DEVELOPMENT OF AN ADAPTATION MODEL FOR HEALTH

INTERVENTIONS FOR SEXUAL AND GENDER

MINORITIES: A GROUNDED THEORY STUDY

by

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Abstract

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A dearth of literature exists on health issues impacting sexual and gender minority (SGM) populations. SGM face health disparities linked to stigma, discrimination, and denial of their civil and human rights. Albeit limited in scope and depth, available data suggests sexual orientation and gender identity have been an important demographic factor associated with higher risk for several negative health outcomes such as cancer, cardiovascular disease, and stroke. Some of the major inequities affecting SGM include tobacco use, alcohol and illicit drug abuse, being overweight/obese, psychiatric disorders, and violence. The SGM who face health disparities created by the use of various substances, overeating, and violence, have required researchers, community partners, and other relevant entities to identify culturally relevant practices and approaches to diminish these inequities.

My dissertation research investigated how various health interventions have been culturally adapted to fit the needs of SGM. The purpose of this study was to develop an adaptation model through the examination of the targeted modifications that researchers, community partners and others make to existing interventions. Heretofore, explorative studies with the specific intent to build an adaptation model of this type for SGM have not been conducted.

The theoretical lens supporting this research included social constructivist grounded theory and queer curriculum theory. Data were collected from interviews with key informants who identified as researchers and community partners involved in cultural adaptation projects for SGM. The final results from the data are presented in two ways: (1) in a diagram that depicts the central phenomena, which I call the emergent model (2) and a narration of the diagram, which examined the details of the model.

A semi-structured interview and qualitative analysis using grounded theory revealed three main themes (cultural considerations, adaptation process, and lessons learned) and a process model. The results of my research are intended to provide a more accessible and relevant route to intervention adaptations relevant to SGM. Implications for social work practice, policy, and research are presented.

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Chapter 1

Introduction

Brief History in Context

In the 1970s-1980s researchers began attempting to describe the "gay experience" by researching gay, white males in mostly urban settings (Liddle, 2007). While groundbreaking, these studies did not typify or represent the lesbian, gay, bisexual, transgender or queer (LGBTQ) culture or the individual experiences of ethnic differences, gender differences, or contemporary influences. Appendix A documents some important events in the history of LGBTQ culture. Notably, the experiences of this culture varies widely with a multitude of social and identity variables such as ethnic group, class, and disability which have shaped the lives and histories of this group (Liddle, 2007). Authors have debated if LGBTQ is a culture, and Morrow & Messinger (2006) declare this group is a culture:

> *Bounded by the challenges of coping with social oppression in the forms*
> *of heterosexism, homophobia, and rigid interpretations of gender*
> *expression. There are GLBT-focused institutions such as churches, civil*
> *rights groups, social groups, and community centers. There are literature*
> *forms, music forms…and artistic expressions that uniquely represent*

GLBT people. Patters of social expression…are passed from generation to

generation among those who are GLBT. (p.7)

Finally and most importantly, what is clear from the histories of this culture is a

commitment to social justice and activism. Even in the face of adversity, sexual

and gender minorities (SGM) and their ally's continue to fight for equality and

basic civil and human rights. I believe my dissertation is a contribution to this

fight for equality.

Scope of the Dissertation

A dearth of literature exists on health issues impacting SGM populations.

As recently as seven years ago, Harcourt (2006) noted that the body of knowledge

on SGM health issues was still in its infancy, mainly due to a lack of data on this

population (Institute of Medicine, 2011). June 2011 marked the date in which the

US Department of Health and Human Services (USDHHS) planned to begin

collecting health data on lesbian, gay, bisexual, and transgender populations in

federal surveys (USDHHS, 2012). At that time, the Institute of Medicine (2011)

noted the importance of taking into consideration a combination of minority

stress, life course, intersectionality, and social ecology, so researchers have a

more complete understanding of health for SGM.

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Nomenclature

Sexual and Gender Minority

For the purposes of this study, it is important to communicate the nuances of sexual orientation and gender/gender identity. Sexual orientation relates to someone's romantic and sexual attraction to another person and includes identities like heterosexual (e.g. attraction to different sex or gender), lesbian and gay (e.g. attraction to the same sex or gender) and bisexual (e.g. attraction to any sex and/or gender) (Teich, 2012). Furthermore, gender identity is an inner sense of self (e.g. male, female, neither, somewhere in between), and gender expression is how people dress and carry themselves (e.g. feminine, masculine, neither, somewhere in between) (Teich, 2012). Queer is a term of empowerment that has been positively reclaimed by many individuals to describe their sexual orientation and/or gender identity and who may not fit into the heterosexual or male/female binary (Beemyn & Eliason, 1996; Teich, 2012). A person who is heterosexual for example, may identify their gender as queer or as a transgender man and similarly a lesbian may identify as a transgender woman or as a non-transgender woman. The possibilities are innumerable with regard to identity and sexual orientation. It is also the case that the similarities between sexual orientation and gender are many; however one common link is gender expression. Many gay, lesbian, bisexual and transgender individuals express their gender outside of hetero-

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normative social expectations (Teich, 2012) (e.g. females must be feminine and males must be masculine). Therefore, sexual minorities do not always fit into a traditional gender binary (i.e. male/female), and gender identity is considered for some, a fluid concept on a continuum. While sexual orientation and gender comprise two different concepts, gender identity and sexual orientation are often considered separable social constructions for many people who identify as a sexual/gender minority on either spectrum (American Psychological Association, 2011).

For my study sexual and gender minorities (SGM) represents a broad umbrella term, which encompasses the identities of individuals from the lesbian, gay, bisexual, transgender, and queer (LGBTQ) community. Specifically, sexual minority refers to an individual who self-identifies their sexual orientation as anything other than heterosexual, or who is sexually attracted to the same sex or gender, or who engages in same-sex sexual behavior (Laumann, Gagnon, Michael, and Michael, 1994). SGM individuals encompass all races, ethnicities, abilities/disabilities, religions, and social classes. These intersections demonstrate the diversity and vast array of differences that exist within the culture.

Gender minority refers to an individual whose gender identity is anything other than cisgender (Anderson & Middleton, 2011). Cisgender denotes or relates to a person whose self-identity and sense of gender conforms with the gender that

corresponds to their biological sex (Anderson & Middleton, 2011; Teich, 2012).

Therefore I use the terms sexual minority and gender minority to comprise

members of a diverse culture, which takes into account LGBTQ sexual

orientation, and sexual attraction, gender identity, gender expression and the

associated cultural history, values, and practices.

Cultural Adaptation

For my study, the term cultural adaptation comprises the definitions of

adaptation and cultural adaptation. Adaptation to interventions and programs has

been defined as any deliberate or accidental modifications, which change

components to a program (Backer, 2001). Cultural adaptation has been described

as program modifications that are culturally sensitive and tailored to a specific

community based on their worldview (Kumpfer, Alvarado, Smith, & Bellany,

2002).

The paucity of national data collection inclusive of SGM creates

difficulties to estimate the size of this population in the United States with a great

likelihood that there is an undercount (Gates & Ost, 2004). Additionally, a lack of

consensus on the definition of sexual orientation and gender categories in research

yields different estimates of the size of this population (Black, Gates, Sanders, &

Taylor, 2000). Taking into consideration these demography challenges in the U.S.

Census and voting polls, in 2004 it was estimated nearly 4 million Americans

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were gay or lesbian (Gates & Ost); this estimate does not take into account bisexual, transgender or other identities in addition to youth. Likewise this estimate does not account for the many people who are private about their sexual orientation, thus the possibility of an undercount. A similar analysis on specific regions of the United States adult population revealed that the proportions of LGBTQ people in certain areas of the country are substantially higher such as San Francisco, California, Hampshire County, Massachusetts, and Portland, Oregon and lower in rural areas of Arkansas, Maine, and Indiana, just to name a few (Gates & Ost, 2004). Therefore it is possible that certain pockets of the United States are home to greater or lesser numbers of SGM adults.

SGM face health disparities linked to "societal stigma, discrimination, and denial of their civil and human rights" (Healthy People 2020, 2011). Albeit limited in scope and depth, available data suggests sexual orientation and gender identity have been important demographic factors associated with higher risk for several unhealthy outcomes such as cancer, cardiovascular disease, and stroke (Institute of Medicine, 2011). Some of the major inequities affecting SGM include tobacco use (Centers for Disease Control, 2008 [CDC]), alcohol and illicit drug use (Herek & Garnets, 2007; Green & Feinstein, 2012; Bux, 1996), being overweight/obese (American Cancer Society [ACS], 2000; Bowen, Balsam, & Ender, 2008), psychiatric disorders (McLaughlan, Hatzenbuehler, & Keyes,

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2010), and violence (Roberts, Austin, & Corliss, Vandermorris, & Koenen, 2010).

Of the major issues, which create SGM health disparities, tobacco addiction is

amongst the deadliest. Every year in the United States almost 400,000 people die

from tobacco-related illnesses (CDC, 2008) and diseases including exposure to

secondhand smoke. Given that SGM smoke at more than twice the rate of the

general population (Austin, Ziyadeh, Fisher, Kahn, Colditz & Frazier, 2004;

McCabe, Hughes, Bostwick, & Booyd, 2005; Easton, Jackson, Mowery, Comeau

& Sell, 2008), they are at an increased risk for all the tobacco-related health

issues. The SGM health disparities created by the use and abuse of various

substances, overeating, and violence have required researchers, community

partners, and other relevant entities to identify culturally relevant practices and

approaches to diminish these inequities (Barrera & Castro, 2006). Thus, my study

narrows in on culturally relevant approaches for the health of SGM.

My study aimed to investigate how health interventions have previously

been culturally adapted to fit the needs of SGM. In order to develop a ground-up

method to model building, a qualitative approach was used to generate cultural

elements, and steps in the adaptation process employed by researchers and

community partners. Specifically semi-structured interviews with researchers and

community partners were used to collect data. The theoretical lens supporting this

research included social constructivist grounded theory (Charmaz, 1990) and

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queer curriculum theory (Sumara & Davis, 1999). My hope is that the outcome of this dissertation will provide future researchers in this area with a more accessible and relevant route to intervention adaptations relevant to SGM.

My dissertation research consists of this chapter, the introduction, and four additional chapters. Chapter two is the literature review, which offers an overview of the existing body of knowledge related to my intervention adaptation study. This review is separated into several parts, the first of which examines the context and prevalence of SGM disparities in the context of health in general. The second part examines related documented interventions that have been culturally adapted for SGM. I conclude chapter two with a rationale for conducting my research based on the gaps in the literature.

A small number of culturally adapted interventions for SGMs have been documented in the literature. Consequently, there is no single agreed-upon theoretical framework to guide the development of specific curricular adaptations for SGM community (McKleroy, Galbraith, Cummings, Jones, Harshbarger, Collins, … ADAPT Team, 2006). Therefore, in chapter three, I framed the arguments and articulated the theoretical framework that guided the research process through grounded theory. The supporting theoretical frameworks provided a lens from which the research questions, methodology, and analysis

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strategy were formed. Specifically, constructivist grounded theory and queer curriculum theory provided a lens from which I approached my study.

In chapter four, I describe the systematic methodological process I undertook for data collection and data analysis. The chapter begins with the goal of the study and the research questions. A description of the grounded theory design follows with a discussion about the research strategy and analysis plan. I conclude with a detailed discussion of the procedures in the context of time allotment as well as considerations for ethical human participant research.

Chapter five documents the results of the interviews and begins with a description of the key informants. Details about each interviewee are presented using pseudonyms to ensure confidentiality. The main themes are presented in this chapter, which ultimately lead to the final model.

Chapter six concludes the dissertation with a presentation and discussion of the model in the context of future directions for this and new research. The limitations are discussed in regards to the research methodology. In addition, implications for practice, research, and policy are presented.

Purpose and Significance of the Study

My research program stands to advance our understanding of how to culturally adapt health interventions so they are relevant for sexual and gender minorities by exploring four conceptual questions: 1) What precipitates the

perceived need to develop or adapt an intervention so it is relevant to individuals who identify as lesbian, gay, bisexual, transgender and queer (LGBTQ)? 2) What is the process in adapting and/or creating the intervention? 3) What can we learn from this process about the characteristics of effective adaptations and/or adaptive interventions, and (4) What guidelines can be recommended for future social service providers who wish to create their own culturally relevant LGBTQ intervention drawing on the emergent model?

The purpose of my research was to develop an adaptation model through examination of the changes that researchers, community partners and others make to existing interventions. Explorative studies with the specific intent to build an adaptation model of this type for SGM service and research have not been conducted heretofore. Exploring and examining the components that influence adaptation will better inform researchers and community partners to develop modifications to interventions that address the needs of their local SGM community. When devising appropriate and practical steps, instructional modalities and materials for guidance, communities and researchers should have a clear understanding of the appropriate steps and sequence to take in adapting curricula or other similar interventions. In addition to community practice implications, the importance of having a documented process model that describes the steps in adapting a health intervention for SGM may be a useful tool

for future research. Specifically, future researchers who embark on culturally

adapting a health intervention targeting SGM now have a tool that can be used to

evaluate the steps in their intervention. If an intervention is adapted using this

model and a future study reveals unexpected outcomes, researchers can revisit the

preliminary model and evaluate the steps they took to identify areas for

improvement or change. The emergent model thus provides a testable tool for

adapting interventions. In the absence of this type of model, there is no

straightforward guidance for researchers and community partners to know if the

steps they took to adapt a health intervention for SGM were the right (i.e.,

effective) steps, or where to begin addressing any future modifications.

Chapter 2

Review of the Literature

Part 1: Context of the Problem

Context

SGM are inherently faced with daily social and emotional challenges

arising from isolation and the associated psychological strain due to their

stigmatized identity and gender identity/expression. Research has consistently

shown that these individuals are increasingly vulnerable especially those without

positive social supports (Hart & Heimberg, 2001). Many of the social

determinants and physical environments affecting the health of SGM individuals

are largely related to oppression and discrimination (U.S. Department of Health

and Human Services, 2011). Some of these oppressive practices include legal

discrimination in access to health insurance, employment, marriage, and adoption;

lack of laws protecting against bullying in schools and in the workplace; lack of

positive social support programs targeting SGM adults and particularly elders;

and finally a shortage of health care providers who are culturally competent and

knowledgeable in SGM health (Healthy People 2020, 2011) (see Appendix A for

examples). The experiences from peer and family harassment as well as their

perception of an unsupportive environment, have been associated with

internalized problems such as isolation and low self-esteem (Grossman &

D'Augelli, 2006; Robinson, 1991) and externalized problems (Elze, 2002) such as family rejection (Robinson, 1991). As a result, many of the specific health consequences faced by SGM youth and adults include increased suicide attempts (Remafedi, Farrow, & Deisher, 1991; Garofalo, Wolf, Wissow, Woods, & Goodman, 1999; Einarsen, Raknes, & Matthiesen, 1994), increased risk for homelessness (Kruks, 2010; Walls, Hancock & Wisneski, 2007), decreased likelihood for lesbian and bisexual women in seeking cancer prevention services (Brandenberg, Matthews, Johnson, & Hughes, 2007; Buchmueller & Carpenter, 2010), higher risk for gay and bisexual men to contract sexually transmitted infections and HIV (Centers for Disease Control and Prevention, 2010), isolation, particularly for youth and older adults (National Resource Center on LGBT Aging, 2012; Cahill, South & Spade, 2009), and high rates of tobacco, alcohol, and other drug use (National Center on Minority Health and Health Disparities, 2009).

Tobacco

SGM adults are two and-a-half times more likely to smoke compared to their heterosexual counterparts (Lee, Griffin & Melvin, 2009). Smoking among SGM youth is even higher (Austin, Ziyadeh, Fisher, Kahn, Colditz & Frazier, 2004; McCabe, Hughes, Bostwick, & Booyd, 2005; Easton, Jackson, Mowery, Comeau & Sell, 2008). In 2009 approximately 17.2% of high school students and

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5.2% of middle school students were current smokers (Substance Abuse Mental Health Services Administration [SAMHSA], 2009). By comparison, prevalence of smoking among SGM youth was 10-20% higher in juxtaposition to heterosexual youth (National Youth Advocacy Coalition, 2005).

Perceived social norms for SGM have also been associated with tobacco and alcohol usage (Eisenberg & Forster, 2003; Perkins & Berkowitz, 1986). Given the salience of stress for this population, it is no surprise that when compared to all other groups, smoking prevalence is highest for SGM (National Center on Minority Health and Health Disparities, 2009; Ryan, Wortley, Easton, Pederson & Greenwood, 2001; Washington, 2002; Gruskin & Gordon, 2006; Tang, Greenwood, Cowling, Lloyd, Roeseler & Bal, 2004; Lee, Griffin & Melvin 2009; Clarke & Coughlin, 2007). A review of the literature identified several speculative explanations addressing smoking prevalence amongst SGM and included (i) high levels of stress, (ii) higher rates of alcohol and drug use, (iii) congregation in social venues where smoking is prevalent (such as bars and clubs), and (iv) direct LGBTQ targeting by the tobacco industry (Ryan, Wortley, Easton, Pederson & Greenwood, 2001). Furthermore, one recent study suggested smoking might be attributed simply to cultural behavior more so than stress (McElroy, Everett, Jordan, & Ge, 2013). Others have stated a lack of age appropriate venues for youth who wish to socialize amongst the SGM subculture,

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may be a contributing factor to tobacco use among those youth (Travers &

Schneider, 1996).

In several studies of youth, the use of tobacco has been a significant

predictor for the use of other chemical substances including illicit drugs and

alcohol (Bowers, Walls, Wisneski, under review; Everett et. al, 1998; Flemming,

Leventha, Glynn & Ershler, 1989; Clark, Kirisci, & Moss, 1998; Orenstein, 2001;

Burkhalter, Springer, Chhabra, Ostroff & Rapkin, 2005). One study found that the

odds of substance use significantly increased with current cigarette use (Everett

et. al, 1998). Longitudinal studies have also found cigarette use to be an entry

drug increasing the chances of successive use of other drugs (Fleming, Leventhal,

Glynn & Ershler, 1989; Lewinsohn, Rohde, Brown, 1999; Patton, Coffey, Carlin,

Sawyer & Wakefield, 2006). Over time, the literature has continued to document

disproportionality in smoking between SGM and heterosexuals.

Substances

Chemical dependency has also been documented in the literature as

disproportionately high in prevalence for SGM (Green & Feinstein, 2012;

Marshal et al., 2008; Wright & Perry, 2006; Padilla, Crisp & Rew, 2010). Like

smoking, substance use and abuse is recognized as higher for SGM when

compared to their heterosexual counterparts (Hart & Heimberg, 2001). High rates

of stress for SGM have been considered a major factor behind substance usage

(Remafedi, 2007; Lombardi, Silvestre, Janosky, Fisher & Rinaldo, 2008). Furthermore, other factors associated with alcohol use include parental and family history of lifetime and current use, use patterns of peers and family, adverse family events and other social factors such as poverty and stigma (Greenwood & Gruskin, 2007). Several studies have concluded that in adults, alcohol abuse and illicit drug use has been higher for lesbians and bisexuals specifically (Bux, 1996; Green & Feinstein, 2012; Cochran, Ackerman, Mays, & Ross, 2004). In regards to gay and bisexual men, national studies have also indicated greater rates of alcohol and psychoactive drug use when compared to heterosexual men (Cochran, Ackerman, Mays, & Ross, 2004).

Obesity

Statistics for obesity and being overweight are topping the priority lists for health practitioners in the United States and like tobacco are considered known risk factors for many preventable diseases such as heart disease, diabetes and some cancers (American Cancer Society, 2000; Haslam & James, 2005). Obesity affects individuals in all age groups, socioeconomic levels, and ethnicities (U.S. Department of Health and Human Services, 2010); however one particularly disproportionate group affected by obesity and being overweight is sexual minority women (Boehmer & Bowen, 2009). When comparing lesbians to heterosexual women, lesbians have consistently higher rates of being overweight

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and obese (Case, Austin, Hunter, Manson, Malspeis, Willett & Spiegelman, 2004; Valanis, Foster, Letizia, & Stunkard, 2000). Like other health interventions, researchers have recommended providers prescribe weight loss programs and other treatments for obesity to be inclusive of personal and individual characteristics including sexual orientation, race, age, and weight (Fogel, Young, Dietrich, & Blakemore, 2012).

Violence

Violence for SGM includes verbal, physical, virtual (e.g. internet and social media), and sexual victimization. Beginning with youth, 82% of LGBTQ middle and high school students experience harassment because of their sexual orientation (The Gay, Lesbian, and Straight Education Network [GLSEN], 2011). Additionally, SGM youth who are homeless are more likely to be physically and sexually victimized compared to their heterosexual counterparts (Whitbeck, Chen, Hoyt, Tyler, & Johnson, 2004). Studies have indicated that high rates of victimization are strongly linked to mental health problems such as depression and lower self-esteem (GLSEN, 2011) and risk for sexually transmitted diseases (Russell, Ryan, Toomey, Diaz, & Sanchez, 2011).

Statistics for SGM adults who experience victimization are also shockingly high. One study found 20% of SGM females and 25% of SGM males had experienced a bias-related criminal victimization (Herek, Gillis, & Cogan,

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1999), experiences which were linked to symptoms of depression, anger, anxiety, and post-traumatic stress (Herek, Gillis, & Cogan, 1999). In a study of adult's age 60 and older nearly 75% reported some kind of victimization in their lifetime based on their sexual orientation; the experiences of those who had been physically attacked reported lower self-esteem, more loneliness, and poorer mental health than others (D'Augelli & Grossman, 2001). The most common type of victimization experienced by SGM is verbal insults (68%) (Fredriksen-Goldsen, Kim, Emlet, Muraco, Erosheva, Hoy-Ellis, Goldsen, & Petry, 2011). In addition threats of physical violence, being hassled by the police, having an object thrown at them, having property damaged or destroyed, being physically assaulted, threatened with a weapon, sexual assault, and intimate partner violence are all disproportionately high for SGM (Fredriksen-Goldsen, Kim, Emlet, Muraco, Erosheva, Hoy-Ellis, Goldsen, & Petry, 2011).

Intimate partner violence (IPV) is one potentially preventable behavior, which largely impacts SGM adults and youth. IPV is a pattern of controlling and abusive behavior in an intimate relationship that can include physical, psychological and verbal threats, sexual assault, and bodily injury (Burke, 1998; Renzetti & Miley, 1996). Across populations, incidence goes largely unreported; however rates have been estimated to be equal or greater for SGM than that of heterosexual women (Greenwood, Relf, Huang, Pollack, Canchola, & Catania,

2002). Next to AIDS and substance abuse, IPV has been described as the third most severe health problem among gay men and may affect 15-20% of SGM couples (Island & Letellier, 1991). SGM individuals who have experienced IPV are at an increased risk for contracting sexually transmitted diseases and infections as well as human immunodeficiency virus (HIV) (Heintz & Melendez, 2006). Not surprisingly, SGM who have experienced IPV are more likely to report having depression and other problems such as hypertension, heart disease, obesity, frequency of alcohol abuse and smoking-related illnesses (Houston & McKirnan, 2007; Schilit, Lie, & Montagne, 1990).

Considering the high prevalence of smoking addiction, substance use, obesity, and experiences of violence amongst SGM, interventions are important opportunities to create change for healthier futures. What each of these behaviors and addictions has in common is that they are preventable in many cases. More importantly, culturally relevant interventions for SGM are essential to the quality of their future health outcomes (Goldbach & Holleran, 2011; Marshal et al., 2008; Green & Feinstein, 2012).

Interventions

Researchers have been tenacious in seeking to document best practices and effective measures that prevent individuals from the general population to never start smoking or use chemical substances, as well as help them quit once

addicted. To address and prevent the burdens of tobacco and other substances on society, different forms of intervention (formal and informal) have been operationalized and tested through research in public health, social work, nursing, and other disciplines (Lantz et al. 2000). Such interventions have encompassed a wide variety of approaches including comprehensive programs in addition to other techniques such as social influence methods, community based programs, mass media campaigns, and policy initiatives (Backinger et al., 2003). Specific youth efforts have included school-based interventions, peer support coupled with educational sessions, motivational interviewing, laser-acupuncture (Garrison et al. 2003), and the use of behavioral and pharmacological aids (Backinger et al., 2003). Taking into account the full gamut of intervention techniques, the highest tobacco quit rates were documented by studies, which covered programs that used motivational enhancement, cognitive-behavioral elements and social influence methods (Sussman, Sun & Dent, 2006). Similarly, programs specifically developed for and tailored to specific developmental age levels increased the probability of tobacco cessation by 46% (Sussman, Sun & Dent, 2006).

In regards to other treatment, one study found in generalized substance abuse programs, former clients who were sexual minorities felt more isolated, not understood by treatment staff, fear of being honest about their sexual orientation, and hearing homophobic comments by staff and clients (Cullen, 2004). Likewise,

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Senreich (2009) found that when compared to heterosexual clients in treatment, sexual minority clients reported less treatment satisfaction, lower levels of feelings of connection to the treatment program, less likelihood of treatment completion, and less abstinence from substances.

The dearth of obesity and violence prevention/interventions, specifically tailored to be relevant to SGM is a major gap in the literature. For example, one study recommended massive intervention efforts and local service provision be directed toward the lesbian community (West, 2008). Likewise, researchers have also recommended an urgent need for obesity interventions to target SGM (Boehmer, Bowen, & Bauer, 2007). Still not enough research has been conducted to know what cultural elements are relevant for SGM. Additionally, IPV for example, has traditionally been conceptualized as a male-female relationship phenomenon and contemporary services are largely based on a heterosexist model of abuse (Hassouneh & Glass, 2008).

The SGM health disparities created by the burdens of tobacco, other chemical substances, violence, and obesity are further exacerbated by a dearth of efficacy studies. While some interventions have been developed to combat these problems, the issue is further compounded in part due to limited evidence of intervention efficacy for SGM youth and adults (Doolan & Sivarajan Froelicher, 2006). This finding is likely due to an insufficient number of available

randomized controlled trials for this population (Doolan & Sivarajan Froelicher, 2006; Dunn, Taylor & Muro, 2004; Senreich, 2010). Regardless of efficacy, researchers have proposed that interventions be culturally grounded in order to be more relevant for SGM (Goldbach & Holleran, 2011; Senreich, 2010; Hecht et al., 2003; Gay, 2000; Harding, Bensley & Corrigan, 2004; Lombardi & van Servellen, 2000). Healthy People 2020 (2011) discussed a need to develop an LGBT wellness model. Scout, Miele, Bradford and Perry (2007) highlighted the importance of cultural competency in fielding an SGM tobacco treatment program. As the research community suggests, SGM have also indicated a strong preference towards an intervention that is culturally adapted, and group-specific (i.e. LGBTQ-only) (Schwappach, 2009; Scout et al., 2007; Walls & Wisneski, 2011; Senreich, 2010; Fogel, Young, Dietrich, & Blakemore, 2012). In addition to a paucity of efficacy studies on culturally relevant interventions for SGM, a gap in these studies exist between adults and youth (Dunn, Taylor & Muro, 2004; Goldbach & Holleran, 2011) with limited to no information about successful interventions with SGM youth. In order to identify any best practices and gather a better understanding of interventions, attention is now turned to curricula and or other health interventions, which have been developed or adapted in order to be culturally relevant for SGM.

Part 2: Adapted Interventions

Cultural Adaptation

A special issue of the Journal of Consulting and Clinical Psychology (2010, Volume 78) published a block of articles on cultural adaptations of smoking cessation interventions for special populations. Although SGM was not a population discussed, a collection of ideas on what to include in smoking cessation adaptations for special populations was proposed (see Figure 2-1).
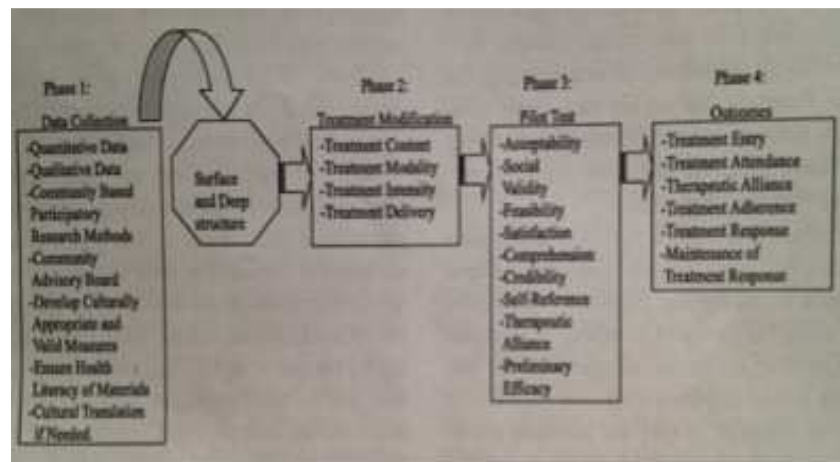
Figure 2-1 Logic Model

The process depicted in Figure 2-1 (Borrelli, 2010) was not systematically derived nor has it be empirically or clinically tested. Nonetheless, it is notable that the process depicted is strikingly similar to a logic model, where proposed outcomes can be evaluated against its inputs, outputs, and other factors (Torghele Buyum, Dubriel, Augustine, Houlihan, & Alperin, 2007). Logic models provide a

framework for evaluators and agencies to conceptualize important components of a program (Royse, Thyer, & Padgett, 2010), however there is little standardization of format, and they can be limited to certain prevailing assumptions about the way the world works (Moss, 2012). Likewise, Figure 2-1 is missing an explanation of its components as well as any deeper understanding of how the phases are connected to one another; therefore it does not account for the steps involved in cultural adaptations of cessation or other health interventions for SGM. However, Figure 2-1 does provide a framework to begin examining the adaptation of interventions, beginning first with tobacco.

As noted above, the development or process of cultural adaptation to curricula and or interventions for SGM health has not been examined. Yet, several studies discussed below, have documented interventions in which they have adapted. The following information provides an overview of empirically published interventions and/or curricula that have been developed or culturally adapted for SGM adults and youth. Where available, efficacy and pilot studies evaluating these curricula are included to provide a richer context for understanding the adaptation process.

Drugs and Alcohol

In a recent national study, SAMHSA (2010) found that only 6 percent of substance abuse treatment facilities offer culturally tailored services for SGM.

SAMHSA provided no information concerning whether these services are considered culturally tailored because of facilitator factors, curricular factors, a combination of both, or something else.

Keeping it REAL (KiR)

An evidence-based intervention developed in Phoenix, Arizona, Keeping it REAL (KiR) (Hecht, Marsiglia, Elek, Wagstaff, Kulis, & Dustman, 2003) teaches adolescents about strategies for resisting drug use and incorporates participant workbooks with related activities and video-based messages to engage youth in conversations about resisting drug use. The curriculum was originally developed with African-American, Caucasian and Hispanic youth using their personal stories in videos to ensure that the curriculum was reflective of the actual life experiences of local youth.

KiR was later adapted for SGM youth and Goldbach & Holleran (2011) utilized focus groups comprised of SGM youth to make the curriculum and its materials as culturally relevant to them as possible. The youth were an integral part of the cultural adaptation including taking the original participant workbooks and making changes they deemed necessary. Core elements of the curriculum were not changed, however new videos and workbook scenarios were created by the youth in an effort to fit their cultural setting. One participant quotation led to a conclusion:

> *Youths felt it was important to infuse sexuality into many of the*
>
> *changes they made…these types of adaptations into the curriculum*
>
> *shows an additional layer to the culture of the community site*
>
> *(p.199).*

Although findings cannot be generalized to the larger SGM youth population, this study offered new insight into cultural adaptations for curricula. Themes that can be further explored from this study included 1.) A fixation with the adult lifestyle of being gay, 2.) A heightened awareness of sex and substance use as a sexual minority, and 3.) An increased awareness of gender as a sexual minority.

Getting Off

Reback, Veniegas, & Shoptaw (in press) developed an evidence-based gay-specific cognitive behavioral therapy intervention (GCBT) for methamphetamine-abusing gay and bisexual men called Getting Off. Their development study has not made it to press; however they have documented elements of the program in pilot and efficacy studies. One study using Getting Off compared outcomes in methamphetamine use and sexual risk behaviors for gay and bisexual men enrolled in a GCBT efficacy study (Reback & Shoptaw, 2011). Results from the study indicated GCBT demonstrated superior efficacy along markers of methamphetamines use at the end of treatment, as well as greater

effects in reducing the number of male sexual partners. The GCBT intervention was developed from a standard cognitive behavioral therapy model and incorporated cultural and social aspects of methamphetamine use by sexual minority males. Findings from another study that compared GCBT and gay-specific social support therapy (GSST) revealed that GCBT produces reliable, significant, and sustained reductions in stimulant use and sexual risk behaviors (Shoptaw, Reback, Larkins, Wang, Rotheram-Fuller, Dang, & Yang, 2008). Still, little is known about what cultural elements were incorporated into the intervention.

Tobacco

The Last Drag

A recognized program by both the Tobacco Control Section of the California Department of Health Services and the national Gay and Lesbian Health Association, the Last Drag is a smoking cessation program for adult SGM and HIV+ smokers in San Francisco, California (CLASH, 1991). The curriculum was created and adapted from the American Lung Association *Freedom from Smoking* (FFS) curriculum intended for adults who are ready to quit smoking. The Last Drag is utilized during a series of seven two-hour sessions that are modeled after FFS with added LGBTQ cultural relevance. The Last Drag is facilitated by an individual who has been certified by the American Lung Association, who has

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prior experience in leading support groups and who is known to be culturally competent with a preference as being an out LGBTQ person. The curriculum states that the facilitator "should be knowledgeable about the historic role of bars in the social fabric of LGBTQ communities and the impact of alcohol and tobacco on LGBTQ people" (p.6). The curriculum is accompanied by several educational pamphlets also titled The Last Drag. Additionally, participants are encouraged to use some form of nicotine replacement or other pharmacological aid in conjunction with the support group.

One pilot study (Walls & Wisneski, 2011) evaluated the Last Drag in a sample of 44 SGM and HIV+ adults receiving services in Colorado. Evaluation criteria included survey questions asking participants if the curriculum was offered in a manner that was culturally appropriate for the SGM community in addition to questions regarding their preferences for classes in a gay-friendly context. Despite low statistical power, there was a significant shift in opinion for participants from pre to post-test in which participants attributed a high level of importance to attending smoking cessation classes in a gay-identified or gay-friendly context. Although no longitudinal or follow up data exist for participants in this study, 90% of those who attended the final session of the group reported being smoke-free. Final conclusions of the study indicated that the inclusion of cultural references in the curriculum, holding classes in LGBTQ-identified spaces

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(e.g. LGBTQ community centers), and using facilitators who are SGM further strengthened the cultural sensitivity of the intervention.

Commit to Quit (The LGBTQ Smokefree Project, NY LGBT Community Center)

The LGBTQ SmokeFree Project offers a 6-week didactic, therapeutic class based on the Transtheoretical Model (Prochaska & DiClemente, 1983). The program was created in 1993 and its materials were formed based on the American Cancer Society's *Fresh Start*, a smoking cessation curriculum for adults. All participants interested in joining the class must first attend a 3-hour "Not Quite Ready to Quit" workshop which focuses on the contemplation stage of change. The 6-week "Commit to Quit" group starts in the planning stage of change, in preparation for individual cessation. The groups are comprised of individuals identifying as LGBTQ, as well as heterosexual allies, and it was the first group in New York to incorporate elements for individuals who are HIV+. Because these groups are advertised for LGBTQ adults and their allies, group members have reported feeling free to share about very sensitive topics, ones in which they may not share in a traditional treatment setting. Additionally, many participants often mention how they do not feel as though they fit in with other treatment settings because they have to continue to "come out of the closet" which makes them feel uncomfortable. Lastly, former smokers who are also

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LGBTQ run the groups. In a recent article about Commit to Quit groups, Warren (2010) declares:

> *Using group level and peer delivered interventions, within an*
>
> *LGBTQ and HIV affirmative setting enables increased and*
>
> *enhanced social support, a factor that has been shown to be highly*
>
> *effective in helping isolated or marginalized populations to change*
>
> *behaviors (p. 4).*

QueerTIPs for LGBTQ Smokers

QueerTIPs, or the Queer Tobacco Intervention Project was the outcome of collaborations between community and academic partnerships in California. The curriculum is modeled after the adult cessation curricula *Fresh Start* (American Cancer Society) and *Freedom from Smoking* (American Lung Association). The curriculum offers a "culturally tailored approach [that] addresses the unique issues facing LGBTQ smokers trying to quit" (Greenwood, 2002, p.5). The curriculum is used in conjunction with nine two-hour sessions and also has two booster sessions three and six months later. A 2-day facilitator training to increase knowledge of SGM smoking cessation needs as well as develop cultural competency also accompanies the curriculum.

A pilot study of QueerTIPs was conducted and reported in the facilitator's manual (Greenwood, 2002). At the conclusion of the pilot study, a 40% quit rate

was achieved by the last class (non-booster session) which they noted as similar to the quit rates in the evidence-based programs QueerTIPs was modeled after (Greenwood, 2002). The author reported participants used a variety of methods to quit including nicotine replacement therapies in conjunction with the support group. Recommendations and themes that can be further explored from the pilot study include a greater need to validate empirical smoking cessation approaches that meet the needs of SGM. Similarly, Greenwood (2002) suggests the development and testing of age-appropriate services for youth.

Conclusions

While the evidence from the literature did not state the specific adaptations or specify the process of adaptation to each intervention, most noted similar themes. Gaps in the literature indicated that interventions for IPV and obesity were hidden, missing, or non-existent. This discussion only includes information from tobacco and substance abuse interventions; as such, little is still known about obesity and violence prevention interventions tailored to SGM. This discussion will begin with peripheral factors, such as facilitation and environmental setting of the interventions; the discussion will continue with relevant themes included in the curricular content review. Beginning with facilitators, cultural competence was highly important. In the examples of smoking cessation curricula, priority was given to facilitators who were either

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out-LGBTQ practitioners, or allies with proven experience and knowledge of the

special needs and histories of sexual and gender minorities. In the drug prevention

curriculum, which was the only specific youth intervention, the authors noted the

importance of having an LGBTQ role model present. The curricula adapted from

evidence-based programs such as Fresh Start and Freedom from Smoking, also

required facilitators to be certified from the respective agencies (American Cancer

Society or American Lung Association). Next, the setting was also noted in the

examples. Hosting a treatment group in a known LGBTQ setting, such as an

LGBTQ community center or HIV health clinic, was identified as important in

creating a safe space as well as helpful for recruitment and retention.

Additionally, group memberships were homogenous (e.g. open only to LGBTQ

individuals) or selectively inclusive of LGBTQ community and their heterosexual

allies. The limited data available suggested participants preferred to be in groups

with other SGM members as this helped them come to terms with their reasons

for using the substances and/or tobacco, many of which were related to their

identity.

In addition to facilitator factors and location specifics, various changes

were made or added to the individual curricula. The addition of cultural

references was mentioned several times; these included conversation topics such

as the LGBTQ community history of socializing in bars, targeted marketing from

the tobacco and alcohol industry, and the parallel of the stages of change as they compare to the coming out process as an LGBTQ individual. In the various groups, participants had chances to discuss these topics and identify new strategies for coping as well as new ways of thinking about them. The youth specifically were noted to have a fixation with the adult lifestyle of being gay, a heightened awareness of sex and substance use as a sexual minority, and an increased awareness of gender. Attention to these topics was recommended for future research.

After reviewing various agency interventions, Scout et al. (2007) clarified four key items necessary for a culturally competent smoking cessation program with sexual minorities: a.) hiring a trained LGBTQ person to facilitate the smoking cessation groups, b.) distribute inclusive and appropriate marketing materials, c.) ensure all non-LGBTQ staff that interact with group members are provided with cultural competency training, and d.) "modify curricula to include LGBTQ-specific and other culturally relevant information for participants" (p.7). These specific recommendations were mostly seen throughout the modified smoking cessation curricula noted above with the exception of cultural competency training for all staff (which may have occurred but was not noted in the published documents).

Researchers and practitioners have begun using a number of different items to tailor their interventions, including materials created in-house as well as evidence-based curricula. In a national study, Mier and colleagues, (2010) found that many organizations tailored interventions based on the following: formative research, cultural specific components, and main lessons learned from pilot studies (such as time constraints to develop the needed changes).

In conclusion, while limited research exists on the adaptation of culturally relevant health interventions for SGM, a repeated theme highlighted throughout is the importance of the cultural grounding of interventions for this population (Goldbach & Holleran, 2011; Marshal et al., 2008). Castro, Barrera, & Martinez (2004) suggest, "the primary aim in cultural adaptation is to generate the culturally equivalent version of a model prevention program" (p.43). Researchers (2004) go on to note that contrasting conditions from a curricular validation group to a current consumer group can lead to mismatches such as specific group characteristics (e.g. language, ethnicity, environmental context), staff characteristics (e.g. cultural competence), and community factors (e.g. community readiness). These mismatches substantiate a need for cultural adaptations particularly to increase treatment participation by the target community and decrease treatment failure (Borrelli, 2010).

Gaps in the Literature

A variety of content and delivery strategies were seen in the interventions and literature noted above; however, for the adaptations that were made, the authors did not document the theoretical foundation used to inform the specific changes or the process used in the adaptation of materials. Holleran and colleagues (2008) found similar problems in adaptations for other cultural groups and called for new research in this realm to more clearly determine the "specific mechanisms, theoretical grounding, and extent of these adaptations" (p.161). Similarly, no interventions for targeted SGM obesity or violence prevention were seen. The limitation of not having a grounded theoretical framework from which to make culturally relevant changes, confines the ability to replicate any form of a potentially systematic process. Further investigation and/or documentation of these processes are necessary for future studies in this area. Furthermore, after reviewing the literature Villanti (2010) noted that adapting adult strategies for youth might not be effective. While specific strategies implemented with adults may not be appropriate to replicate with youth, the cultural relevance of an intervention is highly important regardless of the developmental age group. Culturally grounded interventions for SGM may increase participation and ultimately reduce prevalence of problematic behaviors (Hicks, 2000). Cultural adaptations of curricula are not uncommon, and eleven years ago, Schinke and

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others (2002) observed that over half of SAMHSA's model programs had undergone some type of adaptation, yet all were based solely on ethnicity or language. Castro, Barrera & Martinez (2004) have recommended that a structured adaptation process be created to guide changes in evidence-based practices.

To date studies of health interventions targeting SGM have been reported mainly with convenience samples (Ryan, et al., 2001; Austin et al., 2004; Lombardi & Servellen, 2000; Senreich, 2010; Greenwood, Woods, Guydish, & Bein, 2001; Arday, Edlin, Giovino, & Nelson, 1993). Regardless of whether culturally adapted interventions work better or differently for SGM, it is clear interventions for the general population should have increased sensitivity to the issues that may arise for SGM (e.g. isolation, targeted marketing from the tobacco and alcohol industry, rejection from health care providers etc.). Literature has shown that among barriers to health care, homophobia and heterosexism are at the forefront for SGM (Coker, Austin & Schuster, 2010; Eliason & Schope, 2001). Further exploration is needed to determine the specific changes necessary for adult and youth interventions. The use of relevant theoretical perspectives or practical models may guide the organic process needed to make the necessary changes (Holleran, Castro, Kumpfer, Marsiglia, Coarc, & Hopson, 2008). Clearly, there is much needed work in the realm of cultural adaptations, in particular for SGM better health outcomes.

Chapter 3

Theoretical Perspective

Introduction

In qualitative research, particularly in a grounded theory study where the end point is the development of theory, the use of theory provides a lens for the study (Creswell, 2003). This lens offers guidance as to what issues are important to examine in the research; for example, gender identity, sexual orientation, and heteronormativity. While not deductively tested in qualitative research, theory can still provide a paradigmatic and substantive component to the phenomenon under study (Sandelowski, 1993). The paradigmatic component refers to the nature of knowledge production obtained through qualitative inquiry while the substantive component aids to conceptualize the target phenomena. As noted in chapter two, the specific process of culturally adapting health interventions for SGM's has not been documented in the literature. The theoretical framework I propose bridges considerations for a grounded theory paradigmatic component, and adaptations for the SGM culture which is the substantive component.

Social Constructivism

The Social Construction of Reality was presented by Berger & Luckman in 1967 and it focuses on the way individuals create and promote social realities (constructions). These constructions are spread by socialization with other groups,

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and this interchange of ideas paves the way for internalization of norms, laws and values that shape and control our everyday life. The terms constructionism and contructivism are often used interchangeably, particularly in social sciences (Charmaz, 2000) and are often subsumed under the term constructivism (Andrews, 2012). There are a number of key assumptions found throughout the social constructivist literature: 1) knowledge which is taken-for-granted must be critiqued, 2) history and culture guide the ways in which people construct their world view, 3) knowledge sustains itself through social processes, and 4) social action is paired with knowledge (Burr, 1995).

The first assumption calls for us to question the taken-for-granted assumptions we use in our daily lives; in Doing so, we can identify and begin to recognize phenomena as they are. For example, sexual orientation, in our assumption is heteronormative (ie. every one is heterosexual). The first assumption of social constructivism raises the question of whether there are other ways to conceptualize sexual orientation (ie. gay, bisexual, asexual etc.). Therefore, if we question the assumption of heteronormativity, we can begin to understand the lived experiences of those who do not identify as heterosexual.

The second assumption requires us to acknowledge that the way in which we understand the world is based on the culture and history of our society. For example, in the latter half of the twentieth century in the United States, families

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were loosly defined as a husband his wife and their children, but in the twenty first century it appears that families are comprised of many diverse relationships. The changes in the cultural acceptability of family dynamics is not necessarily a product of culture or time; however, the ways we understand the world are dependent on the norms prevailing in that culture at that time.

The third assumption considers that the way we accept and understand the world is loosely based upon the interactions and social processes in which we are constantly engaged. In other words, what we regard to be true is based upon our experiences. For example, if researchers, public health practioners, social workers, and SGMs disrupt the underlying assumptions of health interventions then alternative understandings can assist us to change existing social structures. Specifically, cultural adaptations for health interventions which target SGM disrupt any taken-for-granted assumptions that all interventions work for all cultures and groups.

The fourth assumption accepts that different social actions are brought about by different truths and different knowledge. In the context of my study, this translates to understnding how a person or social service agency might intervene with a SGM based on their understanding of chemical dependency and its relationship to SGM culture.

Queer Curriculum Theory

One theory that evolved from social constructivism is Queer Curriculum Theory (Sumara & Davis, 1999). This theory takes into account heterosexual privileges and norms that may occur in curricula that have been developed and created for a general "heteronormative" population. Heteronormative, defined by Sumara & Davis (1999), is an underlying assumption concluding that certain norms are fundamentally based upon heterosexuality. In an effort to interrupt heteronormative thinking, Queer Curriculum Theory posits curricula can take many forms, and with a deeper understanding of their theoretical underpinnings, sexuality can be understood as a necessary companion to all knowing (Sumara & Davis, 1999). In other words, this theory provides a process framework for curricula to be developed or adapted by taking into consideration sexuality, with the goal of interrupting privilege. Some of those processes, according to Sumara & Davis (1999) may be how a participant or facilitator perceives, interprets and represents an experience. This theory places an emphasis both on the facilitator and their delivery of core elements of a curriculum, as well as the participant's perception and interpretation of the material. Therefore, there are potentially two broad focus areas in making adaptations to interventions for SGM. The authors suggest heterosexual and normal are synonymous indicating all forms of thinking means that living within a heteronormative culture, one must see, read, and think

from a heterosexual perspective. By interrupting the heteronormative culture of an intervention, not only does the content change, but also the attitudes, perceptions and delivery of materials change.

Gosse (2004) builds upon this theory and offers three tenets to include in a queer curriculum model. The first tenet is, "Asking Questions & Creating Dialogue;" this tenet encourages divergent thinking beyond all norms (sexual orientation, racial inequality, geographic location, socio-economic status etc.). The process of critical thinking and inquiry begins with this first tenet. The second tenet, "Education and Space for All," has macro implications that consider curricula as they are implemented in specific settings. They state that the heteronormative thinking is interrupted when the physical environment is considered safe and relevant to each participant. The third tenet is "Discourse and Symbolic Violence," which relates to language found in curricula that implicate gender binary norms and heterosexual norms (e.g. girls and boys are opposite, girls are weak, boys are strong etc.). Symbolic violence is defined as "the power of the dominant group to constitute and justify domination by imposing what is good or legitimate in society, thereby marginalizing those who do not share these values and access to resources" (p. 37). Symbolic violence can be interrupted by including SGM role models to facilitate curricula, include pictures/diagrams of diverse and relevant situations where possible, and infuse language into the

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documents that is relevant to all participants. Finally, Gosse (2004) notes these tenets will take many shapes and forms depending on the intervention at hand, however the most important task is to continually challenge the shortcomings of words while they are being employed.

Elements from Constructivist Grounded Theory and Queer Curriculum Theory provide important insight into adapting a generalized intervention that transforms into a culturally grounded and relevant intervention for sexual and gender minorities. Specifically, an intervention that is already theory-based and has become the target for adaptation will require a systematic approach (Barrera & Castro, 2006), that remunerates special attention to the experiences and world view of SGM. In particular, consideration of the specifics and underlying assumptions that have been left out of the original intervention (Gosse, 2004; Sumara & Davis, 1999) should be addressed. The lens provided by the abovementioned frameworks allows for careful consideration of various factors that either do not exist, or perhaps need to be modified in a given intervention. They also provide support for collecting data with a priority on the phenomena of the study from shared experiences and relationships with key informants (Charmaz, 2011).

Chapter 4

Methodology

To uncover and examine the complex interaction between health

interventions relevant to the SGM population and the community and researchers,

a qualitative approach was used. Specifically, constructivist grounded theory was

used to explore interactions within these systems as they relate to identifying the

appropriate steps to make cultural adaptations to interventions for SGM.

Research Questions

1) What precipitates the perceived need to develop or adapt an intervention so it is

relevant to individuals who identify as lesbian, gay, bisexual, transgender and

queer (LGBTQ)?

2) What is the process in adapting and/or creating the intervention?

3) What can we learn from this process about the characteristics of effective

adaptations and/or adaptive interventions?

(4) What guidelines can be recommended for future social service providers who

wish to create their own culturally relevant LGBTQ intervention drawing on the

emergent model?

Qualitative Inquiry

To answer the research questions, inductive research methods were

necessary to gain insight into the phenomenon of culturally tailored health

interventions for SGM. Qualitative inquiry is a way of studying the real world as it unfolds naturally (Patton, 2002). Qualitative research explores social or human problems (Creswell, 2007) and involves emergent design approaches that are used to describe life experiences and give them meaning. There are three types of qualitative data and include interviews, observations, and document analysis (Patton, 2002).

Grounded Theory

Grounded theory centers on the rigorous generation of theory from data that is systematically gathered in social research; the end goal is to generate a theory or model that captures a pattern of behavior that is relevant for those involved (Glaser & Strauss, 1967). The inception of this methodology began in the field of nursing and continues to be used in social science and other health related fields (Benoliel, 1996). Grounded theory requires inductive, open-ended data collection methods (Corbin & Strauss, 1998) and the design allows researchers to explore how people define reality and how those beliefs are related to their actions. Charmaz (2008) describes a constructivist approach to grounded theory as one which allows the researcher to take a reflexive stance in order to consider how theories evolve.

Glaser & Strauss (1967) describe the importance of theoretical sampling in grounded theory. Theoretical sampling is a process of data collection specific to

generating theory by concurrently collecting, coding, and analyzing the data and making intuitive decisions about the type of data that may need to be collected next (Glaser & Strauss, 1967). This process allows the researcher to continue to develop and refine tentative categories based on coding. The goal is to reach saturation, which occurs when all data can be coded into categories and no new categories emerge from data (Charmaz, 2011).

While the process in grounded theory is iterative, several steps are necessary to approach the research systematically. The researcher needs to identify a participant sample that is purposive (Patton, 2002) and as such participants, often described as co-learners or key informants, are selected because they are illuminative and rich in information about the specific topic under study. Once the sample has been identified, the researcher collects data accordingly. In addition to interview data, document data collection as potential additional sources is important (Charmaz, 2011). Following data collection, the researcher prepares data for analysis such as transcribing interviews and note taking on document data sources. The researcher then reads through the data and obtains a general sense of the information and materials. Triangulation is used to cross check information obtained in the data such as themes, processes, and structure. The data analysis strategy follows and the researcher codes the data by locating text segments and assigning a code to label them. Data analysis

triangulation may also occur at this stage in order to corroborate evidence from the data back to theory, and use additional forms of data analysis. The researcher allows the data to incubate and finally uses the codes to describe the results of the research in a final report (Patton, 2002). The specific procedures for my study are described below.

<div align="center">Procedures</div>

Sample

There are several strategies for identifying a purposeful sample depending on the type of information the researcher intends to gather. I chose maximum variation sampling, sometimes described as heterogeneity sampling, as it aims to capture information that cuts across a great deal of variation (Patton, 2002). The data presented in the following chapters come from 13 semi-structured in-depth interviews. The variation in my study consisted of a sample of researchers as well as community practitioners from different fields including social work, public health, mental health, and nursing. Inclusion criteria for this sample were selective and deliberate based on the individual's relevancy to the study (Padgett, 2008; Charmaz, 2011). Therefore, the sampling frame began with individuals who were a part of the strategic planning for and process of culturally adapting a health intervention for SGM adults and youth/young adults. The sampling strategy continued with the same caliber of individuals involved in other similar

interventions based on a snowball sampling strategy (presented below). As previously mentioned, theoretical sampling was used to support the constant comparative method (Strauss & Corbin, 1998) in which data were collected and analyzed concurrently to examine and refine variations in the emergent concepts.

The first set of individuals I contacted were the researchers who published about their SGM cultural adaptation. I contacted these researchers through the information provided about any author listed in the publications. In addition to the researchers, I screened for potential community informants from the CenterLink website. CenterLink, Inc. is a national organization which hosts a website where LGBTQ community centers across the United States can collaborate, share ideas, and connect to each other (www.LGBTQcenters.org). From this website I was able to investigate the CenterLink affiliates, locate the health related programs, and contact via telephone and/or email the individuals who are responsible for these programs. For example, when I found that a community center offered tobacco cessation groups, I would contact the person listed on that website to identify potential key informants. In addition to the personal contacts, I used the websites to identify other data sources such as calendars, pamphlets, resources and other materials to confirm the existence of the programs being advertised.

Following initial contacts and interviews with researchers and other health center key informants, I requested a snowball sampling strategy (Patton, 2002)

from these initial contacts. Specifically, I asked the first group of key informants to suggest and recommend (or pass my information onto) other individuals who have participated on similar or other related projects that may potentially be relevant to my study. Subsequent informants were asked to do the same until I was able to reach saturation.

To screen for key informants (participants) I asked them to confirm their role in intervention adaptations for SGM. Potential informants were asked to recall their main role on any adaptation project such as formative research, participated in making changes to documents and trainings, or published about the adaptation. Potential informants who have worked specifically with SGM adults and or youth/young adults as it relates to health interventions were invited to interview. The role of key informants on an adaptation project was particularly important so I could hear from individuals who had some hands on experience and knowledge of the interventions as they were developed and/or implemented.

Figure 4-1on page 49 depicts the sampling strategy that I employed related to snowball sampling. The set of boxes indicate where I first looked for potential participants in addition to the types of interventions that have been adapted.
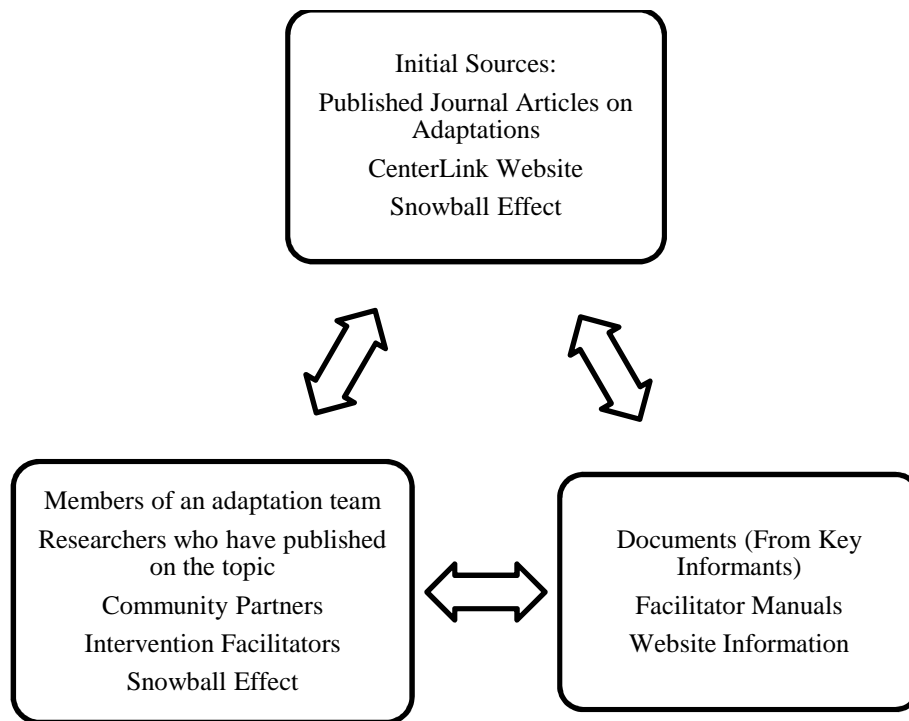
Figure 4-1 Sampling Frame

Types of Data Collected

Data were collected from interviews with key informants, document

analysis from agency websites, as well as documents sent to me by the key

informants. Appendix B includes a list of interview guide and questions. All

interviews were audio recorded for transcription purposes. Once the interviews

were transcribed and checked for accuracy, all audio recordings were deleted

from the audio recording device. The interviews took place in a naturalistic

setting for these informants. Due to the maximum variation sampling technique

and a small budget for the project, all of the interviews were conducted over the

phone (King & Horrocks, 2010). Once consent was obtained and permission to record the conversation, the key informants were placed on speaker phone and I was alone in a private space recording the audio on a digital recorder set next to the speaker phone. Gubrium & Holstein (2002) recommend phone interviews to reduce fieldwork time as well as when resources for the research are limited. The interviews were semi-structured and the interview questions were based on an interview guide (see Appendix B) (Patton, 2002; Charmaz, 2011). This technique allows for topics and issues to be specified in advance of the interview, but leaves room for flexibility in determining the order in which the questions are asked (Patton, 2002). After interviews were conducted, I asked the key informants to pass on any documents they felt comfortable sending so I may examine them in my data analysis process.

 Data Preparation and Coding

Immediate data analysis was fundamental to maximize the potential for theory development and theoretical sampling (Strauss & Corbin, 2008). Transcription of the data was an ongoing process until all data were collected and transcribed word for word by professional transcription services. I crosschecked all professional services by listening to the audio and verifying all data were properly documented in writing. The transcripts were then imported in to the qualitative software, QSR NVivo 10 for analysis. The transcripts were then read

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line by line and I looked for convergence and divergence (Guba, 1978) whereby I identified what items fit together and how different items potentially bridged together. A theme that occurred frequently over the course of data analysis became a core category (Charmaz, 2011).

In addition to using NVivo 10 for open coding, I used a heuristic form of analysis to triangulate during the data analytic phase. Specifically, after I read each transcript and coded the words into categories, I summarized the process described by each participant into an individual model. This heuristic form was used as a tool to facilitate discovery and further investigate my data (Seidel and Kelle, 1995). Each individual model presented a visual alternative to the transcript data. Side by side, the individual models were used to help generate additional codes and begin to connect axial codes. Seidel (1998) describes this process as fitting all the pieces of the puzzle together.

Once all the data were open coded, saturation was reached, and categories were initially created, I then began the process of forming axial codes. Axial codes were formed by forming a synthesis of related categories from those that were originally broken down in the open-coding analysis (Corbin & Strauss, 1998). In general axial codes explore the dimensions and properties of each category and are then compared to subcategories along the lines of each property (Corbin & Strauss, 1998). Cross-referencing the individual models with the open

codes generated the axial themes. Selective coding was the final coding process where I integrated and refined the process model. Ultimately the selective coding brought together the story identified in the open and axial coding process. In the next two chapters, the results from the data are presented (a) systematically in Chapter 5 and (b) in two ways in Chapter 6: (1) in a diagram which depicts the central phenomena (2) and by providing a narration of the diagram which examines the details of the coding method (Creswell, 1998).

Strategies for Enhancing Rigor and Trustworthiness

Validation strategies in qualitative research help to assess the accuracy of findings (Creswell, 2003). Credibility in this research relies on rigorous methods, my personal credibility, and my philosophical belief in the value of this research (Patton, 2002). Triangulation with documents, member checking (Guba & Lincoln, 1985), triangulation with data analysis, and clarifying my credibility was used to validate the quality and accuracy of my research.

Triangulation

Data triangulation involved the use of more than one data source (Padgett, 2008) which included interviews, website, and document data (e.g. Reviewing culturally adapted curricula for SGM). Therefore, triangulation with documents was used to confirm information discussed by key informants. After each interview, key informants were asked to send or refer me to any documents,

which may represent their work. For example, I requested copies of any adapted lessons or curricula as well as other documents discussed in the interview. Additionally I accessed relevant web pages with documentation of their work. For example, if I spoke with a key informant who works as a researcher in a university, I accessed their faculty profile and curriculum vitae and reviewed a list of publications, funding, and any other evidence of their work. Data for key informants who worked in community agencies were corroborated by reviewing agency web pages and reviewing their calendar of events, pamphlets, pictures, and other relevant evidence.

Member checking (Lincoln & Guba, 1985) was used to verify preliminary findings of data by clarifying questions during data collection and verifying themes during analysis with key informants. For example, I used clarifying and summarizing questions in the interview to ensure I understood what they were discussing. Additionally once the model was developed member checking was used to ensure the model reflected what the key informants described in their interviews. I asked each key informant if they would be willing to review the developed model and all but one key informant agreed to check their model. I emailed a copy of the model to participants individually and after their feedback (if provided), I made edits to the model. In addition to the individual models, I sent a copy of the selective model to the key informants for feedback.

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My Credibility

The use of bracketing strengthens the credibility of qualitative research by addressing pre-conceptions, so as to not inject a hypothesis or personal experiences into the study (Creswell, 2003). The following describes my experiences with some of the topics in this study and I note them in order to identify what I bracketed throughout.

My introduction to qualitative research began with an opportunity to facilitate a public health empowerment research group in my BSW internship, in 2005. In my training I learned experientially how to engage youth through collaborative movement regarding an issue of their choosing and keep them engaged in a research project through the duration of one full school year. Following my first facilitation experience, I had the opportunity to facilitate three additional community based participatory research (CBPR) projects in my social work employment. Several years ago I began volunteering with an organization that serves SGM youth. One day, I was speaking with one of my mentees when he said, "I didn't know any gay people when I was young. When I was 13, I saw this really cute guy smoking outside this bar, so I bummed a smoke from him and he was the first gay person I ever met." As we talked, I began to think about the number of SGM youth and adults, who use smoking as a vehicle to socialization. This was a powerful realization for me because it validated my belief that there

are not enough resources for SGM to meet others that are both safe and healthy. It underscores what is already documented in the literature about the disproportionate numbers of SGM who smoke when compared to their heterosexual counterparts. Since that time I have learned through reading and through experience that tobacco is not an easy drug to quit once an addiction has developed. As a former Tobacco Prevention Program Specialist I partnered with the local community in tobacco prevention and control efforts. As a Tobacco Cessation Consultant I facilitated the N-O-T curriculum (ALA, 2009) and the Last Drag curriculum (CLASH, 2007) in diverse settings from 2006-2010. In 2012 the Denver Chapter of the American Lung Association trained me as a N-O-T Trainer. As such I am very familiar with two curricula for smoking cessation, one of which has been culturally adapted for SGM. Additionally, I have worked and volunteered with the SGM population since 1999 in various settings and on a diverse array of projects.   In running the adult cessation group I saw how tobacco had a major impact on the SGM community, especially as many of the participants were well into their 50s and 60s and had several unsuccessful quit attempts coupled with decades of smoking, and other drug use, and many health problems. Their frustrations, health problems and described social burdens around tobacco were motivating for me to continue in the focused pursuit of interventions that are relevant to this population. My education coupled with my experience has

provided me with a strong induction into the field of qualitative research. I believe

it is important to recognize and valorize my experiences through the use of

bracketing and at the same time be open to learning new information that

organically and intuitively derive from embracing grounded theory as a budding

researcher. While many of my experiences have incorporated the topics in this

study, they were set aside to the extent that was possible and the use of

triangulation provided a checks and balance system to my position in this

dissertation.

Timeline to Task

My goal was to collect data in the summer semester; all but two interviews

were conducted in this time frame. As planned, I was also able to use a

transcription service for the interviews to eliminate the lengthy process of

transcription. By utilizing a transcription service I was be able to move directly to

cross checking each audio recording against the typed transcripts. I began analysis

as described above via the constant comparative method and was able to achieve

saturation by September. The axial codes, analysis triangulation, and additional

use of member checking were completed by the end of September.

Ethical Considerations

As this dissertation involves human subjects, The Institutional Review

Board (IRB) at the University of Texas at Arlington approved the protocol to

ensure key informants were afforded appropriate safety and ethical standards. The exempt protocol had a pre-review with the social science IRB coordinator prior to submission. The IRB application was then approved on June 24, 2013 prior to data collection.

The protocol included information about the process by which each participant was informed of his or her voluntary participation and procedures in the study. Prior to interviews, each participant age 18 or over interested in the study had a conversation with me via email or via telephone. For key informants that fit the inclusion criteria, I provided them with information about the study, including answers to questions regarding the study, an explanation of informed consent, and sent a copy of the informed consent document. Consent was also obtained verbally on the telephone prior to the audio-recorder being turned on. Ethical issues in telephone interviewing have been documented in detail by King & Horrocks (2010) who discuss the importance of obtaining informed consent prior to the interview (via email or letter) as well as prior to recording the conversation. Therefore, I sent the stamped, informed consent document prior to the interview via email and then at the time of the phone call I described the procedures over the phone. Each key informant consented for participating including being recorded via digital audio. Once they agreed, I turned on the

recorder and began the interview. All of the key informants consented to be in the

study and to be audio recorded.

Chapter 5

Results

Introduction

In this chapter, I further elaborate on the iterative process of developing a grounded theory model about cultural adaptations for health interventions with SGM. This chapter is organized in conjunction with the process of constructivist grounded theory data analysis (Charmaz, 2011; Creswell, 2007). I begin by describing the key informants, briefly discussing their individual interviews, and include a model depicting their individual adaptation process. I then move into the key themes including examples of quotes involved in the theory development process. Chapter 6 presents a process model that I developed based on the results, and the discussion includes a description of the process alongside implications.

Key Informants and Sample Demographics

To protect the confidentiality and identities of the key informants, pseudonyms are used to describe each individual. One of the key themes in my research regarding cultural adaptations for SGM was the use of gender-neutral names and preferred gender pronouns to interrupt the heterosexist assumptions often found in heteronormative interventions. This theme will be further discussed below. Furthermore, as a form of honoring this theme, the use of gender-neutral names are used for pseudonyms. In addition, because of the individualistic nature

of each project and its originality, it may be possible to link individuals, even with pseudonyms, to the real project they describe. Therefore, in order to honor confidentiality I intentionally refrain from linking key informants to their individual quotes.

Thirteen key informants were interviewed for my study from a combination of university, community organizations, and specialty areas. As mentioned above, to protect the identity of each key informant for the purposes of confidentiality, each individual is referred to by a gender-neutral pseudonym. All key informants were age 18 or older. Of the 13 participants, 3 (23%) identified as male, one (8%) identified as transgender (female to male), and 9 (69%) identified as female. Sexual orientation of the key informants was not discussed in the interviews. Key informants represented different professional roles from various health interventions. Six participants were researchers from university settings and seven participants were community partners from various organizations. Disciplines represented in the sample included public health (n=4), nursing (n=2), social work (n=3), sociology (n=2), and behavioral health (n=2). Table 5-1 lists additional descriptive data for the key informants.

Table 5-1 Sample

Name	Role, Discipline	Health Topic	Target Population	Inclusive or Exclusive Intervention	Location Code & U.S. Region
1. Blaine	Researcher, Nursing	Tobacco	SGM Women	Exclusive	1, Midwest
2. Terri	Researcher, Sociology	Drug Prevention, Domestic Violence Prevention	LGBTQ Youth 6-12th grade	Inclusive	1, Southwest
3. Morgan	Community Partner, Social Work	Sexual Health	LGBTQ Youth 9-12th Grader	Inclusive	1, Southwest
4. Kaci	Researcher, Social Work	Drug Prevention	Youth	Exclusive	1, South
5. Chris	Community Partner, Public Health	Tobacco & Public Health	LGBTQ & HIV+ Adults	Exclusive	1, West coast
6. Devon	Community Partner, Public Health	Health Promotion	Individuals & Families	Inclusive	1, West coast
7. Hayden	Community Partner, Public Health	Tobacco	LGBTQ Adults	Exclusive	1, West coast
8. Taylor	Researcher, Nursing	Obesity	SGM Women	Exclusive	1, South and 1, East coast
9. Francis	Community Partner, Behavioral Health	Health Promotion and Mental Health	LGBTQ Older Adults	Inclusive	2, Midwest
10. Lin	Community Partner, Behavioral Health	Sexual Health	Youth 9-10th Grade	Inclusive	1, East coast
11. Tracy	Researcher, Public Health	Mental Health	HIV+ & SGM Men	Exclusive	1, Southwest
12. Danni	Researcher, Sociology	Substance Abuse, HIV Prevention	MSM Adults	Exclusive	1, East coast
13. Nel	Community Partner, Social Work	Intimate Partner Violence	SGM all ages	Exclusive	1, West coast

Phone interviews were conducted for the entire sample, which represented various regions of the country, all of which were urban. The locations of the key informants were divided into metropolitan and non-metropolitan areas. According to the United States Department of Agriculture Economic Research Services, all areas of the United States are divided into Rural and Urban Continuum codes (ers.usda.gov). Each code represents a certain percentage of the population based on population statistics. Metropolitan counties consist of three codes: 1 (counties in metro areas of 1 million or more), 2 (counties in metro areas of 250,000 to 1 million), and 3 (counties in metro areas of fewer than 250,000). The nonmetropolitan counties consist of nine codes: 4 (urban population of 20,000 or more, adjacent to a metro area), 5 (urban population of 20,000 or more, not adjacent to a metro area), 6 (urban population of 2,500 to 19,999, adjacent to a metro area), 7 (urban population of 2,500 to 19,999 not adjacent to a metro area), 8 (completely rural or less than 2,500 urban population, adjacent to a metro area), and 9 (completely rural or less than 2,500 urban population, not adjacent to a metro area). These codes are noted in the last column of Table 5-1 in order to identify the general size of the city each intervention was developed and/or implemented.

Initial Modeling

After each transcript was read and open coded, I drew up a model that I felt represented the process described by each key informant. To increase trustworthiness, I emailed each key informant the representative model and asked for feedback, potential changes, and fit. Of the thirteen key informants, four provided feedback for their model. Interview summaries and all thirteen model descriptions are provided for each key informant below.

Blaine

Participant 1, hereafter will be referred to as Blaine. Blaine is an associate professor in the field of nursing at a large research university in the Midwest. The interview with Blaine lasted approximately 30 minutes with one short follow up communication for clarification. The cultural adaptation Blaine described to me included collaboration with a local community health clinic that serves an urban community on various health related projects such as cancer screening, alcohol and tobacco cessation, and mental health counseling. The process described by Blaine began with an evidence-based smoking cessation intervention which researchers and community partners identified as heteronormative. Due to this fact, the agency decided to facilitate focus groups with their target population of sexual minority women. Following the focus groups, researchers used quotes from the focus groups to generate themes that were important and representative

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of the target population. The quotes were also used to identify areas for adaptation

in the original intervention. Based on the findings from the focus groups, an

adapted intervention was formed from the original intervention; one component is

for supplemental at home use and the other is the main group intervention.

Blaine's process is depicted in Figure 5-1
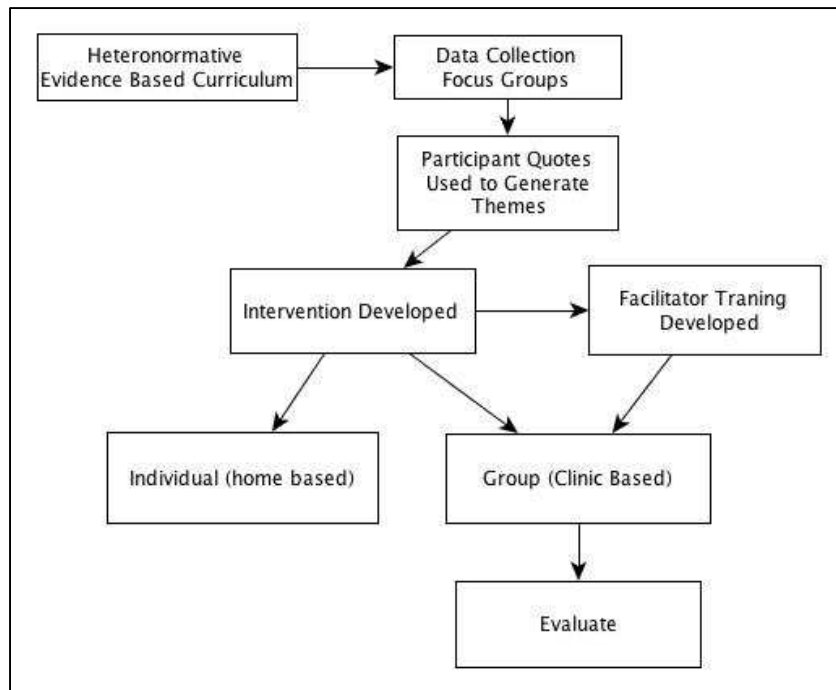
Figure 5-1 Blaine's Model

Terri

Participant 2 hereafter referred to as Terri, works as a full professor in

sociology at a university in the southwestern part of the United States. Terri has

worked on many large federally funded grants and oversees many research

projects related to vulnerable populations, LGBTQ youth, and health. The

interview with Terri lasted approximately 30 minutes. The adaptation described to

me by Terri was a drug prevention and violence prevention intervention that was

adapted for SGM youth from the shell of an evidence-based youth intervention.

Terri's intervention was supported by federal grant dollars and involved

collaboration with a local LGBTQ youth serving organization and the research

institute. Terri described a process depicted in Figure 5-2.
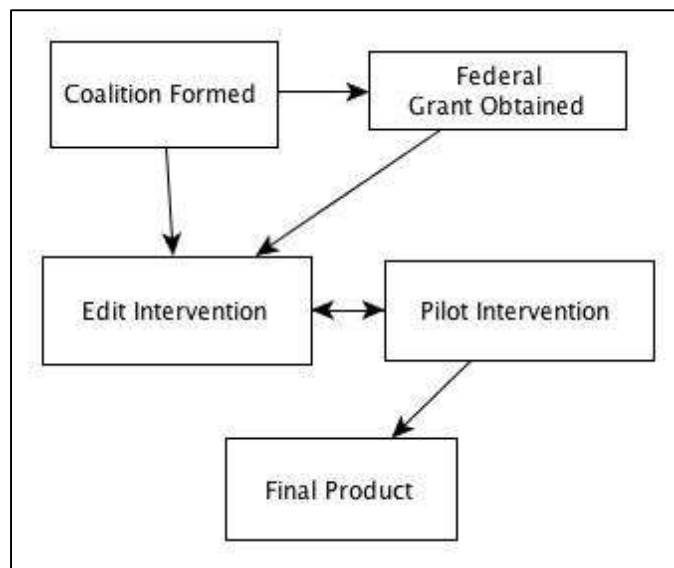
Figure 5-2 Terri's Process Model

Terri's process began with a coalition of community partnerships and the

university which employ's Terri. Once formed, the coalition identified several

target problem areas based on a target population of SGM youth that are served in

one of the local organizations. After the researchers secured federal funding, the coalition identified an evidence-based intervention from which to make cultural adaptations. Terri said:

It's highly modified, but we've started with sort of a shell of another

intervention that was acceptable and then we just built it to fit our needs.

Following the modifications made to the intervention, which were mainly based on practice wisdom and current research, several pilot tests were run. Terri talked extensively about how with each pilot test, more modifications were made based on social acceptability measures of participants. At some point, with increased attendance, and a better "fit" with the community, a final product emerged. Annually, outcome measures are evaluated alongside some process evaluation measures for the purposes of reporting back to the funding sources as well as determining if any additional adaptations are needed.

Morgan

Morgan is the pseudonym for participant 3 and our interview lasted approximately 45 minutes. Morgan works as a community partner in a non-profit organization which trains and implements sexual health promotion to local youth and young adults. The primary mission of the agency is to prevent teen pregnancy and promote sexual health in general. The agency Morgan works for is located in a large metropolitan area of a Southwestern state. Morgan has a master's degree

in social work and has experience serving and training SGM youth and older

adults. The adaptation described to me by Morgan entailed partnerships, as

required by their federally funded dollars. Morgan stated that their funding

requires the use of evidence based practice models and interventions. Morgan was

one of the four key informants whom provided feedback on the model. Figure 5-3

depicts Morgan's process in culturally adapting their main intervention.
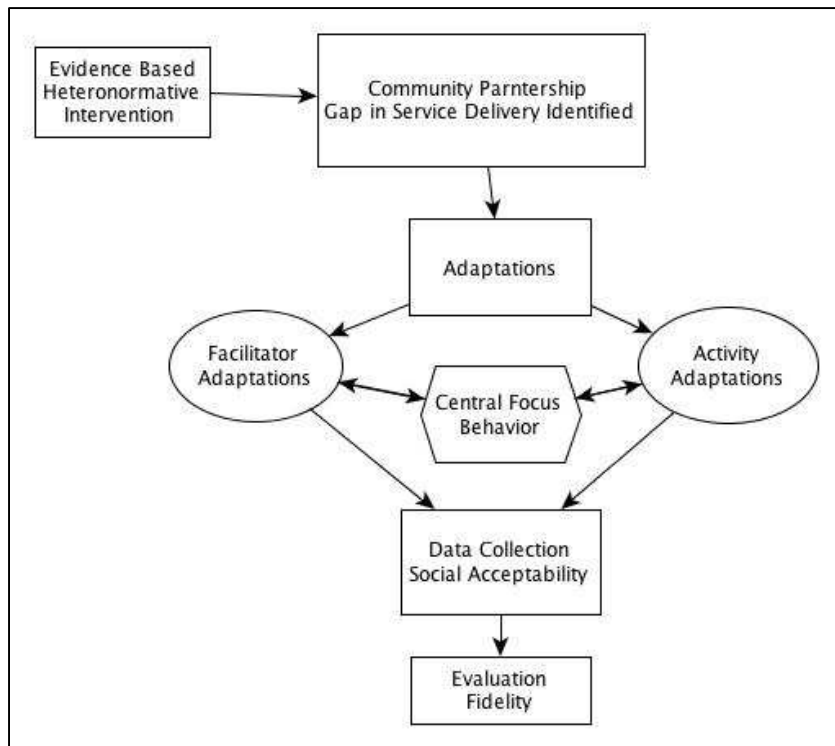
Figure 5-3 Morgan's Process Model

In Morgan's process, for many years, an evidence-based intervention was

used to train adults who educate youth and young adults in school and community

settings. Morgan described that with recent partnerships and practice wisdom,

community partners and employees alike recognized a gap in the current

intervention. Morgan noted they discussed how the intervention, which was

developed based on research from the early 1990's, was heteronormative and

therefore may not be effectively reaching SGM youth and young adults. Based on

newer research and practice wisdom, the partnerships identified areas to change

based on the Red Light, Green Light Adaptations Model. This model, described

by Morgan included the idea that fidelity to the original intervention was highly

important, and therefore they only made changes to the intervention which they

felt were "green." Morgan said in our interview:

> *If we have a program we're replicating that we want to get the*
>
> *same outcomes from the original research, then you want to do it*
>
> *with fidelity…The green light area, you're not changing any main*
>
> *components, any of the objectives, anything that's going to*
>
> *ultimately reach the outcome you want, that's a green light.*
>
> *Changing names to be more gender neutral, the pronous in the*
>
> *role plays, that's a green light application. Then there's yellow*
>
> *and red, and those are ones that might change up fidelity and the*
>
> *outcomes. A red adaptation would be taking out role-plays*
>
> *completely.*

Therefore, the red adaptations would be to change the content or objectives of the intervention, whereas the green adaptations would be changing items that would not disturb the objectives aimed at reaching outcomes. Ultimately, Morgan stated that the main focus of the intervention was based on behavior and not sexual orientation, thus all behaviors should be addressed regardless of how they are affiliated with certain expected norms of heterosexual or homosexual etc. Following changes made to the intervention, the organization gathered data to determine the social acceptability of the intervention. They ran focus groups with local SGM youth and young adults who reported their major concerns and proposed change ideas. Periodically, the organization collects fidelity measurements on the adapted intervention.

Kaci

Kaci is the pseudonym for participant 4. Kaci is an assistant professor of social work that works in a university on the west coast. Kaci specializes in the areas of program evaluation, cultural adaptations, and HIV. The intervention adaptation process described to me by Kaci took place in a southern state several years ago. The interview lasted approximately 45 minutes. Kaci spent some time discussing the differences between the west coast and the south, particularly as it applies to the environment in which the intervention is adapted and implemented. Those differences are discussed in greater detail in the next section depicting

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codes. The intervention adaptations Kaci described included a partnership with a local organization that serves LGBTQ youth and young adults. The intervention targets drug prevention with youth. The process described by Kaci was confirmed via email, and is depicted in Figure 5-4.
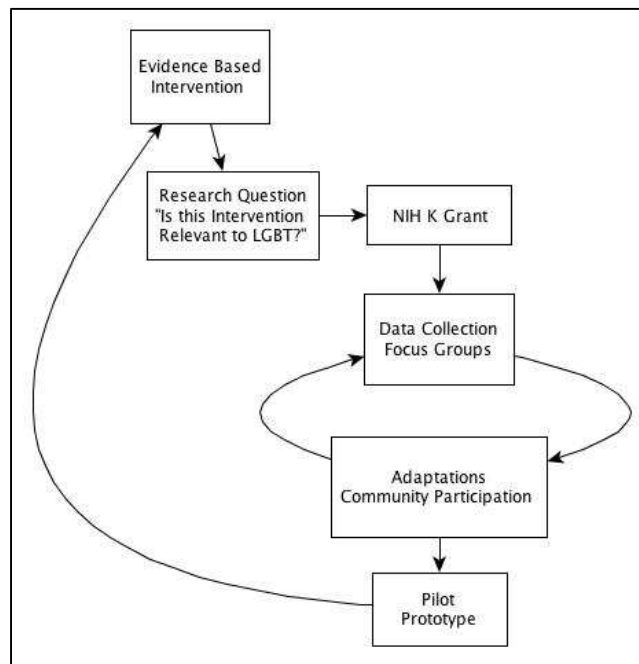
Figure 5-4 Kaci's Process Model

Unlike the process described by the first three key informants, Kaci's adaptation process included partnerships with the target population who played an integral role in making the specific changes to the intervention. A pilot test of the initial prototype did not occur due to time constraints and agency youth retention issues. Kaci noted the importance of continually adapting an intervention until it

"fits" for the local participants and therefore adaptations may need to include the political and environmental context in addition to the cultural factors.

Chris

Participant 5, hereafter referred to as Chris, works as a community partner in public health on the West coast. Chris has a master's degree in public health and over 20 years of experience working with the LGBTQ community on various campaigns and interventions to support healthy living. The interview with Chris lasted approximately one hour and included a discussion about an adult tobacco cessation intervention that was culturally adapted from an evidence based intervention intended for a generalized group (i.e. Heterosexual). The process described by Chris is depicted in Figure 5-5. The process began with an existing agency who had some anecdotal evidence that smoking rates were higher for LGBTQ people. After identifying an evidence based intervention, a coalition was formed and they focused specifically on making changes to the intervention as well as identifying funding sources and promotion for the groups. The intervention has been in its adapted form for many years now and has continued to be supported by the local GLBT community center. Outcome evaluations take place one-month, three-months and six-months after each group has ended. Additionally, the local health commission requires a cultural competency survey

for all participants to determine if the culturally targeted intervention was

culturally relevant.
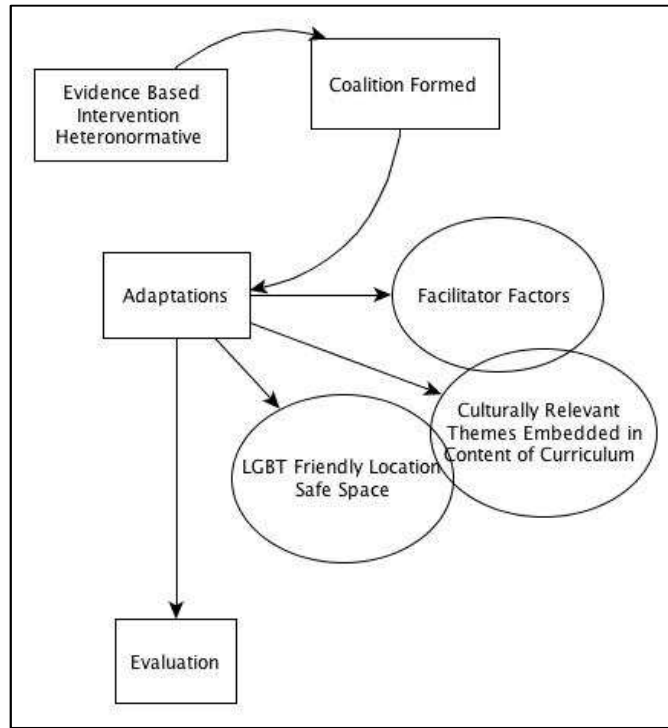
Figure 5-5 Chris's Process Model

Devon

Participant 6 is a cultural adaptation expert with the pseudonym Devon.

Devon has a master's degree in public health and works for a large hospital

system in the Pacific Northwest. Devon has been involved in several cultural

adaptations for health service delivery including for the Latino and African

American communities and most recently SGM. The process described by Devon

in our one hour interview is depicted in Figure 5-6.
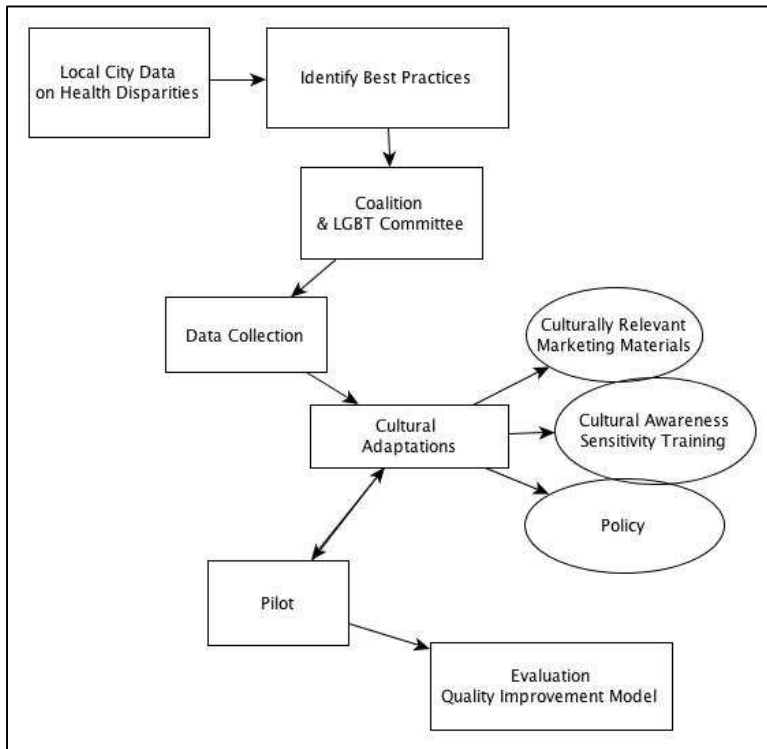
Figure 5-6 Devon's Process Model

Devon described a collaborative process driven by a coalition of local

experts and members of the community. Initially as public health practitioners,

Devon and colleagues often check local trend data on health disparities to ensure

they are serving those populations. After checking recent data, it came to their

attention that perhaps SGM consumers were not feeling safe or being served

effectively. As a result, Devon and colleagues identified some evidence-based

practices to better serve their consumers. They formed a coalition which included

members of the LGBTQ population representing consumers and staff from the

hospital system. The coalition ran several focus groups to determine the needs and areas for change. Based on data from the focus groups, cultural changes were made to several components in their system. The new changes were piloted for quality improvement and then evaluated. After any additional necessary changes they implemented their new program.

Hayden

Hayden is the pseudonym for Participant 7 who is a community partner from the west coast. Hayden has a master's degree in theology and has worked in education and public health for over 20 years. In a 40-minute interview, Hayden described a smoking cessation intervention that was culturally adapted for LGBTQ adults. The process is depicted in Figure 5-7. Hayden describes how many years ago a coalition formed comprised of local LGBTQ citizens and public health practitioners who were concerned about smoking and health related problems surfacing in their community. They also noted that little to no public health resources were targeting the LGBTQ community despite the tobacco industry's efforts to advertise in the local gay bars and other social venues. The coalition began working on adapting a smoking cessation intervention after hearing from local smokers. The intervention was then implemented in a centrally located safe space for LGBTQ people. Hayden mentioned that while their evaluations have evolved over the years, it has mostly been about individual

outcomes as opposed to any social acceptability measures regarding cultural competence. Hayden also mentioned that from anecdotal evidence and practice experience described by facilitators, every so often the coalition will go back and update the curriculum to fit recent trends.

Hayden spoke about the importance of interrupting the social norms associated with smoking:

The other part I think that becomes important too, is our celebration. At the end we do a meal, and its part of our grant money. But it's non-alcoholic, so we're trying to normalize socializing without getting up and going out for a smoke, and being able to socialize without that; which I think is a real critical thing for the LGBT community where again there's high rates of smoking and visits to bars.

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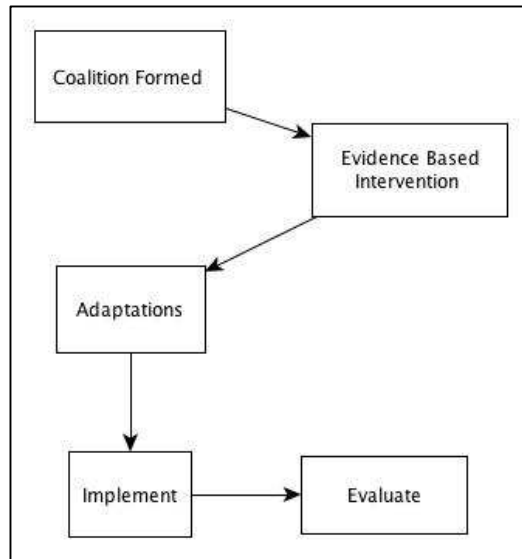
Figure 5-7 Hayden's Process Model

Taylor

Taylor, or participant 8, is an associate professor of nursing in the southern

part of the United States who works in a large research university. In our 50-

minute interview, Taylor described the development process of an obesity

intervention that was adapted for sexual minority women. A popular health

intervention, often used by women was first implemented in a lesbian health

center. After the group was deemed mostly unsuccessful, Taylor was invited to

come evaluate what happened and help the center identify ways to adapt the

intervention so it was more culturally relevant for this population of women. After

collecting data from focus groups and interviews, Taylor partnered with agency

representatives and health experts to adapt the existing intervention. Following

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adaptations, a small pilot group was implemented to help determine social

acceptability and community fit. Following the pilot, additional changes were

made. Currently the intervention is undergoing implementation and evaluations in

two different LGBTQ health related venues. The process described by Taylor is

depicted in Figure 5-8.
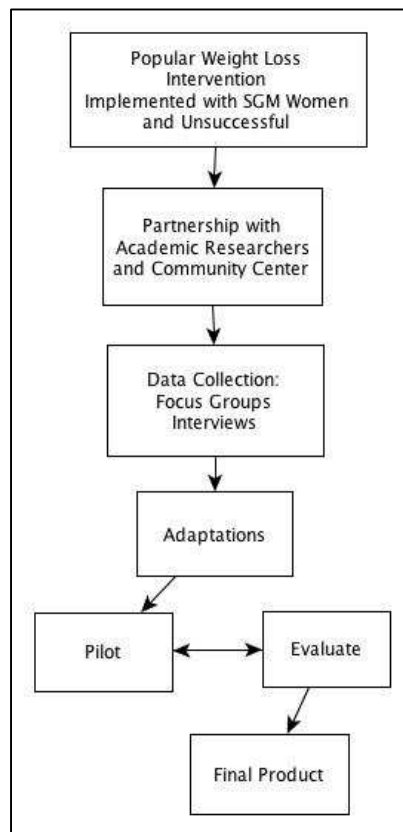
Figure 5-8 Taylor's Process Model

Francis

Participant 9 is Francis who is a community health partner from the Midwest. Francis has a master's degree in political science and government, and currently works for a county health department. The interview with Francis lasted approximately 40 minutes. The intervention and program Francis described was developed thirteen years ago, with Francis being a part of it for over nine years. The main focus of the program is healthy aging for community residents and the intervention targets service providers. At the time of the project development, there was no documented evidence indicating if SGM older adults were accessing any senior services or if service providers were culturally competent in serving this population. With the support of a small grant and county support, a small coalition of LGBTQ older adults was formed. The coalition began documenting their stories and experiences they had with medical service providers and residential living facilities. Additionally, focus groups with older SGM adults were conducted to gather data to determine their needs. Finally, surveys were distributed to local service providers to gather information about the types of services offered and if they are safe and friendly for LGBTQ older adults. Based on the data collected from the coalition, focus groups, and surveys, the program was developed which included several components. One component was a service directory of health providers and other resources offered in the community for

older adults. Service providers were contacted and provided with an application to participate in the service directory. If they indicated on their application they were LGBTQ friendly, the program would list them as such in the directory. Additionally, a training was developed for service providers to education them about culturally responsive care to older LGBTQ adults. Those who participate in the training are then listed in the directory as such. Francis discussed that the training intervention has evolved and continues to change with evaluation efforts and current health and cultural trends. The process described by Francis is depicted in Figure 5-9.
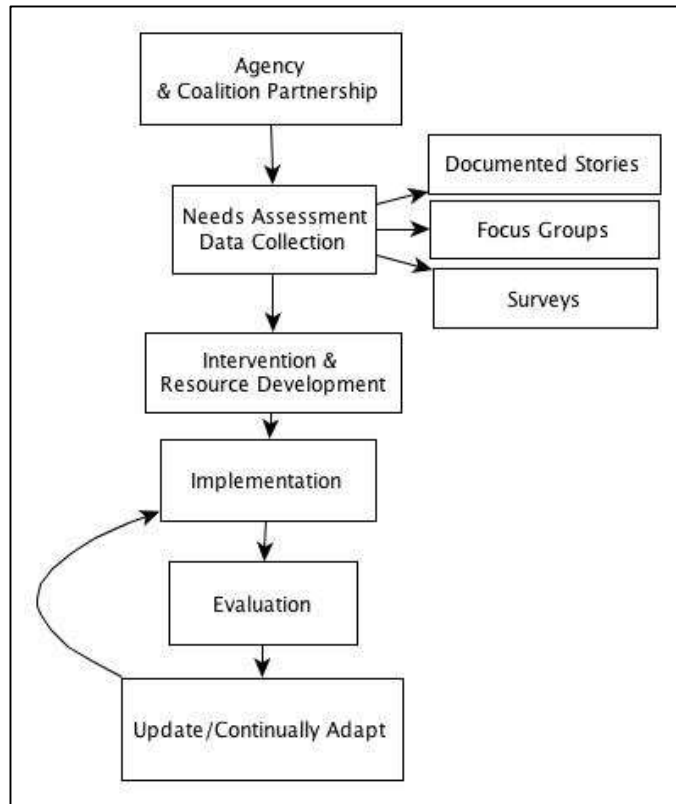
Figure 5-9 Francis's Process Model

Lin

Participant 10 was Lin, a community partner from the East coast who

works in adolescent sexual health. Lin has a master's degree in social work and

works in an agency that serves a diverse urban neighborhood with high rates of

teen pregnancy. The interview with Lin lasted approximately one hour. Lin was

engaged in a process to culturally adapt a sexual health curriculum for high school

aged youth. Originally Lin's agency was awarded a large federal grant, which

required the implementation of an evidence-based curriculum. A partnership

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between the funding source, Lin's agency, a local school district, and the

curriculum developers worked together to identify the intervention. Once an

intervention was identified, one of the partners spoke up to say it was

heteronormative and may not be effective for SGM youth. As a result, the team

members in the partnership brainstormed new ideas to better serve their SGM

students, reviewed empirical literature on relevant topics, and experts brought in

practice knowledge. They collectively developed three main changes to the sexual

health intervention including an instructor training on LGBTQ 101 topics, a pre-

lesson for the youth, and a facilitator guidance handbook for the remainder of the

lessons in the curriculum. Following the initial developments, the collaborative

group piloted the adapted intervention in 3 local schools. Based on feedback from

data collected after the pilot tests, a few minor additional changes were made

which formed the final product. Currently, Lin and others in the partnership are

collecting and analyzing data from observations and teacher fidelity logs. The

process described by Lin is depicted in Figure 5-10.
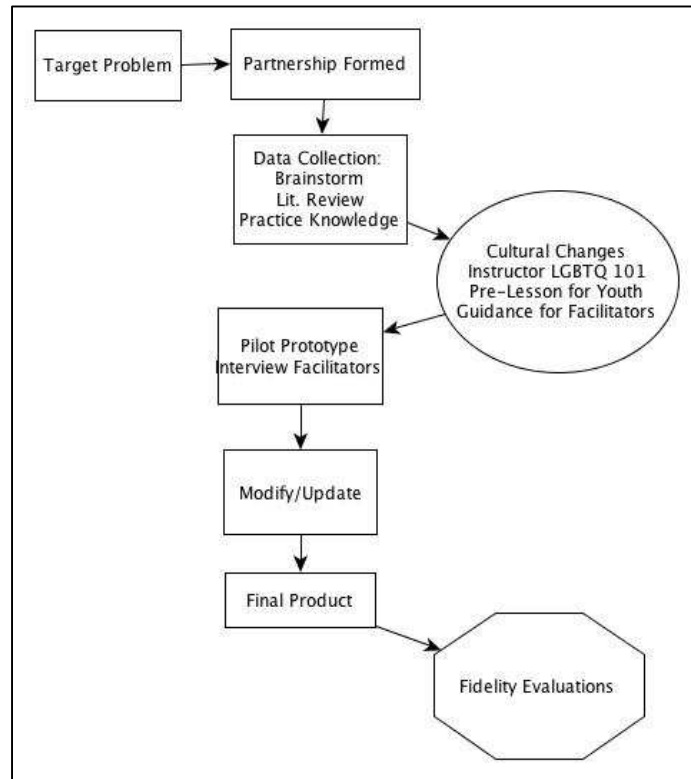
Figure 5-10 Lin's Process Model

Tracy

Participant 11 known as Tracy is an associate professor in a large

university in the western United States. Tracy's public health research includes

cultural adaptations, drug interventions, health disparities, and innovative

technology for health interventions. The interview with Tracy lasted

approximately 30 minutes with one follow up email. Tracy recently partnered

with a community agency to adapt an intervention for illicit drug users who are

SGM. The community agency serves SGM adults and collaborated with several

researchers including Tracy to culturally adapt an evidence based intervention for their SGM drug users seeking help. Tracy identified three major steps in the adaptation process. First, the community-academic partnership collected data through focus groups and interviews with their target population. Second, the group made changes to the original intervention. Tracy said it was important to identify the most essential components of an intervention and then everything else can be adapted. The types of changes included facilitator factors, location, conversation topics, and group homogeneity. After changes were made, the intervention was implemented. Tracy noted the importance that while efficacy may not be expected to be any higher for this sub group as compared to the original intervention test group, the goal is to reach high fidelity so the intervention is equally effective across populations. The process described by Tracy is depicted in Figure 5-11.
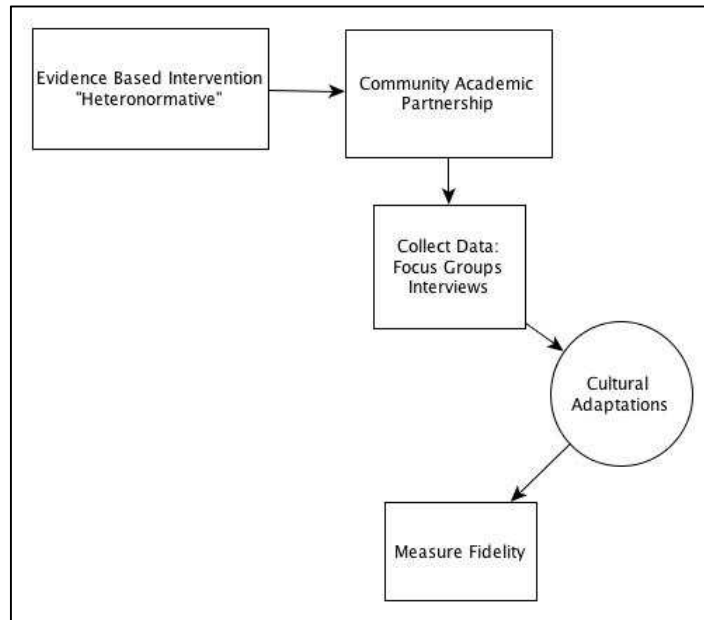
Figure 5-11 Tracy's Process Model

Danni

Danni is the pseudonym for Participant 12 and our interview lasted approximately 30 minutes. Danni has a PhD in sociology and works for an agency that has several health clinics in a large metropolitan area on the East Coast. Danni is the principle investigator for several projects that have been adapted for men who sleep with men (MSM) who have a drug addiction and are at risk for unsafe sex, intimate partner violence, and usage of other drugs. Danni described the use of the 5 step Map of Adaptation Process (McKleroy, 2006), which is a model for adapting interventions targeting people at risk of contracting HIV. In

this process Danni described the five steps including assess, select, prepare, pilot, and implement (see Figure 5-12).
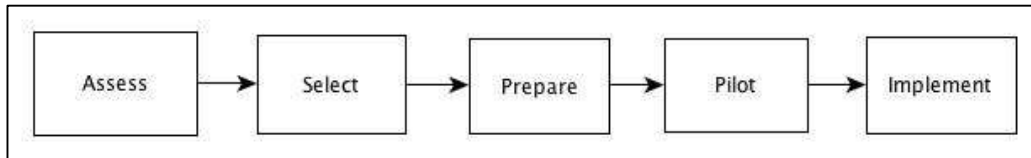
Figure 5-12 Danni's Process Model

Danni was the first and only participant to describe using a process that was previously developed for the specific target population. In the first step, assess, Danni described conducting a needs assessment of the community and also looking at county data for local trends. In the second step, select, the clinic that employs Danni had several researchers and community members work collaboratively to identify an appropriate EBI based on the needs identified. They selected an EBI which was targeting a generalized audience of drug users at risk for contracting HIV. In the third step, prepare, the clinic employees prepared the EBI for changes, which included rewriting some of the language and changing some of the non-essential content. Danni described modifying the intervention from a sixteen week intervention to a twelve week intervention. In discussing the cultural changes Danni said:

> *In any evidence based intervention there are essential components*
> *and non-essential components. You have to determine what the*

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essential components are and then from there you can change the

non-essential components.

Danni was alluding to the importance of fidelity to the intervention. Danni went on to say that if you change an entire intervention, then it is no longer considered evidence based. Next in the fourth step, they piloted their adapted intervention with a small group of 12 people to assess for relevance and fit. In this step they also made some additional refinements. This led to the fifth step, implement, where the clinic began officially registering participants and implementing the intervention.

Nel

Nel is the pseudonym for Participant 13 and our interview lasted approximately 40 minutes. Nel is a community partner from the West Coast with a bachelor's degree in theatre studies but works as a social worker. The agency Nel works for offers many services to the SGM community in a suburban county. The particular project that Nel described to me was about an intimate partner violence intervention service that was adapted to be inclusive and relevant for the local SGM community. Figure 5-13 depicts Nel's process model.
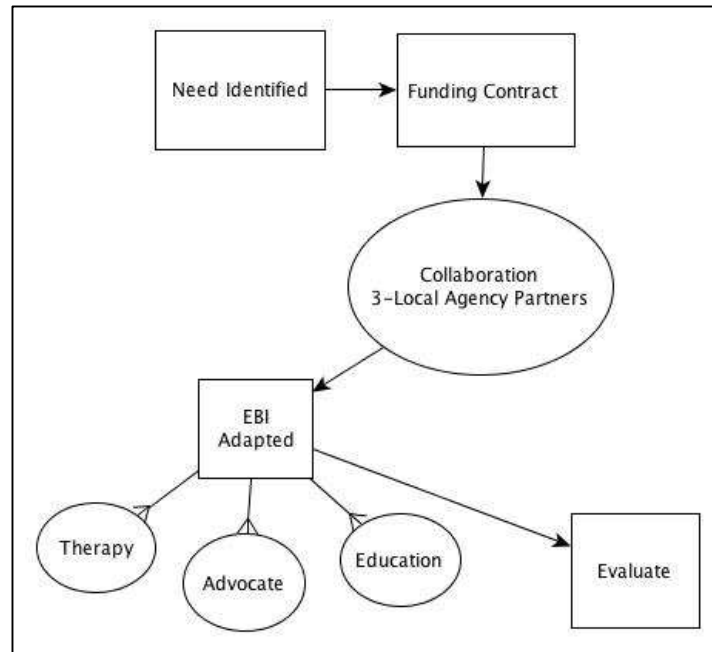
Figure 5-13 Nel's Process Model

Nel stated the first step was that SGM intimate partner violence (IPV) and other

domestic violence issues were topics of conversations in some of the support

groups they offered at their agency. Staff meetings brought this topic to the

surface and the need was identified. The executive director decided to write for a

grant to fund a project for this health issue. After a five year contract was obtained

from a state funding source, the agency collaborated with two other agencies to

begin adapting curricula and developing related services. The tri-collaboration

incorporated a wealth of knowledge and skill sets and based on empirical

literature and practice knowledge, members of the collaboration began their work.

They created an education piece for facilitators of current groups who need

support talking about the unique issues related to domestic violence and IPV in this community. They adapted an evidence-based intervention to be used in for individual and family therapy. In addition, they created a training program for advocates to support victims at court appointments, with restraining orders, emergency shelter services, and other referrals. For the purposes of their grant money, they evaluate their services annually for client satisfaction and basic access data. Nel talked about the unique risks for SGM experiencing IPV such as encounters with the police, or at a local emergency shelter and said:

> *If they see you are a gay man that is HIV positive and a partner is abusive, they can "out" you for your status and also for your sexuality. Maybe if you're not out to your co-workers's or family it could be a powerplay as well.*

Findings

As a reminder, the research questions that guided this study included: 1) What precipitates the perceived need to develop or adapt an intervention so it is relevant to individuals who identify as lesbian, gay, bisexual, transgender and queer (LGBTQ)? 2) What is the process in adapting and/or creating the intervention? 3) What can we learn from this process about the characteristics of effective adaptations and/or adaptive interventions, and (4) what guidelines can be

recommended for future social service providers who wish to create their own

culturally relevant LGBTQ intervention drawing on the emergent model?

When examining the research questions, three key themes emerged from

the data and analysis. In developing or adapting a health intervention for SGM,

researchers and community partners spoke about three main themes (1) Cultural

Components, (2) Adaptation Process, and (3) Lessons Learned. Within the

cultural components, researchers and community partners alike fell into two

camps of thought: (1) exclusive adaptations, or those that target SGM specifically,

and (2) inclusive adaptations, or those that target anyone but are given special

attention to be inclusive of SGM. Each of these themes are documented in a

coding matrix (see Table 5-2).

Table 5-2 Coding Matrix

Themes	Dimensions	Categories	Example Quotes
Theme 1: Cultural Components	Environment	Geographic Location	"It's really important to have critical mass. In other words, a community which is a mecca for lesbian, gay, bisexual, and transgender folks. It's like yeah, that would be really great if you could host the class someplace that you...you have to have not only critical mass of the community, but also folks that are willing to be out or at least partly out, and have somewhere where it all...you know, the things that make a community. Somewhere that's cultural, that also has to do with publication or media, what they call social media now."
		Facility	"First of all it was meant for the [LGBTQ] community, so obviously choosing an organization that provided services openly to the gay community was the first initial important point."

Table 5-2 Continued

Theme 1: Cultural Components	Policy	Advocacy	"We have learned, and one of the things that helped me keep perspective, is that when you're providing services, it's all downstream. You're looking at the dirty creek. You can spend a great deal of time trying to clean it up, but the idea is you've got to go up the creek to find out who is putting the pollution in the feed."
		Agency	"Basically we found that they were not accessing services out of fear that they wouldn't be treated right; so we encourage the agencies to change their policies."
	Language	Name of Intervention	"For the groups it was about language…changing the title for example was one thing. The title came from their own words. Remember we are an urban area so that also plays a role and we also see young women of color so those are factors as well. Those intersections and nuances were considered."
		Gender Neutrality	"They were like, things like gender neutral pronouns. They wanted to see more inclusion of the adult gay community."

Table 5-2 Continued

Theme 1: Cultural Components	Facilitator Factors	Awareness & Knowledge of LGBTQ	"We did stories that not only were stories about our patients and staff, real life stories, but we also gave tips to our staff."
		Being From the Community	"Then we needed to choose somebody from the community to do the class. I think that was one of the things that was really important."
	Target Audience	Inclusive	"These kids were like, 'we don't need this to be a gay intervention we just would like to at least see some aspects of ourselves, I think it would just get us to pay more attention.'"
		Exclusive	"You really think about who's in your space and what that is about and then develop their curriculum also around who you are serving."
		Camps of Thought	"It's like yeah, it's lovely to go in and adapt an intervention and seek NIH dollars to do that. But I think there is a major kind of question right now around adaptation in terms of like, is it necessary? Does the product that we end up with actually do a better job than the one that we already have?"
			"The literature supports that cultural intervention activities are actually more successful."

Table 5-2 Continued

Themes	Dimensions	Categories	Example Quotes
Theme 2: Adaptation Process	Target Problem	Needs Identification	"A few years ago staff who worked here said, 'we have needs, our patients have needs. They don't see us as an LGBT friendly inclusive place, we need to do something about this.'"
	Intervention Source	Evidence Based Intervention	"It's highly modified but we've started with sort of a shell of another intervention that was acceptable and then we just built it to fit our needs."
	Data Collection	Community Representatives	"If you're looking to design an LGBT specific program, you need to have LGBT people at the table."
		Focus Groups	"All of the themes were incorporated into the intervention. All of the changes were based on what the community said to us in the focus groups."
		Surveys	"I would do a survey of the community to find out just what they need and want."
	Modify	Process	"We changed the design, the pictures in the participant booklets and added in relevant content. The idea of how to quit stayed the same but the conversations for the group intervention were based on relevant themes we identified in the focus groups."

Table 5-2 Continued

Theme 2: Adaptation Process	Pilot Prototype	Pilot Testing	"We've had four rounds currently of a modified program taking what we learned and then each time we ran the program we used information on what worked and what didn't work from the one before it."
	Final Product	Dissemination	"We do not publish all of our curriculum. It's never really been funded to be written up, and we don't make it available unless you take a class or a training. The reason for this is because we're not trying to supersede the [name of the original curriculum developer]."
	Evaluate	Fidelity/Process	"We do research and evaluations to make sure the fidelity has been met."
		Outcome	"A big piece of doing this work is evaluation. It's knowing very clearly what are the outcomes you want to see. The clearer you are with those outcomes, you can aim your intervention towards those outcomes and then you're evaluating did it work, did it not work."
		Cultural Fit	"We ask a three question cultural competence survey. Were classes appropriate to your culture? Was the facilitator respectful to your culture? If there was something culturally inappropriate, do you feel you could have brought up the issue?"

Table 5-2 Continued

Themes	Dimensions	Categories	Example Quotes
Theme 3: Lessons Learned	Adaptation Process	Epistemology	"It's like being really mindful of the business, is it practical? Do we really need an intervention for this specifically for gay kids? And just being mindful of that is in some ways potentially an exclusionary type in that, does it eventually sort of further perpetuate the excuse that it's already happening?"
	Challenges	Funding	"We don't have time. Healthcare doesn't have that time anymore. We don't have that luxury. Our costs are too high. Our outcomes aren't as good as we should have. They're really encouraging us, all of us in healthcare to do this work of being more scientific but doing it in a more timely fashion because we've got to cut our costs and we've got to have better outcomes."
		Not Always a Good Fit	"We do lose some people. Certainly, we've lost women, I think, when we had just like two women and twenty five men in one room. I think some of them felt like maybe I'm not coming back. It's hard to know what's in people's heads really."

Table 5-2 Continued

Theme 3: Lessons Learned	Recommendations	Data Collection and Measures	"Having validated measures is really important in data collection. This helps with the funding streams. Making sure these measures accurately reflect what data you're trying to gather including the LGBT demographics. Some may not identify that way, so it's important to ask them more than just their sexual orientation."
		Facilitators	"Also, I think for facilitators, anyone who's leading a group or leading the program, having some kind of tool kit that they can use; like how to steps, 1-2-3."

Cultural Components

The cultural components emerged as one of three key themes in my analysis. Cultural components included five dimensions with several categories in each dimension. The five dimensions were *environment, policy, language, facilitator factors,* and *target audience.* Within each of these dimensions, cultural components manifested as the various elements that were considered, incorporated and/or, adapted in the interventions discussed by the key informants.

Environment

The environment was discussed often with regard to culturally adapting a health intervention for SGM. Key informants spoke about the part of the country they were currently living and what it was like for SGM, what part of the country the intervention was developed (if not where they live), and about the location for implementing the intervention. Two categories fell within the environment dimension: *geographic location* and *facility*.

Geographic Location

Geographic location had an influence on how "out" people were with their sexual orientation, the extent to which local and state policies funded public health programs, and whether or not it was feasible to offer an inclusive or exclusive intervention. On the west coast, specifically California, the laws are very stringent for smoking and one of the key informants spoke extensively about

the fact that SGM are still smoking a lot but are now further isolated because of

the laws:

> *The [smokers], they are pariahs and they feel that what has*
>
> *changed is the environment in California. No smoking pretty much*
>
> *everywhere. The only smoking section is Nevada, next door. Non*
>
> *smoking beaches, bus stops, events, bars, just about everything.*

Another key informant from a different part of the west coast expressed a similar

sentiment:

> *We have to be careful how we say this, but most people are pretty*
>
> *much out of the closet in their life. The interesting thing is, I just*
>
> *said out of the closet but I'm talking about their sexual orientation*
>
> *or their gender identity. They are deep in the closet, more and*
>
> *more so, about their smoking status. That's something we've really*
>
> *noticed. The stigma and guilt has almost been....what was there,*
>
> *perhaps about their sexual orientation/gender identity, is now*
>
> *there about their smoking status.*

Many of the key informants from the various locations on the west coast shared

this idea that the laws and policies have made smoking less acceptable than being

a sexual minority, particularly in the urban areas.

With regard to offering an exclusive intervention, the geographic location was also important as one key participant noted:

> *It's really important to have critical mass. In other words, a community which is a mecca for lesbian, gay, bisexual, and transgender folks. It's like yeah, that would be really great if you could host the class someplace that you...you have to have not only critical mass of the community, but also folks that are willing to be out or at least partly out, and have somewhere where it all...you know, the things that make a community. Somewhere that's cultural, that also has to do with publication or media, what they call social media now.*

This particular key informant was discussing the importance of not only having a community where it would be feasible to offer a SGM exclusive intervention but also where there are social media outlets for advertising about the intervention. Another participant who phrased their words a little differently shared the same idea:

> *Where I live, this lesbian specific group that we're offering [on the east coast] would never fly here. We have absolutely no gay community here. I think it's probably because we're still a part of the old south.*

Facility

The facility was also important in the context of cultural components for SGM health interventions. Key informants that discussed inclusive interventions focused on "clues" or indicators that would help an SGM know they were in a safe and accepting place and could expect culturally competent service. Key informants that discussed exclusive interventions focused on the physical space where the intervention was housed such as an LGBTQ community center or another known facility that houses other services targeting this community. One key informant from an exclusive intervention said choosing the right facility was one of the most important components:

> *First of all it was meant for the [LGBTQ] community, so obviously*
> *choosing an organization that provided services openly to the gay*
> *community was the first initial important point.*

Another exclusive key informant shared this priority:

> *It would be an LGBT friendly, we'll say, LGBT friendly location in*
> *terms of access in many ways. That may not be a health*
> *department, that may not be an AIDS place, because even though*
> *there's a lot of people involved in AIDS-based communities, in the*
> *LGBT community a lot of people ran away from that, and may not*
> *be comfortable going in. You might get space donated from a*

synagogue or church, but that may not be ideal. For us it's the

LGBT Community Center...these locations are culturally gay-

friendly, LGBT-friendly places, neutral and so forth, but definitely

LGBT.

As this theme came up several times, I began asking why, to further probe what it was about an LGBTQ space. One informant said something that typified what others said as well:

The biggest thing that came out of it was that they felt a sense of

safety in the environment and about being who they were; without

having to check their language every time they opened their mouth.

Another similar statement discussed how the physical attributes of a space could make it feel safe:

The first thing that was so noticeable was the environment. Just the

building itself, the furniture and the way it was set up everything

about it was safe. When you walked in the door you were

immediately welcomed. It looked like a living room. It was a great

wonderful, and accepting type of environment.

The idea was really that because of social norms and societal stigma the key informants spoke to great lengths about how LGBTQ spaces were important for

the exclusive interventions so that the participants in a group could focus more on improving their health rather than worrying if they were going to be judged for their sexual orientation or gender identity. On the other hand, participants who discussed inclusive interventions were less concerned about the physical space as it was meant to be inclusive for everyone.

Policy

Policy was another dimension of the cultural components, which had two categories: *advocacy* and *agency*. Policy advocacy was about being engaged in local policy efforts to increase funding for projects and participate in change campaigns on related health topics. Agency policy was about inclusivity for SGM on items such as intake questionnaires, non-discrimination policies, and other safety precautions for clients and providers.

Advocacy

Several participants from both exclusive and inclusive interventions discussed challenges and opportunities in adapting interventions. In particular, one participant spoke about how it is not only important to partner with other agencies, but that it is essential to be connected to funding sources and leaders in the community. Once connected, the opportunity to advocate for policies and measures that can fund local health programs was tangentially connected to adaptation projects. This inclusive key informant said:

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We have learned, and one of the things that helped me keep

perspective, is that when you're providing services, it's all

downstream. You're looking at the dirty creek. You can spend a

great deal of time trying to clean it up, but the idea is you've got to

go up the creek to find out who is putting the pollution in the feed.

The sentiment of this informant was shared by others who often said things like "don't reinvent the wheel," "partner with the community to get the work done," and "the more proposals they see of this nature, the more they will realize we as researchers are advocating for a policy shift in funding." Although the interventions were not necessarily about policy advocacy, the key informants felt with their adaptations that they were making a political and values statement about the way the world works and how to influence the power players around them.

Agency

Policies in the agency were also recognized as important to the process of implementing an intervention that was relevant to SGM. In trying to identify what things needed to be changed in the agency one inclusive informant said:

Well, LGBT when they come to our clinic they look for clues that

it's an LGBT friendly environment. I was like okay, what are the

clues that people are looking for? Help me understand that. The

response was, look for signs. You have brochures that talk about

LGBT, do you have any photos? When you're doing your intake,

do you ask people questions like your sexual orientation, your

identity…They're always looking to make sure it's safe, because no

one wants to come out if it's not safe. They're looking to see if

people have been trained culturally, have some type of cultural

awareness sensitivity training and they can tell.

Another inclusive informant spoke about the intake forms and other information

necessary for facilities to have in order to change policy:

We give them demographic info, but just to let them know that

whether they know it or not, they do have LGBT folks in their

facilities or they may have caregivers who are LGBT. We talk

about the intake forms. We give them information about the kinds

of questions to ask on the intake forms.

Others who discussed what might make an agency more inclusive also shared this

priority:

We discuss putting up a non-discrimination policy to put one on

the intake forms or in their brochures, and put up

nondiscrimination posters in their common areas.

After conducing some research in the community, one inclusive key informant noted the importance of advocating for overall agency policy change so SGM consumers felt comfortable to access health services:

> *Basically we found that they were not accessing services out of fear that they wouldn't be treated right; so we encourage the agencies to change their policies.*

The idea behind this category was to place responsibility with the service provider as opposed to the individual in need of health services. One exclusive informant noted the importance of identifying policy change for the agency and how it will impact the honesty of a consumer:

> *Just because you're calling an organization that serves [this problem] doesn't mean that the organization or the employers aren't homophobic, transphobic, or biphobic. Particularly, if you're filling out paperwork that doesn't give you different options for gender or sexuality. Or if you don't see rainbow flags or the transgender flag up. If there's nothing that indicates it's queer friendly, people may not be honest or even seek the services.*

The key informants expressed that the safer a person felt in an agency, the more likely they would follow up with their intervention plan. Therefore, the agency policies became a factor for the adapted interventions.

Language

The next dimension identified in cultural components was language. Two categories fell within this dimension including *name of intervention* and *gender neutrality*. The name or title of the intervention was particularly important for the exclusive interventions as many of the associated key informants noted these names and play un words (PUN) as clues and cues the intervention was something specifically targeted toward SGM. On the other hand, gender neutrality was a theme more relevant to the inclusive interventions whose key informants discussed the importance of changing gender names and pronouns in vignettes and participant handbooks. In addition gender neutrality was about honoring the diverse identities of people regardless of sexual orientation.

Name of Intervention

Several of the key informants from the exclusive interventions described the very unique names given to the intervention's they described. Many of the intervention titles were derived from the targeted community members. The following quote characterizes this theme:

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For the groups it was about language…changing the title for

example was one thing. The title came from their own words.

Remember we are an urban area so that also plays a role and we

also see young women of color so those are factors as well. Those

intersections and nuances were considered.

Another key informant from an exclusive intervention similarly shared the

process of identifying a relevant title for their targeted intervention:

Deciding to choose….choosing the name and it actually was a

smoker who came up with it, who said the name first. When I heard

the name I said that's it. But we were trying to use their words, and

put things together. Verbs and nouns and things that were familiar

in the community.

Likewise, the names of activities within the intervention were small but important

pieces according to one of the informants:

We do a little thing called 'A Bunch of Fruits' which it basically

sort of allows people to talk to one another. It's a joke with a little

PUN, and it just helps people and its that community thing.

The inclusive interventions did not have an LGBTQ name as many of the key

informants from this camp described the importance of fidelity to the original

intervention. Rather than change the name or the specific content, gender

neutrality was discussed as important.

Gender Neutrality

Gender neutrality encompassed things like gender neutral pronouns, using

preferred gender pronouns (i.e. asking a consumer which pronoun's they prefer),

and updating scenarios to be inclusive of all gender and sexual orientation groups.

In describing what a focus group reported, the informant said, "they were like,

things like gender neutral pronouns. They wanted to see more inclusion of the

adult gay community." Another key informant from the inclusive camp discussed

how the scenarios might change in an intervention in order to be more relevant

and inclusive:

> *Another example might be something about drug use where the*
>
> *example is another male…in your peer group of male friends two*
>
> *are heavy drug users and sell drugs. Two are marijuana smokers*
>
> *who usually buy drugs from the male, from the drug dealers in*
>
> *your group and three are non-users or the occasional users. How*
>
> *do you negotiate that space and use support? Who should you be*
>
> *hanging out with or etcetera. Well, that assumes that everyone in*
>
> *the peer group is male so when the girls read that workbook they*

would say, 'okay. now let's think about, this, let's change this etc.

I'm in a group of girls and the scenario is like this.

The topic of updating vignettes was one of the most common changes made to inclusive interventions. One key informant described why:

Here's a scenario that happens. The scenario is the guy and the girl are in the school parking lot and the guy, or the boy or the young man sees you talking to another male student and becomes jealous and he pulls your arm away and yells at you; I'm just making this up but that particular example doesn't fit real well for our LGBT youth, it's very heterosexual.

Another key informant carried on with this suggestion:

Role plays which are the biggest ones. Just simply changing names and pronouns...it's probably one of the simplest things folks can do. Instead of having it be Jan and John, make it Tyler and another gender-neutral name.

I then inquired as to how a key informant might identify a heterosexist assumption within an intervention.

We see that all the time in workbooks, particularly around LGBT where they're assuming heterosexual relationships and kind of

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norms within the substance abuse culture about who injects first,

who buys the drugs, and who negotiates use.

While mostly the key informants from the inclusive interventions spoke about gender neutrality, one of the exclusive informants used an example to bring home the idea of why many interventions need changing all together:

One example I saw years ago was where it said sex is an important

issue for people: so boys go out and shoot some hoops and girls

get your favorite bath oil and get some bubbles going. In those

gender expectations and rigidity would be certainly a turnoff for

people if we were to adopt that curriculum directly. I think that

was some of it, which was to develop some activities and make

sure it was inclusive of as many people in our community as

possible.

Facilitator Factors

With every intervention, particularly a group intervention, there was at least one facilitator. The key informants from both inclusive and exclusive interventions discussed the particular training necessary for SGM health intervention facilitators, their background, and other culturally relevant

information. The two categories within this dimension were *awareness and knowledge of LGBTQ,* and *being from the community.*

Awareness and Knowledge of LGBTQ

"We have a train the trainers." That quote reflected what most of the key informants discussed regarding training for facilitators. From the inclusive interventions, another key informant said something that was mentioned by other inclusive informants:

> *The facilitator training is based specifically on the [intervention], but many of them have experience conducting similar groups in other places so it is the specific content they receive training on. Many of the facilitators are also trained nurses and social workers with a health or mental health background.*

Not much different from the inclusive interventions, the exclusive intervention facilitators were a cultural consideration as well:

> *And then there's the facilitator. We've always felt it's important that they have training from [the original intervention] that they have their certification for that, as well as some training from [the adapted intervention].*

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One inclusive key informant provided an example of how they train and educate their providers:

> *We created this story booklet. People said, 'we need to really educate our staff, what's a way we could do that?' We decided we would use what's called screen savers on our computers, and that they would pop up and say 'learn about…' and we did stories that not only were stories about our patients and staff, real life stories, but we also gave tips to our staff. 'Okay this occurred, this is what these patients said about their experience in our system about whether they were transgender or a gay couple or a lesbian couple with a child' whatever. Then we married that with tools and tips for how to improve interactions for the future, and then some facts like, 'did you know blah blah blah and here's the story and this is what we, as staff know, blah blah blah, and this is what we, as staff could do to change that story or improve it or keep this good thing going.*

The idea here was to provide a foundation for an inclusive environment. While key informants from both inclusive and exclusive interventions discussed the priority for a facilitator to be a trained, culturally competent leader, I inquired a bit more about how they ensure their training is enough. One said:

How are people deemed culturally appropriate? Except for their

training in the topic and their gusto for working with the LGBT

community, there's not other litmus test that I know of.

After my first two interviews, I began to realize that training was not the only important factor for facilitators. Many key informants discussed how they expect their facilitators to be knowledgeable of SGM culture, history and values. This sentiment was shared by both the inclusive and exclusive key informants; in particular, one exclusive informant said:

For us it's really important to talk about LGBT, history should be

in just about every kind of curriculum because I think knowledge is

power and sort of seeing activism and where you've come from

and where you're going. I think it's just so important in terms of

understanding oneself and having to build self-efficacy and

empowerment, self-esteem…Including some LGBT 101 history is

an important component for the facilitators and the participants.

One inclusive key informant discussed what is included in their training for facilitators about the SGM consumers:

The workshop we do for the volunteers, they have a hotline. In

order to become a volunteer you have to go through a 40 hour

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training. The workshop is a part of that training. I break down

what LGBTQ is, give them working knowledge and info. Talk

about the difference between sexuality and gender. What is

transgender, intersex. What is homophobia, transphobia, and

pretty much oppressions etc. We talk also about what are the

barriers to service.

Another inclusive informant said, "we usually train folks on the curriculum itself,

and then we'll add in a piece on LGBT inclusivity."

I began to inquire more about what it is specifically that is unique to SGM

culture and how might those experiences be communicated to a facilitator. One

inclusive key informant said:

For queer people facing domestic violence and sexual assault, the

topics focus on well, if you're trying to access services at a shelter.

So if you're a woman identified person accessing services at a

women's shelter, your partner could go there too. They assume the

abuse is by a man. If you're a transgender woman you may have

problems trying to get in because your documents say you're a

man or you look like a man. There's issues about staff who are

biased. They're not very friendly or sensitive to calls from queer

people who are experiencing domestic violence.

The idea of bringing awareness to facilitators and providers about the potentially

unique challenges faced by SGM was also shared by another key informant from

an exclusive intervention who said:

> *One of the places where there is a discrepancy between main strem*
>
> *perhaps and the tailored work which is…for gay men, they derive*
>
> *many meanings about themselves and about their culture, by the*
>
> *act of having sex...We try to talk about the way the substance gets*
>
> *integrated into use within the culture is important.*

In addition to the unique training components and knowledge necessary to

facilitate a SGM health intervention, unique to the exclusive interventions was the

idea of having a facilitator who is an SGM.

Being from the Community

For the exclusive interventions, several key informants spoke about the

importance of having a facilitator who is either SGM or in a few cases, a known

"ally," which is what was expressed by this key informant: "Then we needed to

choose somebody from the community to do the class. I think that was one of the

things that was really important." Another similar comment from an exclusive key

informant said:

> *We need to put this in the hands of people who know how to lead a*
>
> *group...our facilitator, we've selected her very carefully; they're*
>
> *going to listen to her.*

The main idea of having an SGM facilitator for the exclusive interventions was closely related to safety, consumer retention, and overall community connectedness.

Target Audience

The target audience was at the heart of the exclusive and inclusive intervention discussions, particularly in determining what might be a good fit for SGM. As previously mentioned, if the target audience was intended for everyone then it was considered inclusive and if it was intended just for SGM then it was considered exclusive. In addition to discussing how these types of interventions are unique, there was also common thread of discussion regarding opinions and value systems related to justifying the intended target audience. The three categories in the target audience dimension were: *inclusive, exclusive*, and *camps of thought.*

Inclusive

A few key conversations informed the category of an inclusive intervention. One similar conversation that occurred with three of the inclusive key informants was about the approach taken to make changes to an original

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intervention, and another was about how they implement those changes. Data collection, a dimension discussed later on, was one way to identify what might need to change. For example, key informants discussed what they learned in focus groups with their target population. One informant said:

These kids were like, 'we don't need this to be a gay intervention.

We just would like to at least see some aspects of ourselves, I think

it would just get us to pay more attention.'

The conversation about inclusive interventions often moved to what might be recommended once adapted:

There are LGBTQ youth in these programs, but the role plays are

so hetero-sexist that we recommend teachers and facilitators use

the adaptations we've created.

The idea of potentially isolating the consumers who are already very marginalized was a common thought amongst the inclusive key informants. In an effort to avoid isolating the SGM consumers, key informants spoke about what might make an intervention more inclusive when taking into consideration the cultural differences:

Another thing is talking about separating sexes. A lot of schools

will have, and I'm using quotation marks which you can't see, but

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'segregated lessons.' All the girls go over here and learn about

puberty, and all the boys over here and learn about puberty. We

talk a lot about what does that look like for trans students, and

gender-queer students, or students who are outside the binary and

it's probably not a good practice that's really right.

Another informant from a similar field shared the same thoughts about isolation:

We will talk through ways to engage everyone in the same room

without making anyone feel isolated. We talk about some boys

want to learn about what's happening in girls' bodies and girls

want to learn about boys' bodies. Often normalizing that

sometimes our bodies don't do what we want them to do, especially

during puberty. Really expanding on the difference between sex

and gender and giving them model lessons to do with young people

as well.

Exclusive

Similar to the inclusive interventions, key informants from the exclusive interventions discussed identifying the target audience and how that influences the various changes that will be made to a health intervention. For example one exclusive key informant said, "You really think about who's in your space and

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what that is about and then develop the curriculum also around who you're

serving." Also in the planning stages, another exclusive key informant said:

> *With LGBT, is it LGBT of a certain age group or a certain income*
>
> *level? The narrower you get in your focus, the more strategic you*
>
> *could be around your intervention.*

After conducting focus groups several key informants noted why

exclusive interventions are important to them and to the SGM community:

> *They talked about being able to say what they wanted without*
>
> *having to monitor or check every word out of their mouth for fear*
>
> *of someone finding out they were a lesbian.*

Similarly, another exclusive informant said:

> *In our focus groups, every time we had focus groups and asked*
>
> *what the women would prefer, they didn't want age discrimination;*
>
> *they wanted all sorts of women as long as they were sexual*
>
> *minority women.*

In identifying some of the appropriate groups that may benefit from an

exclusive intervention, the key informants spoke about their specific target

populations. Comments like, "our groups are tailored to African American sexual

minority women," and "The program we are planning to run...is being targeted

towards older lesbians." This led me to ask some additional questions about what types of things would make an exclusive group unique as far as the target population is concerned. One said something about the reoccurring discussion of social venues like gay bars and how to find healthier venues; another said this:

> *Most of the kids hate their parents and they don't really care about old people. Whereas like with us [LGBTs], there is definitely an ongoing dialogue about things like gay bars and things like that.*

The kids in this particular group were very interested in safe spaces, and where they could access the world of being a gay adult but still feel like a kid. The key informant who made this comment further explained that sometimes groups need to be exclusive so those types of conversations can occur freely and young SGM youth can safely explore their community norms.

Camps of Thought

It was quite clear that everyone agreed SGM need to be included in an intervention, and some took it a step further to say that interventions specifically targeting only SGM may be a better fit. Camps of thought was really about an opinion as to whether the inclusive or exclusive intervention was more appropriate, had better efficacy, or could even be deemed necessary.

One of the main arguments and points of discussion was about efficacy. The question posed by both inclusive and exclusive key informants, both

researchers and community partners alike, all had differing opinions about which is more effective. One exclusive informant noted:

It's like yeah, it's lovely to go in and adapt an intervention and seek NIH dollars to do that. But I think there is a major kind of question right now around adaptation in terms of like, is it necessary? Does the product that we end up with actually do a better job than the one that we already have?

Two other exclusive informants also discussed efficacy:

When people come to a culturally or ethnic, I would say, or language program, I think part of what they're looking for is community. They may not actually say that. Like if you ask them, does it make a difference whether it's lesbian or gay or bisexual or transgender, and they say no, it doesn't really make any difference. Well, I think it does.

Likewise, another said:

Although we have in the past sort of asked does it make a difference that it's available to the LGBT community. Again, some people say yes, and some people say not necessarily. I think that

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has to do with how people feel about themselves, how people feel

their internalized homophobia, how "out" they are.

While those two informants used their personal opinion and practice wisdom to support their efficacy statements, two others incorporated empirical literature. One exclusive informant discussed how the literature is inconclusive regarding efficacy for exclusive interventions, however there is still a valid reason to create/adapt them as such. This informant said:

When you look at outcome literature, there are not many studies

that I know of where a tailored approach has significantly greater

outcome than the standard approach to treatment.

This informant went on to say, "as long as you're clear about that, I mean, you'll see it's still pretty relevant." Others also commented about relevance by discussing that while efficacy may not be increased, it may be just as effective but more relevant. Conversely, an inclusive informant believed the literature does in fact support greater efficacy with culturally tailored interventions: "The literature supports that cultural intervention activities are actually more successful." Generally, there was not a consensus around efficacy, but there was a consensus that inclusive and exclusive adaptations were certainly justifiable. For example, one exclusive informant said:

The way substance gets integrated into use within the culture is important. That is probably the main reason that would justify going forward with uniquely tailored treatment intervention material. It's the right thing to do because you understand how the drug gets used.

This key informant continued on to say that there are differences in how risky health behaviors manifest for SGM when compared to heterosexuals. Furthermore, it did not appear that there was a right or wrong camp of thought, but inclusive and exclusive interventions were both justifiable depending on the other cultural components (i.e. environment, facilitator factors, policy etc.).

Adaptation Process

A second theme in my analysis was about the adaptation process for each of the interventions. In the interviews I asked questions about how the projects got started, who was involved, what did the process entail, and other related questions. The adaptation process involved the following dimensions: identifying a *target problem*, identifying the *intervention source*, *forming a team, collecting data, modifying* the intervention*, piloting* the intervention*,* completing a *final product,* and *evaluating* the intervention outcomes and or fidelity.

Target Problem

Needs Identification

The target problem dimension had one category, which was needs identification. Just as it sounds, needs identification answered one of the original research questions regarding what precipitates the perceived need to adapt an intervention. The answers were somewhat diverse in this category. For example some key informants noticed a need to change or adapt an existing intervention, whereas others had anecdotal evidence that changes were necessary. One key informant who worked with a coalition said:

> *In the evidence based rigorous research in preventing teen*
>
> *pregnancy as well as preventing STI's and HIV with youth, a lot of*
>
> *them, because of that research, they're basically from the early 90s*
>
> *and we really noticed a huge gap, especially for LGBTQ youth in*
>
> *those programs.*

Another said: "It was a research question," which was an uncommon response to this question. For the most part, the other key informants reported the following:

> *A: Back then, in those early days, we only had anecdotal evidence*
>
> *that our community was smoking at higher rates. We had a feeling.*

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B: A few years ago staff who worked here said, 'we have needs,

our patients have needs. They don't see us as an LGBT friendly

inclusive place, we need to do something about this.'

C: "Somebody said that this curriculum was kind of heteronormative."

D: "I decided maybe it would be beneficial to develop a health

improvement weight loss program for lesbian and bisexual women."

Each of the key informants represented in the quotes (A, B, C, and D) all

had a different means to identify the need to change or adapt an intervention.

Generally, and not surprisingly, this was one of the first steps in the adaptation

process.

Intervention Source

Evidence Based Intervention

Identifying an intervention source was another early step in the adaptation

process. Some key informants worked in an agency that was already

implementing an evidence based intervention (EBI), whereas others identified a

need for their community first, and then chose a relevant intervention to adapt.

Across the sample, all used EBI's as a base for the adapted intervention. As noted

above, the inclusive interventions were less modified than the exclusive

interventions. The informants from the exclusive interventions talked about using

the shell of an EBI but the final product ended up being highly modified:

Now we have a curriculum that we have refined but we did start

with something that someone else had already tested. Now, of

course it's different.

Likewise, another exclusive informant said:

We based it off an intervention that was already out in the field but

we really then modified it to a great degree to fit our population. It

kind of looks like a new intervention but not quite.

And finally, one additional exclusive informant said:

It's highly modified but we've started with sort of the shell of

another intervention that was acceptable and then we just built it

to fit our needs.

The informants from inclusive interventions discussed the use of EBI's as well, however they noted only minimal changes. For example, one informant made a comment that was similarly repeated by several other inclusive informants:

What we do is we start with our intervention, the evidence based

intervention. We look at that and then we bring in people who are

good communitiy key informants.

After learning about culture in focus groups, certain cultural components may be added to the EBI, but with the intention to keep implementation fidelity to the original intervention. Ultimately the inclusive interventions were adapted as noted above in the cultural components such as by adding *gender neutrality* as opposed to eliminating any content, like some of the exclusive interventions.

Form Team

Coalition

Once a need was identified as well as an EBI, the next dimension included forming a team to begin the adaptation work. In some cases a team would already be formed and then the other two dimensions would follow. A coalition became the category for this dimension because the general consensus was to partner in such ways as community academic partnerships, as well as with other agencies in the community serving the same population or health topic. One inclusive key informant expressed the importance of collaboration with community members:

> *We partner a lot. You'd want to partner with an LGBT partner who*
> *might have had some experience. I really believe in doing this kind*
> *of work in collaboration with them.*

An exclusive key informant discussed having an advisory committee as a component of the coalition.

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We had a gay advisory committee. I was on there for like five and

a half years, and while I was on the committee, we were also able

to hear people from the bisexual community and then from the

transgender community.

Partnering with the target community was a high priority for all of the key

informants. Another factor discussed by several of the informants is expressed in

this statement:

One of the good things that are coming out of the economic

downturn, is that people are realizing that they've got to work

together.

Forming a coalition was a necessity not only to respect and have SGM at the

planning table, but also due to limits in resources. Once this third dimension was

achieved, that of forming a coalition, the adaptation work began.

Data Collection

Community Representatives Present

Data collection was the next dimension in the adaptation process. Once the

first three dimensions were in place, the coalition began to collect data in different

ways such as *focus groups*, interviews, and *surveys* with an emphasis on having

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community representatives present in each of those categories. In describing the data collection process, one inclusive informant said:

> *Nothing counts for us without us. I firmly believe in that. If you're looking into design an LGBT-specific program, you need to have LGBT people at the table. I mean, without that input we can't really design an intervention, right? It's very important.*

Having the community members present for focus groups and responding to surveys was not only informative but also necessary. One key informant discussed not being from the SGM community, which further justified the reason to access them in order to better understand their experiences and needs:

> *They informed me. We all come from a good place, but if you've never walked, if you're not LGBT and you haven't had [addiction] issues, you cannot really know.*

Focus Groups

"If you're doing a focus group that's a strategy to really understand the issue." I heard this and other similar statements many times from the key informants. Focus groups were the most common form of data collection for both inclusive and exclusive interventions. Likewise, both researchers and community partners shared what they learned from the focus group experiences, why they

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chose to use them as a form of data collection, and how they incorporated what the participants said:

> *We had a series of focus groups with women and asked questions exploring their experiences with treatment before and after. Off the top of my head I can't remember exactly the topics but as I remember we discussed things like barriers, triggers, norms/expectations, and self-efficacy. We wanted to see what was important before making changes to any intervention.* (Exclusive informant)

> *We decided to do focus groups and did those around the country with different LGBTQ organizations, to find out just what older LGBT adults felt they needed and what their fears were.* (Inclusive informant)

> *All of the themes were incorporated into the intervention. All the changes were based on what the community said to us in the focus groups.* (Exclusive informant)

Surveys

Surveys and interviews were also popular for data collection leading to adaptation changes. One inclusive informant said: "I would do a survey of the

community to find out just what they need and want." Sometimes it was easier to collect data from people individually (via survey or interview) whereas other times it was appropriate to do a focus group. One exclusive informant discussed the importance of choosing a survey or interview as an alternative to focus groups when seeking to learn about individual experiences; on the other hand, focus groups were better options for testing out social marketing messages, and understanding group thought. After the data were collected, key informants and their coalitions began to modify their EBI's.

Modify

Process

The next dimension incorporated the process invoked by coalitions to modify and adapt their interventions. Some informants spoke about the idea of social acceptability and continually modifying until it fits. For example, an exclusive informant said:

> *It's building on what's working and really developing the*
> *intervention based on the community, the population, and some of*
> *the more structural laws and policies.*

The modification process for that informant was about finding a fit based on participant retention as well as other factors like local policies and current trends.

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Other informants talked about what they changed as a part of the process to reaching a final product. One exclusive informant said:

> *We changed the design, the pictures in the participant booklets and*
> *added in relevant content. The idea of how to quit stayed the same*
> *but the conversations for the group intervention were based on*
> *relevant themes we identified in the focus groups.*

An inclusive informant discussed how minimal changes were made to the evidence based intervention, but how they also created additional materials in their adaptation process:

> *We created a booklet of those stories. I have maybe 12 or 15*
> *stories, because we did like one a month for like a year. We got*
> *that going. Then we did a pride resource brochure that we could*
> *put up in our clinics with different resource information where you*
> *can call for this or that. When we did a big poster…we worked*
> *with our leadership to create a poster that we have placed all over*
> *our clinics and it says 'health services, we embrace diversity' and*
> *it lists all different types of diversity we embrace.*

The process was about the work that was done to make the changes to the various health interventions. I was very curious about who actually made the changes and

how that was decided. In response, all of the informants said that their ideas came from their data collection, but the coalition and researchers were the ones to make the actual changes. Therefore in order to understand if those changes were a good fit, the next dimension was to pilot the prototype.

Pilot Prototype

Pilot Testing

Piloting the prototype was a dimension with one category: pilot testing. Just as it sounds, all of the intervention adaptations were pilot tested, some more than one test. One example of how a coalition pilot tested multiple times was explained in this statement:

> *We've had four rounds currently of a modified program taking*
> *what we learned and then each time we ran the program we used*
> *information on what worked and what didn't work from the one*
> *before it.*

Piloting multiple times appeared to be more common for exclusive interventions, which generally had multiple changes. Eventually each coalition would determine when the intervention changes were appropriate and considered final.

Final Product

Disseminition

The next dimension in the adaptation process was deciding what to do with a final product, whether to begin implementing it, or disseminating it, or evaluate it. The most common thread of discussion was about disseminating the curriculum and getting the word out about it to potential consumers and to other organizations.

The exclusive interventions targeted such unique SGM sub-populations and as a result several of the informants from this area discussed not publishing their intervention, as it was unique only to their community or their organization. This exclusive informant said:

> *We don't give that out to people to use it, we don't sell it or anything; but if we train somebody, then they would have access to the curriculum. We believe it's more than just the book.*

Likewise, another exclusive informant said:

> *We do not publish all of our curriculum. It's never really been funded to be written up, and we don't make it available unless you take a class or a training. The reason for this is because we're not trying to supersede the [name of the original curriculum developer].*

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Because these exclusive interventions were not widely distributed one key informant said it best when they mentioned: "I think that the other part is how you publicize it and where you publicize it, that makes a difference too." The idea was that they wanted consumers to know they have a specialized intervention but that it was unique to their organization/agency.

On the other hand, inclusive informants were more likely to disseminate their final product, as they wanted to get the word out so more interventions will be inclusive. This inclusive informant said:

> *We have a train the trainer program. We train people to be*
>
> *trainers on our materials, all over the country. We go to*
>
> *conferences and now we have a flash drive that we sell. It has*
>
> *everything on it. Just the manual, the trainer manual, and a short*
>
> *film, and we go to conferences and we teach people how to use the*
>
> *material.*

The inclusive interventions that were widely disseminated and sold or shared were generally those that were not unique to one geographic community or local agency.

Evaluate

Much like the *camps of thought* dimension, the *evaluate* dimension was a popular topic amongst all key informants. There were several categories relating

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to evaluation including *fidelity/process* evaluations, *outcome* evaluations, and social acceptability or *cultural fit* evaluations. Evaluation occurred in several stages of the adaptation process as explained by this exclusive informant:

> *We looked at many things including focus groups, client satisfaction, outcome data, process data and revamped. Kept revamping the intervention to a point I think by and near to maybe halfway through the project it was pretty well settled.*

Fidelty/Process

As many of the inclusive interventions were intended to have high fidelity to the original EBI, mainly the key informants from these types of interventions discussed fidelity measures and other process measures. For example one inclusive informant said: "We do research and evaluations to make sure the fidelity has been met." Similarly, another inclusive informant discussed the importance of using a process evaluation:

> *Quality improvement is our model. What are you trying to do? How you're going to know if your change made a difference? What are your measures? It's just trying to get a little more specific about the work we're doing.*

Outcome

Outcome evaluations were common for both inclusive and exclusive interventions. The following statements represent what the majority of key informants shared:

You'll hear of a best practice, best tactics and bring them to your local community and something happens. They don't work. They don't always work. I think that people always have to be able to look at that. That's why data, evaluating whatever you do is so important because you know whether you're being effective or not. That's the only way you know that it's time to go back to the drawing board. (Inclusive informant)

We do ask people [how long have they stayed sober], but of course you ask the people who stay with the program. What about the people who leave, right, and don't come back? We're required also to do a one-month, three-month, and six-month follow up. We get feedback. (Exclusive informant)

It's the testing of your theories that you're finding out if this works, or this doesn't work. A big piece of doing this work is evaluation. It's knowing very clearly what are the outcomes you want to see.

The clearer you are with those outcomes, you can aim your

intervention towards those outcomes and then you're evaluating

did it work, did it not work. (Inclusive informant)

And we look at outcome data too; is that they really increase in

terms of protective sets or whatever you're looking at. I don't think

it's just one thing. I think it's really kind of an accumulation of

various data points. Top-down, bottom-up. (Exclusive informant)

Cultural Fit

In addition to testing the process and the outcomes, cultural fit was measured by all of the coalitions. Some were mandated by their funding sources to evaluate cultural fit and social acceptability as noted in this statement:

We ask a three-question cultural competence survey. Were classes

appropriate to your culture? Was the facilitator respectful to your

culture? If there was something culturally inappropriate, do you

feel you could have brought up the issue?

In one cultural fit evaluation, a key informant shared the words of SGM youth after they participated in an inclusive intervention:

Originally they felt that whenever an LGBTQ issue came up, that it

was being avoided or stereotyped or not being addressed. They

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also mentioned that sometimes it wasn't the facilitator or the

teacher that was homophobic or transphobic. It was actually the

other students, their peers in the class or the young people in the

class. They wanted more information for the classmates on LGBTQ

communities.

Like the aforementioned statement, the cultural fit evaluations were useful tools to determine if any further changes might be necessary or if the intervention was acceptable for future implementations. One exclusive informant said:

You sort of take a lot of different factors into account and then you

try it and you pass it by the clients and the clinicians and you

revamp and revise based on lots of things. People aren't showing

up to your intervention, that's probably right there that something

is problematic. As you see attendance rates increase and

acceptability and feedback about, if the sessions were helpful, if

they learned anything.

Cultural fit didn't always need to be evaluated formally as one key informant described the "self-select out" process:

If you take gay men and put them into a heterosexual site, gay men

learn very quickly that you can't talk about what kind of sex they

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have because they'll be ostracized. That is something that

dominant culture, other addicts really can't listen to for very long.

It's not experienced in the same way…If you were to do that

[intervention] in a standard treatment clinic, what would happen

is, people would self-select out. The heterosexual people would

say, 'this isn't relevant for me.' They would not participante, you

would de facto develop a group of gay men.

Lessons Learned

The third major theme in my research was about the lessons learned by key informants from both inclusive and exclusive interventions. Three dimensions comprised this theme: *adaptation process, challenges,* and *future recommendations.* In these dimensions key informants shared their project strengths, areas for improvement, and ideas about future adaptation projects.

Adaptation Process

Epistomology

For most of the informants, the adaptation process, in and of itself, taught many lessons. One big picture thinker from an exclusive intervention reflected on contributing to research knowledge:

From a just purely epistemological or a scientific or whatever

aspect and just sort of knowledge approach, I would say that the

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most important thing that I've been learning and continuing to

learn is this sort of like...again, going back to this balancing

between making things that...when we talked about making

interventions for gay youth. It's like being really mindful of the

business, is it practical? Do we really need an intervention for this

specifically for gay kids? And just being mindful of that is in some

ways potentially an exclusionary type in that, does it eventually

sort of further perpetuate the excuse that it's already happening?

Like I would joke about, I'm going to put up flyers that will say,

'are you gay?' like okay how are we even going to do recruitment?

What kind of a setting is an intervention of this kind ever going to

happen? I'm really thinking about broad impact.

This key informant was challenging the camps of thought, in particular how to defend an exclusive intervention if the goal is to reach a wider audience. The lesson learned here was that it was important to have a clear sense of end goals, target audience, and a belief in the work that is being done. On a similar note, another exclusive informant also spoke about epistemology and planning:

You have a sense of what the amount of behavior change you're

going to have based upon your evidence based intervention. It

gives you a mark to look and see...if you tailor this, you at least

want to not erode the efficacy of the behavioral intervention. Just

know, what you're going to get is better attendance. The stability

that people will show up in session, or stay in session, or whatever.

Challenges

Key informants were honest and open about the challenges they

experienced. Of the challenges discussed, *funding* and *cultural fit* were the main

categories in this dimension.

Funding

Funding was often hard to obtain for adapting both inclusive and exclusive

interventions. Justification for the adaptation was a primary challenge as

expressed by these key informants:

My contention is that if we, as a community, gather and focus on

being healthy whatever that means, weight loss will follow. If we

increase our activity and participate in activities that keep us

moving, we're going to lose weight; and our blood sugar is going

to go down and high blood pressure will go down. If we are

creating this community of health and we prohibit smoking within

that environment, that will help. But I can't, people don't want to

hear that because it's not measurable. You'd have to have huge

numbers of people and you can't do it so you can't get it funded, so

we can't do it. (Exclusive informant)

I think that in terms of funding, I will just add; if it's not purely for

the scientific joy of looking at it and it's really about, is there a

public health insurance in this area, that major question is really

about why is what we have not good enough? Can you really

justify that? (Exclusive informant)

We don't have time. Healthcare doesn't have that time anymore.

We don't have that luxury. Our costs are too high. Our outcomes

aren't as good as we should have. They're really encouraging us,

all of us in healthcare to do this work of being more scientific but

doing it in a more timely fashion because we've got to cut our costs

and we've got to have better outcomes. (Inclusive informant)

The discussions about funding challenges were commonplace in the interviews. Many of the key informants were successful in obtaining large research and practice grants for their work, but they also discussed how funding challenges could prevent a project from moving forward.

Not Always a Good Fit

Another challenge shared by the key informants was that health interventions don't always fit for SGM, even with special considerations. This was particularly true when taking into consideration the evolving identities of individuals in the SGM community. Gender was the most common category where an intervention may not fit. One exclusive informant said:

We had one transgender person who was pretty darn upset. He was also very young, about 23 years old. He looked around and, honestly, he was way ahead of his time because most 23-year olds...most...are thinking about quitting when they're 30 or 40, if not later. I think he wasn't seeing his peers, in many ways there.

Another exclusive informant mentioned that their intervention targeting all SGM was not always a good fit and sometimes sexual minority women would self-select out:

We do lose some people. Certainly, we've lost women, I think, when we had just like two women and 25 men in one room. I think some of them felt like maybe I'm not coming back. It's hard to know what's in people's heads really.

Recommendations

There were a couple types of added recommendations across the sample: *data collection and measures*, and *facilitators*. Data collection and measures was informative as to how to collect data, who to collect it from, and what types of data should be collected.

Data Collection and Measures

The term "don't reinvent the wheel" was commonly used when key informants offered recommendations about where to start, what EBI to use, and what data to consider. One key informant spoke to this topic very similarly to what others said:

> *For everyone, there is at least one, and often there's a handful, of*
> *evidence based interventions. That's where you start. Take the*
> *intervention off the shelf and at least eliminate the fact that you're*
> *not starting from scratch.*

Once identifying the right empirical data to consider and EBI that might be a good fit, many key informants spoke about the measures. One informant connected the measures to funding:

> *Having validated measures is really important in data collection.*
> *This helps with the funding streams. Making sure these measures*
> *accurately reflect what data you're trying to gather including the*

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LGBT demographics. Some may not identify that way, so it's

important to ask them more than just their sexual orientation.

Another reflected on the measures they currently use and recommended thinking about how the questions are phrased and the intended data from those questions:

One question, 'if there was something culturally inappropriate, do

you feel you could have brought up the issue?' It's a question we

could reword…it's poorly worded because people often answer it

wrong. Obviously, they're not upset with it, but they say no, I

couldn't have brought it up, because they're basically saying no,

there was nothing culturally inappropriate. The question is really

do you feel you could have brought up the issues, which would be a

yes, hopefully.

Likewise, the types of data collected are also important. This exclusive informant said that while it was not as important to consider how the outcomes are better or different, it is important to consider other things related to fit:

You should be thinking not about…as much about the clean urine

or clean bio-markers. You might want to be thinking about the

number of times they attended, the number of times they speak

within a session, and the length of time they speak within the

session. That's what I think.

In addition to measures, the key informants recommended considering whom to collect data from; they reiterated a few things including:

My main recommendation is to listen to the voices of your

community. Without their voices you may never have a realistic

viewpoint of how to treat them. (Inclusive informant)

Absolutely know your audience and start from there. Knowing the

community. Understanding their age, their background, who is

there. I say that because I've seen curricula developed that is very

lengthy, wordy, inaccessible in many ways not real, if you know

what I mean. It doesn't feel real, it feels canned. I think it's very

important that people use their humanness, tell stories, make it

relevant and encourage people to participate, and making it safe to

participate is so important. (Exclusive informant)

Facilitators

Training staff and facilitators was another category discussed in recommendations. Inclusive informants only mentioned this recommendation. One said:

Also, I think for facilitators, anyone who's leading a group or

leading the program, having some kind of tool kit that they can

use; like how to steps, 1-2-3.

Providing a frequently asked questions (FAQ) list may be helpful for facilitators, particularly those who are unfamiliar with SGM culture. Similar to this recommendation, another inclusive informant discussed training again:

I think number one is making sure staff at all levels, if it's admin to

upper-level staff are trained as well on just general LGBTQ 101

stuff, especially if they're going to provide medical services to

know about inclusive intake forms and to ask for preferred names,

preferred pronouns. Not just call out Sally, if Sally's trans and

goes by Sam-how stigmatizing that could be. Just making sure

everyone who is part of the organization is trained and has some

kind of foundation of LGBTQ stuff. Making that mandatory.

Summary

In this chapter, I presented the results of my study. I examined the major themes and subthemes that emerged from a constructivist grounded theory approach to cultural adaptations of health interventions for SGM. Through my data analysis, a beginning typology emerged; one that begins to formally

illuminate the cultural components, adaptation process, and lessons learned in these projects (see Figure 6-1). The key findings including themes, dimensions, categories and sample quotes are summarized in a coding matrix (see Table 5-2).

The themes that emerged in my study were divided into inclusive and exclusive interventions each with a set of cultural components. The cultural components were embedded in almost every stage of the adaptation process. Key informants were candid about the lessons they learned and recommendations for future projects. Inclusive and exclusive interventions both required identifying a need, selecting the appropriate and intended target audience, and identifying the end goal. The end goal was different for many of the projects; some were about staying true to the original EBI, whereas others were more about being culturally relevant. All projects were about improving the health of SGM.

In the next chapter I discuss these findings in the broader context of social work practice, policy, and research. I present a diagram for the grounded theory model I developed that summarizes my results. I conclude with recommendations and implications for future directions.

Chapter 6

Discussion of Findings

The purpose of my study was to explore the process and cultural elements involved in systematic adaptations to health interventions for sexual and gender minorities (SGM). The results of my study offer a number of implications for social work practice, research, and policy by culminating in a testable adaptation model. In addition to theory building for the adaptations literature, my study also contributes to the evolving social justice discourse on disrupting privilege in a heteronormative society. For example, my research asks the reader to critically examine the heteronormativity in health interventions and social service agencies. This final chapter is organized based on the research questions. Each question is answered with a discussion that incorporates the study themes. The chapter concludes with implications for social work.

The process and cultural elements involved in adapting a health intervention for SGM have not previously been documented or conceptualized into a theoretical model. My study contributes to the knowledge base by bringing to light emergent cultural elements that can alternately be categorized as inclusive to and/or exclusive for SGM; in particular health interventions. The health disparities faced by SGM from the burdens of tobacco, substances, obesity, violence, and potentially other health problems will be ameliorated by a culturally

relevant intervention. In some cases, an exclusive intervention is appropriate, while in others an inclusive intervention may be the better option. As previously mentioned in the literature review, a dearth of research investigates the process and cultural elements relevant to interventions targeted for SGM within the cultural adaptations literature. This study initiates an exploratory discourse regarding SGM populations and relevant cultural adaptations for their health.

Research Question One

What precipitates the perceived need to develop or adapt an intervention so it is relevant to individuals who identify as lesbian, gay, bisexual, transgender and queer (LGBTQ)?

There were several reasons one might consider adapting or developing an intervention. Table 6-1 offers some questions a researcher or community member might consider posing if they perceive the need to adapt an intervention. The first question addressed in the table is: "Is the EBI heteronormative?" I pose this question, as several of the key informants said that it was often someone on their team who reviewed the original intervention and found it to be heteronormative. Posing this question may lead to making an informed decision regarding if a health intervention warrants an adaptation. One of the key informants said that kids in their focus group "wanted to see aspects of themselves" in the intervention. For young people this concept is not uncommon. Beigel (2010)

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noted that heteronormative curricula could send LGBT youth a message that something is wrong with them or they do not exist. Therefore, at the very least, incorporating the inclusive cultural components is important and potentially necessary for SGM to feel included and validated.

The question of underlying or even overt heteronormativity also speaks to the larger issues of cultural heterosexism (Herek, 1995). Empirical studies have exposed that cultural heterosexism in the United States is benefitting members of dominant social groups, particularly who take part in treatment for their health. Specifically, previous research has indicated an overall lack of knowledge, skills, and sensitivity by social workers and other health care providers (Berkman & Zinberg, 1997; Eliason, 2000; & Garnets, Hancock, Cochran, Goodchilds, & Peplau, 1991). The inclusive cultural components should at a minimum be a serious consideration informing practice for all service providers. One of the key informants mentioned that their agency was recently honored with an inclusivity award by a well-known national human rights agency, for their implementation of inclusive interventions for SGM. Consistent with data from the key informants and documented experiences in the literature, this type of inclusivity should be a consideration for all service providers. The elimination of cultural heterosexism requires individuals to institutionally disrupt privilege in interventions for change and thus, become more inclusive for all people.

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The second question I ask is: "Are staff culturally competent/knowledgeable of current LGBTQ issues?" I chose to include this question as it may relate to how an intervention is implemented, and lend information about informal adaptations that facilitators make but are not documented. The cultural components theme included a dimension of facilitators and staff being knowledgeable and aware of issues impacting this culture. This priority is shared by recommendations in the literature as well (see for example, Morrow & Messinger, 2006).

For the third question I ask: "Were SGM in any test group for efficacy or relevancy?" This question requires the researcher/community partner/provider etc. to examine the literature about the intervention they are considering using with their consumers. EBI's are only as good as the people they were tested on. To combat the problem of mismatches, Borrelli (2010) recommended using a priori criteria to determine any potential mismatch(s) between the test and target groups of an EBI. Furthermore, a practitioner can therefore make an informed decision regarding whether to adapt or adopt an intervention if they identify the demographics of the intervention test group.

Table 6-1 Why Adapt?

Questions to Consider	Yes	No
1. Is the EBI heteronormative?	If it is heteronormative, an adaptation should be considered.	If it is not heteronormative, a focus group or social acceptability test might help to ensure it is inclusive for SGM.
2. Are staff culturally competent/knowledgeable of current LGBTQ issues?	Staff who are aware of issues impacting the community might already be making adaptations. Therefore, documenting the adaptations may be necessary for sustainability.	If staff are not trained, have not been trained lately, or are not aware of current issues, an adaptation should be considered.
3. Were SGM in any test group for efficacy or relevancy?	Knowledge of the test groups for efficacy are important, particularly if efficacy is the focus. If SGM were included, it is possible an adaptation may not be warranted unless it is deemed irrelevant to SGM. Therefore question 1 warrants a checklist.	More than likely SGM were not included in an efficacy test group, or the SGM cultural components were not incorporated into the design. Certainly this might warrant an adaptation and a new test group.

In determining what precipitates the perceived need to adapt an intervention, one researcher respondent claimed that it was simply a curiosity in the form of a research question. Other respondents (both researchers and community partners) had anecdotal evidence that the SGM population they were currently serving was addicted to (tobacco, drugs, food) or experiencing violence

at disproportionate rates in the community and therefore they wanted to make an existing intervention relevant. Some of the informants discussed why it was important to know that SGM are experiencing health disparities but that exclusive interventions don't have better efficacy; the reason to change the intervention was to increase attendance and relevancy. In their view it seemed reasonable to expect that efficacy would follow, but it remains unknown until an empirical efficacy study is conducted. On the other hand, other informants (n=4) made the point that exclusive interventions have better outcomes and were therefore necessary for that reason.

Research Question Two

What is the process in adapting and/or creating the intervention?

Emergent Model

Based on the results of the study, I present the emergent model in Figure 6-1. This process model was formed based on the axial and selective coding process during the data analysis phase. After drafting an original model I sent a copy to my key informants and received feedback from two. After final modifications, the model in its current state is a visual aid and testable tool for future research, of which implications will be discussed in this chapter. Beginning with the top of the model, I describe the process, each shape, the (directional) arrows, and follow with a discussion of the specific cultural components.
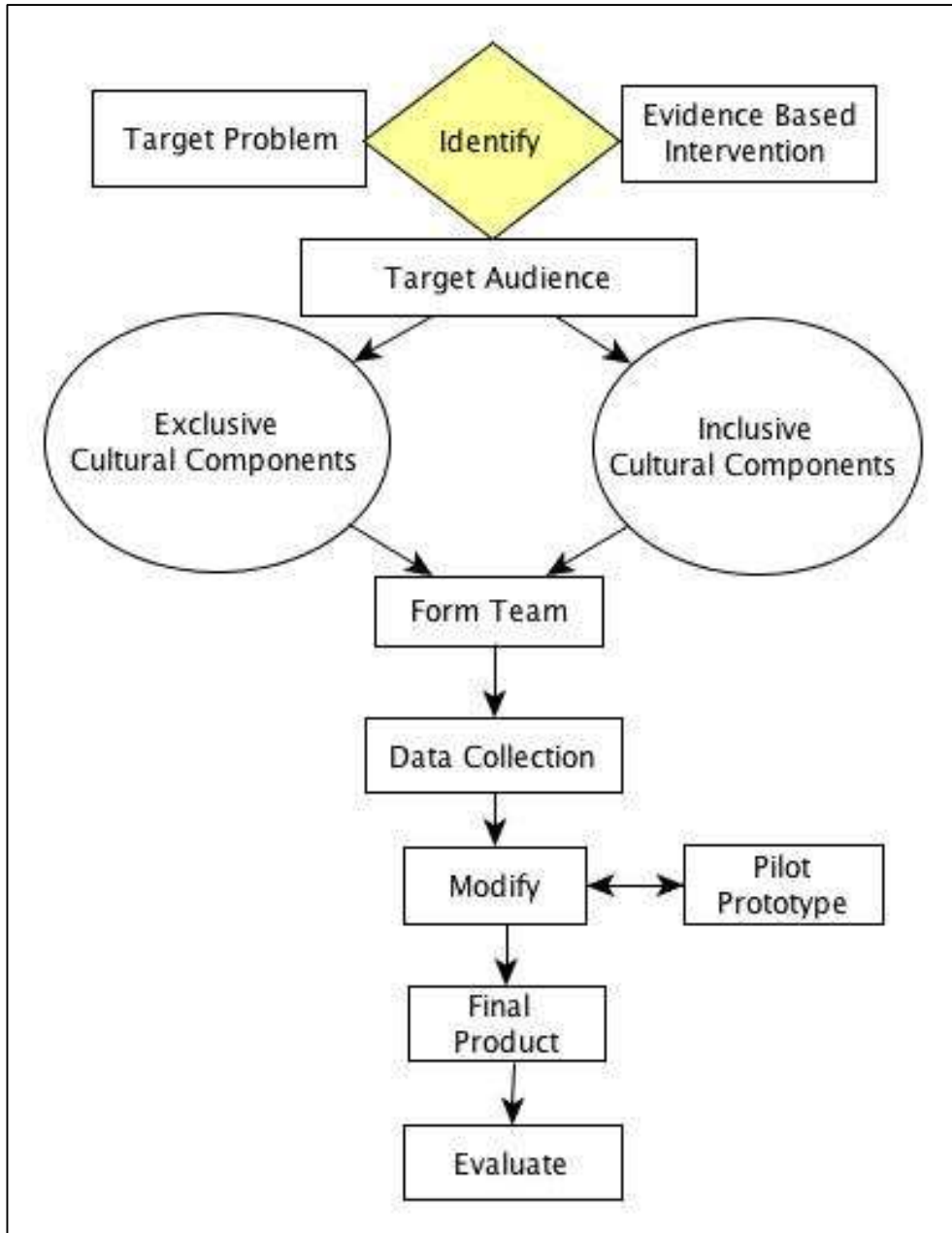
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Figure 6-1 Model for SGM Cultural Adaptations of Health Interventions

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Embarking on a SGM cultural adaptation project journey can take many shapes and forms. While the process does not start the same way for every person or group, there are similarities along the way. It is clear that every person I spoke with who participated in a cultural adaptation of a health intervention for SGM, had to identify several key factors. One such factor was to identify the target problem. Target problems included sexual health, smoking, drug addiction, mental health, intimate partner violence, and obesity. Other factors in the first step were to identify the appropriate evidence based intervention and the appropriate target audience. In Figure 6-1 the "identify" diamond touches these three factors with a blank space at the top to indicate that every process may start from a different place. For example, some projects may already have a specific target audience and then they will identify the target problem followed by selecting an intervention. Other projects may begin with a target audience that is already being served and then the EBI and target problem need to be identified.

Moving along the process, the target audience (exclusive and inclusive) is closely connected to the type of cultural components added to the intervention, as reported in the results chapter. Continuing along the process, at some point a team is formed who is involved in the remainder of the project. The team may be referred to as a coalition, ad hoc committee, or possibly comprised of employees

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from a local organization. The team works together to collect data such as conduct focus groups, interviews, and distribute surveys. Teams use information from the data to adapt the intervention. Given the unique differences of each project, some will modify their intervention, pilot the prototype and then make any necessary final modifications prior to producing a final product. Others will modify the intervention and produce the final product without piloting. Finances and data collection are among the reasons why an intervention may not be piloted. For example, a community agency may not have the funding to pilot their intervention prior to implementing it for the first time. The last step is to evaluate the intervention. Evaluation was a little different for each type of intervention. The inclusive interventions tend to be evaluated for fidelity to the original intervention whereas the exclusive interventions tend to be evaluated for cultural fit.

The adaptation process was somewhat unique for each key informant, particularly given their place of employment (university or community agency) as well as the type of health intervention they adapted. The emergent model depicts their commonalities offering a process not previously seen in the literature. Even in other fields where adaptation models are more commonplace such as psychotherapy, there is no agreed upon cultural adaptation framework (Bernal & Domenech Rodriguez, 2012).

In comparing the emergent model in Figure 6-1 to the logic model for smoking cessation adaptations initially identified in Figure 2-1 of the literature review (p.23), a number of comparisons can be made based on my data analysis. The logic model originally conceptualized by (Borrelli, 2010) had four phases including data collection, treatment modifications, pilot test, and outcomes. This logic model was connected to modifications for special populations (not including SGM). Common between the two figures were data collection and evaluation. Treatment modifications were conceptualized differently. Borrelli (2010) appears to be writing from an exclusive camp of thought in which changes to the full intervention may be necessary for cultural fit. My research adds to the logic model that Borrelli (2010) offers but extends it beyond tobacco to other addictions and related issues, and also adds a more comprehensive approach to the process of culturally adapting a health related intervention for SGM.

Research Question Three

What can we learn from this process about the characteristics of effective adaptations and/or adaptive interventions?

Examining the cultural components identified in the results chapter provides answers to this question. Considering the target audience is one of the first steps in the cultural adaptation process. This dimension revealed "two camps of thought" distinguished by whether an intervention or target audience is

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inclusive or exclusive with implications for who might benefit from the

adaptation and the type of manualized protocol that was updated. These two

camps of thought had strong opinions based on a key informant's knowledge of

empirical data as well as from practice wisdom. Limited theoretical or empirical

research on the idea of "two camps of thought" exists in the extant literature,

particularly in the social work literature. The existing contributions to the

adaptations literature support either inclusive, or exclusive intervention

adaptations; however, there is no mention of how the two camps of thought ignite

a values debate, nor yet how their contrast sheds light on heteronormative

assumptions. Therefore, my study adds this finding to the adaptations literature, as

it is clear research is generally bound solely within one paradigm (e.g. exclusive

or inclusive), without considering the other. The literature suggests that the

definition of a cultural adaptation relates to the motivating factors for engaging in

these types of projects. For example one text explains that there are two core

reasons for cultural adaptations:

> *To protect the scientific integrity of evidence-based research and*
>
> *dissemination by promoting the ecological validity of treatment studies,*
>
> *and to reduce health disparities by making EBTs broadly available to*
>
> *ECG's [ethno cultural groups]* (Bernal & Domenech Rodriguez, 2012,
>
> p.11).

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On a separate tone, Bernal (2009) defines cultural adaptation as:

> *The systematic modification of an EBT or intervention protocol to*
>
> *consider language, culture, and context in such a way that it is*
>
> *compatible with the client's cultural patterns, meanings, and*
>
> *values (p.362).*

The concept of two camps of thought is further compounded by the idea that some researchers believe in tailoring an existing intervention with the goal of staying faithful to the original implementation fidelity, grounded in a single paradigm; while others believe it is important to start from the ground up (see for example, commentary by Palinkas, 2010).

Environment

In addition to the camps of thought and target audiences, the environment was another dimension of the cultural components that emerged. The geographic location was a significant category within the environment dimension. Across the board, all interventions including exclusive and inclusive were developed and implemented in large metropolitan areas. This leaves a big gap in understanding how the emergent model might work in a rural environment. This may also have some relationship to the population statistics regarding where many SGM people live. For example because many SGM live in large urban areas (Gates & Ost, 2004), there may be less of a perceived demand for culturally relevant

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interventions. On the other hand, if fewer SGM people live in rural areas, agencies may consider an inclusive intervention over an exclusive intervention. This is because an inclusive intervention can reach a wider audience, and in small communities this may be appropriate. On the other hand, exclusive interventions were discussed as bringing about a sense of community and camaraderie among other local SGM seeking similar health interventions. Thus exclusive interventions may therefore be considered more beneficial across contexts.

The agency/facility was another significant category in the environmental dimension. For example, providing the intervention in a location that is known or safe for SGM may be appropriate, or adding pictures or other cultural representations on walls of the current agency may help as well. Gay (2000) notes that aspects of the environment have been deemed foundational for effective teaching and learning; these include modifications to provide a safe environment, participant cohesion, and positive participant rapport.

Policy

The policy dimension had two categories: *advocacy* and *agency*. Policy advocacy was mentioned by all of the key informants. There is evidence that policy advocacy, for example, has generated millions of dollars in public funding for HIV prevention programs (Ward, 2008). Key informants discussed the connection between policy advocacy and opportunities. With widespread issue

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awareness, new funding sources may become available, in turn creating more opportunities for advocacy through research and educational programming.

On a more micro scale, agency policy was another category within this dimension. Inclusivity for SGM on items such as intake questionnaires, non-discrimination policies, and other safety precautions for clients and providers was described as important for any agency regardless whether they offered inclusive or exclusive services. This finding is consistent with other research that documents the importance of evaluating agency policy in order to address inclusivity issues (Services & Advocacy for GLBT Elders [SAGE], 2010).

Language

Language is a commonly adapted component to many EBI's, such as translating an English-language intervention into another language (Schinke, Brounstein, & Gardner, 2002). Bernal, Bonilla & Bellido (1995) include language translation as one of the eight core categories for consideration in culturally adapting an intervention. In my study the language categories included *gender neutrality* and *name of intervention*. Rather than translating one language to another, gender neutrality involved transforming heteronormative and cisgender intervention elements to reflect gender neutrality. Gender neutrality made an intervention relevant to any person identifying as any gender or sexual orientation. For example, by changing the names of people in the vignettes to

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androgynous names, the intervention could then be relevant to any consumer. Gender neutrality was also about allowing all genders to receive every component of an intervention as opposed to gender-related material only (i.e. girls receive female instruction and boys receive male instruction). This approach might require researchers and practitioners alike to consider the theoretical framework that underlies the original intervention; particularly those commonly associated with traditional gender role identifications such as Social Learning Theory and Cognitive Developmental Theory (Ifegbesan, 2010).

The language dimension also included addressing the name of the intervention. This was a unique category specific to the exclusive interventions. Once adapted, key informants from the exclusive interventions discussed how the name of the intervention would change to something relevant to the SGM community. This category was similar to those interventions discussed in the literature review such as the GLBT smoking cessation intervention titled "The Last Drag," and the drug intervention "Getting Off" that targets MSM. Like the interventions I learned about from key informants, The Last Drag and Getting Off have a second meaning relevant to members of the in-group, SGM in this case. Drag is an art performance concept for SGM, is a word used to describe the inhalation of a cigarette, and has been used as an adjective to describe the cessation process. Getting off (sexually) is associated with one of the reasons why

sexual minority men initiate use of drugs like crystal methamphetamines (Halkitis, Parsons, & Stirratt, 2001), but in this case is a term also used to describe the cessation process (i.e. getting off crystal meth). These double meanings found in the examples from the literature as well as the exclusive intervention names and titles of activities in my study, were small but important changes for SGM consumers. Additionally the double meanings reinforced the sense of community among LGBTQ participants.

Facilitator Factors

Facilitator factors were important for both inclusive and exclusive interventions. Key informants from both camps believed intervention facilitators needed to be *knowledgeable of LGBTQ issues*, and to *be from the community* for the exclusive interventions. Being culturally competent includes having knowledge of the issues faced by the consumer population. In addition to what my key informants said, previous research has similar facilitator recommendations about cultural competence and awareness of LGBTQ issues (see for example, Lombardi, 2007; Scout, Miele, Bradford, & Perry, 2007; Chojnacki & Gelberg, 1995). There was also a belief that facilitators who are SGM will better empathize with consumers because they are from the same community and consumers will find the intervention to be a better fit if the facilitator is someone like them (i.e. a former smoker, SGM etc.). This finding was also identified in previous research

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noted in the literature review (see for example, Scout, Miele, Bradford, & Perry, 2007).

<div align="center">Research Question Four</div>

What guidelines can be recommended for future social service providers who wish to create their own culturally relevant LGBTQ intervention drawing on the emergent model?

Drawing on the emergent model, both social service providers and researchers are offered a testable tool for future adaptation work with a focus on SGM. Likewise, the process and cultural components ascribed to the emergent model lend insight into the unique elements involved in culturally adapting a health intervention for SGM populations. Every project will have its own organic developmental process. However, the common goal is to make an intervention comprehensive, relevant, and justified for SGM. Consistent with social constructivist theory, social identities of SGM will continue to evolve, thus, the cultural elements will also continue to evolve. For this very reason, I did not include the specific cultural elements in the emergent model. My intention is to have this model continue to grow and evolve in juxtaposition with the lived experiences and identities of SGM populations.

Systematic considerations of possible heteronormativity embedded in generalized health interventions are strongly indicated prior to using this model.

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Considering the history of previous medical and psychological interventions that oppressed SGM (Miller, 2001), researchers and community partners may be reluctant to adopt existing interventions. Careful scrutiny may also be appropriate when evaluating evidence-based interventions as a result of adopting paradigmatic frameworks from queer theories (Butler, 1990). I am suggesting that my model requires attention to social justice and basic human rights related to health, which may be in jeopardy without considering heteronormative biases (Fabeni & Miller, 2007). Without this attention, the point of disrupting privilege in an intervention will be missed.

The key informants in my research offered several suggestions and discussed their lessons learned from their processes. Funding was a very popular topic among the key informants; however, without funding and/or support the model may have limitations. For example, most of the projects described by the key informants in this study were supported by large federal grants from sources including the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC). Not surprisingly, the human capital needed to culturally adapt a health intervention includes time, planning, skills, knowledge, practice wisdom, and intensive collaboration. Collaboration is essential to securing funding, and requires strong decision making based on sound evaluation, program development, and capacity (CDC, 2001).

Implications

My study has several implications for research, practice, and policy in social work. I draw on the emergent model, research process, and overall study to identify future opportunities for exploration.

Research

The emergent model provides a framework for researchers to apply and test future cultural adaptations. But first, the model should be piloted, modified, and evaluated. Following that work, researchers can use the model to cross check the steps they took with the process outlined in the model as well as explore the cultural elements appropriate for their intervention. The emergent model can then be used as a framework to systematically explore future adaptations and assist in programmatic evaluations.

Paired with the model, it may be useful to create a checklist that assists a researcher to identify if an intervention is heteronormative. A telling research question to ask would be "how do we know what is heteronormative?" Therefore, some type of checklist or decision tree may be a useful as well as pragmatic option to determine if an intervention warrants an adaptation. The checklist should be usable by people in the field who do not have a research background and that it complements other indicators of a need for adaptation such as feedback from key constituents and in instances of low population-specific success rates.

Once an intervention is deemed heteronormative and warrants an adaptation, community based participatory research (CBPR) approaches should be considered for future research. All of the key informants in my study discussed working with the consumers in some capacity. CBPR may help to increase sustainability in research projects as well as include local knowledge and skills that may increase the relevancy of the intervention.

Cultural adaptation issues in online and phone application interventions are related to my study and may warrant further exploration. Considering current technological advancements and developments in online communities for health promotion, underlying heteronormativity will need to be examined and addressed. In the same regard, cultural adaptation issues in self-administered interventions may require further exploration.

Practice

Given the limit in knowledge and awareness of the issues impacting SGM, service delivery systems and educational training programs should prioritize revisiting training to ensure that staff members are fully educated on SGM culture and the ways they experience health disparities. SGM may enter the doors of a clinic seeking help to improve their health and never "come out." This is important information for all staff and it goes beyond a simple company diversity training protocol. Specific policies for training were recommended by the key

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informants in this study, many of who currently work in the field and observe the reality of current service delivery by their peers or from client stories.

In tandem with training, facilitators and providers who are heterosexual need to be educated around the power they have as a straight ally. Martin Niemoller once said:

> *First they came for the socialists, and I didn't speak out because I wasn't a socialist. Then they came for the trade unionists and I didn't speak out because I wasn't a trade unionist. Then they came for the Jews, and I didn't speak out because I wasn't a Jew. Then they came for me and there was no one left to speak out for me.*

Straight Allies have the power to speak up about heterosexism and gender bias, but they also need to be made aware of their power, as suggested by one of the key informants. This is a perfect opportunity for social workers and other community providers to be informed of ways to be culturally competent with SGM consumers.

Prior to employing the emergent model, I recommend that service providers and researchers alike examine their values regarding cultural adaptations with respect to the end goal. For example, if the end goal is to attain greater efficacy, perhaps an inclusive approach is better suited until research is conducted to determine efficacy. Similarly, if retention and higher community

participation is a priority, an exclusive intervention may be warranted. After taking into account value systems, it will be appropriate to prioritize resources accordingly.

Health promotion literature such as pamphlets and handouts are additional forms of interventions not specifically discussed in my research. I recommend that practitioners and the educational marketing companies partner together, and use my emergent model, to examine the cultural components and make any necessary adaptations. Moreover, agencies that utilize CBPR approaches to their work may consider using a community advisory board to assist in creating, updating, and critiquing the pamphlets and other similar intervention supplements.

Policy

The health disparities experienced by SGM include access to health care where many SGM have been discriminated against and have not accessed the care they need. The Affordable Care Act (ACA) proposes to make significant progress in ending discrimination toward SGM by insurance companies (Durso, Baker, & Cray, 2013). With the potential for greater access to health insurance and prevention services, the emergent model presents an opportunity for application in policy. The model offers guidance and more importantly, relevant cultural components that can be integrated into policies for health interventions and health

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systems. For example, funding could be allocated to require facilities to have SGM patient navigators and/or SGM ombudsmen. Likewise, some of the funds allocated for use in implementing the ACA could be restricted solely for these positions. Additionally, the ACA marketplace websites and related links could benefit from having guidelines for SGM access. For example, similar to the Web Applications Working Group (www.w3.org) which is provided for online disability accessibility, the ACA has an opportunity to consider their website accessibility issues for SGM. Therefore, the emergent model can be used to support the identification of the types of selections and culturally relevant language on the web so that SGM can access the information they need. The disparities SGM face in accessing health insurance is further compounded by the absence of key federal laws promoting equal treatment, such as marriage equality and anti-employment discrimination for LGBTQ people.

At the time of this writing, there are currently no federal protections for people in terms of employment non-discrimination for SGM. Having said that, the Employment Non-Discrimination Act (ENDA), will be up for review and a vote by the end of November 2013. ENDA would make it illegal to discriminate in the workplace based on sexual orientation, gender identity, and gender expression. If the vote to pass ENDA is successful, the cultural components in the emergent model can be a useful resource for any agency needing to adapt their non-

discrimination policies to be more inclusive of SGM employees. This in turn can support a healthier workplace.

While larger policy implications may have a broader impact, the grassroots implications related to coalition building may have a deeper impact. Hence, implications for overcoming access barriers include developing policies that foster the formation of coalitions. Support and movement behind coalitions for cultural adaptations can be purposed for information sharing, implementation, and problem solving.

Limitations

My study has limitations, primarily given the sampling process and use of a telephone for interviews. Key informants were mainly identified by a snowball sampling method as well as from the articles published by several of them. Although efforts were made toward maximum variation, not one informant from the sample was located in a rural area. The essential purpose of inquiry using grounded theory is to reveal previously undiscovered findings and inform theory building, rather than produce a widely representative sample. As a result the findings may have limited transferability beyond similar urban geographic regions with large population statistics as well as similar organizational contexts. Additionally, it is possible that an exhaustive list of adapted health interventions was not identified. In particular the smaller projects that are not widely distributed

were not culled. Future research should continue to explore the process represented in the emergent model with other health interventions targeting SGM in order to build confidence around transferability.

Additionally, while the interviews were more about tasks and less about emotions, they were, however, all conducted over the telephone. This could have created a potential barrier of building rapport, trust, and having an honest conversation. Although this was a potential barrier, every person was offered electronic video or phone conversation and all agreed to participate via telephone. In addition all were favorably disposed to the work, having expressed well wishes and positive comments about the topic of my dissertation. Several even "welcomed me" into the field of cultural adaptations while others were excited about the idea of creating a pragmatic model for future use. Even with these positive comments, it is still possible that the telephone created somewhat of a barrier for non-verbal communication and cues. All informants were offered the opportunity to follow up with questions or if they could think of anything else to say and several followed up regarding the modeling process.

<div align="center">Conclusion</div>

In my study I identified a process and the cultural elements appropriate for adapting health interventions to be relevant for sexual and gender minorities. The testable prototype that I call the emergent model, offers a guideline for

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researchers and community practitioners who need a tool to adapt a health

intervention. My goal in the future is to take this dissertation research and move it

forward by applying the emergent model to a specific health intervention in need

of adaptation. I would like to partner with the community using a CBPR approach

and implement the emergent model for further refinement and practical

community usage.

Appendix A

LGBT History: Selected Events in the United States

Entire Document Copied with Permission from:

Boulder County Area on Aging (2013).

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Before the 20th Century:

- Historical evidence indicates that gay, lesbian, bisexual, and transgender people have been with us since the beginning of recorded history and probably before.

- 700-400 B.C. The Greek lyrical poet Sappho lived on the island of Lesbos. Sappho, a woman, reportedly had women lovers. It was common for Greek men, including nobility, to have male lovers, and this practice was not frowned upon or seen as an indication of an identity other than heterosexuality.

- Pre-colonial America: In pre-colonial America, and in almost all cultures and religions, there have been individuals who performed the roles of keepers of the rituals, gatekeepers, mediators between gods and humans, between men and women, between the dead and the living. They were most often lesbian, gay, transgender or otherwise androgynous individuals. In Native American culture, they often have been referred to as 'two-spirit.'

- Colonial America: In the 1600s a Puritan minister, Michael Wigglesworth writes of his homosexual feelings in a secret diary.

- l700s and 1800s romantic friendships between women, known as "Boston Marriages," are an accepted practice in the US.

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- 1860: Gay poet Walt Whitman publishes the second edition of Leaves of Grass.

- 1870: The world's first gay periodical was published in Germany.

- 1895: Writer Oscar Wilde is sentenced to two years of prison at hard labor for homosexual acts

The 20th Century --- The beginning of the modern gay rights movement.

- 1913: O Pioneers! is published by lesbian author, Willa Cather.

- 1924: Henry Gerber starts the first gay organization in the US, The Society for Human Rights.

- 1928: Radclyffe Hall publishes the first undisguised lesbian novel, The Well of Loneliness.

- 1933: Adolf Hitler bans the gay press in Germany.

- 1934: The Nazis begin sending perceived homosexuals to concentration camps where they are required to wear a pink triangle.

- 1947: Vice Versa becomes the first lesbian magazine.

- 1948: The Kinsey Report finds that 4% of men identify as exclusively homosexual, and 37% of all men report having had sexual relations with other adult males.

- 1951: The Mattachine Society begins in Los Angeles as a response to police harassment of homosexuals. This is a crucial early step in the early gay rights movement (then called the "homophile" movement).

- 1953: Alfred Kinsey publishes a report on female sexuality in which he claims that 2% of women identify as exclusively homosexual and 13% of all women had participated in homosexual acts on at least one occasion.

- 1955: A lesbian organization known as the Daughters of Bilitis forms in San Francisco to promote community among and provide support for lesbians in the U.S.

- 1956: The Ladder, a lesbian magazine, begins publication.

- 1960: The Daughters of Bilitis hold the first national lesbian conference in San Francisco.

- 1961: Illinois becomes the first US state to decriminalize homosexuality.

- 1961: drag entertainer Jose Sarria becomes the first openly gay candidate to run for elective office in the US, when he campaigns for the Board of Supervisors in San Francisco.

- 1963:The first gay rights picketers protest discrimination in the military.

- 1963: Gay civil rights leader and teacher of non-violent tactics, Bayard Rustin, orchestrates and leads Martin Luther King's famous March on Washington DC.

- 1965:Gays and lesbians picket the White House and Pentagon over discrimination against homosexuals in hiring for jobs with the civil service.

- 1966: In San Francisco, the first gay community center opens its doors.

- 1967: CBS Reports airs the first nationally broadcast documentary on homosexuality in the US. The show, hosted by Mike Wallace, focuses on the challenges faced by homosexuals.

- 1969: On the night of June 27-28, the Stonewall Riots begin in New York City's Greenwich Village. Occurring after a police raid of the Stonewall Inn and lasting three days, they are often referred to as the beginning of the "Gay Liberation Movement." While clearly much gay social civil rights work had taken place before then, the Stonewall Riots both accelerate and mark a turning point in the tenor of the movement.

- 1970: One year after the Stonewall Riots, the first gay pride parades take place in Chicago, New York and Los Angeles to commemorate the event.

- 1971: NOW (National Organization of Women) declares the oppression of lesbians a "legitimate" concern—the former "lavender menace" gains power.

- 1971: The Metropolitan Community Church of Los Angeles becomes the first organization serving the LGBT community to own property in the US.

- 1972: For the first time, an openly gay person is ordained by a major Christian denomination (United Church of Christ).

- 1972: In another first, a gay person is elected to a public office (Ann Arbor City Council).

- 1972: A gay-themed show, "That Certain Summer," is the first of its kind to win an Emmy East Lansing, Michigan becomes the first US City to ban discrimination in hiring based on sexual orientation.

- 1973: The American Psychiatric Association removes homosexuality from its official list of mental disorders.

- 1974: Boston, Massachusetts resident Elaine Noble becomes the first open gay or lesbian person to be elected to a state legislature.

- 1975: The Bisexual Forum is founded in New York City.

- 1975: Clela Rorex, a county clerk in Boulder Colorado, gains national attention when she begins issuing marriage licenses to same sex couples. She contends there are no county laws preventing her from doing so. She is eventually forbidden to continue by the State Attorney's Office. The licenses are not revoked.

- 1977: The first official gay/lesbian delegation is received at the White House.

- 1978: November 27th, San Francisco Mayor George Moscone and openly gay city council member Harvey Milk are murdered by Dan White. Massive demonstrations break out around the country when White is convicted only of voluntary manslaughter and sentenced to just 7-8 years in prison.

- 1979: The first National LGBT March On Washington DC draws 200,000.

- 1980: New York becomes the twenty-fourth state to revoke its sodomy law.

- 1981: Wisconsin becomes the first state to pass a statewide gay rights bill.

- 1982: PFLAG (Parents and Friends of Lesbians and Gays) incorporates as a national organization.

- 1982: The first Gay Games are held in San Francisco, with gay and lesbian athletes participating from 28 states and 10 nations.

- 1983: Corretta Scott King comes out in support of gay rights.

- 1983: The HIV virus is identified.

- 1984: Berkeley, CA becomes the first US city to pass a domestic partner law.

- 1985: Actor Rock Hudson dies of complications due to AIDS.

- 1985: The US Supreme Court overturns an Oklahoma law banning homosexuals, or anyone defending homosexuals, from teaching in public school.

- 1986:Two lesbians in California become the first LGBT couple in the US to be granted joint adoption.

- 1987: The National March on Washington in support of Gay and Lesbian Rights draws 600,000. The number of people participating makes it the largest civil rights demonstration in the history of the US up to that time.

- 1987: The Names Project unveils the AIDS Memorial Quilt on the Capitol Mall in Washington DC.

- 1988: The first annual Coming Out Day is celebrated.

- 1988: The Episcopal Diocese of Newark, New Jersey becomes the first church in the US to support and condone blessing relationships between gay and lesbian couples.

- 1989: Denmark becomes the first to make same sex-marriage legal.

- 1990: The Hate Crime Statistics Bill passes Congress. The new law requires the collection of data on crimes motivated by prejudice against people because of their sexual orientation, as well as, race, ethnicity, or religion.

- 1991: Amnesty International begins including, as prisoners of conscience, men and women jailed because of their sexual orientation.
- 1991: Lotus, a major publicly held US company, becomes the first to extend partner benefits to their LGBT employees.
- 1992: The University of Iowa, followed by the University of Chicago, extends domestic partner benefits to their gay and lesbian employees.
- 1992: Canada joins the majority of NATO countries in permitting military service by gays and lesbians. Bill Clinton becomes the first President to appoint open gays and lesbians to government positions.
- 1992: Colorado voters pass Amendment 2, which would prohibit anyone from making a claim of discrimination based on sexual orientation, and repeal existing antidiscrimination ordinances in Aspen, Denver, and Boulder.
- 1993: The National LGBT March on Washington DC brings a record-breaking crowd of over one million.
- 1993: Domestic partner benefits go into effect in New York City.
- 1993: Massachusetts becomes the first state to pass a law designed to protect gay and lesbian students in its public schools.
- 1994: Deborah Batts becomes the first open lesbian African-American appointed as a federal judge.

- 1994: The American Medical Association comes out in opposition to the supposed "medical cure for homosexuality."
- 1995: President Clinton signs an executive order forbidding the denial of security clearances due to homosexuality.
- 1996: The Supreme Court of the United States declares Colorado's Amendment 2 unconstitutional.
- 1996: The 7th US circuit court rules in favor of a youth that sued the Ashland Wisconsin School District. The youth, Jamie Nabozny, claimed his high school failed to stop the physical and verbal assaults directed toward him because of his homosexuality.
- 1996: A US District Court rules that the Pentagon's "don't ask, don't tell" policy is unconstitutionally discriminatory.
- 1996: The Defense of Marriage Act (DOMA), which defines marriage as the union between one man and one woman, passes Congress DOMA becomes the basis for all Federal laws relating to same-sex partnerships and ensures that no state will be required to recognize a same-sex marriage from another state. President Clinton signs the act.
- 1997: New Hampshire passes a law protecting LGB people from discrimination.

- 1997: Hawaii compromises on same-sex marriages by passing a domestic partnership law.

- 1998: Matthew Shepard's murder in Wyoming begins a renewed battle for hate-crimes legislation at the national level. Such legislation would include sexual orientation along with race, ethnicity, and religion.

- 1999: The Vermont Supreme Court holds that under the state constitution, the state must extend to same-sex couples the same benefits that married couples receive.

The 21st Century --- the beginning is marked by the debate over same-sex marriage

- 2000: The Vermont Legislature creates the status of "civil unions" to fulfill the State Supreme Court's mandate made in the 1999 ruling.

- 2000: A female-to-male transsexual in Quebec Canada is granted the right to have his birth certificate sex designation changed from female to male.

- 2001: The Netherlands offers civil marriage to same-sex couples.

- 2003: Belgium and three Canadian provinces begin to allow same-sex marriages.

- 2003: The Massachusetts Supreme Court rules that gays and lesbians have a legal right to marry under the Massachusetts Constitution.

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- 2003: The U.S. Supreme court strikes down the "Homosexual Conduct Law" (forbidding sodomy) in Lawrence vs. Texas. Equal protection, rights to privacy and liberty are cited.

- 2004: Massachusetts becomes the first state to legalize sex-marriage. San Francisco city Mayor, Gavin Newson, authorizes city clerks to grant marriage licenses to same sex couples.

- 2005: Connecticut legislature is first to legalize civil unions without court mandate.

- 2005: Same-sex marriage, adoption by same-sex parents become legal in Canada and Spain.

- 2005: Maine adds sexual orientation and gender identity to existing anti-discrimination laws.

- 2005: Civil unison law takes effect in Switzerland and New Jersey.

- 2005: South Africa legalizes same-sex marriage.

- 2006: Pension Reform Act allows any person to designate any other person to receive the former's tax-deferred retirement plan and draw it down over time. This helps a younger, terminally ill woman who wants to give her retirement account to her nephew, as well as the single LGBT older person who wants to designate a life-long friend.

- 2006: Updated language in the 2006 reauthorization of the Older
  Americans act expands the definition of caregiver to include LGBT
  chosen families.

- 2006-2011: Progress accelerates, as seven states enact relationship
  equality laws, and six states enact non-discrimination laws. Many
  states pass safe schools initiatives.

- 2006: Colorado passes RIGHTS FIVE specifically aimed at the LGBT
  community, making Colorado one of the most equality-minded states
  in the nation. These laws cover both sexual orientation and gender
  identity concerning:

1. Employment Nondiscrimination

2. Housing and Public Accommodations

3. Hate Crimes

4. Second-Parent Adoptions

5. Designated Beneficiary Agreements

- 2008: Marriage for same-sex couples is legal in CA for several
  months, until voters pass Prop. 8. Protests erupt nationwide. An
  injunction is filed.

- 2008: Older Californians Equality and Protection Act mandates that
  the California Department on Aging and Area Agencies on Aging

address LGBT older adults' needs by including them in needs assessments and area plans; providing LGBT cultural competency training to staff, contractors, and volunteers; and ensuring that all provided services are free of discrimination based on sexual orientation and gender identity.

- 2009: Housing and Urban Development (HUD) issues new regulations prohibiting discrimination based on sexual orientation or gender identity in HUD rental properties and public housing.

- 2009: Administration on Aging (AoA) funds a national LGBT resource center for three years. SAGE/New York receives the grant.

- 2009: HUD commits to first-ever federal study on housing discrimination against LGBTs.

- 2009: Matthew Shepard/James Byrd Jr. Hate Crimes Prevention Act expands federal hate crime act to include sexual orientation and gender identity

- 2009: The U.S. Census bureau announces inclusion of same-sex households in 2010 census.

- 2010: Health and Human Services (HSS) The proposed regulation issued by the Centers for Medicare & Medicaid Services, based on an Obama mandate would require hospitals that receive funds under

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Medicare and Medicaid to allow patients during a hospital stay to designate a same-sex partner as a visitor.

- 2010: SAGE launches the National Resource Center on LGBT Aging www.lgbtagingcenter.org

- 2011: The Department of Justice announces it will no longer defend DOMA (Defense of Marriage Act) in court.

- 2011: The state of New York passes marriage equality legislation "Don't Ask, Don't Tell" is repealed, effective Sept. 20, 2011

- 2011: Health & Human Services (HHS) instructs States that they are empowered to treat same-sex partners the same as married heterosexual couples regarding protection from "spousal impoverishment" under Medicaid.

- 2011: The Presbyterian Church (U.S.A.) approved the ordination of gay and lesbian clergy, joining several other Christian denominations that also ordain gay and lesbian clergy.

- 2012: The Ninth Circuit Court of Appeals rules that California's Proposition 8 violates the US Constitution's 'due process and equal protection' clause.

- 2012: President Obama announces his support of gay marriage, saying his views "have evolved." The First U.S. Circuit Court of Appeals

rules that the Defense of Marriage Act (DOMA) is unconstitutional, setting up a Supreme Court challenge.

- 2012: Maine, Maryland, and Washington pass gay marriage laws, bringing the state total to nine (ten with Washington D.C.) Domestic partnership or civil union laws in nine others. Minnesota voters defeat an effort to add a DOMA to their state constitution. North Carolina voters prohibit gay marriage or civil unions.

- 2012: Gender Identity Disorder, a term long-used to stigmatize transgender individuals, was removed from the American Psychiatric Association's Diagnostic and Statistical Manual of Mental Disorders (DSM). The new diagnosis is Gender Dysphoria, which communicates the emotional distress that can result from "a marked incongruence between one's experienced/expressed gender and assigned gender." This will allow for affirmative treatment and transition care without the stigma of disorder.

- 2013: Jan. 21, 2013: Pres. Obama becomes the first U.S. president to mention gay rights in an inaugural address: "We, the people, declare today that the most evident of truths -- that all of us are created equal -- is the star that guides us still; just as it guided our forebears through Seneca Falls, and Selma, and Stonewall..." he said. "It is now our

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generation's task to carry on what those pioneers began. For our journey is not complete until our wives, our mothers, and daughters can earn a living equal to their efforts. Our journey is not complete until our gay brothers and sisters are treated like anyone else under the law -- for if we are truly created equal, then surely the love we commit to one another must be equal as well."

- Feb. 12, 2013: President Obama references gay service people in his State of the Union address: "This year, I will work with Congress and our military to finally repeal the law that denies gay Americans the right to serve the country they love because of who they are." The Pentagon begins offering some benefits to same-sex couples. Note: significant benefits, such as health care for the same-sex spouse, are still excluded due to the federal DOMA requiring a spouse to be opposite sex. Pres. Obama supports a proposal offering the same benefits to straight and gay immigrants; urged the Boy Scouts to open its ranks to gays; appointed a record number of out LGBTs to serve in his administration.

- 2013: The Supreme Court heard California's Prop. 8 and the DOMA-challenging case of lesbian Edith Windsor, who sought relief from

taxes owed on her inheritance from longtime partner, Thea. She won and subsections of DOMA and all of Prop. 8 was struck down

- 2013: AIDS turns 30.

- 2013: According to the CDC and Prevention, of the over 1 million Americans living with HIV, 31% are over the age of 50. Research indicates that by 2017, half of the people living with HIV in the U.S. will be over more than 50 years old, with 1.4 million cases projected.

Appendix B

Interview Questions

Participant #

Type of intervention (tobacco, alcohol, obesity, IPV etc.):

Initial Open-ended Questions:

1. You have participated in some way on a cultural adaptation for SGM, is that correct?

2. Can you tell me about your job when you participated on the cultural adaptation.

   a. What was your role at that time?

   b. How long had you been in that job role?

3. What is your degree/education?

4. How would you describe the agency/institution you worked for/or supported during this project?

   a. Can you describe the agency values?

5. What population is served by the agency?

6. In what capacity does the agency serve SGM?

Intermediate Questions:

1. Moving on to interventions: What types of interventions, if any were provided previous to any formal curricular adaptations?

2. What prompted a need for providing an _____ intervention for your

   SGM consumers?

3. What prompted a need for adapting a curriculum/intervention specifically

   for SGM? (as opposed to using an existing intervention).

4. What considerations were made in determining the need for adaptation?

5. Was there a theory or philosophy that guided the changes you made and if

   yes, what was it?

6. Would you say the changes made to the curriculum were formal or

   informal?

7. Can you describe those changes?

8. Can you describe the steps and process of making the changes?

9. Looking back on the adaptation project, is there anything you or your team

   wish you would have done or considered differently?

10. What type of training was required and or provided for facilitators with

    regard to the adapted intervention?

11. What special considerations were made for SGM that would be different

    from a generalized intervention?

Ending Questions:

1. Since the adaptation, how have things changed or evolved for your work?

   a. The work of the agency?

2. What would you recommend to other researchers/practitioners for future

   adaptations with this population?

3. Is there anything that you might not have thought about before that

   occurred to you during this interview?

4. Is there anything else you think I should know to understand adapting

   interventions for SGM?

5. Is there anything you would like to ask me?

6. Who else would you recommend I speak with about this project and other

   culturally adapted projects?

Appendix C

UT Arlington Informed Consent Document

PRINCIPAL INVESTIGATOR

Pam Hancock Bowers, School of Social Work

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Phone: 303-229-0264

FACULTY ADVISOR

Dr. John Bricout, School of Social Work

Email: jbricout@uta.edu

TITLE OF PROJECT: DEVELOPMENT OF AN ADAPTATION MODEL FOR
HEALTH INTERVENTIONS FOR SEXUAL AND GENDER MINORITIES: A
GROUNDED THEORY STUDY

INTRODUCTION

You are being asked to participate in a research study about culturally
adapted health interventions for sexual and gender minorities. Your participation
is voluntary. Refusal to participate or discontinuing your participation at any time
will involve no penalty or loss of benefits to which you are otherwise entitled.
Please ask questions if there is anything you do not understand.

PURPOSE

The proposed research aims to investigate how health interventions have been culturally adapted to fit the needs of sexual and gender minorities. Sexual and gender minorities (SGM) are members of the lesbian, gay, bisexual, and transgender population. SGM smoke at twice the rate of heterosexuals and have been identified as a priority population by researchers. Recommendations from the literature suggest smoking cessation and other substance abuse interventions be tailored to fit the needs of priority populations to increase relevancy and potential efficacy. The information gathered from this research will be used to develop a model for future adaptations.

DURATION

You will be asked to participate in an interview which will last approximately thirty minutes to one hour. As needed, a follow up interview may be requested for an additional 30 minutes.

NUMBER OF PARTICIPANTS

The number of anticipated participants in this research is 15.

PROCEDURES

You are being asked to participate in an interview via telephone. The interview will be audio recorded. After the interview, the recordings will be

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transcribed, which means they will be typed exactly as they were recorded, word-for-word, by the researcher. The tape will be kept with the transcription for potential future research involving cultural adaptations for sexual and gender minorities. The digital file and transcription will not be used for any future research purposes not described here.

POSSIBLE BENEFITS

The proposed research program stands to advance our understanding of how to culturally adapt interventions for sexual and gender minorities. The purpose is to develop an adaptation model through examination of the adaptations that researchers, community partners and others make to existing interventions. Exploration with the specific intent to build an adaptation model of this type for SGM has not been endeavored. By exploring and examining the components that influence adaptation, researchers and community partners can be better informed to develop modifications to interventions that address the needs of their local SGM community. By providing appropriate and practical guidance, communities and researchers should have a clear understanding of the appropriate steps to take in adapting curricula or other similar interventions. Additionally, the importance of having a documented process model which describes the steps in adapting a health intervention for SGM will be a useful tool for future research.

POSSIBLE RISKS/DISCOMFORTS

There are no perceived risks or discomforts for participating in this research study. Should you experience any discomfort please inform the researcher, you have the right to quit any study procedures at any time at no consequence.

COMPENSATION

No compensation will be offered for participation in this study. You may, however, request a copy of the completed dissertation and subsequent publications.

ALTERNATIVE PROCEDURES

There are no alternative procedures offered for this study. However, you can elect not to participate in the study or quit at any time at no consequence.

VOLUNTARY PARTICIPATION

Participation in this research study is voluntary. You have the right to decline participation in all study procedures or quit at any time at no consequence.

CONFIDENTIALITY

Every attempt will be made to see that your information is kept confidential. A copy of this consent form and all data collected [including transcriptions/tapes if applicable] from this study will be stored in a locked filing cabinet in the PhD facility space, for at least three (3) years after the end of this research. The results of this study may be published and/or presented at meetings

without naming you as a participant. Additional research studies could evolve from the information you have provided, but your information will not be linked to you in anyway; it will be anonymous. Although your rights and privacy will be maintained, the Secretary of the Department of Health and Human Services, the UTA Institutional Review Board (IRB), and personnel particular to this research have access to the study records. Your records will be kept completely confidential according to current legal requirements. They will not be revealed unless required by law, or as noted above. The IRB at UTA has reviewed and approved this study and the information within this consent form. If in the unlikely event it becomes necessary for the Institutional Review Board to review your research records, the University of Texas at Arlington will protect the confidentiality of those records to the extent permitted by law.

CONTACT FOR QUESTIONS

Questions about this research study may be directed to Pam H. Bowers, Pamela.hancock@mavs.uta.edu or John Bricout jbricout@uta.edu. Any questions you may have about your rights as a research participant or a research-related injury may be directed to the Office of Research Administration; Regulatory Services at 817-272-2105 or regulatoryservices@uta.edu.

As a representative of this study, I have explained the purpose, the procedures, the benefits, and the risks that are involved in this research study:_____

Signature and printed name of principal investigator or person obtaining consent

Date

CONSENT

Do you voluntarily agree to continue with this interview?

Yes   No

Participant Number:_____

By continuing with this interview over the phone, you confirm that you are 18 years of age or older and have read or had this document read to you. You have been informed about this study's purpose, procedures, possible benefits and risks, and you have received a copy of this form. You have been given the opportunity to ask questions before you consent, and you have been told that you can ask other questions at any time.

You voluntarily agree to participate in this study. By continuing with this interview, you are not waiving any of your legal rights. Refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You

may discontinue participation at any time without penalty or loss of benefits, to

which you are otherwise entitled.

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Biographical Information

Pam Bowers earned her BASW from San Francisco State in 2005 and her MSW from The University of Denver in 2006. After her graduate studies, she stayed in the Denver, Colorado area where she worked as a social worker first in tobacco control and later in school social work. Pam's research interests include health disparities and social justice issues in social work practice, policy, and education. Specifically, she plans to continue exploring how to adapt interventions so they are culturally relevant for groups experiencing health disparities. Additionally, she is interested in active learning, community-academic partnerships, and leadership in academia. Her philosophical orientation is deeply rooted in disrupting privilege and building cultural humility, which transcends into the underlying values and assumptions associated with cultural competency. For her future Pam plans to work in academia, partnering with students, the community, and other resources to improve the quality of life for those around her, and to fight for equality and social justice.