et al, 2008). Significant relationships between disclosure of sexual orientation and receiving necessary screening tests were also found among lesbians. For example Diamant, Schuster & Lever (2000) found that lesbians ( $n = 6935, M$  age = 34) who disclosed their sexual orientation had a higher prevalence of Pap smears within the past two years (adjusted prevalence ratio 0.11, 95% CI [0.09, 0.14],  $p < 0.001$ ) compared to those who did not disclose. Despite these benefits, LGB individuals of all ages cite several reasons for not discussing their sexual orientation with their medical providers. Examples from the literature reported that LGB individuals (a) do not think it is an important topic to discuss (Allen et al., 1998; Bjorkmen & Malterud, 2007; Meckler, Elliott, Kanouse, Beals, & Schuster, 2006; Stein & Bonuck, 2001), (b) do not know how to raise the topic in conversation (Meckler et al., 2006; Williams-Barnard et al., 2001; Stein & Bonuck, 2001) (c) feel embarrassed (Meckler et al., 2006; Stein & Bonuck, 2001), and (d) have concerns about the health provider's reaction and impact on future healthcare (Bjorkman & Malterud, 2009; Stein & Bonuck, 2001). The possibility of significant persons, such as family, friends, coworkers, and the insurance company, finding out about their sexual orientation was also identified as a reason for not disclosing their sexual orientation (Ginsburg et al, 2002; Stein & Bonuck, 2001).

“Coming out” is a phrase in the LGB community that describes the process of disclosing sexual identity to others (Bonvinci & Perlin, 2003). Researchers have demonstrated that the degree of being “out” to family, friends, and coworkers can influence disclosure by the

individual to a healthcare provider (Meckler et al., 2006; van Dam et al., 2001). For example, lesbians who are out to less than 50% of their friends (86.7%,  $N = 524$ ,  $p < 0.001$ ) and coworkers (77.7%,  $N = 524$ ,  $p < 0.0005$ ) were more likely to hide their sexual orientation from their healthcare provider than those individuals who were out to more than 50% of their friends and coworkers (van Dam et al., 2001). Meckler et al. (2006) measured the degree of being out on a five-point scale (out to everyone, most, some, few, no one) and reported that the more out a youth was, the more likely the physician knew of the patient's sexual orientation (OR 2.66 per scale level, 95% CI [1.28-5.57],  $p = .001$ ). Similar findings were found in a path analysis of lesbians, where being out had a moderate direct effect on patient disclosure ( $r = 0.32$ ,  $p < 0.05$ ) (Steele et al., 2006).

### **Conclusion**

What we do know is that all young adults are challenged with the task of navigating the healthcare system. However, LGB individuals not receiving care at an LGB-specific healthcare site, such as The Fenway, may be at a greater disadvantage to find adequate healthcare services successfully. Additionally, LGB college students are challenged to access culturally competent healthcare that addresses the various provider and patient factors known to contribute to health disparities in vulnerable populations. Many healthcare providers are potentially limited in LGB-specific health education and are uncomfortable with the discussions that must occur during a healthcare visit with LGB individuals. Discussions must focus on gathering enough sexual history data to properly assess, counsel, and educate the individual to prevent the risk behaviors known to occur in the LGB community that may lead to negative health outcomes. A description of the current experience for LGB college students in the Worcester area enabled the research team to identify a mechanism of action that will focus on promoting a positive and effective

healthcare experience in the local community. Moreover, in remaining true to the tenets of CBPR, this action derived from community members to benefit the Worcester LGB community.

### **Summary**

Understanding the healthcare experience of LGB college students is important because of the numerous risk behaviors, negative health outcomes, and potential barriers in accessing healthcare known to occur in this population. Using the Kilbourne et al (2006) health service framework for researching health disparities, the underlying determinants of healthcare system factors, provider factors, patient factors and clinical encounter factors are used to explore potential influences on the healthcare experiences of LGB college students. Unfortunately, few studies address these factors specifically in LGB young adults, and even fewer in the LGB college community. By approaching this healthcare experience with a study guided by the CBPR principles, an in depth knowledge of the LGB college student healthcare experience was gained by the researcher and community members. This collaborative approach informs community action to improve the healthcare experience and reduce healthcare disparities for this vulnerable group.

## Chapter 2

### Organizing Framework

#### Introduction

This chapter presents the philosophical perspectives congruent with CBPR. In addition, the core CBPR principles will be described and applied to the proposed study of the healthcare experience of LGB college students. The strengths and benefits of using CBPR will be discussed, and a CBPR exemplar will be reviewed.

#### **Community-Based Participatory Research**

CBPR is a collaborative approach to research (Burdine, McLeroy, Blakely, Wendel, & Felix, 2010) that uses various research strategies (McIntyre, 2008; Minkler, 2005) to generate knowledge and build community capacity (Israel, Eng et al., 2005). CBPR has several goals. One goal is to bridge the gap between scientific inquiry and practice by engaging institutional partners (e.g., academic partners, public health departments) and community members in direct action that will provide tangible benefit to the community (Tandon et al., 2007; Wallerstein & Duran, 2010). A second goal is to use the active participation of community members in a reciprocal exchange of skills, knowledge, and expertise for a co-learning process among all members of the research team (Minkler, 2008). A third goal is to sustain established partnerships, generated knowledge, and action strategies beyond the immediate funding period (Israel et al., 2006).

### **Philosophical Perspective**

CBPR is an umbrella term for many organizing frameworks that include action research, community-based research, participatory-action research, feminist participatory research, and partnered participatory research (Minkler & Wallerstein, 2008a). A common assumption among all of these frameworks is the rejection of the positivist paradigm of objective and value-free knowledge development. The epistemology of logical positivism separates the researcher from the object of research and assigns the researcher as the expert knower. Therefore, during the research process, the two distinct entities do not influence one another. In fact, the researcher works diligently to prevent “the truth” from being threatened by his or her values and biases (Guba & Lincoln, 1994). In contrast, action research, based on a participatory worldview (Reason & Bradbury 2008), stems from a critical theory paradigm (Guba & Lincoln, 1994). The ontology of critical theory views the shaping of reality by social, political, cultural, economic, ethnic, and gender factors (Guba & Lincoln, 1994). These factors mold together to create a reality that is observable through sense data. The epistemology of critical theory is transactional and subjective (Guba & Lincoln, 1994). Knowledge development is an “explicitly political, socially engaged, and democratic practice” (Brydon-Miller, Greenwood, & McGuire, 2003, p. 13). Humans and their communities are continually interacting, allowing their ability to self-reflect and collaborate on encountered real world problems (Susman & Evered, 1978). Action research seeks to produce practical knowledge that is useful in the everyday real world (Reason & Bradbury, 2008). This practical knowledge will in turn increase the economic, psychological, political, and spiritual well-being of the individual and the community. Thus, new knowledge informs problem-solving attempts to right the wrongs of a community, emancipation from historically bound constraints is achieved (Guba & Lincoln, 1994; Susman & Evered, 1978).

### **Strengths of CBPR**

Several benefits emerge from a CBPR approach. First, CBPR ensures that the research topic originates from the community and is not forced onto the community by an outside researcher (Viswanathan et al., 2004). This in turn increases the relevance and applicability of research findings to a wide span of community members. Second, CBPR allows a coupling of the unique and intimate knowledge of community members with the expert skills of academic researchers (Israel, Schultz, Parker, & Becker, 2001). This will result in “improved quality, validity, sensitivity, and practicality of research” (Israel, Parker et al., 2005, p. 1464) and enhanced “conceptual robustness and explanatory utility” (Viswanathan et al., 2004, p. 23). Third, the involvement of community members in CBPR allows research methods to be “context sensitive and culturally relevant” (Viswanathan et al., 2004, p. 23). Finally, the equality of partners involved in CBPR encourages the development of trust, because those who formerly would have been subjects of research are now active participants in a research process that will directly benefit themselves and their community (Israel et al., 2001).

The number of studies that have used CBPR has increased considerably since 2000, and it is predicted that this approach will continue to be a popular choice for public health researchers (Minkler, Blackwell, Thompson, & Tamir, 2003; Tandon et al., 2007; Viswanathan et al., 2004). In CBPR, a major deviation from traditional scientific research is to sustain a project that is “community based, rather than merely community placed” (Minkler & Wallerstein, 2008a, p. 5). In a traditional scientific approach, research questions and interventions are developed through generalized study findings and may not translate well into the context of all communities (Wallerstein & Duran, 2010). However, when a community is involved in identifying the research focus, data collection, and analysis, the execution and effectiveness of interventions



improve. For example, CBPR was used to develop, implement, and evaluate the interventions used to reduce HIV risk in a group ( $n = 911$ ) of Filipina female bar workers (Morisky, Malow, Tiglao, Lyu, Vissman & Rhodes, 2010). Key informant interviews, using an interview guide developed with community members, and a community needs assessment informed the intervention of peer education and manager training. Based on the prioritization from the community, three interventions focused on teaching the female bar workers to negotiate condom use with customers, increasing comfort in discussing sensitive issues, developing educational materials, and enforcing the proper use of condoms. Behavioral outcomes were measured by participant HIV and sexually transmitted infection (STI) testing, receiving results of this test, and consistent use of condoms (measured by self-report using a six-item scale,  $\alpha = 0.82$ ).

Female bar workers and bar managers from the community volunteered to be trained as leaders of a distinct intervention group. Three intervention groups were compared to each other (peer-led, manager-led, combination of peer- and manager-led) and to a nonintervention group (standard of care.) A five point likert scale was used to measure consistent condom use ( $0 =$  never use to  $5 =$  always use). A two-year point of evaluation demonstrated that the intervention group combining peers and managers ( $n = 418$ , mean score 3.04, SD 1.87) significantly increased ( $F = 51.07$ ,  $p < 0.000$ ) the likely hood of consistent condom use compared to the nonintervention group [ $n = 141$ , mean score 1.70, SD 0.97] (Morisky et al., 2010). Additionally, 93.78% ( $n = 418$ ) of this combination group had been tested and received their testing results compared to 85.33% ( $n = 150$ ) of peer only, 84.65% ( $n = 202$ ) of manager only, and 51.06% ( $n = 141$ ) of the nonintervention group. The collaborative partnership of researchers and community workers, and the use of community resources (i.e. bars, local businesses, and local hotels)

contributed to the increase use of condoms and HIV and STI testing in a community that had been identified as high risk for infection.

### **Principles of CBPR**

There is no single correct way to conduct CBPR, because methods that work in one community may not work in others (Rhodes, Malow, & Jolly, 2010). Generally, institutional researchers and community leaders come together with a goal of uniting the community in an equal and collaborative partnership that will result in a co-learning experience for all partners. Direct benefits are focused on the community. Sustained partnerships provide institutional researchers an opportunity to rejoin community members in future research projects. With the emphasis on a collaborative partnership guiding CBPR, the use of the following principles (Israel, Eng et al., 2005) is recommended for organization and decision-making throughout all steps of the research process.

#### **Community as a unit of identity.**

Communities participating in CBPR are defined by “a sense of identification with and emotional connection with others through common symbol systems, values, norms, shared interests and commitments to meeting mutual needs” (Israel, Eng et al., 2005, p. 7). Moreover, it is vital that the definition of community come from within the community itself, and not from outside researchers or organizers (Israel, Parker et al., 2005; Minkler & Wallerstein, 2008b). For the proposed study, the community of identity will include self-identified lesbian, gay or bisexual college students in the local Worcester community. Informal discussions with community members about the three-fold concept of sexual orientation lead to the

recommendation that their community identity was best defined by the domain of self-identity (lesbian, gay, or bisexual), versus behavior or attraction.

Common research partnerships include community members (both affected and not affected by the identified issue), organizations, and academic institutions (Rhodes et al., 2010). However, communities may benefit from individuals or groups with complementary skills and resources (Israel, Parker et al., 2005). For example, while examining the factors associated with the use of free condoms by self-identifying gay men, CBPR was helpful in establishing an extensive community partnership that consisted of, (a) an academic institution representative, (b) lay community members, (c) community-based organization representatives, (d) the local public health department, (e) a local community college, (f) gay bars within the state, (g) the statewide lesbian, gay, bisexual and transgender pride association, (h) a black university, (i) a lesbian, gay, bisexual, and transgender health center, and (j) a university health sciences department (Rhodes, Hergenrather et al., 2007). In all partnerships, large or small, the partners must approach the community with an asset-building approach (McKnight & Kretzmann, 2008). That is, instead of recognizing the needs, deficits, and weaknesses of the community, the partners identify the community's strengths, skills, and resources so that they may be used as building blocks in the community development.

### **Building on the strengths and resources of the community.**

Communities possess various capacities, skills, and assets, which are identified and accessed during the research process (Israel et al., 2008; McKnight & Kretzmann, 2008). The theory behind identifying a community's strength and resources is based on evidence that community development flourishes when local members are invested and community resources

are utilized in the process (McKnight & Kretzmann, 2008). Community strengths include community leaders who assist the researcher to access, recruit, and engage community members, and the existence of naturally occurring areas of congregation for the community members (i.e., religious buildings and community-based organizations). Research conducted by Operario, Smith, Arnold, and Kegeles (2010) sought to reduce the HIV-related risk behavior in a group of African American men who have sex with men and women (MSMW) in a California community. Knowing that these individuals often do not identify their same-sex attraction, community mapping (McKnight & Kretzmann, 2008) was used to identify venues frequently visited by MSMW (i.e., nightclubs, bars, and public sex environments). These locations provided recruitment arenas where outreach workers maintained a presence, allowing eligible community members to be identified and approached in a safe and respectful manner. The use of African American outreach workers, who understood the cultural dynamic and implications of leading a secret same-sex lifestyle, is an example of the researchers promoting a collaborative relationship within the community (Operario et al., 2010).

A needs assessment of the lesbian, gay, bisexual, and transgender community in Worcester was conducted in 2006 (Greater Worcester Community Foundation, 2006). To complete this assessment, 376 individuals and 58 organizations completed a web-based survey, ten key informants were interviewed, and four focus groups were conducted with various members and organizations within the community. Individual surveys were conducted with a sample ( $n = 376$ , age range = 12-80 years, mean age not reported) of lesbian (32%), gay (37%), bisexual (13%), transgender (6%) and heterosexual (12%) members of the local Worcester community. Organizations ( $n = 58$ ) who served the lesbian, gay, bisexual, and transgender community were also surveyed. Examples of organizations include those that provided the

following services: (a) educational (53%), (b) human (50%), (c) youth support (34%), (d) community organizing (22%), (e) recreational (22%), (f) advocacy and policy (21%), (g) family and parenting (21%), (h) mental health (21%), (i) substance abuse (17%), (j) housing (17%), and self-help (15%).

Four focus groups were convened; consisting of one youth group, one transgender group, a combination of lesbian and gay men's group and a needs assessment committee group (no data are available about the demographic makeup of these focus groups). Focus group and individual survey participants most frequently cited "open and supportive religious institutions in the [Worcester] County" as a perceived strength in the local community (Greater Worcester Community Foundation, 2006, p.15). Additional community strengths identified in this needs assessment included (a) the growing number of openly gay people in the community, (b) organizational efforts around advocacy issues, (c) participation in gay marriage advocacy efforts, (d) the improvement of the city of Worcester's Gay Pride event, (e) The Pulse, Worcester's lifestyle and entertainment magazine, and (f) inclusion of gay people within Worcester's power structure (Greater Worcester Community Foundation, 2006). These strengths were reviewed and corroborated by the proposed study key informants and several members from the Worcester State University Pride Alliance who provided the principle investigator with a summary of identified strengths. This information was then used to inform proposed research decisions. For example, the recruitment of research participants utilized the various lesbian, gay, and bisexual advocacy organizations within the colleges of the Worcester Consortium (COWC).

### **Equitable and collaborative relationship.**

Traditional research paradigms are based on the power structure between researcher and research participants. Power tends to accumulate in the hands of those who develop knowledge, access knowledge, identify problems, and mobilize research methods and participants to study the problem (Viswanathan et al., 2004). Community-based participatory researchers acknowledge these power imbalances and diligently work with community members at all stages of the research to equalize the power structure. As a result, community members become invested in the research, which in turn develops a sense of ownership (McIntyre, 2008). Additionally, community members, previously intimidated by the power hierarchy in research paradigms, may identify unexplored areas valuable to researchers (Minkler, 2005).

Developing a collaborative and equitable relationship requires time and commitment by all members of the research team (Cargo & Mercer, 2008). Successful collaborative relationships enhance the research process and generate findings more meaningful to the community (Pinto, McKay, Escobar, 2008). Community members have reported that a focus on building relationships and developing trust should occur prior to engaging in the research process (Pinto, 2009; Pinto, McKay et al., 2008). Additional recommendations for successful collaboration include attending community meetings and learning the demographics of the community (Pinto, McKay et al., 2008).

In the fall of 2009, my relationship with the Worcester State University Pride Alliance began. As an outsider, I came to this community with perspectives that were informed by my prior clinical work (Story, Hinton, & Wytan, 2010) with lesbian, gay, bisexual, and transgender persons. Pinto (2009) speculated that a researcher's characteristics, manners, availability, trust

and understanding are factors that affect the ability to create a collaborative relationship with a community. By maintaining transparent intentions of my goal as a researcher, I worked diligently to demonstrate a caring and professional relationship by attending informal meetings and other Pride Alliance sponsored events (Story et al., 2010). My goal has been to establish a trusting relationship with the community, allowing open discussion about their issues. I was reassured that this relationship had developed when the Pride Alliance voted me to be their new faculty advisor for the academic year 2010-2011. This appointment helps with the difficult task of sustaining trusting relationships when conducting CBPR (Story et al., 2010) and offers me the learning process necessary in CBPR.

#### **Co-learning and capacity building.**

A collaborative partnership consists of various members with different talents, skills, and knowledge (Israel, Parker et al., 2005). The reciprocal sharing of these skills among partners provides a learning opportunity for all involved in the research process (Israel, Eng et al., 2005). For example, the personal knowledge of community members provides institutional researchers with a contextual and cultural understanding of the community and in return, knowledge is transferred from institutional researcher to community participants (Israel et al., 2008). This transfer may include skills in problem definition, assessment, research, intervention development, implementation, and evaluation, all of which can strengthen community capacity (Burdine et al., 2010). The co-learning experience within the partnership is an essential component of successful community capacity building (Cargo & Mercer, 2008).

Community capacity is defined by the characteristics of the community that affect its ability to identify, mobilize, and address issues (Minkler, 2008). Chinman et al. (2003) outlined

four domains of community capacity: (a) bonding of community members with the community-at-large and other members, (b) acquiring skills to implement or sustain an effective action, (c) mobilizing necessary resources to achieve community goals, and (d) developing the power and efficacy to apply these skills and resources to achieve benefits for the community. Community members who actively lead by engaging in social networks and accessing power structures (Minkler & Wallerstein, 2008b) provide effective vehicles for building community capacity. As described by Pinto, Menendez, and Spector (2008), male to female (MTF) transgender individuals were able to establish a social network of exchanging necessary goods, services, and information within their safe environment that allowed community members to pursue and maintain a feminine identity. These necessities are often expensive and difficult to access. Therefore, by building on the community capacity, the hidden population of transgender persons was able to access, through MTF community members, hormone medications and other feminizing procedures (Pinto, Menendez, et al., 2008).

One aim of the current study was to develop a mechanism of action to facilitate the healthcare experience of LGB college students in the local Worcester area. This action was derived from an exploration of the factors that influence the healthcare experience for LGB college students. Members of the community who participated in the research partnership assisted in data analysis, thereby increasing the ability of the community to articulate, address, and overcome the barriers that affect health issues of importance (Labonte, Woodard, Chad, & Laverack, 2002). This vital community building block of social advocacy has the potential to influence larger constituents (Gunther, 2008); hence, promoting social change in the community.



### **Knowledge gain and generation of interventions.**

Research findings present new understandings of phenomena allowing immediate feedback from community members to inform action decisions and refine interventions to best meet community need (Viswanathan et al., 2004). This delicate balance of generating new knowledge for direct community benefit is a central tenet of CBPR (Israel, Eng et al., 2005). Such community benefits include political activism, development of community-based interventions, and change in clinical practice that will directly benefit the community (Tandon et al., 2007). CBPR with transgender persons in San Francisco led to the Transgender Community Health Project (Clements-Nolle & Bachrach, 2008). The goal of this project was to estimate the prevalence of HIV and HIV-related risk factors in the San Francisco transgender community. Findings from the research were presented immediately back to the community, and local public health departments (part of the CBPR team) were able to allocate funding for continued research and community-specific interventions focused on the transgender persons of San Francisco. As the Transgender Community Health Project continued, data were used by local human rights committees to prevent discrimination against transgender persons in healthcare and policy changes in transgender healthcare for city employees (Clements-Nolle & Bachrach, 2008).

A key task in the proposed partnership will be to equalize the power imbalance between the researcher (a faculty member on campus) and members of the LGB community (consisting of students on this campus) to promote the knowledge-generating process. By reducing “the „researcher“ and „researched“ distinction common among the traditional research stance” the integration of “knowledge and multiple perspectives results in better research” (Boser, 2007, p. 1064).

### **Ecological focus on public health problems.**

CBPR focuses on the multiple determinants of health and disease, including “biomedical, social, economic, cultural and physical environmental factors” (Israel, Eng et al., 2005, p. 8). In the current study, several determinants of health were explored as conceptualized by Kilbounre et al. (2006). The influential determinants include, but were not limited to, a focused discussion on the various factors (i.e. healthcare system, patient, provider, and clinical encounter) that contribute to access and utilization of healthcare and those cultural and environmental factors that influence an individual’s decision to disclose their sexual orientation to a healthcare provider. These factors emerged from a review of the scientific literature and discussions with the target community (see Chapter One).

Health concerns identified for research studies must come from within the community. However, the academic researcher must possess interest and skill in the topic chosen to complement the community expertise (Rhodes et al., 2010). In the event that the outside researcher comes into the community with a focus, it is imperative that the researcher determine whether this concern is also of high priority to the community (Minkler, 2004). Because the goal of the research is to strengthen and empower the community, selection of the health topic to study is a delicate decision. If the research question is controversial, the research process may further divide an already segregated community (Minkler, 2004). In the current research study, the principle investigator approached the community of interest with several health related topics of interest and the conceptual model of Kilbourne et al. (2006). An informal conversation with the Worcester State University Pride Alliance focused on the clinical encounter factor of health disparities in the LGB community. Members of the Alliance shared stories of disclosing their sexual orientation to their primary care provider, and described many of the influencing factors

found in the literature as facilitating or impeding this process. As the principle investigator listened to these stories, patterns and themes emerged. The PI asked The Alliance to prioritize these themes into research questions that they believed would most benefit the community. A unanimous vote identified that studying the healthcare experience of LGB college students would help the research team identify a potential mechanism to facilitate a positive healthcare experience in the future.

CBPR has been used in research studies that focus on environmental health (Minkler, Vasquez, Tajik, & Peterson, 2008), childhood obesity (Goh et al., 2009), HIV (Griffith, Pichon, Campbell, & Allen, 2010; Rhodes et al., 2010; Weeks et al., 2010) and improving cardiovascular health (Farag, Moore, Thompson, Kobza, Abbott, & Eichner, 2010). CBPR has been successfully conducted in communities of gay, lesbian, bisexual, and transgender individuals (Dodge, Reece, Herbenick, Fisher, Satinsky, Stupiansky, 2008; Pinto, Melendez, et al., 2008; Rhodes, Eng et al., 2007), children (Israel, Parker, et al., 2005), Native American tribes (LaVeaux & Christopher, 2009), and rural Midwest Hispanic immigrants (Cristancho, Garces, Peters, & Mueller, 2008).

### **Cyclical and iterative systems approach.**

The empowering process of CBPR prepares community members to participate in activities that will identify priority needs of the community and then follow up with dialogue and investigation to improve this priority (Viswanathan et al., 2004). By involving community members throughout the research process, and allowing their expert knowledge of the research question to inform research methods, the resulting interventions and community benefits are more effective (Viswanathan et al., 2004). As community members become involved in the data

analysis, their contribution strengthens understanding of the emerging themes and findings (Minkler, 2005).

### **Dissemination of results.**

Research results are disseminated to all members of the research team in a manner that is “understandable, respectful, and useful” (Israel, Eng et al., 2005, p. 9). Community members should have a primary role in deciding how findings, including their own responsibility and involvement, will be disseminated to the scientific community. Examples of public and scientific dissemination include policy advocacy, media reports, scientific papers, manuscripts, and presentations. According to Viswanathan et al., (2004), dissemination has three goals. First, community actions are implemented that are context-specific and culturally relevant, which allows greater benefit to the target community. Next, instrumental application helps to design and apply community-directed interventions that focus on social change. Finally, persuasive application identifies how social structures, policies, and other hierarchal controls influence the health and well-being of the community.

The researcher and the key informants have agreed dissemination of the findings from the current study will include, at a minimum, the researcher’s doctoral degree requirements (dissertation and one peer-reviewed publication) and immediate feedback to the community via presentation by researcher and two key informants. Key informants are acknowledged in the doctoral dissertation. Co-authorship of manuscripts will be based on the manuscript submitted and the amount of contribution provided by the key informants for that particular submission. Process and formative evaluation of the study’s findings by the community will address

strengths, weaknesses and areas of improvement (Story et al., 2010). This evaluation will inform further research studies and encourage the sustained action.

### **Long-term sustainability.**

True participatory research is sustained beyond a one-time research project (Schmittiel, Grumbach, & Selby, 2010). This sustainability refers to either community actions or research partnerships. Israel et al. (2006) outline three dimensions of sustainability that include (a) sustaining the commitment of the partnership, (b) sustaining the generated knowledge and increased community capacity, and (c) sustaining funding, partners, programs, and policy changes.

To maintain sustainability of the partnership in the current study, it was important to “get the right people around the table” (Israel et al., 2006). This included evaluating present community members for their commitment to the task as well as establishing relationships with new community members. Additionally, maintaining an allegiance to the Pride Alliance offers the opportunity for member growth (Israel et al., 2006), especially as current members graduate from the college and new members enter the campus organization. The organizational relationship also encourages the sustainability of the knowledge generated from the current study. Creating an advisory committee of leaders within the Pride Alliance helps guide dissemination and ensure that the capacity and knowledge gained by the organization is not lost when the key informants are no longer involved with the organization (Israel et al., 2006). Finally, CBPR should not be conducted as a sole research study (Israel et al., 2006). Lessons learned, strengths identified, and skills attained from the current study will inform and be utilized in further research to benefit the LGB community. Additionally, as dissemination occurs,

awareness to external healthcare stakeholders may provide the opportunity for future funding of studies.

### **Exemplar of CBPR**

An exemplar of CBPR is found in the work of Scott Rhodes. The team of Rhodes, Hergenrather, Wilkin, Alegria-Ortega, and Montano (2006) conducted eight focus groups to explore the sexual health of male Latinos in an urban North Carolina community. Electronic media and frequented venues, including recreational sporting events, were identified as effective avenues to disseminate HIV-prevention education. The information provided by community members during these focus groups informed the research process and led to two beneficial interventions for the Latino male community in North Carolina. First, Cyber-Based Education and Referral/Men for Men (CyBER/M4M) was developed and has been a successful community intervention to address the online chat-room recruitment of sexual partners by gay men and men who have sex with men [MSM] (Rhodes, Hergenrather, Yee, & Ramsey, 2008; Rhodes, Yee, & Hergenrather, 2006). Second, Hombres Manteniendo Bienestary Relaciones Saludables (HoMBREeS) was developed to create an intervention that utilized lay health workers to address the growing incidence of HIV and STD infection in a North Carolina community of newly settled Latino immigrants (Rhodes, Hergenrather, Montano et al., 2006). As suggested by the partnership, county soccer leagues provided access to Latino males who provided useful information regarding correlates of condom use (Knipper, Rhodes, Lindstrom, Bloom, Leichliter, & Montano 2007). This soccer venue proved to be a plausible resource in the Latino community to design, implement, and evaluate interventions seeking to reduce sexual risk in Latino men. Additionally, the training of lay community health workers (Rhodes, Foley, Zometa, & Bloom,

2007; Vissman et al., 2009) acknowledged the community assets of leadership and built community capacity that will enable sustainable action in the North Carolina Latino community.

### **Conclusion**

CBPR is a collaborative approach to research that focuses on building and sustaining partnerships between institutional researchers and the target community. There is no single way to perform CBPR. However, partners are required to assess their values and agree on a set of guidelines that will inform and strengthen each step of the collaborative process. Applying the principles of CBPR (Israel, Eng et al., 2005) in the iterative and formative research process with an LGB young adult community, allowed the skilled researcher to empower a community towards action that will directly benefit its future healthcare experiences.

### **Operational Definitions**

The following list of operational definitions will be used in this study:

College student: An individual (ages 18-24) attending a 2- or 4- year college or university, part- or full-time.

Healthcare experience: The individual experience of accessing, participating, and receiving healthcare from a healthcare provider.

Healthcare provider: A medical doctor, physician assistant, advanced practice nurse, or mental healthcare provider.

Heterosexual-assuming language: The use of language that assumes someone is heterosexual (e.g. asking a male if he “has a girlfriend”).

Key informants: Members of the target community who possess an intimate knowledge of the issue under study.

Mechanism of action: Social change efforts arising from the knowledge gained from CBPR for that address the priority concerns of the participating community.

Online synchronous focus group: A group of individuals who are online at the same time and discussion among the group is immediate. When one person types a response, text pops up on the computer screen for other group members to read and respond.

Self-identified gay, lesbian, or bisexual individual: A person who describes herself or himself as a lesbian female, gay male, bisexual male or bisexual female.



## Chapter Three

### Methods

#### Introduction

This study used CBPR to describe the healthcare experience of LGB college students. This chapter will describe the methods used to conduct this CBPR study and will include a description of the sampling procedures, data management, data analysis, trustworthiness, and human subject considerations. A thorough description of synchronous online focus groups will be presented.

#### **Design**

Community-based participatory research uses either, or a combination, of quantitative and qualitative methods to collect data. Methods of inquiry are closely linked to the researcher's philosophical perspective, study aims and the element of analysis (Hunter, Lusardi, Zucker, Jacelon, & Chandler, 2002). There are several forms of realism. However, a core assumption among realists is that reality exists independent of the human mind (Frauley & Pearce, 2007). This view is in opposition to constructivism, which acknowledges reality as dependent on the perspective of the observer (Mir & Watson, 2000). Bhaskar's (1998) form of critical realism acknowledges both positions by stratifying the natural and social world into three domains, the real, the actual, and the empirical. Reality (the real domain) exists whether or not acknowledged or experienced by the individual. This reality interacts with the power and structure of mechanisms to produce an event (the actual domain). Identifying this event and the influencing power structure is the goal of scientific inquiry (empirical domain). This form of critical realism lends itself to study of the natural world as well as analysis and critique of social practices and

related theories influencing reality. In this study, LGB college students' healthcare experiences combine both natural (e.g., health and the need for care as natural consequences of biophysical constitutions) and socially produced world (e.g., health and healthcare experiences as affected by education, oppression, and social power). From this perspective, the power inherent in social structures and practices may or may not be exercised in an event or experience. The recognition of latent power (for good) underpins the community-based participatory approach of the current research, because the research intends emancipatory action (an exercise of power) by the community.

Further, Bhaskar's (1998) critical realism permits the selection of research methods appropriate to realist and constructivist approaches to develop knowledge of the stratified domains of reality. Therefore, the selection of a qualitative methodology, specifically, the collection of narrative data via online focus groups, is consistent with this critical realist perspective. Thus, the goal of this research was to examine this underlying social interaction, characterize and describe what was observable, and probe for the unobservable (Frauley & Pearce, 2007). By using CBPR, the college students' healthcare experience was grounded in the reality of community participants, allowing knowledge gained to be more readily applied to benefit the health and well-being of community members (Northbridge, McGrath, & Krueger, 2005).

### **Online Synchronous Focus Groups**

This study used computer-mediated communication (CMC), in the form of real time synchronous online focus groups. Online synchronous focus groups allow a group of invited individuals to access a private online environment where group discussion is interactive and

immediate. When one person types a question or response, text pops up on the computer screen allowing other group members to read and respond in his or her own post.

Online focus groups are an effective strategy to access participants that are hard to recruit due to confidentiality concerns, or when the study addresses sensitive topics such as sexuality (Sweet, 2001). Therefore, online focus groups were useful to gather qualitative interview data from LGB participants who may have otherwise been hesitant to participate due to fear of disclosure. Synchronous online focus groups mimic the group interaction of face-to-face (FTF) focus groups, without the worry of having to sit in a room visually exposed to other participants. Online focus groups increase the ability to maintain a participant's anonymity, which has demonstrated easier disclosure of personal and sensitive information (Ayling & Mewse, 2009). For example, an online study conducted with a sample of gay males reported their appreciation of the anonymity provided by CMC when discussing specific sexual practices (Ayling & Mewse, 2009). In another example, young people (ages 11-18 years), with chronic skin conditions, were finally able to participate in research because CMC provided them protection from being seen by other focus group members (Fox, Morris, Rumsey, 2007).

The implementation of CMC in this study was feasible. First, Lenhart, Purcell, Smith, & Zickuhr (2010) reported data from The PEW Internet and American Life Project that estimated 93% of young adults (ages 18-29 years old) access the Internet. Second, lesbian, gay, and bisexual individuals are common users of Internet chat rooms, discussion boards and listservs (Riggle, Rostosky, & Reedy, 2005). Third, most college campuses belonging to the Colleges of The Worcester Consortium [COWC] (2010) require enrolled students to purchase a personal laptop as part of admission into the college. Therefore, access to the Internet, computer skills,

and familiarity of posting in a chat room were likely to be common practices among the research participants.

## **Sample**

The sample for this study included 19 LGB college students (ages 18-24 years). Because the healthcare experience of lesbians, gays, and bisexuals have been described as different and with varying factors affecting each of the groups (see Chapter One for details), this study segmented focus groups into exclusive groups of gays, lesbians, female bisexuals, and male bisexuals. This allowed the principle investigator (PI) to analyze the healthcare experience within and across the groups. Describing the healthcare experience for each group allowed the CBPR team to develop a mechanism of action directed towards the specific needs of that group as well as general actions that will benefit the entire LGB community. The PI and key informants attempted to recruit at least 10 college students to participate in each of the four focus groups, with a goal of achieving a sample of 6-8 participants in each synchronous focus group session. This number is based on Krueger and Casey's (2008) recommendation to over sample by 50% when recruiting for focus groups. Having too few participants in a group results in a lack of diverse ideas shared between members, whereas, a large group potentially creates isolation among some of the members who are unable to navigate the dialogue pauses and voice their opinion (Krueger & Casey, 2008).

Based on the recommendation of Krueger and Casey (2008), four focus groups were planned to allow ample data for within and across group data analysis. The PI determined that data saturation had been reached when no new data and no new insight to the research question was heard (Krueger & Casey, 2008).

Inclusion criteria for the study were:

1. Self-identified lesbian, gay, or bisexual individual,
2. 18 to 24 years of age,
3. Full or Part time student attending one of thirteen Colleges of the Worcester Consortium (includes 2-year, 4-year, and colleges with graduate schools),
4. Access to a computer and the Internet,
5. Working knowledge of basic computer skills (i.e. ability to check email, log into a secure website with a username and password, type in a chat room),

The exclusion criteria for the study were:

1. Unable to read or write in English,
2. Transgender or questioning individual,
3. Participation in the pilot study.

### **Setting**

LGB college students were recruited from the COWC (The Consortium), a not-for-profit organization comprised of 13 governing member institutions (Anna Maria College, Assumption College, Atlantic Union College, Becker College, Clark University, College of the Holy Cross, Cummings School of Veterinary Medicine, Mass College of Pharmacy and Health Sciences, Nichols College, Quinsigamond Community College, University of Massachusetts Worcester, Worcester Polytechnic Institute, Worcester State University) in central Massachusetts (COWC,

2010). The mission of The Consortium is to support member institutions in advancing their organizational missions and provide the Worcester region with quality higher education. The Consortium achieves these goals by acting as a hub for academic partners to share resources and explore issues related to higher education, provide higher educational opportunities to low income and disadvantaged students and adults, and promote a collaborative relationship between member institutions and local, state and federal government. The vision of The Consortium is to promote the Worcester area as a premiere destination for undergraduate and graduate students and faculty (COWC, 2010).

In the fall 2009, there were 27,248 undergraduate students enrolled in the colleges that make up The Consortium (COWC, 2010). The mean age of students ranged from 20 to 27 years old (COWC, 2010). The majority of enrolled students are Massachusetts residents (COWC, 2010), with 6,612 residing in the City of Worcester, 16,382 residing in Worcester County, and 25,033 residing in Massachusetts. In total, 29,244 students come from the New England area while only 3,944 come from out of New England (COWC, 2010). There are currently 1,831 International students enrolled in the COWC. The composition of minority students in The Consortium compared to the City of Worcester is similar for Asian Pacific Islander and American Indian/Alaskan Native races, however, the Hispanic and black representation in The Consortium is almost one quarter that of the City of Worcester (See Table I).

Table 1

*Comparison of the Minority Population in the Colleges of the Worcester Consortium to the City of Worcester*

Minority Group	The Consortium* ( <i>N</i> = 27,248)	City of Worcester** ( <i>N</i> = 163,637)
Asian Pacific Islander	<i>n</i> = 1157 (4%)	Asian <i>n</i> = 8,911 (5.4 %),
Native Hawaiian/Pacific Islander	no data	<i>n</i> = 398 (0.2%)
Black, Non-Hispanic	<i>n</i> = 1,516 (5.5%)	<i>n</i> = 14,750 (9%)
Hispanic, Latin American	<i>n</i> = 1,533 (5.6%)	<i>n</i> = 31,596 (19.3%)
American Indian/Alaskan Native	<i>n</i> = 108 (0.4%)	<i>n</i> = 474 (0.4%)

\*Data collected from COWC fall 2009 enrollment

\*\*Data collected from 2006-2008 American Community Survey (U.S. Census Bureau, 2010)

The City of Worcester is the second largest city in Massachusetts, spanning over 37 square miles (City of Worcester, 2010). The Office of Economic and Neighborhood Development cites that Worcester strives to create a welcoming environment for both residential and business living (City of Worcester, 2010). Approximately 182,500 people with over 30,000 college residents currently populate the city and there are 3,476 city based businesses (City of Worcester, 2010).

Nine colleges within The Consortium have active student organizations that serve lesbian, gay, bisexual and transgender students (Anna Maria College, Assumption College, Becker College, Clark University, College of the Holy Cross, Quinsigamond Community College, University of Massachusetts Worcester, Worcester State University, and Worcester Polytechnic College). Members of these campus organizations were targeted by the key informants during campus events and campus visits. The PI contacted the Director of Student

Activities (or the equivalent on each campus) for those campuses without specific LGB organizations (see recruitment on p. 54).

### **Key Community Informants**

“Key informants are an expert source of information” (Marshall, 1996). Tremblay (1957) outlined five criteria for selecting key informants. One, the key informant should have a role in the community of interest that will provide continuous exposure to the desired information. Second, the key informant should have direct access to the desired information and be able to absorb meaning from that information. Third, the key informant should be willing and able to share this information. Fourth, the key informant’s communication skills should allow for intellectual dialogue. Finally, key informants should maintain an impartial position and willingly disclose personal biases to the researcher. This study had two key informants who best fit these criteria.

One key informant is a 20-year-old male who attends Worcester State University. He is working towards a degree in psychology and has found a recent passion in political work. As former president of the Worcester State University Pride Alliance (a student organization servicing lesbian, gay, bisexual, transgender [LGBT] persons and allies on campus), this key informant was involved in many projects that directly benefited the LGBT community on campus and demonstrated a commitment to community organizing and capacity building on the University campus. As a psychology major, this key informant has completed an Introductory to Research Methods class as well as an Applied Research Study class. The PI approached him in the fall of 2009 because his insight into the various barriers faced by LGB individuals seeking healthcare provided necessary expert knowledge (see Chapter Two for details).



The second key informant is a 20-year-old female. She is also a student at Worcester State University and looks forward to a future working in community health. In the spring of 2010, after she offered an insightful female perspective to the healthcare experience of LGB college students, the PI invited her to become a key informant for the current study.

The key informants participated at all levels of the research process. This included having a vital role in recruiting LGB college students to participate in the synchronous online focus groups, analyzing focus group transcripts, assisting with member checks, and developing a community action to improve the healthcare experience of LGB college students. The key informants will also serve as liaisons to the community during study dissemination and will co-author manuscripts. Additionally, as collaborative members of the research team, in return for their expert knowledge of the issue, the key informants learned various research and community organizing skills. Both key informants received formalized human subject protection training via University of Massachusetts Medical School (UMMS) Collaborative Institutional Training Initiative.

### **Community partners.**

The partnership of researcher and community representative (i.e., individuals, organizations) differentiates community-based research from community-based participatory research (Israel, Schultz, Parker, & Baker, 1998). In community-based research, the researcher conducts a study in a community setting, or with members of the community. In community-based participatory research, the researcher and community members have an equal responsibility to combine their unique talents and strengths to understand a community phenomenon. The result of community-based participatory research is an action that will have

tangible benefit to community members (see Chapter Two). In this study, two key partnerships existed: (a) between the PI and the COWC and, (b) between the PI and the Worcester State University Student Activities Department. In addition to striving for quality higher education, the COWC supports the research efforts of their faculty (COWC, 2010). The PI is a faculty member on the campus of Worcester State University. The Consortium supported the PI's efforts to pursue this study by offering the full extent of their resources to help the PI identify key community members. The second partnership with the Worcester State University Student Activities Department included access to college students who participate in the Worcester State University Pride Alliance Organization. The mission of the Worcester State University Student Activities Department is to provide a college environment that is conducive to experiences that promote student leadership and organizational skills. One way the department achieves this is to support various student run organizations on campus. Worcester State University Pride Alliance is a major student-lead organization on the college campus. The mission of Pride Alliance is to welcome all students, regardless of self-identified sexual orientation, to a safe campus environment. Pride Alliance invites external speakers to discuss various topics important to the lesbian, gay, bisexual and transgender community. On and off campus activities are organized and executed by the elected officers of Pride Alliance. Three faculty advisors (one of whom is the PI) work with Pride Alliance.

## **Procedures**

### **Recruitment**

Recruitment began after the study received exempt approval from the UMMS Institutional Review Board (IRB). Study participants were recruited by the two key informants

and the PI from the COWC to participate in an online focus group. Purposive sampling was used to recruit participants that met the inclusion criteria, with oversampling of Hispanic LGB college students based on The Consortium's demographic. The key informants recruited study participants during organized events with the nine Consortium campuses that have active student organizations servicing their LGB students. During these events, key informants distributed IRB-approved information pamphlets inviting community members to participate in an online focus group. The pamphlet described the purpose of the study and contained the contact information of the key informants and PI. Participants were assigned to one of four focus groups as follows: one session for gays, one session for lesbians, one session for male bisexuals and one session for female bisexuals.

The recruitment of bisexual college students (male and female) was an anticipated methodological challenge. According to Herek et al. (2010), bisexuals may be a more heterogeneous group than lesbians and gays. Bisexuals may encompass those individuals who “publically identify as bisexual but also those who privately acknowledge same-sex attractions while currently maintaining a heterosexual relationship, and still others who are trying to identify their sexuality” (Herek et al., 2010, p. 195). Additionally, bisexuals tend to attend community-sponsored events less frequently than their lesbian and gay counterparts (Herek et al., 2010). To recruit this hard to reach subgroup of the community, purposive sampling was augmented with snowball sampling. Snowball sampling is used with hard to reach populations and uses the referral of participants to recruit a certain number of additional participants (Goodman, 1961). In this study, potential bisexual participants were asked to recruit three additional bisexual participants for either the male or female online focus group.

The key informant obtained an email address or cell phone number from each potential participant. These students were informed that this information would be shared with the PI. Within 72 hours of notification, the PI sent a confirmation email or text message thanking the individual for volunteering to participate in the study. This correspondence also contained the date and time of the focus group, and the Internet link to access the focus group. Twenty-four hours prior to the designated start time, a reminder email or text was sent to the participants that contained the Internet link to access the focus group.

The PI emailed each faculty advisor of student organizations that serve the lesbian, gay, and bisexual community in the Consortium. Additionally, the Student Activities Directors (or the department equivalent) on the additional four campuses were contacted. The first correspondence was sent via email, with follow-up phone calls made as necessary. The email correspondence included a brief background of the PI and the purpose of the study. Faculty advisors were asked to post an IRB approved pamphlet about the study in the service organization office, and forward an email invitation to members of the organization. In this email, prospective participants were asked to contact either the key informants or the PI by phone, email, or text for further information.








Once the recruitment brochures were distributed to potential participants, many students approached the PI on the Worcester State University campus and asked to join a focus group. The PI used this opportunity to initiate snowball sampling and asked potential participants to contact friends that met the inclusion criteria. The PI emphasized the recruitment of Hispanic LGB college students and students from other Consortium campuses.

## **Conducting Online Focus Groups**

Online focus groups provide an anonymous environment for a group of individuals to share their opinions about a specific phenomenon (Krueger & Casey, 2008; Mann & Stewart, 2006). A benefit of online focus groups is the immediate transcription available to the PI (Mann & Stewart, 2006). Unlike FTF interactions, CMC lacks the visual cues (e.g. head nodding, facial expressions, posture), therefore, “CMC users often incorporate emoticons as visual cues to augment the meaning of textual electronic messages” (Rezabek & Cochenour, 1998, p. 201-2). Emoticons are usually read sideways in text and provide important clues to “subtle and not-so-subtle meaning” (Rezabek & Cochenour, 1998) of written text. Additionally, the use of acronyms to shorten phrases or common verbalized words in FTF conversations are an important aspect of online conversation (see Table 2). The use of paralinguage provides an explicit form of text communication that is free from transcriptional bias (Mann & Stewart, 2006). The use of emoticons and other paralinguage have been commonly used in internet chat and text messaging or instant messaging realms, but have recently crossed over to other CMC including email and word processing software (Boldea & Norley, 2008). Crusader-services© (2010) provides a variety of readily available smile emoticons for quick insertion into online dialogue (see Table 2, bottom line) that prevent the participant from having to turn his or her head sideways to read the emotion.

Table 2

*Examples of Emoticons and Acronyms Used in Internet Language*

:\$ embarrassed	:> mischievous	:“( or ;( crying	:( unhappy,	:) happy	:~) smile	:/ Sarcasm
:o surprised	:? Or :S confused	:@ angry	:L laughing	:p sticking tongue	:X zipped lips	:I Not funny
=.= tired	=X no comment	6_6 suspicious	9_9 rolling my eyes	;O) joking	:() loudmouth, talks all the time	() hugs
A3 anytime, anywhere, anyplace	AAMOF as a matter of fact	AFAIAC as far as I am concerned	AFAIK as far as I know	AFAIR as far as I remember	AHEM throat clearing sound	AIGF all in good fun
AOTA all of the above	BATTY, g@y gay	LES or LESBO lesbian	BIWM bisexual white male	BROMANCE non sexual relationship between two men	2BH to be honest	4RL? for real?
 crying	 embarrassed	 light bulb	 shouting	 arrogant	 confused	 angry

**Moderating online focus groups.**

The PI moderated the focus groups. Ms. Sally Hopper (Owner/President, Crusader-Services), from Crusader-Services© provided the moderator with training on how to effectively use the features of the software. In turn, the PI provided an in-service to the key informants. Additional consulting services and technical assistance were available 24-hours a day. Crusader-Services provided the necessary web-hosting services. A web-host is a company that provides continuous connection to the Internet through servers. These servers locate registered web pages and allow other computers to download the web contents. The software package included the following services that were available to the PI:

1. Pop up one time message to respondents as they enter the room

2. Emoticons
3. On-line Moderator Guide
4. On-line probes and ability to add / change probes
5. Extensive email editor capable of html, graphics, logo, etc.
6. Log of all emails sent out and
7. Thumbnails of graphics
8. Download of transcripts in HTML direct to browser, Plain ASCII text or Spreadsheet ready TSV files. Transcripts include line-by-line time stamps.
9. Sort transcripts by both respondents and researchers or only respondents or only researchers
10. Researchers have access to transcripts immediately.

Both key informants were logged into the focus group as clients. Their role was to assist in deciphering the paralanguage used and to take field notes [i.e. key discussion points, important quotes, observations, and perspective of the group mood] (Krueger, 1998). Field notes are a vital data component in the analysis phase because they provide the necessary contextual data used to enhance qualitative descriptions (Rodgers & Cowles, 1993). An advantage of having them logged into the focus group as a client was the real time conversations that occurred between the key informants and the moderator (PI). While the moderator waited for participants to log into the group or respond to a post, the key informants were able to direct, clarify, or question the flow of the group directly to the moderator without interrupting the flow of the group. The

moderator found it helpful to have a pop up message from a key informant alerting her to the fact that a participant had not responded to that question or had provided conflicting information in a prior statement.

Online focus groups use different strategies to accomplish similar goals found in FTF focus groups. The PI sent potential participants a link via text message that directed the participant to a welcoming message (see Figure 2). In the second focus group, participants were unable to connect to the link that started the study. The moderator, in conjunction with Crusader-Services© scrambled to identify the glitch, but had no success. To prevent the loss of participants, the PI sent a text message to each potential participant and asked for an email address where the study link could be forwarded. All potential participants agreed to provide an email address and all were successfully linked to the study via the welcoming message so that they could provide informed consent. For focus group three and four, when the PI confirmed group details with potential participants, an email address was requested and documented in the event of a similar glitch.

Once connected to the study site, a welcome message appeared. This message included the purpose of the study, the expectations of the focus group session, and the informed consent fact statement (Krueger & Casey, 2008; Mann & Stewart, 2006). Components of the informed consent included an outline of the study's risk and benefit to the participant, a statement that participation in the study is voluntary and confidential, and a statement that at any time the participant may choose to leave the focus group session (Krueger & Casey, 2008). Additional informed consent information included, (a) contact information for local and campus mental health services in the event of distress experienced by participation, (b) contact information for direct access to the PI in the event that a participant requires one-on-one assistance during the



group, (c) an outline of the incentive program, and (d) a statement that all information shared in the focus group is confidential and not to be shared outside the group. Participants were given the opportunity to read the consent and ask the PI questions via phone, text, or email. Informed consent was achieved when the participant clicked on the “agree” button sequentially after the consent post. If the participant did not agree to the terms outlined in the informed consent fact statement, the software generated a message explaining that the session would be terminated and they should log out immediately.

Once the participant pressed, “agreed” to the informed consent fact statement, a survey collected the participants’ demographic information and their choice of community organization to receive an anonymous donation (see Human Subjects Consideration, p. 79). Completion of the informed consent and demographic survey lasted no longer than ten minutes. When the survey was complete, the participant clicked on the “end survey and enter focus group” button. At this time, the participant was assigned a confidential software generated anon link (e.g. Anon455) that automatically generated a username and password for the participant and directed them into the synchronous chat room for the online focus group to begin. Participants were asked to write down their username and password in case they were disconnected from the focus group and need to log back into the focus group. One participant accidentally logged himself out and successfully re-entered the group using this information.

As the participants entered the synchronous room, the usernames popped up on the computer screen. The PI waited for fifteen minutes after the scheduled start time of the focus group session to allow time for study participants to complete the informed consent and the demographic survey. The decision to allow late entrance into the synchronous focus group was at the discretion of the moderator. In one group, a participant had sent the PI a text message stating

that she would be fifteen minutes late for the group. The PI granted permission for the late entrance because of the low number of group participants and because the anticipated entry time was early enough in the questioning, that she could read back on the transcript to catch up with the conversation.

Figure 2. Schematic for Conducting the Synchronous Online Focus Group

Welcoming Message:

Thank you for participating in this online focus group. The main goal of this focus group research is for College students to have an opportunity to discuss their recent healthcare experiences and explore some ideas that might make it more positive in the future. Information provided during this discussion is anonymous and confidential. Stories should not be shared outside this group. In the event that you lose connection to the website, use the link from your email or text message to access the website again. You will be assigned a random username and password by the software, which be unidentifiable.. At anytime during this session, feel free to send me a confidential instant message by pressing on the “access moderator” button in the lower part of your computer screen. A mental health clinician is also available for you to speak with on the phone should you begin to feel distressed. There are two other individuals in the room with me to help take notes. At the conclusion of the session, this discussion is available in a transcript format to the researchers only, to conduct an analysis. Please remember to be respectful of other people’s comments in your responses. Participants whose comments are disrespectful to other group members” will have their session terminated by the moderator. I am going to post the informed consent fact sheet. Please read the consent and directions carefully.

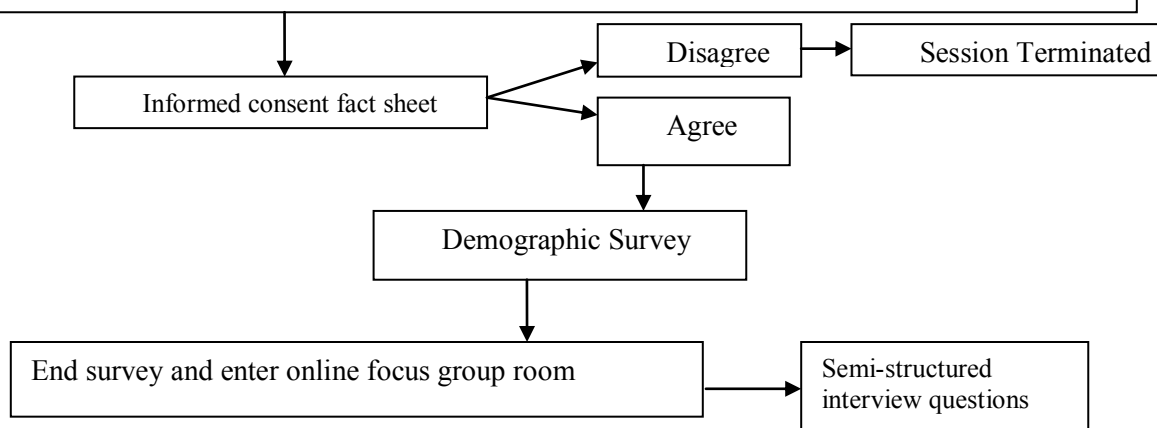


Figure 2. A schematic of the moderator’s welcoming message, followed by instructions to complete the informed consent and demographic survey.

**Debriefing.**

Following each focus group, after the moderator ended the focus group, the PI and key informants had an online debriefing session. This session was vital to capture and document first impressions and highlights of the focus group, and if applicable, compare the group to previously conducted groups (Krueger, 1998). Important questions considered during the debriefing sessions included: (a) What are the most important ideas discussed? (b) Did these points differ from what we expected and from previous groups? (c) Are there points or quotes that need to be included in the final report? (d) Did anything unexpected occur? (e) Do we need to change anything for the next group? (Krueger, 1998). The PI had a peer debriefing session with Dr. Carol Bova (dissertation committee chair) after the first group and the third group. Dr. Bova provided expert assistance in conducting and analyzing focus group data, and provided useful clinical knowledge about the LGB population. All debriefing sessions with the key informants were electronically transcribed by the software and debriefing sessions with Dr. Carol Bova were documented by the PI and used during the data analysis phase of the study.

**Measures**

Four types of data were collected for this study: (a) demographic data to describe the sample, (b) qualitative interviews using a semi-structured interview guide, (c) debriefing session notes, and (d) field notes. Demographic data (see Table 3) was collected via survey after the completion of the informed consent. The survey document was made accessible to the PI through the software upon completion of the focus group.

Table 3

*Demographic Measurements of Sample*

Demographic	Unit of Measurement
Age in Years	Continuous variable
Race	(1) American Indian or Alaska Native; (2) Asian; (3) Black or African American; (4) Native Hawaiian or Other Pacific Islander; (5) White, non-Hispanic, and (6) Hispanic
Marital Status	(1) Single, (2) Partnered, (3) Married, (4) Divorced, (5) Separated, (6) Widow
Years of College Completed	(1) < 1, (2) 1, (3) 2, (4) 3, (5) 4, (6) 5, (7) > 6
Type of Health Insurance	(1) Public, (2) private, (3) school, (4) other,
Date of Last Healthcare Service in Months	(1) < 1, (2) 1-2, (3) 3-5, (4) 6-8, (5) 9-12, (6) 13-18, (7) > 18
Type of Healthcare Provider	(1) Medical Doctor or Nurse Practitioner (2) Physician Assistant, (3) other, (4) unknown
Type of Healthcare Service	(1) Primary Healthcare, (2) Urinary/Gynecological, (3) Emergency Healthcare, (4) Mental Health (5) Specialized Healthcare
Presence of Chronic Illnesses	Listed by participant
Disclosed Sexual Orientation to Provider	(1) Yes, (2) No
Self-identified sexual orientation	(1) Lesbian, (2) Gay, (3) Male Bisexual, (4) Female Bisexual

A semi-structured interview guide was used to conduct the focus group interviews (see Table 4). This guide was developed by the PI and members of the Worcester State University Pride Alliance after a thorough literature review. Key informants reviewed these questions for clarity, length, dimension and direction (Krueger & Casey, 2008). The semi-structured interview guide was finalized after completing the pilot study.

Table 4

*Semi-Structured Interview Guide for Synchronous Online Focus Group*

Aim	Question	Probe
Explore factors (e.g. healthcare system, provider, patient, clinical encounter) on the healthcare experiences of LGB college students (ages 18-24) in the local community.	Please describe what your healthcare experience has been like?	What were some of the things that made this a good or bad experience?
	What has it been like for you as a college student to get healthcare?	How is this experience different from when you were younger?
	Please describe any problems that you have faced when getting healthcare?	How did you deal with these issues? Insurance? Availability of healthcare provider? Was there something about the provider or the environment that influenced your decision?
	What does seeing this sign in the healthcare setting mean to you? (Insert visuals: Pink Triangle, HRC Equals Sign, and Rainbow Flag)	Who initiated the conversation about sexual orientation?
	Please talk about how you did/did not chose to disclose your sexual orientation to your healthcare provider?	Do you think it is important that the healthcare provider know your sexual orientation?  Did you feel like this conversation was confidential

Table 4 *continued*  
Aim

	Question	Probe
Identify a mechanism of action to facilitate a positive healthcare experience for LGB college students (ages 18-24) in the local community.	If you could create an ideal healthcare experience for college students your age, what would it look like?	<p>Do you think that college students would be interested in learning how to change their experiences?</p> <p>Do you think community resources exist to make this a request reasonable?</p> <p>Location?</p> <p>Money?</p> <p>Time?</p> <p>How could we reach the largest amount of college students at once?</p> <p>Who should be involved in the planning?</p>
Conclusion	Here are some of the main points that have I have summarized from participating in this group. (listed). Does this summary sound complete?	Does anyone think that we have missed anything?
Thank you	I want to thank everyone for his or her participation in this research focus group. After I end the session, please be sure to log out of website on the computer that you are using.	

## **Pilot Work**

A synchronous online focus group was conducted by the PI and key informants to pilot the operation of the Crusader-Services© online focus group software. Specific aims of this pilot test included:

1. To provide the moderator with experience conducting a synchronous online focus group
2. Evaluate the process of participants accessing the secure online focus group
3. Evaluate the usefulness of the semi-structured interview guide

The key informants recruited a convenience sample of four members of the Worcester State University Pride Alliance to participate in this pilot study. Community members who participated in the pilot study were not eligible to participate in the full study. Pilot participants completed an informed consent and demographic survey. All remaining procedures, as outlined for the full study, were followed, including the documentation of field notes by the key informants. However, additional questions were asked of the participants at the end of the interview guide (see Table 5).

Table 5

*Semi-structured Interview Guide for Pilot Study*

Aim	Question	Probe
To provide the moderator with experience conducting a synchronous online focus group	Please describe the environment of the focus group?	Did you feel safe to discuss personal and sensitive issues?
		How could the virtual environment be improved?
Evaluate the usefulness of the semi-structured interview guide	Please comment on the questions that were used during the focus group?  Is there any other question that you think should be added to this interview in future focus groups?	Were questions clear?
		Did you understand what the question was asking you?  Were there any questions that you found offensive?
Evaluate the process of participants accessing the secure online focus group	Please describe your experience using this online focus group software.  Is there anything that would have made your participation in this group easier?	Did you experience any problems?
		Were you able to set up your username and password without difficulty?  Was it easy for you to navigate the synchronous group page  Did you feel like you could keep up with the conversation?
Conclusion	Here is a summary of the key points brought up by this group. Do you have any other recommendations for the researchers to consider for future focus groups?	

The transcript of the focus group was readily available in Microsoft Word format and was read over by the PI and key informants. Based on the pilot study, the PI felt comfortable



moderating an online environment and all participants agreed that they felt that the venue was welcoming, safe, and comfortable to discuss sensitive issues about their sexuality. Additionally, based on feedback from the participants and analysis of the transcripts, the semi-structured interview guide was revised.

### **Data Collection**

The PI conducted three focus groups and an individual interview for 19 participants. The number of participants recruited to each group was an important decision made by the PI. Too many participants may cause difficulty for the moderator to control the online dialogue (Mann & Stewart, 2006). Additionally, it is essential that the moderator be in control of monopolized dialogue from any participant who can type the fastest. These participants may dictate the tone and speed of the dialogue and speedy dialogue tends to be superficial (Mann & Stewart, 2006). Therefore, the following statements were pre-loaded into the software to address monopolized conversation: (a) “can we hear the contribution of another group member at this time”, (b) “that is a very important point, now we need to hear from another group member”, or a more direct statement for repeat offenders, (c) “you are very quick to contribute to the group so I want to make sure that we give others who may not type as fast, an opportunity.” Furthermore, moderators must read, interpret, enter discussion questions, and probe for information while maintaining a discussion that elicits information helpful in achieving the purpose of the session. Therefore, the interview guide questions were pre-loaded into the virtual room so that the moderator was able to insert a discussion question with a click of the mouse. A drop down menu provided quick insertion of probing questions into the online dialogue. The PI was trained to set up the virtual room prior to each focus group, which accommodated the fluid nature of the semi-structured interview guide.

It was anticipated that each session would last a maximum of 90 minutes (Krueger & Casey, 2008). However, the moderator found herself having to terminate the focus group after two and half hours for two groups and the individual interview, and three hours for one group. Throughout each session, the moderator was diligent about providing positive feedback to the participants and asking participants if they wanted to continue or stop. Only one participant from one group logged himself out of the group before the moderator closed the group.

During each group, the key informants were responsible for documenting field notes. Field notes provide descriptive details of the group that can be used during the analysis phase (Krueger & Casey, 2008). During FTF focus groups, the contextual research environment (e.g., temperature, seating arrangement, and non-verbal communication between participants) is observed, recorded, and analyzed. This process is different in CMC as the research environment is limited to the computer terminal. Researchers are challenged with the task to facilitate and understand the participants' environment by the provided text (Mann & Stewart, 2006).

The PI provided each key informant with a notebook for documenting field notes. In keeping with Krueger and Casey (2008), the front page contained the name of the study, the date and time of the focus group, type of participants (segment group), the name of the moderator, and the names of the key informants present online. Consecutive pages were set up with one line down the middle. The left hand side was titled "notes" and the right hand side was titled "quotes". Key words and concepts were documented under notes and check marks are placed each time it is brought up in conversation. Notable or interesting quotes were documented in the right hand column. Data were separated with a horizontal line and numbered with the corresponding question asked by the moderator.

Key informants were logged into the focus group as clients, which allowed their postings to be visible by the moderator but not participants. The key informants provided process field notes (during the course of the online focus group), as well as traditional field notes (at the conclusion of the focus group during the debriefing session). These conversations were immediately available as text documents. At the conclusion of the focus group, the PI was able to access transcripts in three different forms, (a) moderator and participant discussion transcript, (b) moderator and client discussion transcript, and (c) moderator, participant and client discussion transcript where the postings from the key informants (clients) were embedded in the group transcript to allow easy recollection of contextual conversation.

### **Data Management**

Descriptive statistics were calculated using Microsoft Office Excel 2007. The focus group transcripts were immediately available in a Microsoft Word document. Transcripts, debriefing notes, and field notes were maintained on a password-protected computer accessible only to the PI. Firewall, up-to-date anti-virus software, and encryption software protected this computer. Data was backed up every 24 hours password protected drive on a WSU network server. Hard copies of the transcripts were printed out after the focus group and kept in a locked file cabinet in the PI's office. During the analysis stage, the PI and key informants had access to the hard copy of transcripts. Key informants were only able to view electronic and hard copy transcripts in the presence of the PI. This practice ensured the protection of participant data. Transcripts will be deleted from electronic files and hard copies shredded 12 months after the study's final publication.

## Data Analysis

Descriptive statistics were calculated using Microsoft Office Excel 2007 software to describe the sample characteristics by their demographics (see Table 2). Computer word processing software (Microsoft office) was used to analyze all qualitative data. Available data for analysis included focus group transcripts, field notes, and debriefing session text. The PI used qualitative analysis strategies (Coffey & Atkinson, 1996; Miles & Huberman, 1994; Sandelowski & Barroso, 2003) to analyze the focus group data within and across groups.

To analyze specific aim number one (describe factors that influence the healthcare experiences of LGB college students [ages 18-24] in the local college community) a codebook was created. The major concepts (first level descriptive codes) of the Kilbourne et al. (2006) framework (healthcare system factors, patient factors, provider factors and clinical encounter factors) and concepts (sub-codes) identified through the PI's review of the literature (e.g. healthcare availability, healthcare provider attitude, and characteristics) started this codebook. The PI read each transcript for understanding and a sense of wholeness (Sandelowski, 1995), and wrote a preliminary summary of each transcript. Using an iterative process, the assigning of first level descriptive codes (Miles & Huberman, 1994) organized and simplified large data segments into retrievable terms (Coffey & Atkinson, 1996). Additional codes were added for any new factors that emerged from the transcripts (Sandelowski, 2000). All codes were electronically highlighted and color-coded with a label in the margin of the electronic transcript. Once the transcript was coded, the segments of data were electronically cut and pasted to a new blank Microsoft Word document. All data corresponding to the same first level codes were pasted together in a Microsoft Word file. The PI read through the first level coded data and assigned labels (Miles & Huberman, 1994) based on the review of the literature or the emergence of new

factors, similar to the way in which first level codes were assigned. Labels were electronically highlighted with a color-coded note in the margin.

The labels used in the coding process provided meaning to the text (Miles & Huberman, 1994) and were analyzed for categorical relationships (Coffey & Atkinson, 1996). Categories are a group of codes that represent a “common element or property” (Coffey & Atkinson, 1996, p. 27). All decisions regarding the choice of labels and categories were documented in the codebook. Categories were presented in a table under the appropriate segmented focus group name (i.e. lesbian, gay, male bisexual, and female bisexual group). The PI continued data transformation until themes (defined as the patterned display or repetitive nature of the data) were identified within and across data groups (Sandelowski & Barroso, 2003).

A similar process was used to analyze data to address specific aim two (identify a mechanism of action to facilitate a positive healthcare experience for LGB college students [ages 18-24] in the local college community). The assigning of first level codes was an inductive and iterative process (Miles & Huberman, 1994), meaning that the PI assigned codes using short phrases of participant text from the transcript. Labels and categories were used to identify themes within and across samples groups (lesbians, gays, and bisexuals). The emerging themes were used to identify and describe a mechanism of action, derived from the community, for the benefit of the community, to facilitate a positive healthcare experience.

### **Trustworthiness**

A strength of qualitative research is the rich data provided by participants. However, the emergence of highly subjective data must not compromise the rigor of the research design.

Trustworthiness is a four-fold concept (Lincoln & Guba, 1985) used to demonstrate the rigor and

relevance of qualitative research findings. The components of trustworthiness include (a) credibility, (b) transferability, (c) dependability, and (d) confirmability, (Lincoln & Guba, 1985).

Credibility is the ability of the researcher to construct thick rich descriptions that closely represents the raw data (Lincoln & Guba, 1985). To ensure credibility, and prevent introduction of PI bias into the research, the PI employed peer debriefing with Dr. Carol Bova and the key informants. Discussing and documenting various steps of the research process with Dr. Bova and the key informants allowed the PI to remain objective and transparent (Lincoln & Guba, 1985). Additionally, informal member checks were performed during each focus group by the use of various probing and clarifying statements (Mann & Stewart, 2006). These types of statements allow immediate comment by the participant on the initial interpretation of the researcher. Additionally, at the conclusion of each focus group, a summary statement was included in the semi-structured interview guide. This procedure allowed for a formal member check where all focus group participants were able to post their agreement or disagreement with the researchers' impression of the data generated (Krueger & Casey, 2008). Once data were analyzed, formal member checks with five members of the Worcester State University Pride Alliance occurred. Each member represented one of the three groups (lesbian, gay, bisexual) segmented during recruitment. During formal member checks, emerged data in the form of codes, categories, and themes were assessed to determine whether an accurate representation of the healthcare experience of LGB college students had been portrayed. Additionally, a copy of the healthcare experience model (see Chapter 4 for more details) was shared with members of the Worcester State University Pride Alliance, and two known members of the research study. With their feedback, this model was modified twice to clearly represent the data.

Transferability refers to ability of research findings to be applied in another context or with other participants (Lincoln & Guba, 1985). To achieve this, the PI has provided an extensive and rich description of contextual details (i.e., sample characteristics), that may be assessed by future researchers for applicability in their research design.

To demonstrate dependability and confirmability, the PI maintained a reflexive journal throughout the research study. This journal was separated into three sections. The first section included scheduling of the focus groups and logistical material (i.e., dates and times of scheduled focus groups, anticipated versus actual participants per focus group, contact information for Crusader-Services© in the event of technical difficulties, contact information for University of Massachusetts Medical Center 24-hour mental health service). The second section was used for the PI to journal and reflect on the experience of being the researcher and her reaction to various research-related events (i.e., philosophical assumptions brought to the research, psychological and emotional responses to participants, data, and analytic procedures). This section is important because the researcher is immersed in the data and is considered a mechanism of data collection (Rodgers & Cowles, 1993). The third section documented the emergent design of qualitative research. All decisions made during the research process, including, but not limited to, changes to the interview guide and decisions made during the analysis sessions were documented (Lincoln & Guba, 1985). Documentation of the analysis process allows the PI to retrace her insights and speculations that contributed to analytic decisions (Rodgers & Cowles, 1993). This journal is an audit trail that will assist other researchers in tracing decisions, conclusions and interpretations made during the research process, thus providing sufficient support of the research findings (Krueger, 1998).

## **Reflexivity**

I currently work as a faculty member in the Department of Nursing on the Worcester State University campus. As an undergraduate educator, I am immersed with the community of interest on a daily basis. I also have clinical expertise in adolescent mental health, and I am currently certified as a Public Health Clinical Nurse Specialist. I worked five years as a nurse manager with lesbian, gay, bisexual, and transgender adolescents in a residential home. During that time, I witnessed the challenges encountered by LGB adolescents during their healthcare experiences. My collaborative work with medical and mental health providers exposed me to the numerous psychosomatic symptoms (abdominal pain, headaches, social isolation, various anxiety and depressive symptoms) and high-risk behaviors (truancy, violence, substance-use, eating disorders) that occur in the LGB population. I believe that many high-risk behaviors found in the LGB community are stress-induced reactions to discrimination, fear, and limited ability to discuss their sexual health with skilled health care providers. Healthcare providers have the unique opportunity to engage the patient in dialogue that will promote a healthy bio-psycho-social-sexual young adult. I hope that knowledge gained from this study can be used to strengthen the resources in the greater Worcester community, allowing LGB college students to become healthcare advocates for themselves as well as other community members.

## **Human Subjects Considerations**

The study was reviewed and granted exempt status from the UMMS IRB. The PI received a letter of support from the COWC and Worcester State University Student Activities Organization. Informed consent was obtained anonymously online prior to collecting demographic information and initiating focus groups questions. The direct benefit to the



participant will be in the form of a community-derived action to facilitate a positive healthcare experience for LGB college students. There were no anticipated physical risks associated with participating in this study. However, there was the rare chance that a participant might experience distress associated with discussing sensitive personal information such as sexual orientation and past healthcare experiences. The PI is a registered nurse with a mental health counseling background. In the event that a participant began to feel distressed, he or she would have been able to access the private messaging window and contact the moderator for assistance. In the event that a participant's use of emoticons demonstrated distress, the PI was prepared to initiate this private messaging window and assess the participant's situation. A licensed mental health clinician (MHC) was available by phone for consultation during each focus group in the event that a participant became distressed.

In addition, the following message was posted on the online whiteboard screen: "in the event that you require immediate mental health assistance, please have someone drive you to the University of Massachusetts Medical Center University Campus Emergency and Trauma Center (55 Lake Avenue North) where 24-hour mental health services are available (866-549-2142)." In considering the possibility of a delayed distress reaction from participants, the PI included a list of mental health clinicians on each campus with his or her contact information (see Appendix C). Participants were asked to contact their personal mental health clinician or refer to this list and contact the appropriate clinician should distress occur because of this focus group interaction.

No individual stipends were offered to participants who agreed to participate in this study. At the conclusion of the demographic survey, there was a list of three community-based programs that provide services to the local LGB community. Participants were asked to select the organization to receive an anonymous fifteen-dollar donation. At the completion of the study,

the PI contacted all of the programs to explain the purpose of the study and the anonymity of the donations they received. Community members identified the following programs to receive these donations.

1. AIDS Project Worcester (Worcester and Southbridge, MA) has been providing, for over 20 years, a comprehensive range of services to support the medical care and various services needs of persons living with HIV/AIDS and those at greatest risk for the disease. All services are offered in English, Spanish, and ASL (translation services available for other languages as needed) and are available in both office locations as well as in the home, hospital, respite settings, detoxification/ substance abuse treatment programs, shelters, neutral locations, various community settings, etc. based on client need (AIDS Project Worcester, 2010).
2. Safe Homes (Worcester, MA) is a program for gay, lesbian, bisexual, transgender, and questioning young people between the ages of 14 and 23, led by youth and professional staff, as well as volunteer adult advisor. Safe Homes offer support and resources in a safe and nurturing environment. Specific services include HIV testing, peer leading, trainings on various LGBT related topics, crisis evaluations and drop-in centre hours to interact with the program staff (SafeHomes, 2010).
3. Worcester LGBT Asylum Support Task Force (United Church of Christ, Worcester, MA) is a community-based organization of volunteers who are dedicated to supporting and empowering LGBT individuals who are seeking asylum or refuge in the United States (Hadwen Park Congregational Church, n.d.)

## **Summary**

This study used CBPR, with synchronous online focus groups, to describe the healthcare experiences of LGB college students. Additionally, researchers aimed to identify a mechanism of action to create a positive healthcare experience for this LGB sub-group. Participants were recruited from the colleges of the Worcester Consortium into segmented groups of lesbians, gays, female and male bisexuals groups. Qualitative interview data within and across groups were analyzed to describe the healthcare experience of LGB in the local community and identify a mechanism of action to improve this healthcare experience in the future. Methods to ensure trustworthiness and human subject considerations were adhered to throughout the research process.

## Chapter Four

### Results

#### Introduction

Qualitative content analysis was used to describe the healthcare experiences of lesbian, gay, and bisexual college students in the local community. One overarching theme (not all the same), one main theme (comfort during the clinical encounter), and three sub themes (personalizing the clinical encounter, deciding to disclose and social stigma, and seeking support of self-identified sexual orientation), and a preliminary sub theme (perceived confidentiality) emerged from the analysis of study aim number one. One major action (internet action) emerged from the analysis of specific aim number two.

#### **Participants**

Three focus groups (lesbian, gay, female bisexual) and one individual online interview (male bisexual) were conducted with 19 participants. To maintain anonymity, the sample demographics will be reported in aggregate. The sample consisted of self-identified lesbians ( $n = 7$ ), gays ( $n = 7$ ), female bisexuals ( $n = 4$ ) and a male bisexual ( $n = 1$ ). The mean age of the sample was 20.7 years (SD 1.2, range 19-24), and the mean number of completed college years was 2.4 years (SD 1.2, range 1-5).

Sample demographics are presented in Table 6. The sample was predominantly White, non-Hispanic (85%) and single (79% did not have a current partner). All of the participants were insured; the majority of participants received insurance coverage from a private source (63%). Three participants (16%) had a chronic health condition (identified on the demographic survey as

depression, anxiety, chronic back pain, and ulcerative colitis). Eleven (58%) participants reported that they disclosed their sexual identity to their HCP.

Table 6

*Sample Demographics*

Demographic	N	%*
Race		
Black or African American	1	5
White, non-Hispanic	16	84
Hispanic	1	5
Undisclosed	1	5
Marital Status		
Single	15	79
Partnered	4	21
Health Insurance		
Public	3	16
Private	12	63
School	1	5
Unknown	3	16
Healthcare Services		
Primary Healthcare	16	84
Mental Health	1	5
Specialized Healthcare	2	11
Disclosed to HCP		
Yes	11	58
No	8	42

\* All percentages are rounded to the nearest whole number, therefore, race does not sum to 100%

Eight participants (42.1%) across all four groups reported that they only saw their HCP for annual physicals and health requirements related to being a college student (e.g. health forms and required immunizations). The remaining participants did not specify the reason for healthcare visits. Table 7 reports the participants' use of healthcare services within the past 18 months. All but two participants were seen by their HCP within 12 months of the focus group. The majority (52 %) of participants were seen within three to eight months of the focus group.

Table 7

*Elapsed Time Since Last Healthcare Service*

Last Healthcare Service (reported in months)	N	%
< 1 m	3	16
1 - 2 m	3	16
3 - 5 m	5	26
6 - 8 m	5	26
9 - 12 m	1	5
13 - 18 m	1	5
> 18 m	1	5

Three participants reported receiving healthcare or mental health services on their college campus. One female bisexual received her gynecological healthcare from her campus health services department. One lesbian participant reported receiving mental health services through the college counseling department.

### **The Healthcare Experience of LGB College Students**

The female groups (lesbian and bisexual) provided a more detailed account of their healthcare experience compared to the male group. The females' conversations were dynamic and contained strong emotional statements, and required fewer prompts from the moderator. The longest gap in conversation in the lesbian group was one minute thirty seconds and in the female bisexual group was less than one minute. In contrast, the male group required multiple prompts from the moderator to answer the questions and provide more detail. The male group had no

gaps in conversation greater than one minute. Participant quotations are portrayed verbatim except in situations where spelling errors, typographical errors, abbreviations, and offensive language inhibit clarity.

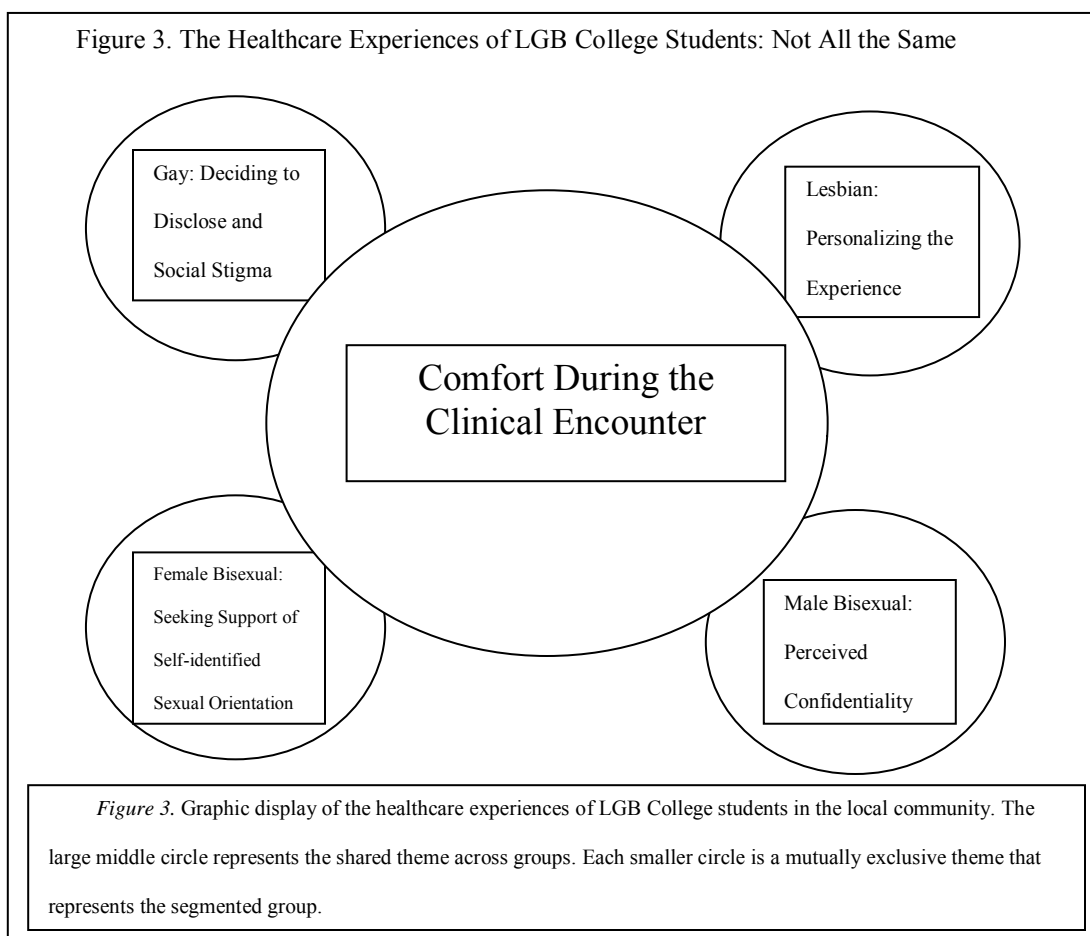
Initial descriptions of the participants' healthcare experiences included: "fine, no change since high school", "pretty normal", "been great...have the same pediatrician I've had since I was like 13", "pretty basic", and "fairly standard." However, as the focus group progressed, participants began to provide more detail to their statements. With minimal probes for the females and additional probes for the males, participants initiated conversations about positive and negative healthcare experiences, and provided rich details of these experiences, allowing themes within and across groups to emerge. For example, a gay participant summarized his negative healthcare experience, "I described some of the awkward conversations [with HCP's] I've had, not to mention the HIV/AIDS stigma that comes into play when the statistic for „at risk populations“ pops into their heads." Whereas, a female bisexual recalled a more positive experience with her HCP:

I think because my doctor and I know each other so well and she knows my entire life story and everything that my experiences are exceptional, I wish everyone had my doctor... it felt good. She [did not] have anything negative to say... I mean she was very positive... she was genuinely interested in my sexual preferences. I don't think I could ever tell my new doctor though.

In contrast, a lesbian participant described her experience with the HCP, which she labeled as both positive and negative, "I like my PCP, but I don't really have a relationship with them. I feel like I could switch docs every time I go in and it wouldn't make a difference."

## Not all the Same

Although there were a variety of positive and negative healthcare experiences shared during the focus group sessions and the individual interview, experiences were unique. With the exception of discussing the important aspects of comfort during the clinical encounter, it was difficult to identify similar themes across group experiences. What constituted a good healthcare experience differed for lesbian, gay and bisexual participants, and can be summarized as the theme, not all the same. The variety of different healthcare experiences between lesbians, gays, female bisexuals, and male bisexuals was captured by this overarching theme, while the differences and similarities within each group were described by one main theme and three sub themes and a preliminary sub theme (See Figure 3).





The main theme, comfort during the clinical encounter, was the only shared theme. Each group demonstrated a unique focus during the group session. Lesbians provided detailed accounts of their experiences and tended to link a personalized clinical encounter to a more positive healthcare experience. In contrast, self-identified gays portrayed a more apprehensive approach to their healthcare as they focused on topics related to disclosing sexual orientation, and emphasized the role of social stigma during their healthcare experiences. Female bisexuals were confident of their sexual identity. However, they all emphasized the importance and challenge of feeling socially supported as bisexual individuals. A preliminary sub theme of perceived confidentiality emerged from the interview with a male bisexual. A common theme that emerged from all three groups was comfort during the clinical encounter.

### **Comfort During the Clinical Encounter.**

The importance of comfort during the clinical encounter was a main theme that emerged from the healthcare experiences of LGB college students. Comfort was defined as the participants' feelings of ease and safety during the clinical encounter and within the healthcare environment. One male participant best describes the impact of comfort on the clinical encounter: "when I was asked about being sexually active it was the nurse who had asked and she just made it a comfortable enough of a situation that I replied honestly." Participants described various ways that comfort emerged or did not emerge during the clinical encounter and linked the outcome of disclosure or better healthcare experiences to experiencing comfort during the clinical encounter. Participants also identified that the HCP was able to promote comfort during the clinical encounter with his or her characteristics, attitude, communication technique, and reaction to sexual orientation disclosure. Additionally, the physical environment, such as

visual signs and symbols in the healthcare agency, played an important role in promoting comfort.

### **HCP characteristics and attitudes.**

Certain HCP characteristics and attitudes were identified as promoting comfort by enhancing the health care provider-patient relationship. Characteristics identified by the participants included gender and age. There were differences in the participants' preference for a same-sexual orientation HCP. Of the eight males who commented on the preferred gender of their HCP, two reported that they had no preference (although earlier in the conversation one had said they had both and preferred male providers), one preferred a man, and four preferred a female. Of the two males who preferred female HCP's, one was a bisexual male who explained that:

in my life experiences, it's always been easier to talk to girls, like I am afraid of being judged by other guys, not just sexual stuff, but everyday normal things...I feel like girls are more willing to talk about it and be accepting and supportive.

Two female bisexuals and one lesbian expressed similar feelings and further clarified that younger age women were more understanding compared to older age women. One male preferred a younger healthcare provider, but did not specify the desired gender. The other male who preferred a female HCP explained that he was: "not comfortable having those awkward semi-sexual moments/conversations with a male, let alone letting him touch or examine me."

Only one participant was able to confirm that her HCP was gay, and one male participant speculated that his HCP was gay. None of the participants searched for a lesbian, gay, or bisexual HCP when choosing his or her HCP. Although all of the participants agreed that it was

not necessary for their HCP to identify as LGB, two lesbians added that it would certainly make it easier and more comfortable. One female described her clinical encounter with a gay HCP. She was wearing a rainbow necklace (a symbol of Pride in the LGB community) and when the provider asked about it, she disclosed, as did he. “I felt much more comfortable with having a male PCP after he told me that”, as she recalled that it was nice not having to explain every detail of her sexual identity and sexual encounters. All lesbians and two males suggested that a HCP specialized in LGB health would make them feel more comfortable during a clinical encounter.

### **HCP communication.**

Communication, both verbal and non-verbal, was discussed as an important way that a HCP influenced comfort during the clinical encounter. All three groups indicated that they preferred a HCP who had an inquisitive attitude and asked questions during the clinical encounter, instead of relying on the patient to bring up discussion topics. As described by one female: “I like doctors who ask questions, [because] sometimes I forget everything I may want to say, a nosy doctor is [kind of a] good...seems they are more thorough.” “I feel better when they ask a lot of questions and go beneath the surface and not just talk about or diagnose the obvious,” explained one male. When the HCP initiated topics to discuss, participants indicated that it was a cue that this was an appropriate topic for conversation. For example, one participant recalled the conversation of disclosure with her provider: “It was pretty straight forward. He asked if I was sexually active, I said yes. He asked men or women and I said women.” This participant did not experience the awkwardness of how to initiate the conversation or worry about how her HCP would respond because he had brought up the conversation with his questioning.

Communication was seen as one way that HCP's convey acceptance of the participants' sexual orientation. When a participant felt discomfort because of a lack of self-identity acceptance, answering health history questions and engaging in physical assessment exams were challenging. Two male participants recalled similar negative healthcare experiences that instilled a lasting skepticism of HCP's. One of the participants detailed the experience:

once I told the nurse that I was gay she started talking to me differently and once I told her that I was sexually active and once was unprotected she basically insulted me for making a mistake and then gave me attitude for the rest of the visit.

In contrast, a lesbian explained that her primary healthcare provider was off campus but she received her gynecological care from the campus health service. She felt discomfort with her off-campus HCP because of the way he talked to her and looked at her, that she could not bring herself to share her sensitive health information with him.

Non-verbal communication that contributed to the comfort of the participant included personal distance during the clinical encounter, the use of gestures, body language, facial reactions, and eye contact. A female participant provided an example of how a HCP's non-verbal communication created an uncomfortable clinical encounter: "when she checks my blood pressure she stands so far away from me... apparently it was supposed to make me feel worthless." Male participants were astutely aware of the HCP's non-verbal communication. "I pay close attention to comments made and the tone of voice and gestures/mannerisms. If they can manage not to start shifting in their seat when topics [related to being gay] come up I appreciate it", one male explained. Another male attempted to provide an explanation for this HCP behavior: "I just feel like they're very used to prescribing birth control and having routine

visits.” However, he agreed that: “once the subject of anal sex comes up they seem to be caught off guard and look at me differently.”

In contrast, a male group member described comfort during the clinical encounter: “She was doing all the things that display that [comfort], she was sitting down, her body language was receptive and was looking at me when I was talking.” This participant explained that he felt he could share his sexual orientation with the HCP and felt that he could ask her questions and all information would be confidential. A specific type of communication that often made participants uncomfortable was the HCP use of language reflecting heterosexual assumptions about the participants’ sexual orientation.

***Heterosexual-assuming language.***

Conquering heterosexual assumptions and communication was a challenge identified across all three groups. However, the female participants emphatically discussed how frustrating these assumptions were to overcome during the clinical encounter. “I am straight until proven otherwise,” one bisexual female declared with agreement from the rest of the group. Two females determined that their providers assumed they were heterosexual based on their looks: “I get that a lot as well. It’s frustrating! What does a lesbian „look like“, right?” All seven of the lesbian participants made similar comments: “If they [the HCP] wouldn’t assume that we are all straight, that would be nice.” The conversation angered one female participant to recommend that providers:

Not to walk into that office with me there and assume that I am straight, or that I love attending college, or that I know how to ride a bike. They need to be clear and ask when they don’t know something. If I were asked more questions instead of expected to tell

them their assumptions were wrong, it would be a more positive experience for me overall.

Male participants were more casual about the HCPs' assumptions of heterosexuality and addressed the group conversation with joking comments or sarcastic responses. To try to lighten the discussion, one gay participant suggested that: "Doctors should assume everyone is gay, then straight people should come out to them as straight." Another participant explained:

Well naturally when the quote „have you been having sex?“ comes up in the examination room, they assume I'm having sex with a woman. I'm quick to smash their assumptions by saying something like, „yes, with my boyfriend“, or something even if I am single, just to throw their heteronormative assumptions back in their face.

In general, participants preferred that a HCP not make assumptions of sexuality. This included the common use of the question: "Are you sexually active?" Across all groups, participants identified that they were asked this question by the HCP, and disliked it because it was not a good indicator of sexual orientation, and more often than not, this was the HCP's chosen method of assessing sexual orientation. Only three participants recalled his or her HCP asking them to identify whether they were having sex with a male or female. One participant reflected: "I'm glad he asked [who I was having sex with] because I wouldn't have brought it up." In various situations, the participants would answer this question by affirming sexual activity, but would add a clarifying statement that it was with a member of the opposite sex. This mode of questioning was not helpful to bisexual participants, because if he or she were sexually involved with a member of the opposite sex, the HCP assumed the participant was heterosexual.. One participant summarized the participants' position on this issue: "It feels good when a

[doctor] says more than just "are you active?" That's so vague [and kind of] weird. I'm not sure how they could change their wording but it seems that universally, [especially] for young [people], it's just disliked." In response, all group participants agreed that they were more likely to disclose their sexual orientation when a HCP asked them a more specific question. For example one participant stated: "If my doctor asked if I was gay, I most definitely would tell him."

### **HCP reaction to disclosure.**

"You never know who is going to take offense to the way we are," one male participant wrote when asked about disclosing his sexual orientation to his HCP. Another participant added his description of how he felt embarrassed and uncomfortable after disclosing his gay sexual identity. The participant wrote: "It feels like they are looking at you like you did something wrong...you almost want to apologize for being gay." These males agreed that each of these responses contributed to feelings of discomfort during the clinical encounter and for one participant, caused him not to return to the HCP. For one lesbian, she explained that: "I'm not out to half my family because their reaction would be harmful to me. I think that has a lot to do with how I come out, to who, and when." This participant provided this rationale as a reason for why she chose not to disclose to her HCP, but had disclosed to her mental health clinician. "I don't think my [doctor] realizes that that there's an extra step for LGB people when accessing sexual health services and that extra step is vulnerable and for some of us, dangerous and scary." In a prior conversation, this participant acknowledged that the only reason why she chose to disclose her sexual orientation to her mental health clinician was that her friend had disclosed to this provider and felt comfortable with the: "lgbt friendly counselor."

Additional stories were shared within the lesbian group about how the reaction of the HCP is an important way for the HCP to promote a comfortable clinical encounter where the patient feels safe to discuss sensitive topics. Lesbians explained that it was:

Uncomfortable because you never know what kind of reaction you may get based on what your answer is [to the question about your sexual orientation], so many of the gay community may have to lie just because they're nervous of what the outcome might be and that's not fair because straight people don't have the type of struggle we have.

A male participant who had not disclosed his sexual orientation to his HCP expressed his dilemma as follows:

If [I] disclose to a [doctor], their job is to help you and keep you safe and healthy in a nutshell. However, there are people as well [that] hold personal thoughts on matters, some [doctors] might be accepting and willing to help and others may not do so. [A doctor] can't drop you as a patient directly for disclosing but may be a factor in health assessment and questioning.

This participant continued to reason that he did not feel safe and accepted in his healthcare environment, which was why he had not disclosed to the HCP. His need for safety, acceptance, and support resonated with other participants' descriptions of comfort. Three female participants agreed with the following general statement that described a HCP's positive reaction: "It was a good experience. He was kind, nonjudgmental and didn't make it awkward."

One recommendation from a female participant was that sexual orientation information should be collected on the healthcare form and filled out prior to entering the exam room. She stated: "The doctor could react to it [the specified sexual orientation information on the form] in



private if need be.” This would minimize the possible discomfort experienced by LGB patients. Other recommendations to create a comfortable clinical encounter were discussed across all three groups. Office staff, exam rooms, and visibility of LGB-friendly symbols were among the most discussed topics.

### **Physical environment.**

Participants were shown three pictures, a pink triangle representing LGB safe space, a rainbow flag representing Gay Pride, and the Human Rights Coalition equals sign. They were asked how they would feel if they saw these symbols in the healthcare environment. Across the three groups, there was an overwhelming response of feeling comfortable, safe, happy, and being able to “breathe a sigh of relief.” Of the three symbols, the rainbow flag was the most recognized by participants. Two participants suggested that the flag should be visible from the moment a patient walks into the office, while others thought that it was more important for it to be in the exam room. In the lesbian group, the rainbow was recognized as being the most inclusive and the “one that involves the most risk for the provider to put on their door.” One female participant suggested that: “The room [is] more inviting with LGBT friendly stickers.” Providers who wore any of these symbols on their clothing were acknowledged as brave, and promoting the most comfort and safety during the clinical encounter.

In summary, LGB participants explained the various facets involved in creating comfort during the clinical encounter. Participants often preferred a younger female HCP. Participants“ acknowledged the verbal and nonverbal communication techniques of their HCP, and disliked the use of heterosexual-assuming language and the question “Are you sexually active?” These assumptions and narrow focused questions were not conducive to disclosure or any conversation related to sexual orientation.

## Personalizing the Clinical Encounter

Personalizing the clinical encounter was a sub theme that emerged from the lesbian focus group. Personalized care was described by the group as care that was focused on their individual needs, and required their HCP to demonstrate initiative in asking individualized and personalized questions during the clinical encounter. One participant wrote that the HCP who personalized care during the clinical encounter: “Is interested in getting to know me and personalizing our experience together so I feel like my doctor isn't some stranger.” A group member who described her ideal healthcare experience supported this statement:

[an ideal healthcare experience is] just to have all doctors being accepting and inviting to all types of people from different walks of life and to be interested in the lives of their patients...it's always so institutional and distant, not personal and warm.

This distant and non-personal encounter led a second female participant to refer to her HCP as a stranger:

I was nervous about telling her, so I wasn't sure what to expect. I'm out to some people, but not to others. I haven't really had to tell strangers before. So I probably would have felt better if she has smiled or said “good for you”; or something, but honestly I was just glad that she accepted the information without issue and seemed to care about how I felt about it.

Throughout the focus group, one female provided continuous commentary about her negative experiences. She described her visits as: “pretty much them [HCP's] asking for their paperwork, I don't feel like they really care about me or are interested in my life,” and “I felt she didn't care too much and that she didn't really have any interest in getting to know me that well...a little disappointing.”

Participants recognized the temporal influence on the ability of the HCP to provide personalized care effectively. Lesbian participants disliked being a number on the HCP's daily schedule: "if I don't see my doctor and see a different one and she knows me based on notes...and it annoys me... I'm not me I'm #22 on her list of people she's seen today."

Two additional female participants agreed that: "[I would like my HCP] to listen to my heart/lungs for more than 30 seconds and actually stay in the room for more than 5 minutes, she doesn't even care to ask [about] my [gynecological] health." Although some participants complained that time limitations originated from the healthcare provider, one female participant acknowledged the possibility that her public insurance coverage prevented the HCP from spending enough time with her to become "personally involved."

The HCP who "took interest in a personal level" was described as asking specific questions related to the participants' history and probing to gather more than just what the health forms asked. As described by the only male participant that discussed a personalized healthcare experience a positive personal clinical encounter was when his HCP, "was interested in getting to me as a person, as opposed to just making the exam a hi, how are you? Please remove your gown type of situation." For the majority of the gay focus groups, discussions focused on various decisions about disclosure and the role of social stigma in healthcare.

### **Deciding to Disclose and Social Stigma**

Eleven of the participants reported that they disclosed their sexual orientation to their HCP. Only three of those disclosed participants were male. Male disclosure of sexual orientation was based on two factors, (a) perceived significance and relevance of sexual orientation to health, and (b) participant perceived social stigma.

### **Perceived significance of sexual orientation to health.**

Male participants were less likely to have disclosed their sexual orientation to their HCP. Four participants admitted that they were not sexually active. Therefore, according to their belief, it was not medically necessary to disclose their sexual orientation to the HCP. One participant reasoned: “I don’t think it’s necessary unless sexually active. There are no risks factors for being gay.” Another reason cited by male participants included the irrelevance of sexual orientation to the current topic of discussion: “I haven’t disclosed my [sexual orientation] to my doctor because I felt it was irrelevant to any of my present healthcare needs.” Additionally, this participant clarified that “I have no apprehensions about telling a HCP; it just hasn’t seemed necessary.” For the two males who received healthcare from specialized HCP’s, they explained the awkwardness of “just com[ing] out and say[ing] „I’m gay“, when we were talking about something else.” These opinions were in contrast to two disclosed males who wrote: “I think it is part of the practice of health care to know sexual activity and [sexual orientation] is part of that” and “I just feel like it's a part of who I am and if someone is supposed to be caring for my physical well-being and testing me for STDs they're going to know about that part of me.” Social stigma attached to the gay community is another factor considered by gay participants when deciding to disclose.

### **Perceived social stigma.**

Compared to the female groups, the male participants discussed social stigma and its influence on their healthcare experiences and their decision to disclose. One male participant explained he felt like he scared people in the medical field: “especially when the subject of my sex life comes up. Gay immediately connotes images of promiscuity and the HIV/AIDS epidemic and I feel like the dynamic in the room gets awkward once the person asking me finds

out.” Two males respond with their frustration that: “STI’s are something that is shoved down our throats,” and that: “there is a huge stereotype that all gays have AIDS.” One male participant stated:

There is a [HIV/AIDS] stigma because that seems to be the only STI that is ever talked about and it is very strongly linked to the community, when in reality if the goal is to be safe there should be information about all of the dangers not just one.

This male recalled how one HCP: “ask[ed him] if it was protected [sex] and [saw] their mannerisms become awkward as I suppose they realize[d] I’m a higher risk statistically for HIV/AIDS.” Another male participant who was “brought up in a catholic home...and was always told it wasn’t okay [being gay]” cites an additional social stigma that contributed to his nervousness when telling people, including his HCP.

In contrast to the social stigma experienced by gays, female bisexuals expressed their struggle with society understanding and validating their self-identity. Although all of the participants asserted confidence with their self-identified sexual orientation, the lack of social support was a challenge that affected their relationships.

### **Seeking Support of Self-identified Sexual Orientation**

According to female bisexual participants, it was their comfort with self, which provided the tools for a positive life, including a positive healthcare experience. While discussing various clinical encounters, two female bisexual participants posted identical responses at the same time:

Participant 1: “I think the more [comfortable] someone is with themselves, the more willing they will be to share themselves with others”

Participant 2: “being comfortable enough to chat with your HCP begins with the ability to be comfortable with oneself”

Another group member added that she used to be hesitant to talk about her sexuality because of her lack of knowledge, but as she talked more about herself, and talked to other bisexuals, she began to feel more self-confident and supported with her sexual identity. This participant had the most positive healthcare experience across all groups. She described her relationship with her HCP as a “strong bond” that would be difficult to replicate because the HCP knew everything about her life, accepted her sexual orientation, and provided the support she needed: “I think everyone needs someone to confide in... my HCP is mine.”

The need to be comfortable with self is challenged by the lack of support found in family and friends. All four of the female bisexual participants presented stories that included various accusations and name-calling. One participant recalled being told: “[bisexuality] makes you greedy” because she was able to have sexual relationships with males and females, without the need to choose like heterosexual females or lesbians. One participant attempted to rationalize this claim: “we're not straight OR gay, so we don't jive perfectly in either camp.” This comment stimulates an interactive conversation between three of the four participants.

Participant 1 “well maybe it’s the circles I find myself in but I don’t find that many [people] are accepting of my bisexuality, men are either hoping they get a 3sum or they are mad [and] say things like why aren’t I good enough, women if they are lesbians think I’m not serious [and] don’t want to get involved with a confused girl hung up on dick”

Participant 2: “we're on the fence, so to speak”

Participant 3 “exactly, so we have our own little [group] but it’s hard to know [who is] a member”

Participant 1: [and] who will accept you

Participant 4: “yeah we’re the middle child.. we get the [expletive] end of the stick”

Religious accusations were also common. “It’s against the Lord’s wishes” one female recalled being told in public. By far, the comments that provoked the most anger from female bisexuals were those that questioned the legitimacy of their sexual identity:

Participant 1: I don’t know if this is a feeling I get specifically from health professionals or the world in general... but when I have told people they seem to think it’s a phase and therefore think that all I do, based on my sexuality is out of lust and confusion.

Participant 2: I believe that people think being [bisexual] isn’t real. Sometimes when I tell people I’m [bisexual]... they are like “oh so you kiss girls when you’re [deleted] drunk to impress men?”

Participant 3: I don’t like feeling like I have to explain, if you don’t understand why I am turned on the way I am, I will say the same to you.

Two female participants addressed the need for support from family and friends. One participant, in response to identifying the ideal healthcare experience, provided this explanation: “if there was more support in the LGB community, [especially] for younger [people] like before college even:” then the self-confidence of the bisexual group would improve. Another group member added, “my other friend is 16 and [bisexual]... me and my 22 year old friend are all she’s got.”

Whereas the female bisexual group was confident and sought support from others, the one male bisexual interviewed was cautious and concerned about confidentiality of his sexual orientation. As this participant recalled his healthcare experiences, the emphasis placed on perceived confidentiality emerged as a theme.

## **Perceived Confidentiality**

Confidentiality of information shared during the clinical encounter was not a concern to many of the participants. All but one participant agreed that their HCP verbalized that visits were confidential, or, participants just expected that their healthcare visits were confidential due to privacy laws, and did not let it influence their healthcare experience. One gay participant had a unique healthcare situation where his HCP was also the family practitioner. This provider cared for all members of his family and the participant explained: “it’s really difficult for me to open up to him” for fear that his family would find out his sexual orientation. Although concerning for this participant, the role of confidentiality during the healthcare experience did not spark much conversation in any of the focus groups. However, for the one-on-one interview with a male bisexual, the majority of the conversation focused on his fear of a non-confidential clinical encounter.

Perceived confidentiality emerged as a preliminary sub theme from the interview with a male bisexual. Because only one participant shared his experience, the results of this preliminary analysis must be reviewed with caution. The male bisexual participant spent a lot of time during the interview discussing confidentiality and the role it played during his healthcare experiences. This participant was unsure how to initiate a conversation about his emerging sexuality with his pediatrician because he was “afraid the [doctor] would tell [his] parents.” He also stated: “I knew she [the pediatrician] used to talk to my parents afterwards and wasn’t sure if it would be confidential so I was afraid to say anything.” When asked how the provider could have addressed confidentiality during the visit, the participant replied: “I wish she could have brought the topic of sexual activity up and stated that it would stay between us.” This male participant did not like the idea of a written statement of confidentiality because he feared the document would be



misinterpreted as a contract, and could be a paper trail that accidentally disclosed his sexual orientation.

In review, LGB participants shared a different healthcare experience that was best described by one main theme (comfort during the clinical encounter) and three sub themes (personalizing the experience, deciding to disclose and social stigma, seeking support of self-identified sexual orientation) and a preliminary sub theme (perceived confidentiality). To improve these healthcare experiences in the future, participants were asked to identify a mechanism of action. Very few actions were suggested during the focus groups. Initial actions were focused on changing the characteristics and attitudes of the HCP as well as promoting the use of the rainbow flag within the physical healthcare environment. To maintain the CBPR tenet of action, a mechanism of action conducted by the community for the community, the moderator probed for more community based action items. Analysis of aim two (identify a mechanism of action to facilitate a positive healthcare experience for LGB college students [ages 18-24] in the local college community), yielded one action.

### **Internet Action**

Lesbian participants identified that a peer support group had the potential to improve the healthcare experience of LGB college students. One participant clearly outlined: “I don’t have people my age who are gay that I can talk to. I don’t feel as though I have a gay community. So I would add that in to a healthcare experience, ideally.” This idea is shared by one female bisexual who states that pre-college LGB individuals need to be supported during their sexual identity process, and the use of peer support groups in the younger LGB population could improve their use and understanding of the healthcare system. The discussion of peer support in the lesbian

group quickly transitioned to the involvement of community organizations or a college consortium gay straight alliance. Participants suggested that these organizations could train healthcare advocates or “gay mentors” who would help the LGB individual navigate the healthcare system.

When asked how to reach the community members with these action items, the groups unanimously voted for a social network site in the form of an online blog or Facebook. Participants were adamant that using the internet would reach the largest portion of the LGB college community and safely provide health education and a comfortable place for members to talk with others. Lesbian participants recommended the creation of a Facebook group to disseminate information. One female provided her rationale: “Facebook has become everyone’s go-to place for info...it’s becoming more helpful than Google.” Although one gay participant agreed that: “Facebook is the best way to get to our age group” because: “I personally read my Facebook more than any other form or contact,” the males debated whether social networking sites are feasible and reliable routes for health information. Only one participant questioned the use of Facebook. He stated: “I don’t really feel like using a social networking site is all that professional. And maybe being “friends” with or “liking” your HCP wouldn’t aid in confidentiality.” However, through member checks with four members of this focus group, it was brought to attention that participants misunderstood the use of Facebook as introduced by the moderator. Instead of using Facebook as a social network site to gain information or access group belonging, participants thought that using Facebook was a mechanism of communicating healthcare needs with their HCP. Once clarified by the key informants and PI, the four participants agreed that use of Facebook to reach out to college students with health-related information was a feasible and valuable action. Overall, females showed much more enthusiasm

about the use of the Facebook group, whereas, males supported the implementation of an online blog or electronic newsletter to reach the community. The potential of having a social network site hacked or corrupted was a major concern of the gay participants.

For those college students who are not on Facebook or are opposed to receiving health related information via a public social network site, mass emails to the school provided email address was introduced as a solution. Newsletters and emails could provide LGB college students with information about which local providers are gay friendly and who have specialty training that may be of use in the LGB community (e.g. eating disorders, depression, safe space training). The two female groups asked if an online chat such as the online research focus group could occur more often to allow them to ask questions and “meet” others like them. One female bisexual even suggested having the HCP online in a chat like this to create a “no judgment zone.”

College Alliance Towards Community Health (CATCH) is a social network group that will be housed on Facebook and provide the local LGB community with a comfortable forum to network with other LGB college students and learn about the health needs of the LGB young adults in college. The specifics of CATCH will be described in detail in chapter five.

### **Summary**

One overarching theme, one main theme, three sub themes, and a preliminary sub theme emerged from these data to describe the healthcare experiences of LGB college students in the local community. An overarching theme, not all the same, emerged and represented the different experiences described by the segmented groups of lesbians, gays, and bisexuals. Data were analyzed within and across groups. Across group analysis presented a main theme of comfort

during the clinical encounter. Comfort was described as the feelings of ease and security during the clinical encounter and within the physical healthcare environment. Figure 3 depicts the mutually exclusive themes that emerged within each of the three focus groups and a preliminary theme in the one-on-one interview with a male bisexual. These identified themes of personalizing the experience (lesbians), deciding to disclose and social stigma (gays), seeking support for self-identified sexual orientation (female bisexual), and perceived confidentiality (preliminary male bisexual) provided a thick, rich description of the healthcare experience for LGB college students. In turn, future action and intervention within the community, and by the community, to facilitate a more positive healthcare experience can be implemented.

According to participants, the use of online social network sites in the form of a blog or electronic newsletter are efficient and successful methods to reach out to the LGB college community. The focus of these actions should be supporting the local community by helping LGB college students make informed healthcare decisions based on their self-identified sexual orientation and scientific research that supports health interventions for this community.

## Chapter Five

### Discussion

Little is known about the healthcare experiences of LGB young adults and even less is known about LGB college students. Understanding the healthcare experiences of this age group is important because research indicates that LGB individuals are at greater risk for various mental health disorders (Austin et al., 2009; Bostwick et al., 2002; D'Augelli, 2002; Diamont & Wold, 2003). LGB individuals also demonstrate increased risk behaviors such as cigarette smoking (Remafedi et al., 2008), alcohol use (Corliss et al., 2010), drug use, (Corliss et al., 2010), and high-risk sexual activity (Rhodes et al., 2007). As the LGB young adult assimilates to his or her college environment and is exposed to the stressors of adulthood and the burden of social stigma and societal disapproval associated with their sexual orientation (Meyer et al., Saewyc et al., 2006), the LGB college student may increase their susceptibility towards mental health disorders due to participation in high-risk behaviors.

The purpose of this qualitative study was to describe the health care experiences of lesbian, gay, and bisexual college students (ages 18-24) in the local community. Understanding the healthcare experience of this group has the potential to help LGB college students effectively access and utilize healthcare to reduce the negative long-term health consequences associated with high-risk behaviors.

Using community-based participatory research (CBPR), synchronous online focus groups were used to gather qualitative data from LGB college students in the local community. One overarching theme, one main theme, and three sub themes were identified. A preliminary sub theme was also identified but will not be discussed. This preliminary theme emerged from the

healthcare experience of one participant during an interview instead of from a focus group. The development of the social network group College Alliance Towards Community Health (CATCH), will be described in detail. This mechanism of action is consistent with a principle of CBPR and aim number two of this study. Additionally, study limitations will be addressed and implications for nursing practice and future nursing research will be outlined.

Focus group participants were self-identified lesbian, gay, and bisexual college students. Unlike the estimates of Long & Stockley (2010) who reported that 14.8% of 18-25 year olds were uninsured, all participants in this study had insurance coverage. However, because the study purposefully recruited a sample of college students in Massachusetts, any uninsured student would be required to enroll in a college health insurance plan per Commonwealth of Massachusetts law.

### **Comfort During the Clinical Encounter**

In this study, a main theme, comfort during the clinical encounter, emerged from the LGB group experience. Participants defined comfort as feeling at ease with a sense of safety during the clinical encounter and within the healthcare environment. Participants outlined the various factors contributing to comfort during the clinical encounter, which included the healthcare provider characteristics and attitude, the healthcare provider's communication techniques, and various aspects of the physical environment. The descriptions of the factors in this study are similar to findings from previous research (Eliason & Schope, 2001; Ginsberg et al., 2002; Hoffman et al., 2009). For example, Hoffman et al., (2009) found similar preferences in healthcare provider characteristics in a sample of lesbian, gay, bisexual and transgender youth (age range 13-21,  $M = 16.2$  years,  $SD 2.2$ ). Preferred HCP personal characteristics included

being a good listener, respectful, honest, nonjudgmental, comforting, supportive, personable, and friendly. Eliason & Schope (2001) found that younger age female HCP's were preferred by the LGB sample was also supported in this study. Ginsberg et al. (2002) found that confidentiality and privacy of medical information was an important topic for lesbian, gay, bisexual, transgender, and questioning youth. Furthermore, Allen et al. (1998) reported that three quarters ( $n = 75$ ) of the youth sample (ages 14-18) answered that if their HCP had verbalized confidentiality of medical information during the clinical encounter, that they would have disclosed their sexual orientation. This was not a major finding in the current study as lesbian, gay, and female bisexual participants were confident visits are confidential and private because they expect that healthcare providers adhere to current federal privacy laws. Therefore, confidentiality findings of this study are more consistent with the findings from Meckler and colleagues (2006), who found 14% ( $n = 12$ ) of LGB youth feared that their parents would be told by their healthcare provider after disclosure.

The heterosexual assumptions of HCP's are well documented in the LGB health literature (Dorland & Fischer, 2001; Herek, 2004; Mathieson, 1998). In this study, there was a universal dislike of the question: "Are you sexually active." Participants were clear that they preferred that their HCP directly ask about sexual orientation. These findings are consistent with those of Meckler et al. (2006) who reported that 65% ( $n = 76$ ) of a youth LGB sample answered: "Just ask me" as a healthcare provider action that can positively influence the disclosure of sexual orientation. Participants in this study identified several other questions that are preferred to elicit sexual orientation disclosure. For example, some lesbians recommended that healthcare providers directly ask: "What is your sexual orientation", while other lesbians and female bisexuals encouraged the use of question such as: "Are you attracted to males, females, or both?"

The use of open-ended questions to stimulate discussion about sexual orientation is also recommended by Alexander & Schrauben (2006) and Allen et al. (1998).

The physical environment was a major contributor of comfort for LGB college students in this study. Specifically, the visibility of the rainbow flag in the healthcare setting demonstrated a safe and LGB friendly arena. The uses of these symbols remain a common recommendation to healthcare providers (GLMA, 2006). However, no study participants cited current recommendations of displaying posters, subscribing to LGB magazines, posting a visible non-discriminatory notice, and offering LGB health-related brochures (Coren, Coren, Pagliaro, & Weiss, 2011) as measures to create a comfortable environment.

### **LGB Individuals as a Sub Group**

Many studies that explored various aspects of the LGB youth healthcare experience (Alexander & Schrauben, 2006; Bonvicini et al., 2003; East & El Rayess, 1998; Ginsberg et al., 2002; Hoffman et al., 2009; Mayer et al., 2008) examined data from the perspective of the greater group (i.e. LGB). Some studies examined data as a dichotomous sample [gay/lesbian and bisexual] (Allen et al., 1998; MDPH, 2009) or combined lesbian with female bisexual and gay with male bisexual (Ridner et al., 2006). Additionally, the Institute of Medicine (2011) report, *The Health of Lesbian, Gay, Bisexual, and Transgender (LGBT) People: Building a Foundation for Better Understanding*, detailed findings in aggregate versus sub groups. In contrast, this study collected and analyzed data from the perspective of each sexual orientation sub group (i.e. L, G, and B). Analyzing data within segmented groups allowed the themes of personalizing the experience, disclosure and social stigma, and seeking support of self-identified sexual orientation



to emerge, thus adding to the literature and enabling a more directed action be developed for each group, since they are “not all the same.”

### **Personalizing the clinical encounter.**

Lesbians described a positive clinical encounter with their healthcare provider as one that was personalized. Participants did not want their healthcare provider to be a stranger. Although Hoffman et al. (2009) found that a LGB group preferred the characteristic, being personable, in this study, the lesbian focus group wanted their healthcare provider to provide personalized care during the clinical encounter. Additionally, Hoffman et al. (2009) reported being supportive as a preferred characteristic of the healthcare provider, whereas in this study, support of self-identified sexual orientation emerged from the female bisexual focus group.

### **Deciding to disclose and social stigma.**

The theme of deciding to disclose and social stigma emerged from the gay focus group. The decision to disclose in this group was inconsistent as some group members believed that sexual orientation was not pertinent or relevant to the health visit, while others were concerned about the social stigma tied to sexual orientation. These findings are supported by past research that found that LGB individuals do not think sexual orientation is an important topic to discuss (Allen et al., 1998; Bjorkmen & Malterud, 2007; Meckler et al., 2006; Stein & Bonuck, 2001) and do not know how to raise the conversation of sexual orientation during the clinical encounter (Meckler et al., 2006; Stein & Bonuck, 2001). However, these studies reported their findings in aggregate, whereas in the current study, it was only the gay focus group that identified importance and relevance to the conversation as a barrier to disclosure.

As reported by the IOM (2011), LGB individuals encounter stigma during their developmental path of sexual self-identity. This stigma “shapes how they perceive and interact

with all aspects of society including healthcare providers” (IOM, 2011, p. 45). In the current study, gay participants reported that sexually transmitted infection (STI) and HIV stigma is prominent in the healthcare setting. One participant explained: “STI’s are something that is shoved down our throat” while another participant added his perception that HIV stigma plagues the gay community in the healthcare setting. These comments are similar to comments verbalized in focus groups of LGB youth conducted by Ginsberg et al. (2002).

### **Internet Action**

A recent PEW report (2009) collected data about the Internet use of American adults (age 18 - 29), and noted that this age group remains the most likely age group to go online over the past decade (Lenhart et al., 2010). Current online access in this age group is estimated at 93%. In the PEW report, 66% of the group owned a laptop computer and 93% owned a cell phone. Approximately half (55%) of the 18-29 year olds surveyed had accessed the Internet wirelessly on a laptop or cell phone, and approximately a quarter (28%) had accessed the Internet on an e-book or gaming device (Lenhart et al., 2010). Seventy-two percent of the online users within this age group use social network sites, including the most popular, Facebook.

### **Social network sites and facebook.**

Boyd & Ellison (2007) defined a social network site (SNS):

As a web-based service that allows individuals to (1) construct a public or semi-private profile within a bounded system, (2) articulate a list of other users with whom they share a connection, and (3) view and traverse their list of connection and those made by others within the system (p. 1).

When an individual joins a SNS, he or she begins to search for other users of the site whom (a) they are friends with offline, (b) are not known offline, but have a common interest identified through the SNS, or (c) have a shared friendship with a mutual individual. The goal of SNS is the display of the user's friend network on his or her profile. This information enables other friends to peruse the friend list and develop their own relationships with mutual friends. One popular SNS in today's society is Facebook, which was created in 2004 with an intended audience of Harvard University students. As the website grew in popularity, neighboring college campuses were invited to join. In September 2005, the site was opened worldwide.

Facebook currently has 500 million active users worldwide (Facebook, n.d.). Approximately 50% of the active users login to Facebook on any given day and each user has an average of 130 friends (Facebook, n.d.). Active users collectively clock in over 700 billion minutes on Facebook every month. One aspect of Facebook is the ability to join a group. This group may be a virtual group or an extension of a face-to-face group that has chosen an online component to their group dynamic. According to PEW Internet (2011), in the American Life Project Survey, 75% of American adults are active in some type of organized group and 82% of SNS users have a profile that is linked to an active group. Additionally, 65% of SNS users read updates and group messages online, and 30% of active group members have posted news about the group on their SNS profile (PEW Internet, 2011).

### **SNS and health information.**

There is an emerging body of research investigating the use of social media in an individual's quest for health information. In a PEW Internet Report (2009), it was reported that 72% of 18-29 year olds visited the Internet for health information. The term e-patient is assigned

to individuals who seek health information online. Information sought online included, but was not limited to (a) reading an individual's healthcare experience or health commentary on a website, blog, or news group, (b) consulting the rankings or review of healthcare facilities, (c) signing up for customized healthcare updates, and (d) listening to a health issue on a podcast. In general, e-patients are likely to engage in other forms of social media, such as SNS.

Silenzio, Duberstein, Tang, Lu, Tu, and Horman (2009) are researchers spearheading exploration of the use of a SNS as a venue for prevention (specifically suicide) in the LGB youth community. Using computer simulation, Silenzio and colleagues (2009) were able to determine that effective and wide spread dissemination of preventative interventions were feasible using a SNS platform. As indicated by participants in this study, the use of the Internet, was a feasible and effective venue to create a mechanism of action that will benefit LGB community members. college students are busy but have the mobile technology and Internet access to belong to and contribute to an established group on Facebook.

### **College Alliance Toward Community Health (CATCH)**

In the current study, the community discussed the feasibility of establishing a health oriented SNS group to reach the largest amount of LGB college students with information to improve LGB college students' healthcare experiences. The creation and goal of a health-oriented SNS, College Alliance Towards Community Health (CATCH), originated from the various recommendations of focus group participants. The name and acronym CATCH is the product of one key informants' imagination and the profile picture for the Facebook page was professionally designed based on conversations with the key informants and several members of the Pride Alliance.

The mission of CATCH was derived from the descriptions provided by participants when asked what would make their healthcare experiences more positive. The mission of CATCH is to provide LGB college students in the local community with a comfortable forum to learn about various healthcare concerns of lesbian, gay, and bisexual college students. The group provides an opportunity for LGB members to network with other members and community organizations in a respectful manner that is convenient to the college student.

The PI of the study will establish this group site on Facebook and will be the system administrator along with two members of the community who volunteer to have administrator responsibilities. CATCH will be an open group, which means that any Facebook member can choose to join. However, the PI will begin soliciting group members through the Worcester State University Pride Alliance, who in turn, will connect their LGB friends to the groups' site. The PI will be responsible for monitoring the site for the use of disrespectful language and postings that do not coincide with the mission of the group. The system administrator has the authoritative rights to remove any group member who violates the mission of the group.

At least monthly, the PI will update the groups' status on Facebook. When a status is updated on Facebook, members of that group have the ability to see that status update in his or her news feed. As one participant said, it is not that college students are not interested in improving their health; it is that "we let it take a backseat to everything else." Based on the data about Facebook usage, the possibility of group members being exposed to information posted by the group is likely. As members scroll through the profile news feed, he or she can decide if the posting from CATCH interests them enough to continue reading. Otherwise, the posting will remain on the groups' virtual wall indefinitely so that any member may access the information in the future.

CATCH will (a) provide links to the latest statistics in LGB-related health, (b) provide contact information for LGB friendly healthcare providers in the community, and (c) collaborate with community organizations (e.g. post events, forums, and activities) to raise awareness of LGB health in the local community. Additionally, CATCH will provide a discussion forum for members to network with other members in a safe and comfortable virtual atmosphere. This will be conducted on the discussion board portion of the group site. Either the group administrator or group member can initiate discussion threads, which are conversations that are left open indefinitely for the group to make comments. One example of a discussion thread that may occur on this group site includes the individual quest for locating a LGB friendly healthcare providers. Other members are able to post recommendations, summaries of experiences, and other information that would be helpful to this individual and many other group members. The discussion forum does not show up in the members' status updates, but requires the members to click into the group page and select discussion board. Once a member posts a response to the discussion question, Facebook notifies him or her when sequential responses are posted.

Group expectations are established when the group is created, and as administrator, the PI has the authority to terminate any individual who posts an inappropriate response or uses offensive language. As indicated in the study, the healthcare experiences of LGB college students' needs to be recognized as unique entities within the LGB population. To maintain the tenets of CBPR, the postings, links, and discussion threads will originate from community participants' Facebook participation and will address the variability in topics to meet the needs of all self-identified group members.

Based on study data, initial postings on CATCH will include information to help address heterosexual assumptions and promote a personalized healthcare experience in the healthcare

environment. Posted information will provide group members with the knowledge and skills to respond appropriately to a HCP who assumes his or her heterosexuality. Additionally, educating the community members about appropriate conversations to initiate with their HCP is an important aspect of facilitating a comfortable clinical encounter and personalizing the healthcare experience. Additionally, in the week prior to day events or during the weeks of awareness months (see Table 9), status updates and postings will focus on raising awareness to how that event affects the LGB college community's health.

Table 8

*World and National Awareness Dates*

Cervical Health Awareness Month	January
National Wear Red Day	February 4
National Colorectal Awareness Month	March
National Women and Girls HIV/AIDS Awareness Day	March 10
Alcohol Awareness Month	April
Sexual Assault Prevention and Awareness Month	April
World Health Day	April 7
Hepatitis Awareness Month	May
Mental Health Month	May
National Women's Health Week	May 8-14

World No Tobacco Day	May 31
Men's Health Month	June
Men's Health Week	June 13-19
National HIV Testing Day	June 27
Ovarian Cancer Month	September
National Gay Men's HIV/AIDS Awareness Day	September 27
National Breast Cancer Awareness Month	October
National Latino HIV/AIDS Awareness Day	October 15
Great American Smoke Out	November 17
World AIDS Day	December 1

Most important, the development of action must provide the community with a sense of ownership, sustainability, and understanding of the direct benefit to its members. Therefore, an additional goal of CATCH will be to engage group members and co-administrators to seek out current happenings related to LGB health and feel confident to post links of their own interest that may be of benefit to other community members.

### **Organizing Framework**

The usefulness of the Kilbourne et al. (2006) framework for understanding healthcare disparities from a health services perspective was limited outside of guiding the semi-structured



interview questions. Participants in varying degrees discussed the four interacting concepts of healthcare service factors, patient factors, provider factors and clinical encounter, but certainly, the healthcare disparities experienced by the LGB college students cannot be fully explained by this framework.

### **Healthcare system factors.**

First, LGB college students did not identify healthcare services factors as important influences during their healthcare experience. One could argue that the participants' descriptions of the physical environment or the mention of social stigma may fall under this concept. However, further exploration into this is required. Additionally, the preliminary theme of perceived confidentiality may also be considered a healthcare system factor; however, as presented in chapter four, this theme requires further investigation in the community. Nonetheless, the more traditional factors of insurance, availability and access were not discussed in this study. Perhaps, the Qualifying Student Health Insurance Program adopted by The Commonwealth of Massachusetts has reduced the barriers to accessing healthcare for young adults enrolled in institutions of higher education.

### **Patient factors.**

Patient factors also did not emerge as a major influence on the healthcare experience. It did however, influence the decision to disclose sexual orientation to the HCP. As discussed particularly in the gay group, the choice to disclose appeared to be based on the individuals belief that sexual orientation was important to his or her overall healthcare. The influence of the participants' psychosexual development on the healthcare experience did not emerge as a major

influence. The limited diversity of the sample does not allow an adequate understanding of the influence of race, ethnicity, and culture on the healthcare experience.

### **Provider factors and clinical encounter.**

The two concepts from the Kilbourne et al. (2006) framework that were also discussed during this study were various provider factors and clinical encounter factors. Similar factors that emerged from the focus groups included provider attitudes and biases, and within the clinical encounter, provider communication was a major finding. Therefore, the interaction of these two concepts is important to understand the healthcare experience and may begin to explain a foundation for health disparities to be built on, however, further exploration into all these factors is indicated.

### **Study Limitations**

As with all CBPR and focus group research, findings from this study are not to be generalized beyond the research community of LGB college students in the COWC. Additionally, the sample recruited is not representative of the local geographical community, as only one participant identified himself as Hispanic, and one female identified herself as Black. The poor turnout of male bisexuals for the focus group also requires preliminary findings to be read with caution, as the experience of one male bisexual may not be representative of the group. Additionally, only one focus group was conducted for lesbians, gays, and female bisexuals, therefore, additional focus groups are needed to further explore their respective experiences. Further, the high rate of disclosure among female participants may have contributed to a more positive healthcare experience for participants, thereby influencing their recollections of healthcare experiences. Finally, the fast pace of CMC in the form of synchronous online focus

groups may have impacted the ability of the moderator to follow responses in a sequential fashion (participant answers may not be posted directly after the question it was answering), thus affecting the analysis of transcript data.

### **Implications for Nursing Practice**

This study provides registered nurses and advanced practice nurses (Nurse Practitioners) with descriptions of positive and negative healthcare experiences of LGB college students. Nurses are in the position to prevent the heterosexual assumption of patients in his or her area of work and role model a comfortable clinical encounter for all college students, including those that identify as LGB. Nurses need to evaluate the LGB friendliness of the health office, and educate staff about the appropriate display of LGB related symbols and communication techniques to promote a comfortable and safe clinical encounter for the LGB college student. Additionally, nurse educators need to educate nursing students about LGB sensitivity and the use of positive communication techniques with all their patient, and especially LGB patients.

### **Implications for Further Research**

According to the IOM (2011), the current state of knowledge about LGB youth and young adult health is limited because this sub group has a low incidence of chronic illness and interacts with the healthcare arena less often than other LGB sub groups. Further research is needed to describe the healthcare experiences of male bisexual young adults in college, as this sub group was difficult to recruit. Additionally, more focus groups with an ethnically diverse sample (including Black and Hispanic participants) will better represent the demographic makeup of the local geographical community and the college population. The implementation of CATCH to facilitate a more positive healthcare experience in the local community will need to

be evaluated for effectiveness and sustainability in the local community. The evaluation process is currently in the early development stages.

Based on the findings of this study, further research is needed to explore the relevance and significance of sexual orientation in the delivery of healthcare to gay men, as this was an ambiguous facet of the focus group. Additionally, a better understanding of the role disclosure plays on the patient-provider relationship and overall satisfaction with the healthcare experience is needed.

### **Summary**

This study described the healthcare experiences of LGB college students (ages 18-24) in the local community. Themes emerged that were supported by prior research. However, in the current study, findings were more specific to the sub group of lesbians, gays, and female bisexuals, opposed to findings that described the aggregate (i.e. LGB). This study contributed to the current literature by addressing a major gap in knowledge, since this was one of the first studies to explore the healthcare experiences of LGB college students. Additionally, the innovative use of online synchronous focus groups to collect qualitative data is a novel method in nursing research.

This study identified implications for nursing practice at the Registered Nurse and Advanced Practice Nurse role. Nurses are trained leaders, and in the healthcare setting, nurses serve as role models. Therefore, nurses need to use language that does not reflect assumptions of heterosexuality, use positive verbal and non-verbal communication, and create a comfortable and personalized clinical encounter by altering the physical environment. The creation of a SNS, College Alliance Towards Community Health (CATCH) was developed as an internet

mechanism of action to meet the principle consistent with CBPR and address aim number two of the study. Recommendations for further research include addressing a major limitation found in this study, the poor recruitment of male bisexuals in the local community. Additional studies can evaluate the effectiveness and sustainability of CATCH, and the ability to facilitate a positive healthcare experience for LGB college students in the local community.

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