



Community Based Participatory Research: The Application and Lessons Learned from a Study with LGB College Students

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Abstract

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Keywords

CBPR; Lesbian; Gay; Bisexual; Health Disparities; 18-24 year old; College students

Cover Page Footnote

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ABSTRACT

Lesbian, gay, and bisexual (LGB) individuals are members of a vulnerable group where health disparities have been identified. To gain a better understanding of the LGB college student healthcare experience and its contribution to the healthcare disparities found in LGB population, a community based participatory research (CBPR) approach was used to fill the gap. This paper will outline the CBPR process with an emphasis on how the principle investigator applied the tenets of CBPR when working with a local LGB college community. Several lessons learned from the research process are also shared in this paper.

Keywords: CBPR, Lesbian, Gay, Bisexual, Health Disparities, 18-24 year old, College students

INTRODUCTION

Vulnerable populations are at risk for health disparities (DeChasney, 2008). Kilbourne, Switzer, Hyman, Crowley-Matoka, & Fine (2006) defined a health disparity as an, “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). In 2002, the Institute of Medicine (IOM) outlined the derivation of health disparities to be from various sources including factors within the health care system, the healthcare provider, or the patient. Kilbourne and colleagues (2006) expanded on this IOM outline to develop an understanding of the etiology of health disparities from a health services research perspective. Identifying similarities to the IOM, Kilbourne et al. highlighted the clinical encounter (which is the intersection of individual and provider factors during a health care encounter) as a major contributor to the etiology of health disparities. For example, a negative provider attitude or lack of provider acceptance of the patient characteristics (e.g. age, race, gender, sexual identity) during a healthcare visit could influence the patient’s decision to return to that healthcare provider, or any healthcare provider in the future. This lack of access to sensitive healthcare has been known to contribute to health disparities in vulnerable groups (Jillson, 2002).

Background and Significance

Lesbian, gay, and bisexual (LGB) individuals are members of a vulnerable group where health disparities have been identified (IOM, 2011). For example, depression (Diamont & Wold,

2003), anxiety (Bostwick, Boyd, Hughes, & McCabe, 2010), eating disorders (Austin et al., 2009), obesity (Boehmer, Bowen & Bauer, 2007), and suicidality (D'Augelli, 2002; Silenzio, Pena, Duberstein, Cerel, & Knox, 2007) are some of the health outcomes that are found at significantly higher rates in the LGB community. Of greater concern is the contrasting incidence of high risk health behaviors linked to these disparities when comparing LGB individuals to their heterosexual counterparts. Examples include cigarette smoking (Remafedi, Jurek, & Oakes, 2008), alcohol use (Corliss et al., 2010), illicit drug use (Corliss et al., 2010), and high-risk sexual activity (Rhodes, McCoy, Hergenrather, Omlin, & DuRant, 2007). Studies have reported 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), at the same time that sexual identity is acknowledged (Bilodeau & Renn, 2005; Edwards & Brooks, 1999; Saewyc et al., 2004) and may be amplified during the college years.

It is important to understand that having an LGB identity is not the risk factor for these disparities. The environment in which people are born, live, learn, work, and age affect a wide range of risk factors and health, functioning, and quality-of-life outcomes (World Health Organization [WHO], 2008). LGB individuals are often stigmatized by a prejudiced and discriminatory society because of their nonconforming sexual identity, which in turn increases stress (Meyer, 1995; Meyer, 2003; Saewyc et al., 2006). When the stress increases, risk behaviors found in high prevalence in the LGB population may be triggered, thereby contributing to the disparate health outcomes in this particular group.

This phenomenon is concerning for young adults (ages 18-24) who have the lowest rate of insurance coverage which leads to reduced healthcare access (Park, Paul, Adams, Brindis, & Irwin, 2006) so these triggers may not be identified by healthcare providers. For LGB individuals, the additional burden of social stigma and societal disapproval may also contribute to their delay in seeking healthcare (Stein & Bonuck, 2001; van Dam, Koh, & Dibble, 2001). Therefore, the LGB college population is extremely vulnerable and prevention and detection of these behaviors is important to prevent poor health outcomes in the long term. Yet, little is known about the healthcare experiences of LGB college students. What we do know about this age group (ages 18-24) is limited to studies combining adolescent (ages 13-24) and general adult populations (ages 19-99) or, our knowledge 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.

To gain a better understanding of the LGB college student healthcare experience and its contribution to the healthcare disparities found in LGB population, a community based participatory research (CBPR) approach was used to fill the gap. CBPR has been recognized as a viable approach to research aimed at learning more about health disparities in various populations (Viswanathan et al., 2004). This paper will outline the CBPR process with an emphasis on how the principle investigator (PI) applied the tenets of CBPR when working with a local LGB college community. This paper adds to the literature by providing the tactics and lessons learned from a collaborative research team which consisted of members with different sexual identities, but with the same objective; to describe the healthcare experiences of LGB college students as a first step in eliminating the health care disparities that plague this vulnerable population.

METHODS

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, Schultz, Parker, 2005). CBPR has several goals. One goal is to bridge the gap between scientific inquiry and practice by engaging institutional partners 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 of CBPR

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 emancipation from historically bound constraints (Guba & Lincoln, 1994; Susman & Evered, 1978), some of which may be contributing to the health disparities found in the community.

Selecting CBPR as a Research Approach

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 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.

When a researcher studies a sensitive topic such as sexual identity, it is important to acknowledge and anticipate methodological challenges. Non-participation and validity of reported data are two main concerns when there is a focus on sexual identity. The desire to avoid stigma and discrimination related to sexual identity disclosure is a driving force that researchers, working with the LGB population need to offset in order to demonstrate a safe and inviting research process. The IOM (2011) reported that sexual minority participants are “more likely to trust researchers who evidence knowledge and sensitivity about their community and culture” (p. 3-3). Therefore, the decision to use a CBPR approach was logical, especially since the primary researcher did not have sexual identity concordance with the target population.

Conducting 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 or academic 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 with direct benefits focused on the community. In this study, the PI partnered with two college students (bisexual female and gay male) as key informants who represented the community of interest. These two students were selected because they were an expert source of information (Marshall, 1996) with solid communication skills and provided the PI with access to the desired population (Tremblay, 1957). With the emphasis on a collaborative partnership guiding CBPR, the following application of principles (Israel, Eng et al., 2005) provided organization and decision-making support for the partnership 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). In this study, community was defined as self-identified lesbian, gay or bisexual college students in the local geographical college community. Discussions between the PI and community members

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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 sexual behavior (men who have sex with men or women who have sex with women) or attraction (homosexual or bisexual [note this use of bisexual is different than the defined identity of bisexual as explained by the community]).

Building on the strengths and resources of the community.

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. Strengths in this LGB college community included two community leaders who acted in the capacity of key informants. These two leaders helped the researcher, who does not identify as a sexual minority, to access, recruit, and engage LGB college students throughout the research process.

Based on a needs assessment of lesbian, gay, bisexual, and transgender individuals in the local geographical community, many strengths and resources were identified. Focus groups and individually survey participants most frequently cited "open and supportive religious institutions in the County" as a perceived strength in the local community (Greater Worcester Community Foundation, 2006, p.15). Additional community strengths identified 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's Gay Pride event, (e) The Pulse, the community's lifestyle and entertainment magazine, and (f) inclusion of gay people within the community's power structure (Greater Worcester Community Foundation, 2006). These strengths were reviewed and corroborated by the key informants and several members from the LGB geographical community. These strengths were used to inform proposed research decisions. For example, the recruitment of research participants targeted the various lesbian, gay, and bisexual advocacy organizations within the colleges/universities of the local geographical area.

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 during all stages of the research to equalize the power structure and maintain a collaborative relationship. As a result, community members become invested in the research, which in turn develops a sense of project ownership (McIntyre, 2008).

In this study, two key collaborations existed: (1) between the PI and the consortium of colleges/universities in the local geographical area and, (2) between the PI and the Student Activities Department of the PI's academic institution. In addition to striving for quality higher education, the consortium supports the research efforts of their faculty (Colleges of Worcester Consortium, 2010). 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 to assist in recruitment of the sample. The second partnership with the academic institution's Student Activities Department provided access to college students who participate in the University Pride

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Alliance Organization. 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, which included the two key informants. In the fall of 2009, my relationship with the Pride Alliance began as a faculty observer. I attended informal and formal meetings of the organization and engaged in the work of Pride Alliance to demonstrate my sincere interest and desire to assist the organization in fulfilling their mission.

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 individuals. 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 Pride Alliance sponsored events (Story et al., 2010). My goal was to establish a trusting relationship with the community, allowing open discussion about their issues which informed research decisions. I was reassured that this relationship had developed when the Pride Alliance voted me to be their new faculty advisor for the following academic year. This appointment helped with the difficult task of sustaining trusting relationships (Story et al., 2010) and offered 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 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 provided the PI with a contextual and cultural understanding of the LGB college community and in return, knowledge gained from the research process was shared from the PI to community participants (Israel et al., 2008). Skills in problem definition, assessment, research, intervention development, implementation, and evaluation, all of which can strengthen community capacity, were primary skills shared from the PI to the key informants, who in turn shared with the community at large (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 was built during the course of the research process as evidenced by the increase in the numbers of students and faculty, of all sexual identities, who joined and mobilized with Pride Alliance. With a growing body of supporters, campus wide initiatives, including the creation of gender neutral bathrooms was achieved.

Knowledge gain and generation of interventions.

Generating new knowledge for direct community benefit is a central tenet of CBPR (Israel, Eng et al., 2005). A key task in the study's research partnership was to equalize the power imbalance between the researcher (a faculty member at the academic institution) and members of the LGB community (consisting of students across the local community) to promote the knowledge-generating process. The Pride Alliance maintained updates on the study in monthly meeting agendas and periodically, I would attend groups or meet with Pride Alliance members individually to discuss various aspects of the research process. By eliminating the use of terminology such as "the researcher" and "those being researched" the integration of

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“knowledge and multiple perspectives result[ed] in better research” (Boser, 2007, p. 1064) because the community believed their contribution was valuable in benefitting the community as a whole.

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 Kilbourne and colleagues (2006). The influential determinants included, 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. Also included were cultural and environmental factors that influenced 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 prior to initiating the study.

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 PI 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 University’s Pride Alliance focused on the clinical encounter factor of health disparities in the LGB community. Members of the Pride 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. Stories shared by the students in Pride Alliance were abundantly negative and fueled the group’s decision to learn how to make these healthcare visits a more positive experience. It was believed that if the clinical encounter was more positive, then LGB college students would access their healthcare provider appropriately, thereby providing a comfortable opportunity to discuss behaviors that may contribute to negative health outcomes in the future.

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). A description of how the community was involved in identifying the research question, however, their involvement did not end there. Community members were involved in the data collection via online synchronous focus groups (Stover, 2012), and member checks were conducted at the conclusion of each group. The key informants provided analytical support to the PI which also added to trustworthiness of emerging themes (Minkler, 2005).

Dissemination of results.

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Research results from studies conducted using CBPR, 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. 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 hierarchical controls influence the health and well-being of the community.

The PI and the key informants agreed that the dissemination of the findings from the current study would include, at a minimum, the PI’s doctoral degree requirements (dissertation and one peer-reviewed publication) and immediate feedback to the community via power point presentation. To date, the key informants and the LGB college community are acknowledged in the doctoral dissertation and one manuscript. The key informants are co-authors on one manuscript (Stover, Hare, Johnson, in press). One key informant has presented a poster at the academic institution’s scholarship day and was an invited speaker to a meeting of State High School principals. The academic researcher has presented a poster at one regional and one national scientific conference and authored one additional peer reviewed manuscript.

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. 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 university and new members enter the campus organization. The PI has since left the academic institution where this study occurred, and the two key informants have graduated, however, the team has pursued additional opportunities to replicate this study with a sample of transgender individuals as that group was purposefully excluded from the sampling criteria in this study. To address the sustainability of community action, it is important to discuss the community identified action that emerged from the study.

College Alliance Towards Community Health.

College Alliance Towards Community Health (CATCH) is a social network group that is housed on Facebook and provides the local college community, with a unique focus on LGB college students, with a comfortable forum to network and learn about the health needs of the LGB young adults in college. The creation of this social network group was a direct suggestion from the first focus group consisting of seven lesbian college students. One participant stated: “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.” In response, other participants added that they believed a community could be developed using technology, and that the use of Facebook was the current trend in college students. “Facebook has become everyone’s go-to place for info...it’s becoming more helpful than Google.” All subsequent focus groups agreed that the development of a Facebook group focused on health for college students, with special attention to those that identify as LGB would

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be a sustainable intervention in the local college community. “Facebook is the best way to get to our age group” because: “I personally read my Facebook more than any other form of contact,” one gay male contributed. Facebook has over 500 million active users worldwide and approximately 50% of the active users login to Facebook on any given day. 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). Based on these statistics, the research team agreed that developing this SNS was a reasonable action. The name and acronym CATCH is the product of one key informants’ imagination and the profile picture (a palm of a hand appearing to catch a rainbow) 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 all focus group participants.

The PI of the study established this group site on Facebook and was the system administrator for one year when it was turned over to one of the study’s key informant to solely manage. CATCH is an open group, which means that any Facebook member can choose to join. The administrator is 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.

For the first year, at least monthly, the PI updated 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.

Based on the community’s suggestion during the focus groups, the research team decided that initial postings on CATCH would include information to help address heterosexual assumptions and promote a personalized healthcare experience in the healthcare environment. Posted information provided group members with the knowledge and skills to respond appropriately to a HCP who assumes his or her heterosexuality. For example, two weeks prior to National HIV Testing Day (June 27), a post would occur that alerted group members of the need to know their HIV status. Suggestions about how to ask a healthcare provider for a HIV test was posted as well as a link to find safe HIV testing sites in the community (based on zip code). This information would continue to be posted until June 27. Other CATCH postings provided (a) links to the latest statistics in LGB-related health, (b) contact information for LGB friendly healthcare providers in the community, and (c) collaboration with community organizations (e.g. post events, forums, and activities) to raise awareness of LGB health in the local community. Additionally, CATCH provides a discussion forum for members to network with other members

in a safe and comfortable virtual atmosphere. CATCH currently has 54 members, which is down from a high total of 100 members.

RESULTS

The research team of the PI and two key informants conducted three online synchronous focus groups, with each group segmented into a self-identified sexual identity (lesbian, gay, female bisexual). The findings from the focus groups are published elsewhere (Stover, Hare, Johnson, in press) and the method of conducting the focus groups is published elsewhere (Stover, 2012). However, several lessons learned from the CBPR process are shared in this paper.

Lessons Learned

“Key Informants Open the Door.”

I am a heterosexual female college professor who wanted to conduct a study with the LGB college community to address healthcare disparities. There were two power differences in this scenario that needed to be equalized in order for me to access the desired sample. I needed the community to gain trust in a professor who worked in their institution of study and who identified as societies “dominant sexual identity.” This required prolonged engagement with the community in the beginning stages of my doctoral work to develop a collaborative and equitable relationship (Cargo & Mercer, 2008) that would generate research ideas and processes that would benefit both the researcher team and the community. The selection of two key informants was invaluable at this stage, as they introduced me to the community and modeled a relationship with me that others in the community were encouraged to mimic. By de-emphasizing the differences in sexual identities between me and the community, and maintaining a non-judgmental and non-assuming approach during engagement, the forum to discuss sensitive and personal information quickly developed. However, the influential role of the key informant must not be overlooked. As articulated by one informant:

“It is my belief that without the key informants, [the PI] could not have conducted or completed her research. Finding and maintaining participants for the study would have been impossible without an LGB contact. Our roles were crucial in the development of her research not only as a source for LGB information but also as a second set of eyes and ears to help with the analysis process.”

Not all Community Members will be “On Board.”

The research team conducted a pilot focus group consisting of four community members (mixed gay and lesbian identities). The goal was to perform a synchronous online focus group, become familiar with the software, and determine the clarity of interview questions. During the pilot interaction, one male who identified as gay, asked me why I was bothering with this study because doctors were not going to change the way they treated the community. I explained that I was trying to understand what occurred during a healthcare encounter between community members and their healthcare providers so that I could educate and raise awareness among providers. The participant was emphatic that I was wasting my time and no healthcare provider would listen to me and LGB college students were not interested in understanding this aspect of their health. This interaction worried me because I feared that other community members would feel similarly. However, I had to move forward knowing that I was utilizing CBPR because I

wanted to be on the same page as the community and conduct research that was derived from the community and deemed important for the members. I did not encounter any other comments such as this one when conducting the full study, however, it is possible that community members who were not “on board” with my intentions chose not to participate. Nonetheless, it was reassured at the end of the study one key informant wrote:

“As a member of a disenfranchised group, I was at first leery of someone outside of this community wanting to “research” on the LGB community. However after talking with [the PI], I quickly realized how valuable she was to our community and how important it is to have ‘straight allies’ advocating on our behalf.”

I realized that my engagement and/or my purpose may not have reached all community members. Or, this community member had not had the same evolution from skepticism to acceptance that the key informant had identified. However, as the PI, having had this interaction in the beginning of the study humbled me and the research team, making us work harder during recruitment and data collection to demonstrate our sincerity and intentions as community driven. *Sustainability is More Than Just Implementing an Action.*

Sustaining a mechanism of action, even though derived from the community, is a challenging task. With the graduation of the key informant who managed CATCH, there has been a marked decrease in posts on the social network group site. As a first time researcher using CBPR, I have learned that educating and involving more people about the action arm of the study is vital, especially when partnering with a transient population such as college students and a hard to reach population such as LGB individuals. Additionally, in the dynamic world of technology, new social media applications, including Twitter, Instagram, and Snapchat have taken over the popularity of Facebook.

CBPR is a Journey.

I entered this partnership thinking that I could immediately derive an intervention directed at decreasing the healthcare disparities in the LGB community. That was not the case. I had to meet the community at their level. Action had to begin by assisting the community to understand the role that their sexual identity played in their overall health. This included an exploration of how certain interactions during a clinical may or may not inhibit the discussion of sexual identity with the healthcare provider. Helping the community put these puzzle pieces together is an important first step in beginning to reduce the disparities; a first step on a long journey which will require multiple projects with larger and more diverse LGB samples. However, these first steps are critical in the development of the individual as CBPR researcher, the individual as CBPR participant, and most importantly, the development of the partnership between researcher and participant. As observed by one key informant, “Community-based participatory research was the right fit for this group as it allowed us to tell our story while collaborating for the benefit of our community.”

DISCUSSION

The goal of this paper was to outline the application of CBPR to a study that explored the healthcare experiences of LGB college students. Using the Kibourne et al (2006) model for researching health disparities in vulnerable populations, it was evident from this study that the clinical encounter was the etiology of a poor healthcare experience for LGB college students

(Stover, Hare, Johnson, in press). The stories and examples that the community shared with the research team provided a baseline description of the healthcare experiences for lesbians, gays, and female bisexuals that can now be used to support future research proposals to address healthcare disparities in this population. The use of CBPR was instrumental in accessing the sample for this study as the LGB population is often cited as an invisible community (IOM, 2011).

The collaborative partnership of researcher and key informants differentiated this CBPR study from community-based 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 CBPR, the researcher and community members have an equal responsibility to combine their unique talents and strengths to understand a community phenomenon. The driving force of CBPR is successful collaborative relationships which enhance the research process and generate findings that are more meaningful to the community (Pinto, McKay, Escobar, 2008). In this study, the collaboration of an academic researcher with two key informants proved successful in remaining true to CBPR tenets and creating a resource available to community members to improve future clinical encounters with their healthcare providers.

CONCLUSION

In order to address healthcare disparities in various populations, it is important for researchers to understand the underlying factors that contribute to the healthcare disparity in a specific population. CBPR was a successful choice to approach the research problem of increased healthcare disparities and their corresponding high risk behaviors in LGB college students. Although the sustainability of the community derived mechanism of action is limited, there are still valuable lessons to be learned from this collaborative experience. 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 focused on healthcare disparities in the LGB community; thereby, supporting the writing of this paper.

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