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AN ASSESSMENT OF THE HEALTH NEEDS OF THE TRANSGENDER COMMUNITY IN
MONTANA

By

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Bachelor of Arts, St. Mary's College of Maryland, St. Mary's City, Maryland, 2010

Thesis

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An Assessment of the Health Needs of the Transgender Community in Montana

Chairperson: Dr. Annie Sondag

The transgender community has been identified as a group at high risk for HIV transmission and increased possibility for poor quality of life. This paper represents the results of a qualitative research study using interviews and Photovoice as methodologies to explore the contextual factors that define and shape the lives of people in Montana who identify as transgender, and specifically to explore factors that influence their risk of infection with HIV/AIDS. Ten major themes emerged from the interviews as well as the discussions surrounding the photographs. Sense of self was identified as a core category related to the overall health and risk behaviour of the transgender community in Montana. The other nine major categories, including 1) age of transition, 2) the importance of love, 3) availability of support, 4) passing as your identified gender, 5) normalization in society, 6) ignorance surrounding gender variance, 7) health care, 8) legal issues, and 9) life in Montana, were seen as contributing to the development of a stronger or weaker sense of self. The findings from this study will be used by the Montana Department of Public Health and Human Services to increase awareness of the lived experience and health needs of the transgender community in Montana.

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CHAPTER 1: INTRODUCTION

HIV/AIDS IN THE UNITED STATES OF AMERICA

Human Immunodeficiency Virus (HIV) is a virus that cannot be treated naturally by the human body. HIV can live for long periods of time in the cells of the body, and also alters the immune system, making people more vulnerable to infections and diseases. Left untreated, HIV can transition into Acquired Immuno Deficiency Syndrome (AIDS), which happens when a person is diagnosed with one or more opportunistic infections (OIs), certain types of cancer, or a very low number of CD4 cells (cells that are designed to activate the body's immune response), and ultimately ends in death (U.S. Department of Health and Human Services [USDHHS], 2012).

HIV was first reported in the United States (US) in June of 1981. Since that time, the US government estimates that 1.7 million Americans have been infected. The most recent reporting year available for national prevalence estimates is 2008, at which point approximately 1.2 million people were currently living with HIV (National Institute of Allergy and Infectious Disease [NIAID], 2011). Centers for Disease Control and Prevention (CDC) estimates that one in five of people living with HIV are unaware of their infection status, and approximately 50,000 new infections occur each year (2013).

In July 2010, President Barack Obama tasked the Office of National AIDS Policy with developing the US National HIV/AIDS Strategy (NHAS), which has three primary goals: 1) reducing the number of people who become infected with HIV; 2) increasing access to care and improving health outcomes for people living with HIV; and 3) reducing HIV-related health disparities. According to President Obama, “success will require the commitment of governments at all levels, businesses, faith communities, philanthropy, the scientific and medical communities, educational institutions, people living with HIV, and others” (The White House, 2013). Using this action plan, the CDC has again streamlined its HIV planning processes that have been in place since 1993 when it first began to require health departments receiving federal HIV prevention resources to “share the responsibility for developing a comprehensive HIV prevention plan with representatives of affected communities and technical experts” (CDC, 2012). Currently, every state in the US is required to have an HIV Prevention Planning Group, or HPG, consisting of key stakeholders and members of the communities affected by HIV/AIDS. Using the various HPGs to help target prevention needs and interventions, it is hoped that the ambitious goals outlined in the NHAS can be achieved.

According to national data from the CDC (2013), the groups currently known to be at highest risk for infection of HIV, in decreasing order of prevalence, are:

- White men who have sex with men (MSM);
- Black MSM;
- Hispanic/Latino MSM;
- Black heterosexual women;
- White heterosexual women;
- Hispanic/Latino heterosexual women;
- Black male injection drug users (IDUs); and
- Black female IDUs.

American Indians (AI) and Alaskan Natives (AN) are also experiencing an increase in HIV transmission, and ranked fifth in “estimated rates of HIV infection diagnoses in 2011, with lower rates than in blacks/African Americans, Hispanics/Latinos, Native Hawaiians/Other Pacific Islanders, and people reporting multiple races, but higher rates than in Asians and whites” (CDC, 2014). Both male and female AI/AN had the highest percent of estimated diagnoses of HIV infection attributed to injection drug use in comparison with all races and ethnicities in 2011 in the United States. In 2011, men comprised 76% of new HIV cases in the United States, and women accounted for 24% of new cases (CDC, 2014).

However, a recently published meta-analysis of 29 research studies conducted with transgender communities from across the United States suggests that members of the transgender population could be in the greatest risk of all communities affected by HIV/AIDS (Herbst, Jacobs, Finlayson, McKelroy, Neumann, & Crepaz, 2007). This project was aimed at learning more about the transgender community in Montana in terms of their physical, mental, and social health, as well as their HIV prevention needs.

HIV/AIDS REPORTING IN THE TRANSGENDER POPULATION

Transgender communities in the US are beginning to be thought of as one of the communities at highest risk for infection (CDC, 2013). The Presidential Advisory Council on HIV/AIDS (PACHA) passed the *Resolution on Effectively Addressing the HIV/AIDS Epidemic in Transgender Populations* in February 2013. The resolution acknowledges the disparities experienced by transgender people in multiple aspects of American society, including: education, housing, employment, legal systems, and health care. There

are a total of 15 recommendations for appropriate action at the federal level to address the needs of transgender people, such as reporting accurate statistics about the HIV/AIDS epidemic among transgender populations and delivering services in a culturally competent manner. The efforts being made at a national level to address the needs of transgender people demonstrate the increasing awareness created around this marginalized community.

According to the National Center of Transgender Equality (NCTE) (2009), there is not a lot of information available about the number of transgender people living in the United States. This is due to the fact that there has been no widespread effort to collect this data. Transgender people are not considered in the reporting criteria of the US Census or other agencies, including CDC reporting for HIV/AIDS, and many transgender people choose to keep their identities a secret. Also, because of the relatively small number of transgender individuals living in America there has not been a push to change reporting options to include them in epidemiological data, meaning they often fall into the category of Men who have Sex with Men, but can also fall into homosexual or heterosexual categories. Transgender individuals embody a very diverse range on the gender continuum; it is not unusual for a male-bodied MTF to identify as heterosexual and have sex with male partners. Kammerer, Mason, Connors, and Durkee (2001) suggest “that while sex, gender, and sexual orientation are interrelated, they are also separate...Sex is an issue of anatomy, and gender is an aspect of identity, of self. Are you attracted to someone male by sex, male by gender, female by sex, female by gender, or some combination thereof?” This example provides a clear description of the inadequacies of the typical sex and gender reporting options found in epidemiological data.

In 2002, California became the only state to collect epidemiological data regarding its transgender population by creating two new gender reporting options: “FTM” (Female-to-Male) and “MTF” (Male-to-Female). Transgender persons, particularly African Americans, were found to have the highest HIV diagnosis rate of any group in the state, including MSM, which is traditionally the largest group (Keller, 2009). Herbst et al. (2007) conducted a meta-analysis of 29 research studies from across the US. An average of the information found in the studies shows 27.7% of MTFs tested positive for HIV infection, and 11.8% of MTFs self-reported positive infection status. Lower prevalence was found among FTMs. This information tells us a number of things. First, depending on the reporting method used in the study you can arrive at a vastly different conclusion—if a report relies on self-reporting alone, it is possible to underestimate the population infected with HIV. Second, every study used in the meta-analysis found a different rate depending on location. The following studies all used self-reporting methods: a study done by Kenagy and Hsieh (2005) in Philadelphia shows 6% HIV positive rate; a study by Nemoto et al.

(2006) shows 26% in San Francisco; and in Minnesota, a less populated state than Pennsylvania and California, Bockting et al. (2005) shows .5% (as cited in Herbst et al., 2007). These three very different locations report very different rates of HIV infection. While data is collected in Montana following the traditional reporting protocol for HIV, no data has yet been collected regarding the status of the transgender population, and we cannot generalize the information from places like Philadelphia and San Francisco to a rural state.

HIV/AIDS IN MONTANA

1,126 cases of HIV have been reported since 1985, 652 of whom were Montana residents at the time of diagnosis (Montana Department of Public Health and Human Services [MTDPHHS], 2013). As of December 2012, there are 548 people living with HIV (PLWH) in Montana, and approximately 20 new diagnoses have been reported each year since 2000. The state epidemiological data has been broken down into the following table by risk behavior, provided by MTDPHHS (2013):

Risk Behavior	No. of MT Residents 1985-2012
Male-to-male sexual contact (MSM)	340
Injection drug use (IDU)	60
MSM & IDU	57
Heterosexual contact	28
Not reported/not identified (NRR/NIR)	59
Other (hemophilia, blood transfusion, and perinatal exposure)	16

TABLE 1: RISK BEHAVIORS LEADING TO HIV TRANSMISSION IN MONTANA

The following table includes the Montana state epidemiological data for reported cases of HIV broken into categories of race, provided by MTDPHHS (2013):

Race/Ethnicity	No. of MT Residents 1985-2012
Non-Hispanic (NH), white	555
NH, American Indian/Alaska Native	49
Hispanic, any race	20
NH, black/African American	19
NH, other (all other races, including mixed race)	8

TABLE 2: RACE/ETHNICITY OF INDIVIDUALS DIAGNOSED WITH HIV IN MONTANA

According to Sondag and Strike (2011), as of 2008 there had been 63 total reported cases of HIV from within the AI/AN community, including individuals of mixed race. Of those 63 people, 33 were living at the time of publication.

The strategy used by the CDC to target the HIV epidemic is called High-Impact Prevention, which allows the CDC to invest prevention resources in places and populations that are most affected by HIV. This generally means states with large metropolitan regions receive the most funding because HIV is typically concentrated around urban areas (CDC, 2012). Montana is considered a low-incidence state, and therefore receives limited federal funds to provide HIV education and prevention services.

There is no information in Montana regarding the status of transgender individuals who may be living with HIV/AIDS. Montana, like most states, reports their findings on a gender binary system, using the CDC-approved risk categories of male-to-male sexual contact, heterosexual contact, IDU, and male-to-male sexual contact and IDU, along with age, sex, and race. As mentioned earlier, these categories are not diverse enough to gain accurate insight into the risk for infection of the transgender community in Montana.

PURPOSE

The purpose of this study was twofold: 1) to provide the Montana Department of Public Health and Human Services (MTDPHHS) with a description of the lived experience of the Montana transgender community and the contextual factors that influence their risk of infection with HIV/AIDS and 2) to apply grounded theory techniques to generate a theory that will endeavor to explain the contextual factors that define and shape the behavior of people in Montana who identify as transgender.

RESEARCH QUESTIONS

What are the contextual factors that define and shape the behavior of people in Montana who identify as transgender?

- a) What are the *individual* factors that contribute to the risk of HIV infection?
- b) What are the *interpersonal* factors that contribute to the risk of HIV infection?
- c) What are the *institutional* factors that contribute to the risk of HIV infection?
- d) What are the *community* factors that contribute to the risk of HIV infection?
- e) What are the *public policy* factors that contribute to the risk of HIV infection?

SIGNIFICANCE

Currently limited information exists regarding the transgender population living in Montana, and information available about transgender experiences in the rural American states is also limited. This study provided Montana's HIV Prevention Planning Group (HPG) with information necessary to better serve the transgender communities impacted by HIV. In addition, the Photovoice portion of this study gave voice to the largely marginalized transgender population in Montana, allowing them to directly tell their stories to policymakers, which is a key aspect of long term empowerment and identity-building.

DELIMITATIONS

The delimitations of the study were:

1. The study was delimited to male-to-female (MTF) and female-to-male (FTM) transgender and gender non-conforming individuals aged 18 or older who live in Montana;
2. Data was collected through interviews with transgender and gender non-conforming program participants and interviews with key informants, along with secondary data from the literature review;
3. Data collected from participants was restricted to self-report; and
4. Participants in the study were volunteers who could discontinue involvement at any time, at their own discretion.

LIMITATIONS

The limitations of the study were:

1. Data collected during interviews were limited to the experiences of the participants.
2. Data collected was limited to the participants' honesty, openness, and willingness to share.
3. Data collected was limited to those individuals who are recruited by key informants and gatekeepers in addition to the key informants themselves.
4. Data analysis was limited to the researcher's bias and ability to carry out the study methodologies.

DEFINITION OF TERMS

Cisgender

“People who are cisgender are not transgender; their gender identity matches up with the sex they were assigned at birth. The vast majority of people are cisgender.” (Teich, 2010).

FTM

“The shortened form of female-to-male: transgender people who are assigned female at birth and transition to male.” (Teich, 2010).

Gender binary

“The gender binary is a social system whereby people are thought to have either of two genders: man or woman” (Teich, 2010).

Gender nonconforming/genderqueer

“A term that describes people who feel that they are in between male and female and/or are neither male nor female, or reject the gender binary altogether. It is a term that should be used only if a person self-identifies as such.” (Teich, 2010).

MTF

“The shortened form of male-to-female: transgender people who are assigned male at birth and transition to female.” (Teich, 2010).

Out

A term for being open about one’s identity, with oneself and others, whereby one comes to terms with one’s own self-identity. The word “out” is sometimes tied to a person’s sexual orientation, so occasionally in transgender literature this is referred to as “openness,” since a transgender individual is being open with their gender identity as well. (Zians, 2006).

Rural

“Territory, population, and housing units located outside of urbanized areas or urban clusters. Rural areas have fewer than 2,500 people or areas where people live in open country.” (Rural Institute of Montana, 2010).

Trans*

“It expands the boundaries of (the transgender) category to be radically inclusive. It can be understood as the most inclusive umbrella term to describe various communities and individuals with nonconforming gender identities and/or expressions en masse” (Jones, 2013).

Transgender

“An umbrella term for many different identities. People who are transgender have a gender identity, sex, and/or gender expression that does not line up with the sex they were labeled with at birth.” (Teich, 2010).

Transition

“The process that some transgender people undergo to live as the gender and/or sex that they feel they are, rather than the sex they were assigned at birth.” (Teich, 2010).

Two-spirit

“Two-spirit is a term that refers to Native American/Alaska Native lesbian, gay, bisexual, transgender (LGBT) individuals. It means having both female and male spirits within one person, and has a different meaning in different communities.” (Naswood & Jim, 2010)

Urban

“Territory, population and housing units located within urbanized areas and urban clusters: areas with a Census population of at least 50,000 and are densely populated, typically with more than 500 people per square mile; and any densely settled area with a Census population of 2,500 to 49,999.” (Rural Institute of Montana, 2010).

CHAPTER 2: LITERATURE REVIEW

INTRODUCTION

The purpose of this study was twofold: 1) to provide the Montana Department of Public Health and Human Services (MTDPHHS) with a description of the lived experience of the Montana transgender community and the contextual factors that influence their risk of infection with HIV/AIDS and 2) to apply grounded theory techniques to generate a theory that will endeavor to explain the contextual factors that define and shape the behavior of people in Montana who identify as transgender.

This section provides a review of literature regarding the theoretical basis of the study, a brief overview of the transgender population, and a discussion of the various health issues that the Trans* community faces, both in general and in Montana specifically.

THEORETICAL BASIS

This section will attempt to summarize the various theoretical underpinnings of the proposed study. This qualitative needs assessment will use the socio-ecological model as a framework for the interview questions provided to key informants in order to determine the contextual factors that define and shape the behavior of people in Montana who identify as transgender, including behaviors that put them at risk for HIV infection. The methodology and analysis will be based on grounded theory. The concepts of minority stress theory and the still-emerging transgender theory are important concepts for understanding the target population of this project.

The Socio-ecological Model

The socio-ecological model (SEM) for health promotion programs was developed by McLeroy, Bibeau, Steckler, and Glanz (1988). The model establishes two key concepts: behavior affects and is affected by multiple levels of influence, and individual behaviors shape, and are shaped by, the social environment. The five levels of the SEM are:

- *Intrapersonal*, as in individual characteristics that influence behavior, such as knowledge, skills, or self-efficacy;
- *Interpersonal*, meaning the interpersonal processes and groups providing identity and support, such as family, friends, or peers;

- *Institutional* (also known as *organizational*), as in the social institutions such as schools, local stores, or work settings with organizational characteristics that have formal or informal rules and regulations;
- *Community*, or rather the community norms and regulations that could be spoken or unspoken or social networks; and
- *Public policy*, as in the policies and laws that regulate or support healthy behavior choices at the local, state, or federal levels (McLeroy et al., 1988).

According to Winch (2012), researchers have intuitively placed some factors in a variety of locations since the SEM was first proposed. There has been disagreement in the literature over where factors such as culture, social class, racism, gender, economics, and employment fit within the five categories.

A visual representation of the SEM as depicted by Glanz (2013) is provided below:



FIGURE 1: SOCIO-ECOLOGICAL MODEL

Grounded Theory

Grounded theory is an ideal research design for studying how “individuals interact, take actions, or engage in a process in response to a phenomenon” (Creswell 1998, p. 56). Grounded theory takes the researcher through a specific analytical process in order to generate various propositions or hypotheses that lead to a theory regarding the context and conditions in which the phenomenon occurs. Data collection takes place primarily through interviews. Creswell (1998) suggests, due to the systematic analytical procedures grounded theory requires, it lends itself to high scientific credibility.

According to Glaser (2007), many recent research studies that claim to use grounded theory are actually qualitative descriptive analyses of a given phenomenon (as cited in Birks & Mills, 2011). Birks and Mills (2011) outline the following criteria as being necessary in a grounded theory study:

- *Initial coding and categorization of data* (also known as *open coding*), when the researcher identifies important words, or groups of words, in the data and then groups related codes into categories;
- *Concurrent data generation or collection and analysis*, when the researcher generates some preliminary data from a purposive sample and analyzes it before more data is collected;
- *Writing memos*, which are written records of a researcher's thinking during the process of undertaking a grounded theory study;
- *Theoretical sampling*, whereby the researcher makes a decision about what or who will yield the most information-rich data to meet the needs of the ongoing analysis;
- *Constant comparative analysis*, where inductive and abductive logic is used to constantly compare incident to incident, incident to codes, codes to codes, codes to categories, and categories to categories throughout the data collection;
- *Theoretical sensitivity*, a concept that accounts for the fact that researchers are a sum of all of their personal, professional, and intellectual experiences;
- *Intermediate coding*, the second step in the analytical process that occurs during the processes listed above whereby the researcher begins to link the categories found in the initial coding stage;
- *Selecting a core category*, which occurs after the intermediate coding, involves potentially choosing one core category that encapsulates and explains the grounded theory as a whole; and
- *Theoretical integration*, when the researcher employs a storyline technique to provide a comprehensive explanation of a process in relation to a particular phenomenon that ideally includes variation as opposed to a "one-size fits all answer to a research question" (pg. 12).

The following is a diagram designed by Birks and Mills (2011) to describe how the processes described above occur and work together to generate a grounded theory.

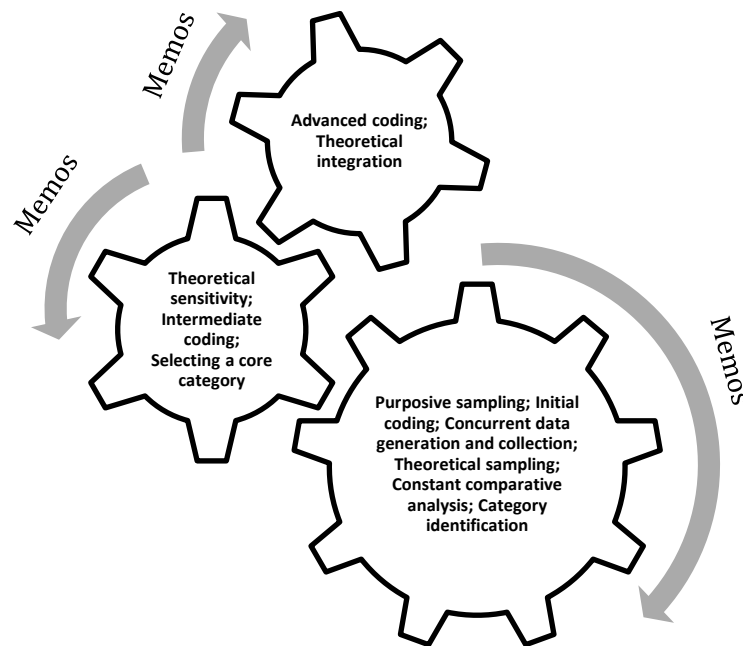


FIGURE 2: GROUNDED THEORY PROCESS

Minority Stress Theory

According to Effrig, Bieschke and Locke (2011, p. 144), “minority stress theory posits that the increased stress faced by minority individuals leads to an increased level of psychological distress when individuals are unable to successfully increase their level of coping.” Meyer (2003) identified two types of stressors: distal, which are objective, external stressors such as violence and discrimination; and proximal or internal stressors resulting from internalizing the negative reactions encountered in society (as cited in Effrig et al., 2011). Bockting, Miner, Romine, Hamilton, and Coleman (2013, p. 943) state “the stress associated with stigma, prejudice, and discrimination will increase rates of psychological distress in the transgender population...[the stress] is also socially based and chronic.” Bockting et al. (2013, p. 944) continue on to discuss that coping with stigma means that a transgender individual must conceal their identity, which reinforces their desire to pass, a theme that is discussed later on in the chapter, but also that “concealment...can result in hyper vigilance and a preoccupation with hiding, which itself can become a significant source of stress.” Bockting et al. (2013) found that both distal and proximal stress were positively associated with psychological distress, and confirmed that family support, peer support, and identity are protective factors, and negatively associated with psychological distress.

Yang, Kleinman, Link, Phelan, Lee, and Good (2007) further discuss stigma and its lasting effects on a person's psychosocial well-being. Jones et al. (1984) describes stigma as the result of a "mark" that is placed on an individual to describe a "deviant condition identified by society that might define the individual as flawed or spoiled" (as cited in Yang et al., 2007, p. 1525). Yang et al. (2007) suggest that stigma "endangers what is most valued in one's innermost being," and can lead to: distinct physical experiences occurring with the loss of social position, for example dizziness, headaches, fatigue, and exhaustion; weakened social ties resulting in feelings of overwhelming shame, humiliation, and despair; and disrupted social interactions due to feelings such as shame or guilt encompassing not only the individual but also their friends and family.

Balsam, Beadnell, and Molina (2013) suggest that the impact of minority stress extends beyond merely psychological distress. Negative health outcomes such as poorer quality of life, substance abuse, and other risky behaviors should also be taken into consideration. Levitt and Ippolito (2013) also suggest negative outcomes related to social interactions and concealment, specifically job loss and social rejection. Levitt and Ippolito (2013) also suggest that while there are some commonalities that transgender individuals share with other marginalized communities, there are five distinct stressors as well: 1) coming to terms with the loss or gain of gender-related power; 2) greater vulnerability to job discrimination because of fewer legal protections afforded nationally; 3) difficulty hiding their gender minority status if they choose to do so due to their identifying documentation; 4) challenges in creating sexually intimate relationships due to prejudices against their bodies; and 5) difficulty in finding a safe community after being rejected by friends and families of origin.

Transgender Theory

Transgender theory is still in development, and has arisen out of a discussion surrounding both feminist theory and queer theory, both of which emphasize the concept of having a binary gender society, where we have either male or female personalities. According to Nagoshi, Brzuzy, and Terrel (2012), transgender theory incorporates the idea that instead of "either/or" people can be "both/neither," and suggests that transgenderism is more about transgressing the gender binary than physically transitioning from one gender category to another. Nagoshi et al. (2012) continue on to suggest that transgenderism involves "a fluid self-embodiment and a self-construction of identity that dynamically interacts with this embodiment in the context of social expectations and lived experiences" (p. 409).

According to Tauchert (2002), a view of gender that is based on the body, for example the notion that femaleness is created from the potential for pregnancy, "reinforces traditional stereotypes about gender and gender roles," while considering gender to be merely a social construct "is also problematic in that it

denies the sense of identity that comes from a body that continues to exist as a seeming self between the social performances of gendered behaviors” and reinforces the idea that personal choice is involved in subverting the identities associated with femininity and masculinity (as cited in Nagoshi & Brzuzy, 2010, p. 436).

RESEARCH STRATEGY

Data will be collected through two primary methods: key informant interviews and a Photovoice project to be completed by members of the transgender community.

Photovoice

Photovoice is a technique based on empowerment theory, documentary photography, and feminist theory. Due to these underlying concepts, Photovoice is ideal for working with marginalized communities. “It engages community members—whose voices are typically not heard—in a participatory process to identify, represent, and change their community through photography, dialogue, and action” (Strack, Lovelace, Jordan, & Holmes, 2010, p. 630). The end goal of a Photovoice project is to address the root causes of a social issue by providing a conduit through which community members can directly speak to policymakers regarding self-defined concerns. Participants are provided with cameras and asked to photograph various aspects of the environments where they live, work, and play. Those photos are then described by the person to whom they belong, and are presented as physical examples of the lived experiences of the community to policymakers (Wang & Burris, 1997).

There are a couple of examples of successful Photovoice projects in the transgender community. One was conducted in West Bengal, India (Boyce & Hajra, 2011). The researchers chose photographic research as a methodology because it allowed them to emphasize subjective data as something that is produced through ongoing social experiences and perceptions. Boyce and Hajra (2011) stated:

Photographs can facilitate research in a register that can match this objective—potentially capturing layers of emotion, intuitive experience, and a sense of self that may not be verbalized other than in response to images...The aim of working with photographs in this way was to explore day-to-day experiences and their relationship to research participants’ perspectives on self and social context.

Another example of a Photovoice project within the transgender community occurred in the San Francisco Bay Area (Hussey, 2006). In this study, five self-identified FTM individuals were given cameras and asked to “tell the story of their experiences of gaining access to health care by taking

pictures” (p. 134). Six main barriers to accessing health care were identified, including: the health care system, provider competence, vulnerability, invisibility, perseverance, and activism. The researcher selected this methodology as a way to provide insight into a community that health providers know little about, specifically the transgender community in the San Francisco Bay Area, in order to make recommendations for removing barriers to care.

Lopez, Eng, Randall-David, and Robinson (2005) utilized Photovoice as a methodology and grounded theory as an analytical tool in combination. Their goal was to “provide the means for participants to move beyond merely reporting results to policy and decision makers to suggesting strategies” that are specifically tailored to specific conditions of their lived experience (p. 101). Grounded theory provides a framework for identifying areas of intervention and potentially leading to the development of actionable steps toward addressing need (Lopez et al., 2005).

OVERVIEW OF THE TRANSGENDER POPULATION

The following section attempts to explain the changing landscape of transgender vocabulary, social movements, and general demographic information.

Terminology to describe people who land outside of the binary gender system is fluid. For the purposes of this study, the term *transgender* will be used as an “umbrella” term to describe any person who has a gender identity, sex, and/or gender expression that does not line up with the sex they were labeled with at birth (Teich, 2010). Another term that is becoming common is *Trans**. The asterisk is a reference to online search terminology—according to Jones (2013), an asterisk is included when conducting an online search, perhaps through Google, to act as a placeholder when you aren’t sure what you are looking for, and will return a wider array of data than you would otherwise receive. The asterisk in *Trans** is used similarly, and is used in an attempt to be “radically inclusive” (Jones, 2013). It is meant to encompass all terminology that begins with the word “trans,” such as transgender, transsexual, trans person, etc. Also, it includes anything else that does not start with the word “trans” but falls under the transgender umbrella, such as genderqueer, two-spirit, etc.

The root of the word *transgender* is the Latin word *trans*, meaning “across” (Teich, 2010). Kammerer et al. (2001) suggest that while transgender originally meant “across gender,” as in moving within the gender binary system from one conception of gender to another, such as masculine to feminine, it is also now considered to mean “to go beyond” gender, in the sense that a *Trans** individual doesn’t need to fit into *either* masculinity *or* femininity, but could instead fall into the categories of *both* or *neither*.

While the definitions and the terminology have not yet been fully agreed upon, community members do agree that these are all self-identifying terms. Some people may fall under the transgender or Trans* umbrella, but they do not identify with the transgender or Trans* community. According to Jones (2013), we should always attempt to “respect the words that people use to describe themselves by using those same words to describe them and not questioning their use of the terms.”

According to the NCTE (2009), a number of theories have been discussed regarding why transgender people exist, but there is no scientific consensus. Various theories include: cultural lenses, and the roles of masculine, feminine, and a binary gender system having varying degrees of societal importance depending on what culture you are from; a potential matter of biology, considering that the chromosomal makeup of men and women is generally much more complicated than the notion of “XX and XY” taught in basic science classes; a medical matter, where there could be differences in brain structure or hormonal fluctuations; and psychology, primarily resting in the idea that a person can choose to express their gender identity, sex, and sexual orientation in ways that feels most appropriate to him- or herself. Roughgarden (2004) suggests that even though people turn to science in order to establish criteria for what the word “male” means to define a man, and criteria for the word “female” to define a woman, society can struggle with coming to terms with a concept like transgenderism because there are so many shades of gray.

While forms of transgenderism have existed in various cultures since human society formed, some of the earliest recorded attempts at medical solutions began occurring in the early 1900’s. Two doctors in particular, Dr. Harry Benjamin and Dr. Magnus Hirschfield, were pioneers in transgender studies, even though doctors who believed in the existence of a transgender community were often ridiculed and lost professional standing in the eyes of their peers (Teich, 2010). After World War II, Christine Jorgenson, born George Jorgenson, became a global celebrity and brought the existence of the transgender community into the national dialogue. Decades later, a grassroots movement began to form around a growing centralized transgender community, and from that movement increasing recognition has been brought to the needs of those who identify within the transgender spectrum (Kammerer et al., 2001; Currah, 2008).

However, not all individuals who identify as transgender are equally political, and transgender politics are not considered to be well-established or uniform. Susan Stryker, a leading researcher and advocate in the field of transgender studies, stated in an interview that “it certainly appears that we have a trans movement today—however polyvocal, multidirectional, and contradictory it might appear when we are involved with it on a day-to-day basis” (Currah, 2008, p. 95). Even with all the progress that has been made, the transgender community has a long road ahead to gain equality in society. The Human Rights

Campaign (HRC) conducted a study in 2002 regarding the attitudes of American voters toward transgender people and issues in public policy. Only 61% of respondents thought the transgender community needed laws to protect them from job discrimination, 77% thought that transgender students should be allowed to receive an education in public schools, and 75% thought that federal hate crime laws should apply to transgender individuals (Moulton & Seaton, 2008).

The transgender community is still not fully understood. As mentioned in Chapter 1, this is largely due to lack of a transgender reporting option in government data collection, such as the U.S. Census and epidemiological information. However, another reason is limited accessibility. Later in this chapter, we explore the social discrimination that transgender individuals face, which encourages them to keep their true identities hidden. This means that researchers have a difficult time accessing members of the transgender population who do not wish to be identified as part of the Trans* community, for fear of their safety and other reasons. Most of the data collected is on individuals who are considered to be out, and who are open about their lives as transgender people. Their perspectives on social issues could be very different from those who wish to remain invisible or closeted.

A study was conducted in 2007 by Rosser, Oakes, Bockting, and Miner who conducted an Internet-based survey with 1,229 total participants from 48 states (excluding Montana and South Dakota, where no participants responded). Due to the anonymity, reach, and decreased burden on participants provided by an Internet-based survey, the researchers were able to reach a broad range of respondents that represented both out and closeted members of the transgender community. Rosser et al. (2007) found several key characteristics in their respondents, primarily that they were:

- More educated but reported less household income than the general U.S. population;
- More likely to be single, never married, or divorced;
- More likely to report no formal religion;
- Mostly receiving income from formal employment, with only 4% reporting income from sex work and 8% reporting living on Social Security or disability funds; and
- Less likely to live in major metropolitan areas.

Factor and Rothblum (2008) conducted a survey of 166 individuals across the United States (respondents contacted the researchers to request a survey if they wished to participate) that explored the topic of gender identity and community in FTM, MTF, and gender nonconforming/genderqueer individuals. The researchers found that MTF individuals often identify as transgender earlier in life than FTM individuals, but do not outwardly present as transgender until much later in life. MTFs were also less likely to disclose to their parents or seek outside support for an average of ten years after coming out to themselves. FTMs

were found to talk to others about their gender experience, sometimes even before self-identifying as Trans*. Dr. Johanna Olson, a prominent figure in transgender medicine in Los Angeles, CA, spoke during the Gender Expansion Project Conference at the University of Montana, on October 25, 2013. She suggested that the reason why FTM individuals may self-identify as Trans* later in life than MTF individuals involves societal expectations of males and females; young women who seem to act in a more masculine way could just be considered tomboys and be seen as normal, whereas young men who appear to act in a more feminine way are more noticeable and become aware of the ways in which they are transgressing social boundaries at younger ages.

Kirk and Kulkarni (2001) emphasize that while studies like the ones mentioned above are important for painting a broad picture of the transgender community in the U.S., it is also important for public health professionals not to stereotype within a community. While there are commonalities across the spectrum, how an individual defines him- or herself and how their life experiences have shaped their opinions is difficult to generalize. It is necessary to acknowledge the importance of individual stories of self-discovery, and accept that there will be outliers from the definitions we seek to create of the iconic transgender experience. This is one of the reasons why localized community needs assessments are important before planning public health interventions.

HEALTH ISSUES OF THE TRANSGENDER POPULATION

The following section describes the health problems encountered in the Trans* community. According to the World Health Organization (WHO), *health* is defined as “a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.” In keeping with this definition, the issues affecting the social, mental, and physical health of the transgender community are outlined below.

Social Health Issues

The two most commonly discussed aspects of social health for transgender individuals include the experience and impact of social isolation as well as being victims of high rates of violence. Many of the difficulties transgender people have in terms of social health can be attributed to transphobia, or the experience of discrimination based on having a gender identity or expression that varies from the sex assigned at birth (Snelgrove, Jasudavivius, Rowe, Head, & Bauer, 2012). Garfinkel (1967) suggests that transpeople evoke negative reactions in others because they violate a belief in the naturally observed dichotomy of gender and sex; essentially, members of the general population who express transphobic views see the transgender identity as something fraudulent that has committed a moral transgression against nature (as cited in Norton & Herek, 2013).

Social stigmatization and resulting internalization of negative self-image has lasting effects on the overall health of a transgender individual. Kammerer et al. (2001) found that the most harm to social health of Trans* people is done by having their reality denied by others in the community around them, from family or friends to coworkers or teachers. The researchers also found that the stress of trying to conform to accepted gender norms and avoid discovery contributes to an inability to function in society, especially in receiving an education or holding down a job. This can lead to economic instability and participation in risky behaviors such as prostitution and cycles of “acting out” where they participate in drug and alcohol abuse or unsafe sex practices. The lack of a visual and supportive, unified transgender community can also lead to risky behaviors, such as sex work. One participant in Kammerer et al. (2001) said that the reason she became a sex worker was because she thought that it was her only option; it was all she had ever seen a transgender person do. Kirk and Kulkarni (2001) stated that a group mentality can be a “sanctuary in the midst of an oppressive society” (p.157). The researchers suggest that the overwhelming prejudice and stressors the Trans* community must overcome to live in ways that feel true to them are a major source of health issues that extend beyond the social sphere to endanger them physically and mentally.

The lack of societal support for a Trans* person to live in their gender identity fully also affects their exposure to violence. Zians (2006) found that respondents feeling safe where they lived was positively correlated with feelings of strong social support; 13% of respondents reported not feeling safe in their communities. Xavier et al. (2004) suggests that fear or distrust in social infrastructures like the police is a result of secondary victimization, where they are victimized a second time by the people from whom they sought help (as cited in Testa, Sciacca, Wang, Hendricks, Goldblum, & Bradford, 2012). A well-publicized event occurred in 1998 when paramedics found Tyra Hunter injured after a car accident, discovered that she had a penis, and left her to die (Zians, 2006). Zians (2006) states that one transgender person is estimated to be murdered every month, and that 60% of all transgender persons have, at one point in their lives, been a victim of hate-related violence.

Testa et al. (2012) has found that research consistently shows rates of violence in the transgender population exceed estimates of violence in the general U.S. population. Research conducted by Kenagy (2005) found that over ½ of respondents had been forced to have sex, 56.3% had experienced violence in their own homes, and 51.3% had been physically abused. Acts of violence are infrequently reported to police. Testa et al. (2012) found that offenders can be anyone from complete strangers to immediate family members or longtime friends, and in some cases has also been the reporting police officer. Kenagy (2005) found that there was a slight difference in the amount of violence experience between FTM and MTF individuals. Specifically, trans women were more likely to have experienced violence in their

homes, and they were more likely to have been physically abused. At the time of publication, Moulton and Seaton (2008) found that only seven states have hate crime laws that cover crimes motivated by bias against victims based on gender identity and/or expression. Those states include California, Connecticut, Hawaii, Minnesota, Missouri, Pennsylvania, and Vermont.

Zians (2006) suggests that there is a strong positive relationship between good mental health, increased life satisfaction, and good social support. When strong social support is lacking, mental health is affected as well. Testa et al. (2012) suggests that physical violence also impacts mental and physical health, and a history of physical or sexual abuse has a positive relationship with suicidal ideation, suicide attempts, and substance abuse.

Mental Health Issues

In the literature, the most commonly discussed, and perhaps the most severe, mental health issue for the transgender population is depression and suicidal ideation. This is a significant factor when talking about HIV prevention because “engaging in risky behavior itself can be a slow form of suicide” (Kammerer et al., 2001, p. 26). It is necessary to develop an understanding of the ways in which internalization of discrimination and negative self-image lead to poor health. Access to appropriate and culturally sensitive health services has also been shown to influence mental health. Finally, the most controversial topic in transgender mental health is the inclusion of gender dysphoria in the DSM-V, which is used as a gateway to medical services for many members of the Trans* community and is considered to create further stigma against the community.

According to research conducted by Zians (2006), 55.1% of transgender respondents admitted to feeling sad or depressed. In Grant, Mottet, and Tanis (2010), 41% of respondents said they had attempted suicide, compared with a national average of 1.6%. Kenagy (2005) found that 67.3% of respondents who had attempted suicide said it was because of their status as transgender individuals. According to the National Institute for Mental Health (NIMH), most suicide attempts are signs of “extreme distress, with risk factors including precipitating events such as job loss, economic crisis, and loss of functioning” (as cited in Grant et al., 2010, p. 14). Grant et al. (2010) suggest that the rate of suicide attempts in the transgender population is a direct result of bias experienced in the lives of transgender people, “given that respondents...reported loss in nearly every major life area, from employment to housing to family life” (p. 14).

Ability to access appropriate health care services is also correlated with good mental health. According to Newfield, Hart, Dibble, and Kohler (2006), research participants who were receiving hormone therapy

showed a significant increase in their quality of life, regardless of what stage they were in the process. Participants identified the hormone therapy as being key to their well-being. Hancock, Krissinger, and Owen (2011) demonstrated that the self-rated happiness of transgender participants was positively correlated with listeners' perceptions of voice femininity and the speaker's likeability of their own voice.

Another common and controversial issue when discussing mental health of transgender individuals is the inclusion of gender identity disorder (GID) in the DSM, now often referred to as gender dysphoria with the publication of the DSM-V. According to Teich (2010), the name change was considered due to the belief among many professionals that GID was stigmatizing, and gender dysphoria is now defined as "a mental health condition in which a person desires to be the opposite sex of that with which he or she was born" (p. 78). While the American Psychological Association (APA) ultimately recognized that homosexuality was not a psychiatric illness, but that societal and internalized homophobia may affect access to appropriate care and cause mental distress and compromise mental health overall, the same has not yet happened for transgenderism (Mayer, Bradford, Makadon, Stall, Goldhammer, & Landers, 2008).

If a person seeking sexual realignment surgery (SRS) chooses to not speak to a mental health professional, they may be denied care, as many physicians deem surgery to be inappropriate and unethical without a diagnosis. Of course, "pathology is implicit in the mental health diagnosis of GID...and the implications of these diagnoses are that gender variation implies abnormality, illness, and a need for a viable cure" (Zians, 2006, p. 30). The NCTE emphasizes that the continued incorporation of gender dysphoria in DSM criteria creates a stereotype that the transgender community as a whole suffers from mental illness. "A lifetime of experiencing loss can cause anxiety disorders, depression, and other psychological issues. These are not the root of their transgender identity; rather, they are the side effects of society's intolerance of transgender people" (NCTE, 2009, p. 2).

Physical Health Issues

According to Grant et al. (2010), the word "transition" describes a process that some, but not all, transgender individuals undertake, and it applies to each individual differently. While some people may want to simply make a social change with no medical component, for others one or multiple medical procedures are considered necessary to embody their current gender. Also, there are individuals who will have no visible transition and instead accept that they have a gender definition that defies convention. Regardless of what the transition process looks like, there are several physical health issues that can influence the entire transgender community.

Tobacco, Alcohol, and Drug Abuse

According to Zians (2006), several national research studies identified high prevalence of substance abuse in the Trans* community. For example, McClements (1999) found, out of 392 respondents, 16% had received treatment for alcohol addiction and 23% had received treatment for drug addiction. Furthermore, 66% of respondents had experimented with cocaine, 48% had experimented with crack, and 24% had experimented with heroine (as cited in Zians, 2006). Zians (2006) also found that 25% of respondents were of the opinion that they drank too much, and 2.2% felt that they needed treatment, but had no access to the appropriate services. Also, 54.5% of respondents said they used too much tobacco, and over 1/3 of those individuals rated their tobacco dependency as either seriously or severely distressing. Stall et al. (1999) suggested that the prevalence of tobacco use may be higher in the LGBT population than in mainstream society. Use of drugs and alcohol could be a symptom of the societal pressures placed on the Trans* community daily (as cited in Grant et al., 2010). Grant et al. (2010) found that over ¼ of the respondents had misused drugs or alcohol specifically to cope with discrimination.

HIV and STD Infection

One of the reasons that little is known about the health issues of the Trans* population is that the only data available is on people who are “out”—researchers are unable to access members of the community who do not wish to be seen. Another reason that little information is available is that epidemiological data doesn’t have an additional category for the transgender community, so they often fall into the category of MSM, homosexual, or heterosexual (NCTE, 2009; Kirk & Kulkarni, 2001). This is especially problematic in HIV and STD reporting, which are trends monitored by the state and the federal government.

In 2007, California became the first state to include a transgender reporting option on their HIV testing forms. Upon making this transition, the state discovered that their transgender population had a higher prevalence of HIV than the population traditionally considered to be most at risk, White MSM (Herbst et al., 2007). The findings of Grant et al. (2010) suggest a prevalence of HIV in the transgender population at four times the national average. A frequently cited statistic for the national averages of HIV and STD infection in the transgender population is found in Herbst et al. (2007). The researchers found that 27.7% of MTF participants tested positive for HIV infection, while only 11.8% self-reported as being HIV positive. Also, 21.1% of MTF respondents reported having a prior STD infection.

Most of the research about transgender populations and their risk of HIV and STDs has been focused on the MTF community, who are considered to be more at risk than the FTM community (Herbst et al., 2007). Kenagy (2005) identified a statistically significant difference in HIV status between the MTF

community and FTM community: 10% of respondents who identified as MTF were found to be HIV positive, as opposed to 0% of those who identified as FTM. Also, the MTF community was found to be less knowledgeable about their potential risk factors and their HIV and STD status. According to Kirk and Kulkarni (2001), research studies from across the nation have shown that in major U.S. cities the percentage of HIV positive transgender individuals ranges from 20% to 50%, but these studies were done specifically with community members who are sex workers. Little information is known about the HIV status of non-sex workers and those in rural communities.

Alarminglly, Zians (2006) has found that there is no relationship between knowledge of HIV status—either positive or negative—and safer sex behaviors. Herbst et al. (2007) has suggested that race plays a role in contracting HIV and/or STDs, and that African American Trans* community members are more at risk than White members. Nuttbrock, Hwahng, Bockting, Rosenblum, Mason, Macri, and Becker (2009) have found that among MTFs of color, the number of lifetime commercial sex partners was associated with contracting HIV, Hepatitis B, and Hepatitis C. However, the number of lifetime casual partners was associated with syphilis, but not HIV or Hepatitis B and C. The number of committed sex partners was not associated with either HIV or STDs. The researchers also found that unemployment and whether or not the individual was out to family members, friends, and coworkers were associated with HIV and both Hepatitis B and C. Nemoto, Operario, Keatley, and Villegas (2004) found that among MTF participants in San Francisco, the influence of drugs and alcohol, the desire for social affirmation, and searching for love can contribute to risky sexual behavior. Mental health can also play a role, as Kammerer et al. (2001) have suggested that participation in risky behaviors can be thought of as a slow form of suicide. Finally, Kosenko (2011a) states risk factors for contracting HIV and STDs have been documented to include the following:

- Stigma and discrimination;
- Involvement in sex work;
- Lack of education about HIV and STD transmission;
- Desire to conform to gender roles (submissive behavior corresponding with feminization);
- Needle-sharing for hormone, silicone, or illicit drug use; and
- Unprotected anal sex.

Kosenko (2011b) found that identifying whether or not transgender individuals practice safe sex is difficult due to definitional disagreements within the community. Communicating about safer sex involved managing personal information about HIV status, trans identity, and sexual practices. While revealing an identity as Trans* or an HIV or STD positive status could be inevitable in a sexual

relationship, it can also be a barrier to negotiating for safe sex because “the partner’s reaction was far less predictable. Protecting oneself from physical or emotional harm at the hands of one’s sex partner meant carefully choosing who and what to tell” (Kosenko, 2011b, p. 481). Sexual safety was found to be anything from condom use to simply ensuring that the person with whom you are having sex is “clean.” Determination that a person is “clean” could come from reading how they interact socially with other people and making an intuitive guess, or it could be as complicated as an elaborate process described to the researcher as “fluid bonding,” where two HIV negative partners may dispense with condoms for intercourse within their relationship and being honest with your primary partner about any secondary partners and their HIV status. So, a transgender individual who may not necessarily be monogamous could still have negotiated sexual safety with their various partners.

One unique risk factor that transgender individuals face related to HIV infection is known as a “pumping party,” where participants receive injections of black market silicone or hormones at a social gathering. Kammerer et al. (2001) recall being told of drag shows “where all the performers who wanted hormones lined up and received them in turn from a single needle that was not cleansed between shots. These potent drugs are taken without assurance of quality, dosing prescription, or medical monitoring of effects” (p. 20). MTF individuals in particular have been reported to have people who are not within the medical profession inject silicone into their breasts, cheeks, hip, and/or buttocks. The silicone used is often industrial grade and not meant to be used medically, and is sometimes mixed with “paraffin, motor oil, cooking oil, antifreeze, or other non-sterile materials to make it flow more easily through the syringe and into body tissues” (Keller, 2009, p. 43).

General Health Concerns

According to Kirk and Kulkarni (2001), biological males and females who are not anticipating hormone therapy or surgery will be at risk for potential health issues that affect the cisgender population, based on genetics, environment, and lifestyle. There is extreme reluctance across the transgender spectrum to have health appointments that are related to the natal sex of the individual, such as prostate, breast, cervical, or ovarian exams to check for cancers; this is largely due to fear of embarrassment over genetic inconsistencies and a strong aversion to genital examinations (Mayer et al., 2008; Kirk & Kulkarni, 2001).

Health Concerns Related to Medical Transition

For the community of transgender individuals who has decided to undergo transitions that involve surgical alteration or hormonal treatments, the risk factors above are similar but have added components

associated with medical complications. The hormone therapy itself can have increased risk of negative health outcomes such as hypertension, elevated blood pressure, diabetes, heart disease, central nervous system disease, pulmonary embolisms, tumors on the pituitary gland, and an exacerbation of cardiovascular problems. There is also a risk for infection and complications after surgery, as many participants must travel large distances to receive care and do not have direct access to their physicians post-surgery, and pre-operation preparation may have been inadequate due to time constraints (Kirk & Kulkarni, 2001).

There are costs involved regardless of the type of transition an individual visualizes for him- or herself. According to the NCTE (2009), these costs could manifest either financially, due to medical bills or discrimination in employment settings, or socially, through transphobia or ostracization from friends and family members. However, the cost of *not* transitioning at all could be more severe in the long run. An individual who feels unable to transition or chooses to not transition at all could face “a lifetime in which they never feel congruence between their body and sense of self,” which can not only lead to depression, but also to a life where they are unable to live fully as they wish to live or have an opportunity to fulfill their dreams (p. 5).

Access to Health Care

The struggles of transgender people to access unbiased, knowledgeable health care resources is largely colored by discrimination and misunderstanding. Grant et al. (2010) suggest that transgender and gender nonconforming individuals frequently experience discrimination when attempting to access health care, and that this is even more frequent if the individual is also of an ethnic minority. Transgender individuals are often turned away from medical services because of their transgender status (Grant et al., 2010; Kenagy, 2005). According to Bockting, Knudson, and Goldberg (2006), transgender persons are often reluctant to reach out for care at all. This can be caused by past experiences of discrimination at a health care facility, perceived higher risk of discrimination based on the stories of their peers, and concern over being denied access to care if they fully express any mental health issues. In fact, Grant et al. (2010) found that 48% of their respondents delayed seeking care because of the direct cost, 28% delayed care due to fear of discrimination, and 50% found that in order to receive appropriate care they had to first educate their clinician on transgender health needs. Also, the researchers found that the likelihood of a patient being discriminated against increased when medical providers were aware of that patient’s transgender status.

Finally, the researchers discovered that their study participants were less likely than the general population to have health insurance coverage; 19% of participants lacked coverage, compared with 15%

of the general population. Those with insurance were more likely to be covered with state programs and less likely to be covered by an employer. The HRC published a report in 2008 suggesting explicit bias in the health care system. According to Moulton and Seaton (2008), “coverage is usually explicitly excluded for treatment related to transsexualism, even though the claim would be paid if the exact same treatment or procedure were utilized for some other medical reason” (p. 25). An example provided in the report described a cisgender man with low testosterone levels receiving hormone therapy that was covered by insurance, whereas a trans man would have to pay for the same treatment out of his own pocket.

Snelgrove et al. (2012) identified several areas where physicians felt the need to be more informed. In a qualitative study involving interviews with 13 physicians, the researchers found that clinicians lacked knowledge about transgender health needs and also lacked access to specialists who could be used as resources. If opportunities did present themselves to increase learning, the physicians suggested that many of their peers simply lacked interest in learning about the subject. There was also a general misconception regarding the inclusion of Gender Identity Disorder (GID) in the DSM-IV and how it correlates with other more well-known mental illnesses, along with the stigma associated with being diagnosed with a mental illness. Lastly, the physicians voiced concern over the ethical considerations of being a voice capable of swaying the decisions of their patients to undergo physical changes of any kind in order to identify more fully with their gender identity.

Lim (2013) suggests that the passage of the Patient Protection and Affordable Care Act (ACA) will lead to overall improved health outcomes for sexual minorities. The ACA includes federal nondiscrimination protection, makes prescription drugs more affordable, and ensures the insurance companies will be unable to deny coverage to individuals with preexisting conditions, and it also specifically provides funding for research into LGBT health needs.

Health Concerns Related to a Rural Environment

The U.S. Census Bureau (2013) estimates that as of 2012, the population in Montana has exceeded 1 million people, increasing since the last official count in 2010 that confirmed a population slightly under 1 million. Montana mostly consists of rural areas. A rural area is described as all population, housing, and territory not included within an urban area, with a population of less than 2,500 people (Rural Institute of Montana, 2010). Furthermore, almost half of the population in Montana resides in a number of frontier areas, where fewer than six people live in a square mile (Winbush & Crichlow, 2005). Nayar, Yu, and Apenteg (2012) describe frontier areas as having a distinct culture defined by self-reliance, conservatism and religiosity, distrust of outsiders, and individualism, with much value placed on family and work effort. According to Winbush and Crichlow (2005), while ¼ of the U.S. population lives in rural areas,

only 10% of physicians practice in those communities, and in the past 25 years 470 rural hospitals have closed.

Providing health care in a rural or frontier environment can provide unique challenges, such as: economic disincentives for private providers; reliance on generalists; provider shortages; greater use of subprofessional staff; geographic isolation; and informal family and community support systems (Nayar et al., 2013; Winbush & Crichlow, 2005). The percentage of people without health insurance is also higher in rural areas. On a national level, 20% of the 41 million uninsured Americans live in a rural area. In Montana, 70% of the uninsured population lives in a rural area. Oftentimes, decisions must be made about whether or not the expense of health insurance is worth the peace of mind that coverage can provide (Winbush & Crichlow, 2005). While the U.S. does not have a comprehensive rural policy at a national level, efforts have been made to start addressing rural health disparities within the Patient Protection and Affordable Care Act (ACA), developed as a platform of the Obama administration. According to a policy brief published by the National Advisory Committee on Rural Health and Human Services (2011), a number of provisions in the ACA attempt to focus on rural communities through: building capacity in order to align rural areas with Healthy People 2020 goals; developing more in depth understanding of health disparities through data collection; and emphasizing more balance in the Prevention and Public Health Fund managed by the CDC between areas with the greatest need or numbers of people and rural populations that are suffering disproportionately from chronic disease and lower quality of life.

Living in a rural area affects many aspects of quality of life for a transgender person. Swank, Frost, and Fahs (2012) have found that sexual minorities in a rural community are more likely to endure a history of subtle discrimination over his or her lifetime, and that community coping resources are limited in a rural area, leading to an increase in social stress. Willging, Salvador, and Kano (2006b) conducted research regarding attitudes of health providers in rural areas and found that while providers claimed to be accepting of sexual minorities, in reality homophobia, moral and religious guidelines, and lack of education led to increased feelings of social isolation in clients, resulting in clients terminating services. Clients who self-identified as a member of a sexual minority were met with laughter, discouragement, blame for their own problems, resentment for what was seen as “forcing” their lifestyles on their fellow community members, and fear they may convert others to their lifestyles. Issues identified for sexual minorities living in rural communities that can contribute to hesitation toward help-seeking for health care needs including the following:

- Economic insecurity;
- Geographic isolation;

- Perceptions of provider bias;
- Distrust of locally provided services in sparsely populated town/confidentiality concerns;
- Lack of LGBT social networks;
- Ideals of self-reliance; and
- A belief that admitting to any mental illness is a personal shortcoming (Willging, Salvador, & Kano, 2006a; Mayer et al., 2008; Herbst et al., 2007).

CHAPTER 3: METHODOLOGY

INTRODUCTION

The purpose of this study was twofold: 1) to provide the Montana Department of Public Health and Human Services (MTDPHHS) with a description of the lived experience of the Montana transgender community and the contextual factors that influence their risk of infection with HIV/AIDS and 2) to apply grounded theory techniques to generate a theory that endeavors to explain the contextual factors that define and shape the behavior of people in Montana who identify as transgender.

DESCRIPTION OF TARGET POPULATION

The target population for this study consisted of people living in Montana over the age of 18 who identify as transgender. Terminology to describe people who land outside of the binary gender system is continuing to evolve and expand; however, for the purposes of this study, the term *transgender* or *Trans** is used as an “umbrella” term to describe any person who has a gender identity, sex, and/or gender expression that does not match the sex they were labeled with at birth (Teich, 2010). In this study, an effort was made to include Male-to-Female (MTF) and Female-to-Male (FTM) transgender individuals, as well as those who consider themselves to be gender nonconforming.

The size of the transgender population in Montana is not currently known, nor is the size of the transgender population in the U.S. According to the American Psychiatric Association (APA), 1 in every 30,000 persons is MTF and 1 in every 100,000 is FTM (Keller, 2009). However, these estimates were determined from surveys conducted in smaller European countries examining the number of transgender persons seeking some form of health care, which could lead to an underestimation of true population size, especially since many *Trans** persons often choose not to self-identify as transgender in a health care setting for fear of discrimination (Kirk & Kulkarni, 2001). The NCTE (2009) suggests a slightly larger percentage, ranging from .25% to 1% of the U.S. population. Given that the population of Montana is about one million, a conservative estimate of the number of transgender people living in the state would range from 2,500 to 10,000.

PROTECTION OF HUMAN SUBJECTS

This study was completed in accordance with the University of Montana Institutional Review Board (IRB).

STUDY DESIGN

For information on the process of conducting a grounded theory study, please see the section in Chapter 2 entitled “Theoretical Basis: Grounded Theory” on page 10.

Data was organized and analyzed according to the socio-ecological model (SEM). This model provides a framework for conceptualizing how health and quality of life are influenced by multiple factors at various levels. These levels of influence include: the individual’s knowledge, beliefs, and behaviors; interpersonal groups such as friends and family; organizations that provide support; communities and social networks; and public policies that influence the quality of health services and other needed resources. For more information on the SEM, please see Chapter 2, “Theoretical Basis: Socio-Ecological Model,” on page 9.

PROCEDURES

Both primary and secondary data were utilized in this study. The methods of primary data collection for this study were key informant interviews, the information resulting from the Photovoice assessment technique, and a brief demographic questionnaire completed by the Photovoice participants. The secondary data sources included previous research studies. The two main methods of primary data collection are described below.

PRIMARY DATA COLLECTION

Key Informant Interviews

Instrument Development

The first source of primary data was the key informant interviews. The interviews were semi-structured, with questions based on the categories outlined in the socio-ecological model (SEM). Depending on the depth of the response, these questions were followed by probes in order to elicit further information. The loosely-structured key informant interview guide can be found in Appendix C.

Sample Selection

Seven individuals were recruited to participate in interviews regarding the contextual factors influencing a transgender person’s risk of HIV infection in Montana. Initially, a convenience sample of two or three key informants who were known to the researchers were contacted by phone, briefed regarding the purpose of the study, and asked if they would like to participate in an interview. Additional participants were recruited according to the grounded theory technique of theoretical sampling. Theoretical sampling

is a method by which clues arising during analysis are identified and pursued in an intuitive manner by the researcher (Birks & Mills, 2011). Participants all met at least one of the following criteria:

1. An activist in the transgender community in Montana; or
2. A health care provider well-versed in the transgender health needs in Montana.

Key informant interviews continued until data saturation occurred.

Data Collection

Key informants interested in participating identified a convenient meeting time and place for the interview. The key informant was provided with a verbal description of the study and a copy of the interview questions prior to the meeting. At the interview, they were asked to read and sign an informed consent regarding the nature of the study. The interview lasted approximately one hour, was audio recorded, and then transcribed verbatim. After double-checking the transcription for accuracy the audio file was destroyed. Names of key informants are not connected to the data.

The interview consisted of the researcher soliciting information regarding the interviewee's perspectives on contextual factors influencing a transgender person's risk of infection of HIV in Montana. An example of the interview questions can be found in Appendix C. Upon completion of the interview a contact summary sheet was completed to record general information about the key informant and interview, such as meeting time, date, and location, age, gender, and qualifications for being included in the sample pool. The grounded theory technique of memoing also took place in order to identify areas that needed more information in order to identify the next key informants. An example of the contact summary sheet can be found in Appendix D.

Data Analysis

Data analysis took place in accordance with grounded theory methodology. Each interview was analyzed and coded prior to embarking on the next. According to Creswell (1998), this analysis took place in three steps. First, the interviews were subjected to open coding. In this step, the researchers identified categories within the interviews relevant to the phenomenon being studied. This resulted in the reduction of the database to a smaller set of themes or categories that characterized the phenomenon being explored.

Transcriptions of key informant interviews were read by two additional researchers, who identified their own open coding schemes. The researchers met to discuss their individual coding schemes and combined them into one master coding scheme. This process allowed for the coding scheme to be triangulated, reducing researcher bias. After the coding scheme was developed it was uploaded into NVivo, a

qualitative data analysis software package. This allowed for effective organization of the interviews and ultimately showed coverage ratios by theme.

The second step outlined by Creswell (1998) is known as axial coding. In this step, the researchers identified the interrelationship of the categories: causal conditions that influence the central phenomenon, the strategies for addressing the phenomenon, the context and intervening conditions that shape the strategies, and/or the consequences of undertaking the strategies.

Finally, the third step suggested by Creswell (1998) is called selective coding. In this phase, the propositions or hypotheses of the theory was developed by writing a “story” regarding the connections identified through axial coding.

Throughout all of these steps, the coding scheme was constantly being revisited and compared with new, incoming information in order to further refine the themes and categories that were emerging.

After the final coding scheme was developed, it was emailed to key informants and Photovoice participants in an attempt to further triangulate the data. Feedback was received from two key informants and one Photovoice participant.

Photovoice Technique

Instrument Development

The data collection instruments for this part of the study consisted of a brief demographic questionnaire, photographs taken by participants, and several open-ended questions asking participants to describe to the researcher the meanings of the photographs they captured.

1. **Demographic Questionnaire:** Participants were asked to complete a brief demographic questionnaire (please see Appendix J). This questionnaire was assigned a number that corresponded with the individual interview that occurred at the culmination of the Photovoice project, and is not identified with the name of any participant.
2. **Photographs:** Each participant was offered a digital camera and asked to take photographs that illustrate the challenges they face in maintaining their health. Instructions about what to photograph mirrored the levels of the socio-ecological model. They were asked to take photographs that illustrated individual, interpersonal, organizational, community and policy challenges they face as transgender individuals. Participants were provided with informed consents outlining the confidential nature of the Photovoice process when they were introduced to the project and a second consent form

providing the researchers with permission to use the photographs provided if a participant or another human subject was identifiable in the photograph (please see Appendices E and K).

3. **Narrative Descriptions of Photographs:** Participants met individually with the researchers and fully explained the one to five photographs they considered to be the most important in relation to challenges they face as transgender individuals. The interview instrument was semi-structured (please see Appendix G), with questions designed to draw out descriptions of each of the one to five photographs brought to the meeting by the participant. These questions were based on the SHOWeD method (Wang, Morrel-Samuels, Hutchison, Bell, & Pestronk, 2004).

This semi-structured interview procedure was revised in accordance with suggestions made by a gatekeeper of the transgender community to ensure that it was culturally appropriate.

Sample Selection

Ten participants were identified, and nine ultimately completed the project. Initially, key informant interview participants were asked if they were willing to contact one or two transgender persons known to them and request their participation in the Photovoice project. If an individual was interested in participating, the key informant provided him/her with a brief written description of the project and the project director and co-director's contact information. Interested individuals were then asked to contact the researchers via phone or e-mail at which time they received further information about the study and had the opportunity to have their questions answered. If, during the initial contact, the individual expressed a desire to participate in the study, he/she was invited to attend one of two meetings during which participants were asked to read and sign an informed consent. In accordance with the principles of grounded theory, theoretical sampling was used to find individuals who self-identify with one of the following characteristics in order to provide information beyond what was able to be provided by the key informants:

1. Female-to-Male, or FTM;
2. Male-to-Female, or MTF; and
3. Gender nonconforming/genderqueer.

Data Collection

Data collection for the Photovoice aspect of the study took place in three stages over the course of the study. Data in the forms of photographs were collected, and then the researchers collected narrative stories told about each of the chosen photographs. A description of the three stages follows:

Stage One— Participants were invited to a preliminary meeting to discuss: 1) the purpose of the study; 2) the timeline of the study; 3) the Photovoice technique; 4) ethics in photography, including the need to obtain written consent from every individual that appears in a photograph (see Appendix K); 5) the proper technical use of the digital cameras provided, if the participant requested a camera be provided to them; 6) the socio-ecological model; and 7) any related questions. Participants were asked to read and sign an informed consent. Snacks and drinks were provided to those in attendance. After the meeting, participants were asked to go out into their environments and begin the project. Two meetings were held in order to accommodate the different schedules of the group. A Trello account was created to help everyone stay in touch, although it ultimately was not used by any participant. For a copy of the materials provided to participants in this orientation stage, please see Appendix L.

Stage Two— The research assistant contacted each participant a week after their preliminary meeting via email or phone call to check up on how the project was going, and whether or not there were any questions regarding the project or the use of the cameras.

Stage Three— Participants identified a convenient meeting time and place for the face-to-face interview to which they brought one to five photographs that they deemed to be most important. The interview lasted approximately one hour, was audio recorded, and then transcribed verbatim. Interviews were conducted under the terms described in the section above, “Photovoice Technique: Instrument Development,” item 3, page 33. Please see Appendix G for the semi-structured interview guide.

Interviewees were also asked to complete a demographic questionnaire providing basic information regarding their status as transgender individuals (see Appendix J). Interviews were assigned a number that corresponds with the questionnaire, and neither were attached to a participant’s name. This demographic survey was pilot-tested and revised in accordance with suggestions made by gatekeeper(s) of the transgender community to ensure its cultural competency.

Upon completion of the interview a contact summary sheet was completed to record general information about the conditions of the interview, such as meeting time, date, and location.

These stages are outlined in the figure below:

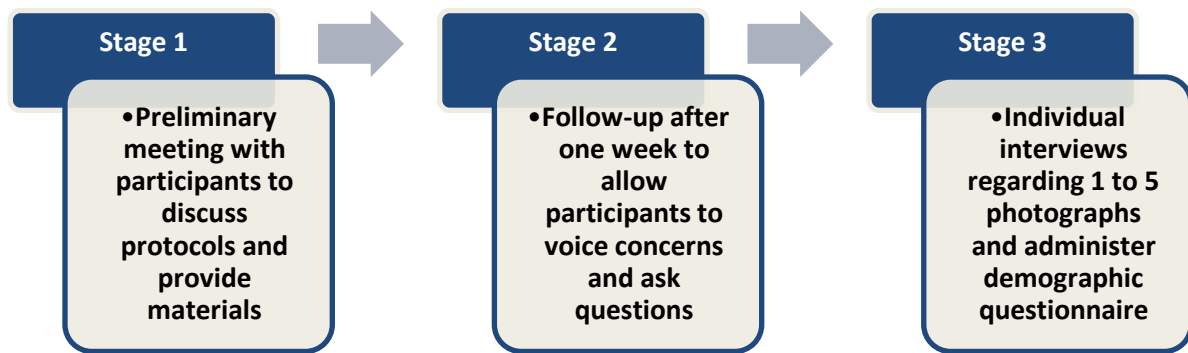


FIGURE 3: STAGES OF PHOTOVOICE PROJECT

The researchers offered \$100 per participant in order to acknowledge the participant for his or her time.

Data Analysis

Interviews

The transcribed interviews were analyzed in the same manner as mentioned in the section above, entitled “Key Informant Interviews- Data Analysis,” on page 31 in correspondence with the grounded theory analytical strategy outlined by Creswell (1998) and Birks and Mills (2011).

Demographic Questionnaire

Descriptive statistics were used to analyze the demographic survey distributed to participants. This provided a detailed description of the characteristics of the transgender individuals who participated in the study.

SECONDARY DATA COLLECTION

Traditionally, the literature review is completed at the end of the primary data collection when conducting a grounded theory study. According to the fathers of grounded theory, Glaser and Strauss (1967), delaying the literature reviews allows the development of a theory that is uninhibited by prior knowledge. Glaser (1998) also said that it is unclear what literature is relevant until the primary data has been collected. Heath (2006, p. 520) supported this idea and suggested that if the literature review was conducted before the study had been almost completed, “the result would be a constructed theory, supporting what was already known, rather than an emergent theory providing new insights” (as cited in Thornberg, 2011).

Thornberg (2011) suggests that there are problems with the notion that the literature review should come last, such as: researchers cannot unlearn what they already know, so they would be prohibited from performing research within their own fields of study; it is an excuse for “lazy ignorance” of the existing literature; it is necessary to conduct a literature review in order to submit proposals for funding of research that include strategies for project significance, data collection, and data analysis; ignoring existing research means that researchers run the risk of repeating mistakes or missing well-known aspects of phenomenon; and assuming that researchers cannot separate existing theories from their own data underestimates their ability and should be able to be mitigated in other ways.

Therefore, in conjunction with the views of Thornberg and those cited in his study regarding the dangers of postponing the literature review, secondary data was collected pre-primary data collection in order to inform the project. A key aspect of qualitative research involves the recognition of the researcher as an individual with biases that must be admitted in the beginning of the research process. According to Dey (1993, p. 229), “It is better to make ideas and values explicit rather than leaving them implicit and pretending that they are not there” (as cited by Thornberg, 2011). The completion of an early literature review allowed for any bias and assumption to be met by empirical data prior to beginning the study, thereby avoiding contamination of the data through lack of proper preparation.

A comprehensive review of recent literature was conducted to identify: risk behaviors specific to the transgender population leading to infection of HIV; barriers and enhancers to accessing appropriate services; health issues specific to a rural state such as Montana; and known health and social issues affecting the transgender community in order to provide context for the study. Information from the literature review will be used to supplement data gathered from primary sources.

CHAPTER 4: RESULTS

INTRODUCTION

The purpose of this study was twofold: 1) to provide the Montana Department of Public Health and Human Services (MTDPHHS) with a description of the lived experience of the Montana transgender community and the contextual factors that influence their risk of infection with HIV/AIDS and 2) to apply grounded theory techniques to generate a theory that will endeavor to explain the contextual factors that define and shape the behavior of people in Montana who identify as transgender.

This assessment consisted of key informant interviews and a Photovoice project. The individuals involved in this assessment came from a variety of cities in Montana in order to include opinions from across the state. The demographic information of the participants is included here.

DEMOGRAPHICS

Key Informants

Seven interviews with key informants were conducted from December 2013 to March 2014. Individuals that participated were activists in and allies of the transgender community. While most individuals have lived in several counties in Montana and other US states at different times in their lives, currently they are located in these counties: Missoula (3 interviews), Lewis and Clark (1 interview), Flathead (1 interview), Silver Bow (1 interview), and Glacier (1 interview).

The key informant interviews ranged in duration from forty minutes to one hour. Interviewees ranged in age from mid-20s to over 50 years. Six interviews were conducted face-to-face, while one was completed via Skype. All of the interviews were conducted by the research assistant. Themes from the key informant interviews will be discussed in conjunction with the Photovoice project, and will be discussed following the demographic information of the Photovoice participants.

Photovoice Participants

Ten people participated in the Photovoice project. Two orientations were held in January 2014 to introduce the project in order to accommodate the schedules of every participant. Five participants attended the group orientations in person, three people attended remotely via Skype, and two people were

met with individually due to time conflicts with the group orientation times. One participant dropped out of the project due to a busy schedule, so only nine participants were ultimately interviewed and included in the project. Only three of the participants needed cameras provided to them; all other participants used cameras they already owned or their mobile phone cameras.

Approximately two weeks from the orientation dates individual interviews were scheduled for each participant to share their photographs and descriptions of the photos with the research assistant. Six interviews were conducted face-to-face, and three were conducted via Skype or phone while the research assistant viewed the photographs on her own computer screen. Interviews lasted from fifteen minutes to one hour. Some individuals chose to share one photograph, while others chose to share five. Participants ranged in age from 19 years to 36 years. While six participants considered themselves to be native to Montana, three reported that they had moved from somewhere else: Georgia, Florida, and Wyoming were listed as the states they had most recently moved from. One of those individuals has been living in Montana for one year, and two have been here for three to five years. Six individuals reported being from rural communities, or communities with populations of less than 2,500 people. The other three identified their community as being urban, or with more than 2,501 people.

The participants represented a variety of identities within the Trans* community, described in the table below.

Identify as...	Number of Participants
MTF transgender	5
FTM transgender	3
FTM transsexual	1

TABLE 3: PARTICIPANT IDENTITIES

It should be mentioned here that the options provided to the participants included:

- Cross-dressed;
- Transvestite;
- Drag queen;
- Drag king;
- Male-to-Female (MTF) transgender;
- Female-to-Male (FTM) transgender; and
- Gender nonconforming.

Participants were also provided with an option of “other,” with the request to “please describe.” Three participants used the “other” option: one participant wrote in “FTM transsexual;” another who had selected “MTF transgender” chose to also write in “woman;” and one individual who selected “FTM transgender” also chose to write in “gender nonconforming.” One topic that was discussed with the interviewees was the fact that while some members of the Trans* community choose to identify as transgender, others wish to be seen solely as the gender with which they identify—man or woman, and some individuals also mentioned that they see the notion of gender as something that is fluid. This topic will be discussed within the themes at more length later in the chapter.

The researchers wanted to have a sense for where the participants were in their transition, as our gatekeeper and some key informants had suggested that length of time spent in and after transition had some bearing on a person’s perception and sense of self. The following table describes where our participants chose to place themselves in terms of where they are in their transition.

Stage of transition	Number of Participants
I just began	2
I am about ¼ of the way to my end goal	2
I am about ½ of the way to my end goal	1
I am about ¾ of the way to my end goal	2
I have finished my transition	2

TABLE 4: STAGE OF TRANSITION

The majority of participants felt the need to emphasize that many Trans* individuals feel as if their transition will never be over, because: 1) we are all always in transition throughout our lives, and 2) their transition will never be finished, because they will always need to take hormones to maintain their transition.

THEMES

Several themes were identified relating to the needs of the transgender community in Montana through conducting the key informant and Photovoice participant interviews. These themes were organized into ten sections: 1) sense of self, 2) age of transition, 3) the importance of love, 4) the availability of support, 5) passing as your identified gender, 6) normalization in society, 7) ignorance surrounding gender variance, 8) health care, 9) legal issues, and 10) life in Montana. There were two “overarching themes” that the researchers felt permeated throughout each of the others, which were gender binarism and

minority stress theory. When necessary, these issues have been supplemented with information pulled from secondary data, in accordance with grounded theory analysis, to provide a well-rounded picture of the issue. In order to express these properly, and to give the reader a sense of how impactful these subjects are, they have been included before the discussion of the ten major thematic categories. Each topic is supported below with quotes from either the key informant or Photovoice interviews; the quotes chosen offer the best representation of the theme. Quotes from key informants are notated with “KI” and quotes from Photovoice participants are notated with “PV” to differentiate between the two groups. When appropriate, a photograph from the Photovoice participants along with their description of that photograph has been included. The quotes have also been adjusted to allow for easier reading; meaning, words such as “like,” “you know,” “um,” “yeah,” and other words that affected the flow of reading were removed.

Overarching Themes

Gender Binarism

According to the organization Gender Spectrum (2014):

For many people, the terms ‘gender’ and ‘sex’ are interchangeable... Western culture has come to view gender as a binary concept, with two rigidly fixed options: male or female... Like other social constructs, gender is closely monitored by society. Accepted social gender roles and expectations are so entrenched in our culture that most people cannot imagine any other way.

The quote is referring to something known as the gender binary system, also referred to as gender binarism, whereby western cultures see gender expression as “temporally and contextually fixed, with prescribed forms of expression—one is born female/male, behaves in a feminine/masculine way at all times throughout one’s life” (Wiseman & Davidson, 2011, p. 529). According to Rosenblum (2000, p. 505):

The gender binarism so tightly requires the attribution of gender that the power of medicine is employed to transform intersex bodies into categorizable ones: as a matter of course, babies born with an aberrant mix of gender traits are quickly repaired to, at least physically, comply with the M or F box on the birth certificate.

Non-binary genders are, therefore, gender identities that don’t fit within the accepted binary of male and female. People can feel they are both, neither or some mixture thereof.

Many scholars have contested the existence of a clear gender binary. For example, Lorber (1993) argues that the gender binary is quite arbitrary and leads to false expectations of both genders. “Combinations of

incongruous genes, genitalia, and hormonal input are ignored in sex categorization, just as combinations of incongruous physiology, identity, sexuality, appearance, and behavior are ignored in the social construction of gender statuses” (Lorber, 1993, p. 569). Wiseman and Davidson (2011) identify three separate ways that gender binarism negatively affects the transgender community: 1) it artificially divides acceptable expression of gender to masculine or feminine, which each have social role expectations that are seen as natural to that biological sex such as appearance, hobbies, behaviors, attitudes, and beliefs; 2) it emphasizes the need to be certain about one’s gender identification and its permanence, as well as the need to silence grief and uncertainty to oneself and others; and 3) deviation from the typical expression of gender for one’s biological sex creates the need to disclose and explain, or confess, to one’s self, family, friends, strangers, professionals, and the law. According to Westbrook and Schilt (2014), our society’s need to place people into categories according to their sex and gender is an inescapable and generally unremarkable staple of everyday social interactions, which occurs every time we see another human being and their visible physical characteristics, and think to ourselves that that person is man or woman. It only becomes a problem “in instances of ambiguity, which can create an interactional breakdown, generating anxiety, concern, and even anger” (p. 35).

Our gender binary society and the programming we all encounter as we grow up helps us determine how to best act towards ourselves and others in accordance with our gender. Gender binarism is something that permeated throughout the interviews and ten themes listed below. Instead of including it as a theme, we decided to list it separately before the other themes were discussed to give the reader a sense of the pervasiveness of the topic, and how it influences our understanding of not only the themes themselves but also the context in which members of the Trans* community live their lives.

“...you are in the same bathroom all through preschool. You hit kindergarten, it’s boys and girls, and cooties develop. There is this separation. The split occurs right there. You split who you take yourself to be and who you present yourself to be. It’s a mindfuck.” – KI 3

“...you are growing up in this society that constantly tells you that you are this gender, or you are this sex, and sex and gender are one and the same, and any thoughts of variance are wrong. And the entire time you are just thinking well, what the hell is wrong with me? This isn’t how I feel, this isn’t who I am. I know now, I know that I am a woman, but society tells me that I can’t be a woman. So I have to conform to what society thinks or I am going to get outcast. Do 20 years of that...The problem is that society is enforcing this gender binary, which is in turn causing all of these mental health issues.” – KI 1

“Trans theory will set us free. I think that those unspoken rules affect all of our lives, not just the transgender community. All of the rules associated with the gender binary that we are expected to just fall in line with, and if you don’t, regardless of what it is, you are going to be social punished in some way. And I think that as we keep transgressing these different binary expectations it will allow for everyone to live a more fulfilled life in their own gender expression without feeling like

they need to be something more or something else...So I think that's really the furthest reaching implications of the transgender movement, that it really will work to set us all free." – KI 2

"This is an area of socializing, of social interaction, where you're not socialized to necessarily know what to do the way you are as a cisgender person." –KI 4

"We are brought up that way. With the media, with parents, with our teachers, they say you need to do X, Y, and Z. And the transgender community, they are out of the box. They get to a point where they say I can no longer do X, Y, and Z to fit into your definition of what I should do. I can imagine how hard that would be, to have this perception of what you need to do to be accepted by your family, by your teachers and your peers, and I think that has huge influence." – KI 5

"I mean there was so much that was done to us, you know, with the churches. And our little two-spirit people, they would take them out to the Catholic schools and stuff and shave their heads. The native people, back then it was an honor to have a two-spirit person in your family. If that little child wanted to dress like a little girl and was a little boy, or dress like a boy but was a girl, they allowed it, and they nurtured that two-spiritness. But now it's not like that, because we were brainwashed by the churches and believed that was wrong and we were going to go to hell. But now a lot of people are turning back to their native ways of believing, and accepting that. The old, old elders, you ask them about the two-spirit people, and they say oh yea, we had them, but they never talk about it because they were told it was bad." –KI 7

"I had to deal with stereotypes. I had to deal with, well, if you were born a male or assigned male at birth, people look at anything that is male-oriented or male-related and point that out to you. So if you are a transwoman, and like cars, it's like oh, that's because you were a guy. No, it's because I like cars! And if you are a transman and like cooking, that must be because you were a woman. No, it's because I like cooking!" – PV 8



"The colors of the rainbow is the pride symbol. I like how this rainbow is up and down, and normal rainbows are horizontal. It's just different. Defying the binary. It's not as big of a thing as everyone makes it seem like. It's just developing your own personality, or your own identity, rather than having someone else do it." – PV 9

Minority Stress

For an in-depth explanation of the concept of minority stress, please see Chapter 2, “Theoretical Basis: Minority Stress Theory,” page 12.

This sense of stress was evident in all of the interviews, and the reader will notice it running as a thread throughout the themes below. A couple examples of distal and proximal stress experienced by our participants are expressed through photographs below.



“I like to remain mostly anonymous about the things I make. It kind of makes me feel weird. But at the same time I want to show people my things. I have this fear of having to explain myself, to explain the decisions that I have made in my life. It affects little things that I feel passionate about. We were just talking about big news articles where people were being asked really inappropriate questions about their genitalia, or why they would do such a thing, or if it was a phase. Wearing hightops was a phase. Having sexual reassignment surgery was not a phase. They question your value system, they question your decision-making skills, they question whether or not you are crazy. Personally I still struggle a lot with being classified as crazy. There is this perception that you are unhinged, that you are weak in some way, that you are faulty, you’re defective. And it gets spread into everything. That base fear of being found out, revealed, of being criticized, of being murdered, raped. That fear trickles into everything. I can talk a lot about not having to live in fear of this, but it takes a lot. It is constantly on my mind. I’m sure I’m not the only one.”– PV 3



"You can see pain when you first look at the picture. But then you look at it hard enough, and you'll see that I've always felt that my anger is inward directed. So I abused myself, essentially, which is hard to accept, subconsciously, that I did it to myself. I felt as though my pain had to be legitimate, so I would cut. That's what started the cutting. It's not just that, though. A control over anxiety. The fear, terror, confusion, guilt, abandonment, especially my abandonment. And ownership over myself. I did it to myself. It's my body. Nobody has the right to condemn my scars. They are a part of my story." – PV 9

In fact, Photovoice participant 9 wrote the following poem regarding the above image that she would like included with this report:

Scars and Butterflies

Today I do not want to die.

Today is just as any other.

My Scars are beautiful. They tell a story.

I am alone, lost and scared. This hurts the most, the pain is unbearable. No longer am I grounded in reality. I find I am unable to turn down the volume, to be rid of the cycling and racing thoughts that scream through my mind. I have never known love, only pain and anger. Never have I known the absence of fear. Never have I felt embraced. I feel nothing. I need to feel. I need to bleed away my pain.

My sleeves are stained red from the truth.

My butterflies.



"I knew it was time to get comfortable enough were I could start considering carrying a loaded gun on me. There is this threat upon me being trans. And I do feel a lot of times like I do have a target on my head. So I do carry any time I can carry because of self-protection of me or somebody else, because I do hang out a lot of times with trans people." – PV 8

Section 1: Sense of Self

Theme 1: Embracing who you are

A common thread throughout the interviews was the fact that it was important to embrace and respect your identity as a trans* individual, because then other people would respect you for that, too.

"What I try to work with my clients on is that if you embrace who you are from the inside to the outside, then people will get it. But if you try to slap on an external identity, and believe in it from the inside out, then you look like an actor." – KI 3

"You just have to, at some point, accept who you are. We were made this way for a reason. You can't just deny your past, you can't deny the fact that you were born one gender and now you are another...I guess society has a role to play in it, but then we have to be confident on our own. We can't expect others to make our happiness, or make us feel beautiful, we have to feel beautiful within ourselves. It's just crucial to respect your body." – KI 6

"I'm not timid about anything. If someone says something or has questions, I just say yea, if you have questions I'll answer them, and this is who I am. I'm no different from you. And I think it makes it hard for people to say well that's wrong, because someone is standing up for it, instead of being timid about it, where they can tear you down very easily." – PV 6

It was also noted that when people respect themselves and embrace their identity, they take better care of themselves, because they have more self-worth.

"I think the answer to getting people to be more responsible about their sex and health in general is about helping them feel like own their bodies. That their body and behavior doesn't belong to this amorphous social judge. To be able to openly present yourself for judgement. I don't fear anyone finding out who I am...When you enter that second adolescence, and you become increasingly sexually active, you need to respect your body and yourself." – KI 3

“And at what point do you cease to have your own self-worth when everyone is constantly trying to undermine, not everyone but you know, society at large, often tries to undermine their selfhood in so many ways. At what point do you stop caring about things like your health, or your sexual health? At point do you just say, fuck it? Once we see more acceptance I think we will start seeing things like HIV rates go down dramatically, because people will feel the need to protect themselves, because they will feel more worthwhile.” – KI 2

“How self-actualized you become as a transperson has a lot to do with it. For me, as a transwoman, do I accept myself as a woman, am I totally comfortable in my skin as a woman?” – KI 4

“If someone cares about themselves, they are going to care about their future. They are not going to participate in risky behaviors. If someone doesn’t care about themselves, doesn’t have any self-respect, why does it matter?” – KI 1

“I know before coming out, trans individuals often feel hopeless or misguided, and unsure of themselves. They dive into lifestyles they wouldn’t normally participate in to hide their identity or fit in. I could see that playing a role in risky behavior.” – KI 6

“I try to encourage all of our young two-spirit people that I meet to come to our two-spirit gathering. Once they realize they have value, they have a purpose in life, that this was a part of our culture, they walk away with a sense of pride. And once you have that sense of pride in you, it makes you want to take care of yourself and who you are.” – KI 7

“Three years ago, if I was walking down the street and I had been abducted, I would honestly feel like, don’t even bother saving me. I would honestly feel like I’m not even worth it anymore. To some degree, as silly as it sounds, the fact that someone would have looked at me and seen that I looked like an attractive target, it would have been a compliment. In some silly, twisted way, it would have been a compliment. I feel differently now because I started my transition and moved here. I’ve basically just never had any self-worth. I never had any self-esteem, or felt like I was worth anything. But now I feel like, now that I am here in Missoula, and actively studying towards a career that I want, I feel like I’m kind of owning myself in a way. Making myself worth something, and finding some self-worth in this inherent strive to make myself worth something. And now if I was abducted, then I would feel like I wanted to keep living, because I just started.” – PV 4



“I have this whole routine that I have set up for myself in the morning. I do have anxiety, I do struggle with depression, and if I don’t remember to do those things in the morning it can get very overwhelming. It’s a reminder to myself that I don’t need to make decisions that bring me to self-harm. If I do find myself in that position I can always remind myself of what I need to do or who I need to talk to about what. Stopping short of a daily affirmation, it is a way that I remind myself that it is going to be ok. Regardless of how I feel, this is great. It has to be. There were so many points in my life that I felt like there wasn’t an option. I felt like I have to be this way, I have to be a woman who knows how to be a woman. I have to remind myself that I don’t have to feel that way ever again. I don’t have to feel trapped ever again. I don’t have to feel like there is nowhere for me to go, or that I don’t have anyone to talk to ever again. Also acknowledging that those feelings that I was having were not unusual, they were not out of the blue, I am not an alien. I’m not the only person who has ever had that feeling of feeling trapped like that.” – PV 3

Theme 2: Growing older

It was noted that when someone first transitions, they can feel vulnerable. But, as time passes, they can establish a stronger sense of self-identity and self-worth. As mentioned above in “theme 1: embracing who you are,” your sense of self is imperative to the importance you place on self-care. So, when people are in the early stages of their transition, they may be more likely to participate in risky behaviors.

“In my first sexual experience as a transwoman, it was with a man, and I didn’t tell him, and he read me in bed. Which is how people get killed, that was dangerous. Thankfully nothing happened, but I was willing to take that risk. I never questioned that.” – KI 4

“I remember when I was younger, I was very afraid to tell people who I was, what I was. The reaction a lot of the time was not always positive, but not always negative though, either. I’ve been doing this going on 11 years, so I’m a lot more comfortable with my identity being trans. I am much more open. I remember when I wasn’t, I did go to an extent to hide who I was, thinking that it would make things better, it would make things easier.” – KI 6

“I felt like there was this standard I needed to apply myself to in order to be accepted as a male, as a guy. And I was like oh, I remember that feeling, when I was 12 or 13 and being pressured to have sex for the first time. Everyone is doing it, you should do it, because that is how you know you are grown up, that is how you know you are an adult. That’s different situations, but the same terrible lie, it’s a lie. I don’t have to have someone sleep with me to prove my masculinity or my worthiness in the place that I’m at.” – PV 3

Section 2: Age of Transition

Theme 1: Transitioning at an older age

People who transition at an older age often face problems related to having been seen as their first identity for longer, and having established a life that now needs to be revalidated or, often times, recreated. It was also mentioned that a person transitioning at an older age can experience a second adolescence after they begin to live as their correct gender.

“When people begin to come out, and go on hormones, that second adolescence is partly due to a change in your hormone orientation. Sometimes that re-excites your dopamine receptors in the brain, that leads to arousal, so you can get kind of confused for a while. But, you also don’t have the identity you built when you were 11, 12, 13. You have to rebuild an identity.” – KI 3

“Older trans individuals, it can be a lot more difficult, because they have a longer period of time that they have been seen as their prior individual self.” – KI 6



“It’s a number of hotels. What it really signifies for me was a time of experimenting, a time when I found myself for the first time as a single woman, and wanted to experiment with what it was like to have sex with a man. I had never really done that until I transitioned. And I did, a few times, and it was neat, it was interesting, it was different. But, I always look back on it kind of scared. I took every precaution that I could. I had a friend and she was my call person, I could always call her and say ok, I am going to be at this place, so she can check on me, and I always used protection, and I always wondered, what if something could have happened no matter the protections, but at the same time who is to say I wouldn’t do it? I’m glad I had that experience. You can never be too safe, but at the same time it doesn’t mean you should avoid it.” – PV 8

Theme 2: Transitioning at a younger age

Several interviewees mentioned that people are transitioning at younger ages than they previously were. This was seen as a result of society becoming more open and more aware of the existence of gender variant individuals. The subject of more information becoming available, and the normalization of the transgender community will be discussed later on.

“I think the advent of role playing games that were internet-based, and people being able to don an avatar of any gender, age, or power they wanted to, and finding out that their psyche responded to that. So, you get this burst of younger people coming in, in my observation...Even now we get much younger ages; I see first, second, third grade students coming in and identifying as transgender.” – KI 3

“I know we have a lot of transgendered people on the reservation, and actually they are coming out much younger, still in school, and they go to school as females.” – KI 6

However, if there are not resources available to children, it can cause a lot of pain later on in life. The longer an individual goes without acknowledging their true identity, and without being supported in that identity, the more difficulty they can face.



"I see flashbacks of my childhood - feeling frustrated. The agony of knowing I wanted to play with the other boys because I belonged there but felt the agonizing reality of being an anatomical female. My mom wouldn't let me forget my birth sex. The numerous times she had me wear dresses and makeup for special occasions or begged me to fix my hair properly. She cringed when I expressed that I wanted a crew cut or yelled 'Don't pull your hair into a ponytail!' The focal point in the picture is the bottle of testosterone and syringe. Being a female to male, it has an important factor in my life. Injecting testosterone brings me closer to the body image that I have always seen. The closed door represents missed childhood opportunities because I didn't know about it nor did my parents support me in portraying (identifying) as a male. By glancing, one might not know a child identifies as transgender nor have the means to come out safely. The bottle of testosterone and syringe is a way to help the child but that child may have a closed door. It's frustrating to hide the truth or have acceptance if the truth is known."

Section 3: The Importance of Love

Theme 1: Facing rejection or loss

All of our interviewees discussed losing relationships with friends, colleagues, and family members, be they parents, siblings, or children. It was mentioned that the people who know the transitioning individual must transition as well. Some people experience that transitional process more smoothly than others. For some people, loss of a job or of their status in their community was mentioned as well.

"A lot of my friends, you know, they lost everything. They lost their job, they lost their kids, and they lost their friends. They have to rebuild. They have to rebuild from the bottom up." – KI 5

"Loss is such a huge part of the transgender experience. Most people I know who transition go through a great deal of loss. Usually of relationships, of some level. Either it's family, or it's friends, or coworkers." – KI 4

"I've lost my entire family through this process. I am fully alone. Alone. I am on my own." –PV 9

Being rejected by your friends, family, or by romantic partners can all create potential for participating in risky behaviors. Some interviewees described how being rejected by your support systems can lead to personal resource insecurity, as in financial or housing troubles, which can in turn lead to risky behaviors.

“It’s a slippery slope towards insecurity, once the closest people in your life banish you, whether it’s your parents and you’re young and you need help with normal things, like college applications or making sure your cell phone stays on. If you don’t have a cell phone how do people get in touch with you, how can anyone who wants to be a part of your network get in touch and know you are safe? How do you get a job because no one can call and get a hold of you? How do you get housing, if the landlord can’t call you? And when you are in such a disadvantaged point, and you have no power, and you are just desperate for a place to stay safely for the night, you are probably less likely to stand up to that individual letting you sleep on their couch and say no, I want to use a condom.” – KI 2

“There’s a whole issue with [transactional sex] because, when it comes down to it, do I get my money and have unprotected sex with this person, or do I starve for the next week or get kicked out of my house because I can’t make rent?” – KI 1

Rejection can also lead to searching for anyone who accepts you, which can open up possibility for participation in risky behaviors.

“I think it is a matter of acceptance. If you are finding, after you transition, acceptance in that support group you are less likely to subject yourself to risky behavior. If you are not finding acceptance, that is one more door that is closed to you. I think that as your world, your sphere of relationships with other human beings becomes smaller, you are more likely to fill those gaps with risky behavior.” – KI 4

“Take the person that comes out to family who disowns them, their friends think they are freaks and quit talking to them, and they have absolutely no one in their life, no one who supports them, understands them, wants to talk to them. All of a sudden, someone shows interest in them. That person enters into a relationship with them. They are the only person in that person’s life who actually recognizes them, who actually treats them with any dignity and respect. And then they decide to have sex, and they don’t want to use a condom. Are you going to stand up for your rights?...In reality, for an individual who has lost everything and all of a sudden has something, they are going to want to hold onto that. Generally speaking, they will take that risk.” – KI 1

“The constant rejection, if you are getting rejected by everyone else and you aren’t even accepting of yourself, you are going to migrate to anybody who is going to give you love and affection. The more rejection that a person faces, within their families, and their friends, their employer, their churches, that may lead them to go out and find someplace where they can be accepted...You are going to migrate to wherever you get love.” –KI 5

“Well, in terms of being a trans guy, it’s like when I have found myself having sex with another potential partner and they tell me they aren’t comfortable using a condom. I thought to myself you know, if this person doesn’t want to use a condom, does that mean they don’t want to have sex with me because my body is not the body that they expected? It’s hard not to internalize that. I don’t want to feel rejected. I want to be wanted. It sounds like such an easy thing, right? When

you're not feeling so confident in your body, it is devastating when you get to that point that someone suddenly for whatever reasons doesn't want to have sex with you because of this, but what you are feeling is that it is you. You don't have a penis, or you don't have a vagina. Or, they are just having sex with you because they feel some sense of pity, and really you should just go with it because what if you never feel close or intimate with somebody ever again.” – PV 3



“I went through a period of time where I was not necessarily being safe when it came to sex because I was thinking well, if I say no, that I want them to use a condom or that they can't not use it or whatever, they probably won't want to sleep with me, and let's be honest I better get it while I can because when I start this transition people are going to look at me weird. All these kind of irrational things go through your head. So, that's a definite risk factor for people in the community. And I could see that being something that a trans person might think, I don't think that's only me that has ever thought that. I learned all about what it's for and why you need to use it, and that it's both people's responsibility. But when you kind of get into that situation, for me I just froze. Because even in times I would tell myself, I'm not going to do that again it's dumb, you need to speak up for yourself, I still would do it a couple times after that. I think it is pretty fear based. Fear of rejection, I think is the biggest part. I think for anybody, it is hard to be rejected. Having that fear is kind of normal. But for somebody going through something that is different, they think well maybe I can't be intimate with anybody because they might think I'm a freak.” –PV 7

Theme 2: Searching for love

As we began to discuss in the theme above, losing or being rejected by the people who used to provide a person with love in their life means that they are now needing to fill a need that some of the interviewees described as a basic need to love and be loved, or a basic need to be unconditionally accepted. This instinct is a powerful one, especially when it comes to a person's willingness to participate in risky behaviors. Also, searching for love can feel difficult for a transgender individual.

“Always for a transperson the concern is about how am I going to find love? Who is going to love me? If you think about it, naturally, most people don't gravitate towards transpeople. A heterosexual man or woman is not looking necessarily for a transperson. So the field is pretty

narrow...I think it is harder for a transperson to get over that initial hurdle and to meet somebody with whom they can click, with whom they can have that kind of romantic relationship at last. So to find romance is real difficult. The reason I mention that is because I think that as a result transpeople are more inclined to put themselves into riskier situations...I think there is that desire to love and be loved, and if you ask me that is the strongest basic desire, instinct if you will as human beings, that we have. Let's say they are able to hook up, then the likelihood of them having unprotected sex is greater because they are trying, so desperately, to love and be loved."
– KI 4

"The desire to be accepted is powerful, honestly. You can talk a trans individual into a lot of situations or scenarios because they are willing to try and fit in. I know as a transwoman myself a lot of guys push for unprotected sex, and they feel like I'm not going to say no because of my limited pool of partners. And definitely social situations, too. When I was younger I would just try to fit in with the party scene at school, and drink along with them, and experiment with drugs..I would say trans individual are people who really push for that. They strive to fit in more than most cisgender individuals do." – KI 6

"Everyone has their story. The bottom line is I think we make it too complex. Isn't that what everyone is looking for? To be unconditionally loved and accepted? And we do, we make it so complex, because of our societal expectations." – KI 5

"My boyfriend had broken up with me, and I wanted to jump into a relationship, which isn't the healthiest thing to do. I found that a lot of men want to experiment, which was a Catch-22 because I was looking for a relationship, but at the same time I also wanted to experiment, so we were helping each other in a way. But a lot of time I was hoping it would end up in a relationship. It didn't really have anything to do with my previous relationship, except that I was feeling lonely and desperate." – PV 8

"You need to know that someone is going to accept you. You might have to be more patient than the average person, but you are going to find that somebody and it is more important for you to be safe about it, for you and your body, than to just have those few moments where you aren't afraid of rejection." – PV 7

Section 4: Availability of Support

Theme 1: Needing support

In the last section, the themes of loneliness and rejection were discussed in terms of how they could lead a person to participate in risky behaviors. The interviewees also mentioned the other side of the topic, which is that if someone feels supported they will participate in healthier behaviors. The more support that an individual has throughout their transition, the more they will respect themselves, which has been demonstrated above to be critical in their health and well-being. This support can be in the form of a church group, family, friends, or in available community resources.

"Having the support structure in place is night and day for a trans person. Having people that support you and tell you that what you are doing is awesome, that you look great, and that you seem so much more happy, and reaffirming that your gender is great, it really helps people be assured of themselves, and helps people continue forward in a manner where they respect

themselves as individuals. When an individual enters into transition, the number one thing that I urge trans people to do is find some form of support structure. It doesn't have to be your family, it doesn't have to be your peers. Go to a group, do something, hell, even if it online, find someone to talk to, to connect with, to have that support. Having any kind of support that reaffirms your identity, reaffirms who you are, is ultimately bettering your mental health and your well-being as an individual. And it is allowing you to reaffirm your own identity, and to reassure yourself that what you are doing is alright.” – KI 1

“My mother has been a huge support in my life. She helped me start hormones at 15.” – KI 6

“What I’m finding is that those that had a good childhood, a good foundation, they had a more successful transition.” – KI 5

“I was real fortunate in my transition that I had my recovery group, my church community, and I had my ex-wife, she was my best friend throughout my transition. I had supportive people with me all the while.” – KI 4

“Something that really helps is having a community to support you.” –PV 3



“This shows part of my weekly routine. The bottle is available for a shot to the thigh, which is usually a primary place for FTMs to inject themselves. It’s simple, but I’m lucky that I have someone to do it for me. I like to also do it in the deltoid area, and doing a shot in the shoulder is hard to do on yourself. You have to be really self-reliant in a lot of ways. I went to the doctor 4 times just to get instructions on how to get it done, and paid \$43 dollars each time. To do it at home, it’s \$.20 per syringe. It would be great to have a place where transpeople could go and ask questions in the community, especially in the beginning. Where to put it and how to dispose of it properly, without the big cost associated with a doctor. For children growing up not knowing better or being desperate, to have a safe place that is affordable.” – PV 1

It is important to mention that the availability of the internet has made finding a supportive community easier in recent years, especially in a rural state like Montana.

“The internet can be really helpful too. Oh my gosh! How do you navigate through all of it? There is tons of information...I think the internet can be really good for individuals who aren’t out yet, there is a lot of fear, and where they can go to find help and support in making a successful transition.” – KI 5

One key informant mentioned that the availability of information on the internet could actually cause problems for the Trans* community in Montana. This key informant was concerned that individuals on a self-directed path could end up in risky situations without being fully informed, either because they are starting to transition without going through the appropriate amount of counseling or without enough support, or possibly getting their hormones and supplies off the internet. Of particular concern was the danger of potential violence.

“My fear is that...people don’t recognize the risk. They don’t realize how scary it is to go to a bar in a small town, and to come on to somebody, and assume they might be friendly, and to do it in front of their comrades, that’s how people end up killed.” – KI 3

Theme 2: Building a support network

Having a support network is not a given for trans individuals. As discussed earlier, they often face rejection from people who were once close friends or family members. Because of this, they sometimes have to actively choose to move away from a support network, and take steps to building a new one on their own.

“For a lot of students here, their families don’t get it or don’t want to get it, or are just distant, and they begin to form families of choice, and build that network.” – KI 3

“I always tell people if you have people in your life that don’t support you and that are actively hurting you, they don’t need to be a part of your life. Family, that’s where the hardships are. Friends, it’s easy to say yea, screw you, I don’t agree with you or whatever, and distance yourself. But family is really difficult. I definitely urge people to be patient with family. But, at the same time, if you being patient with your family is outweighing the benefits of you just blowing them off and helping yourself, say bye. Get yourself in a good place. Get yourself in a place where you can support and respect yourself as an individual.” – KI 1

“Going from one support network to another is difficult. A lot of people refuse to change their way of thinking, or they don’t want to believe a certain aspect because of religion or whatever, so that can be a lot more difficult. But you do, you have to be more active, you have to be willing to sit and talk with people, or help them understand, the ones you want to hold onto. And you can also give up on them if they turn away from you.” – KI 6

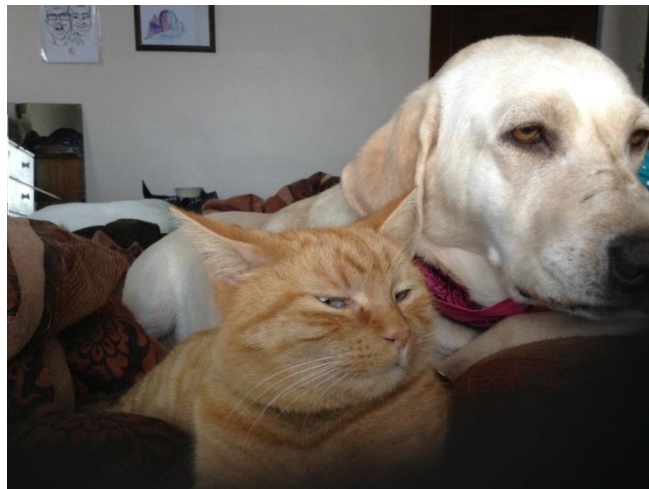


I didn't have many friends. I felt stuck in a box. But, growing up there was always a piano in my home. I could sit at the piano for hours and play, and without really saying anything or making it obvious to anyone in my house, I could express myself. The piano was always important, and is an image of self-expression for me. I am here. And even though I can't speak, I have feelings. I think a lot of this is significant today, because even today I find myself in a room, with the doors locked, playing the piano to express myself. A lot of what I found myself expressing over the years was issues of self-identity, issues of who am I, what am I. Eventually what I found was that I could write down, on paper in words, the things that I wanted to say, just really kind of dark, loathful feelings. But everything I played was so cheerful and floaty. I would set words to a song, words that said I want to die, but what people would see or hear were these floaty, elegant, cheerful songs. In my mind, what I was trying to tell them was that I wanted to die. It's not always easy to express yourself. Even when you know exactly what you want to say, it just chokes up in your throat, and you can't say it. You want to express yourself, you want to put yourself out there, you want to say this is who I am, but on some level if you can't tell people who you are people will never know who you are. This has a lot of meaning for me. Just find your own voice. And do whatever you have to do to make people understand you. Do whatever it takes to let people know that hey, I'm hurting. Hey, I need someone. I just need a hug. Simple as that. No matter how you do it...don't do what I did. Don't hide behind the music. I always knew what my songs were saying when I was young, in my home, but as I grew older I realized other people weren't interpreting it as I was. So don't hide behind the music, and wait for people to just figure it out. Put yourself out there. Because, when I felt this way, if I had been made a victim I wouldn't have cared. I would have sat there and let it happen, and wouldn't have wanted to be saved. I wanted to die. I tried several times to kill myself, I failed obviously. Just don't be the kind of person that hides behind the music." –PV 4

Some Photovoice participants mentioned the important role their pets play in their support network, due to the unconditional love they provide.



“Everyone needs a loving and understanding little cuddle bug. Seriously. Emotional support! Everybody needs emotional support. He wants to be with me regardless. He probably does not care who I’m sleeping with, as long as I’m sleeping with him.”—PV 3



“I came out as a lesbian in Sydney, MT. Cowboy country, you know. And for them a lot of times it was like oh, well you haven’t had the right man yet. And I would ask, have you had the right man yet? And they would say God no, why would I? Well, why would I? But, and then I came out as trans here. And I went back home for Christmas and the couple of family members that did know a little bit beforehand, for some of them it was fairly easy. They asked a couple of questions and then just said well this makes a lot of sense, just knowing you. The most problem I had was at work. A lot of people sitting around listening to Rush Limbaugh at work. And I remember when they were worried that there was a gay guy in football, and wondering if it was going to be a problem or not. And they were sitting around agreeing with him, about how LGBT people shouldn’t have rights and everything. That was the environment. So I was lying in bed, thinking about this project, and I just started talking about how they don’t care what my status is, they don’t care what I identify as. They care that I love them, and that I feed them.” – PV 6

Section 5: Passing as your identified gender

Theme 1: Going stealth

There are many benefits of being able to pass as the gender you identify with. One that is commonly mentioned is that you experience less discomfort surrounding the fact that you were assigned a sex at

birth that corresponds with a gender that you don't see yourself representing. People also don't want to be seen as a "trans" man or woman, they want to be seen simply as a man or a woman.

"I do have some transgender friends who are stealth, and I respect that, too. I respect where they are at. They've done their struggles, and they don't want the pressure anymore." – KI 5

"Well, I know a lot of people, their fear is to be recognized as trans. Before you become trans, you don't want to be known as trans, and once you are seen as trans, you want to be seen as the gender you identify as. So a lot of people go to a lot of trouble to hide what they are, or what they feel other people won't accept." – KI 6

"I think there are a lot of trans people out there that just want to pass, and want to blend in, and don't want anyone to know. They don't want anyone to know that they are gender diverse because they don't feel like a trans person, like a male to female individual, they do not feel like a trans person. They feel like a woman. They just want to be acknowledged as a woman, and they want their body to be as close to being, or be, the woman that they feel they are, and once they get to that point they are at that point. They are done." – KI 1

"I think there are a lot of things that we don't even realize are spoken rules, like the bathroom designations, that really are very vivid for individuals who don't identify one way or another. I think that when you never really feel like you can just kind of go on autopilot, or just be yourself, it is probably a constant kind of gnawing for individuals who are transitioning. People that pass don't experience that the same way as the looked-at-ness of someone who is mid-transition." – KI 2



"When I look at this picture, I see a person who can use it with ease. The strong desire to be that person to use it, to not worry about the transsexual factors of not being read or product mishaps. On the other side of the divider is the toilet I feel compelled to use due to safety and mechanical issues. It's easier to make adjustments in the privacy of the stall rather than pray an anatomical guy doesn't walk in."—PV 1

Public Safety Survey

1)

☐ Male

☐ Female

☐ TransMale

☐ TransFemale

“The residence life office and office of public safety sent out this survey about how to improve safety across campus. And the very first question was with which of the following do you most closely identify. There were four choices. And right away, I had to stop and I had to think about that a lot, because being a public safety survey I can completely understand why they would want to draw that line between cisgender female and transgender female. But it also left me with the dilemma that even though this was anonymous, I had to make a choice right now to either identify myself as a transgender female or to in a sense lie to the survey and check myself as female, which I would have liked to do. Because, at no point in my life did I ever say I want to be a transgendered female. I want to be a trans woman. The idea has always been to become a female, to become a woman. Plain and simple, to be a girl.” – PV 4

Theme 2: Needing active participation

While some people try to hide the fact that they are a member of the Trans* community, either because they find it to be too stressful or because they simply no longer identify as “trans,” there was a sentiment expressed by our interviewees that the Trans* community needs people to participate, and to be open about their identity, in order to help the community move forward.

“As an organizer, it frustrates me. I get it, I totally get it. As an organizer who is 6 foot 2 and is 240 pounds, and has a very big frame, I accept the fact that I know that I won’t pass, and I use the hardships of not passing to make lives better for the entire trans community. If I would have been 5 foot 6 when I transitioned and maybe 120 pounds, I can’t say that maybe I wouldn’t just pass and disappear. There is definitely part of me that because I couldn’t pass really encouraged me to become an activist and really encouraged me to reach out.” – KI 1

“I don’t have much connection with trans individuals in my area, a lot of them aren’t really out or involved in any way. It seems to be that people are so concerned with living in stealth, they just don’t want to stand up for the community anymore. They stop making the effort. All of a sudden, they are no longer trans. They are just their gender. And I feel like that’s not really helping our progression. We need to make a difference for the ones below us, make it easier.” – KI 6

“I think it is very powerful, for those who are early in transition, who live in fear, to tell them you don’t have to live in stealth. For them to see the community out there. To see how empowering it can be to be out there, and be yourself.” – KI 5

“It’s kind of interesting, because at one point I wanted that, too. I just wanted to pass, and be as stealth as possible and be treated as a woman. And I do want that still. But, not at the expense of

the transgender people. A lot of times people transition and they can be stealth, they just move away and totally leave the community. So here you are, part of a community that is supporting you, and then you are good to go and you are done and you leave and everyone else gets left behind. So, I can't do that. You are trading one secret for another, you are going from knowing who you are and not telling anybody to knowing who you were and not telling anybody. Where is the freedom and liberty in that?" – PV 8

"I have one acquaintance who is post-operative and who is on hormones, and she told me she no longer identifies as trans. And I think that is absolutely ridiculous. It's like saying, if you are a woman, and you are only attracted to other women, and you never want to be with a man, that's like saying well I'm attracted to women, but I don't identify as a lesbian. You are a lesbian, that's just who you are. I understand that there is this new age movement not to put labels on people, but labels help others understand an individual. And I think it is important for people to embrace certain identities and not be ashamed of those. So I embrace my transgender identity, I'm not ashamed of that, I just don't want to look trans. I want to look like a girl." – PV 2

Theme 3: Being able to pass

Being able to afford the surgical interventions that can help you pass is an indicator of a degree of financial stability, and can lead to less discrimination in other areas of your life. It was also mentioned by some interviewees that they are afforded a sense of security in being able to pass as the gender with which they identify.

"I think you see an attitude shift between those that are pre-operative and those that are post-operative, part of that being the financial structures. Those who are able to obtain those surgeries are generally better educated, generally have better access to resources, better access to health care, and are overall just better off."—KI 1

"And my only saving grace is that I pass so well? That's just fucked up. Just because my Adam's apple is prominent, I have facial hair, my voice is deeper, I dress masculine, that affords me some kind of safety."—PV 3



"This one is just me wearing a tie. It's a geeky tie. After transitioning, and being a man, I can wear geeky things without people questioning it. I have a Nintendo jacket. Love Nintendo, have always loved Nintendo. And when I looked like a lesbian, and I wore it, people would just be like oh that's a cool jacket, why are you wearing it? And now that I look like a man, people are like hey man, nice jacket! The male privilege is very interesting." – PV 6

Section 6: Normalization in Society

Theme 1: Increasing acceptance

As transgender individuals and their stories are normalized through pop culture, we can see a shift in attitudes towards the gender variant community.

“Well, if you think of popular movies like TransAmerica. If you look at public figures like Chaz Bono. If you look at other figures that are just making it a household identity.” – KI 3

“Culturally I think it is becoming more acceptable, and I think as gender roles are changing and becoming more malleable, as people are presented with that thought that what if I fell in love with someone, and I think I’m a cis, straight person, and my new boyfriend is trans. I think a lot of people are thinking about that and becoming more open to that and thinking well, whoever I love, I love.” – KI 2

“There is finally a lot of research being done. That gender confirmation surgeries reduce risk factors, of suicide, of attempting suicide, of mental health issues, and the costs of this simple surgery are far less than a lifetime of mental health services because this person doesn’t have access to their hormones or that. So I definitely think we are at a huge turning point in how trans people are respected in the U.S., and the access they have. I’m hoping that once these things become more accessible we will definitely see a drop in suicide and HIV risk.” – KI 1

“About maybe 4 or 5 years ago, during our Indian celebration, our Native American Indian Days, we actually had a two-spirit contingency that marched through there, with a banner and all that. And we didn’t know how we were going to be accepted, because it has never ever been done, and as we were walking down even our chief announced us as we walked by, Montana Two-Spirit Society. We didn’t know what was going to happen, if someone was going to shoot at us or throw rocks at us, cuss us out or whatever. And I could not believe the reception we got from the people. Giving us thumbs up. Saying it was about time. Cheering, screaming for us as we walked by. It was really nice.” – KI 7

Even though we see this change happening, it is happening slowly and over time. So, while the interviewees were optimistic about change, they also emphasized the need for more patience.

“Trans people as a segment of the population is still relatively new. We’ve been around since the dawn of civilization, but where we are significant enough to be recognized as a class of people is relatively new. So we have to give society a little while to adjust and catch up. But I think that is happening. What I like to say is that we are changing the world, and I believe that. And this is how we are doing it. This study at all is not something that would have been conceived of, maybe even ten years ago. We are getting there, just slowly.” – KI 4

Theme 2: Wanting to be seen as normal

People need a chance to learn that transgender individuals are just regular people, that they aren’t so different from anyone else, and they wanted to be treated just like any other person. As society has an

opportunity to learn more about the Trans* community, hopefully they will become better understood and accepted.

“People have this idea that trans people are just out there, just really socially outcast. And besides for the fact that I had this particular thing wrong with me, that I had corrected, in all other respects I am pretty socially in the main.” – KI 4

“People just need to be informed, or to come hang out with a person like me to understand I’m just a regular person, just like the rest of us.” –KI 6

“Breaking down some of those barriers, how is it going to be done? By educating. By educating people on the true internal landscape, by having transgender people tell their stories. I think that is so empowering when you listen to the fact that their life is not easy, at all. Who would choose this? People need to see that this is not a lifestyle. They are just people, too. And they are stronger than we are, I think.” – KI 5



“When I was taking this, I was feeling attractive. I’m no different from any other girl. Of course other people feel this too, but specifically women feel the need to be attractive. And that’s how I was feeling here.” –PV 2



“For pretty much anybody, you want to just be another person in the crowd. To just be normal. And that’s the reason why I took it. It doesn’t matter who you are, whether you are transgender, whether you are any part of the LGBT community, or just someone who has low self-esteem. You want to be normal. Being transgender, I stand out. You can’t miss me coming down the sidewalk. But, that’s not how I see myself, as someone who stands out. I see myself as just another person walking to school. There are people that look and people that comment. And there’s people that sit there and go, I like what she is wearing, that’s a great shirt. I’ve experienced every single part of that, whether it be bad or good. It’s definitely something that impacts me in my day to day life.” – PV 5



“I’m getting ready for the day, washing my face. I just wanted to take some photos of really normalizing things. People ask me all the time, oh what do you do with your day, in your spare time, and I just say you know I am really pretty boring. I don’t like to stay out late at night when I work at 7 in the morning. I like to stay home and watch Japanime. I like to do research on all the designs of home décor lamps that are coming out that year. That’s what is fun to me. It’s nice to not feel like you are a two-headed puppy. People say oh how unusual, how unusual that you are trans. You must be a unicorn. No, not really. You would be surprised at how many of us are out there, just washing our faces in the morning.” – PV 3

Section 7: Ignorance Surrounding Gender Variance

Theme 1: Lacking comprehensive sexual education

Lack of knowledge was mentioned throughout the interviews as being a major barrier to overall good health and well-being, particularly in regards to HIV risk. Lacking quality comprehensive sex education was seen as a problem because people weren't receiving knowledge about different types of sex, or even about different types of gender and sexual orientation, either at all or until much later in life.

"I think that sex ed in the majority of communities never addresses trans individuals and rarely addresses LGBTQ oriented individuals. I think that that general lack of a direct approach in sex education—that if you are only hearing about sex education between one man and one woman having regular vaginal intercourse, it might not seem so relevant to you, and you might not pay so much attention...And when we talk about contraception as just a method of preventing pregnancy, then people who can't get pregnant, maybe it's not at the forefront of their mind! I think that once we open up sex ed to talk about more than just heterosexual relationships, we will be able to have more robust conversations about things like consent and contraception negotiation between all kinds of individuals." – KI 2

"The fact that there isn't, or hasn't historically been comprehensive sexual education that's gender inclusive—if you're not educating people, they're not going to know." – KI 1

"Sex is something to find so easily. Instead of pushing people away from it, push people towards good information, and if you are going to participate in that, take the right precautions. Inform them to make better decisions, so you aren't just being reckless to try to fit in." – KI 6

"They need more education. I know the schools are not educating on transgender or any of that, on the reservation, as far as I know. I think it would be wonderful if they could get that in there, to teach about two-spirit people on the reservation." – KI 7



"I wanted to portray something about how it is empty. What could happen if you are not protected for a sexual act. A transgender person is human, and needs to be protected sexually as well. This image could educate other people because no matter who it is to fill the clothes, everyone needs to be smart and use protection. We need to get the word out, and educate people. Supply people. We need to educate and have resources for children who are feeling frustrated with their bodies. The only thing I remember in my sex class was that we talked about STDs!" – PV 1

Theme 2: Misunderstanding HIV and how it is transmitted

Several interviewees mentioned the fact that there is a perception in society that HIV is the gay disease. This makes prevention challenging, because traditional prevention messages may not be reaching the Trans* community.

“They think HIV is the gay disease. It’s not. Make knowing your sexuality and knowing about HIV and your status fun and enjoyable, and de-shame it. If the goal is to reduce transmission of the disease, and the transmission mode is through sexual contact, we have to make it ok and safe for people to know their status.” – KI 3

“Even now that misconception is still out there, despite huge efforts amongst HIV professionals. You get this interesting misconception where you think ‘well, I’m not gay, even though I’m a male-bodied individual having sex with another male-bodied individual, so I’m not at risk.’ No, no, no. That’s not how things work.” – KI 1

“When we go to Adam and Eve, before when I looked like a woman they just said oh you don’t need protection. You are lesbians. But you should, even if you are two women. As two women, I never had condoms pushed on us, never once, even when we were buying dildos.” – PV 6

Theme 3: Believing that the transgender community doesn’t exist

It was noted that there is a lack of understanding in society about the gender spectrum, and that the Trans* community exists in the first place. This creates a lack of identity for an individual who identifies as gender variant, because they might not know what they are feeling, or that there is a word to describe how they feel.

“There’s a lot of people who will say, ‘well, there is no risk of HIV because there are no statistics.’ Well, it is a marginalized part of the population, not very many people participate in studies, not very many people do studies on trans individuals, and so those statistics just aren’t there. It doesn’t mean that the community’s not there.” – KI 1

“I met individuals who hadn’t transitioned yet, and there is still that confusion, separating the gender identity from the sexual orientation. I met individuals who did have risky behaviors, and they just weren’t sure, ‘well, am I gay?’ They themselves couldn’t separate sexual orientation from gender identity. And that’s one of the biggest things from the non-transgender community, because I have a lot of friends and family who ask me a lot of questions, and that’s the biggest confusion. They don’t see how to separate the two, that they are two separate issues.” – KI 5

“It took me two years to process my identity, and who I am, and my discomfort, just to the point where I felt safe. Telling somebody that I am transgender, and realizing that I can make changes, that I can change. Before, my perfect answer was joining the army. And then I realized, oh my god, something is wrong.” – PV 9

“I think it was a missed opportunity because if I was more knowledgeable about it, I could have transitioned earlier. I didn’t know who to go to or who I was. I basically just stuck my nose in a

book, and excelled in school, and didn't have a social life. I remember in college I briefly saw a movie where a guy had a phalloplasty and I thought that was the coolest thing ever. I looked into it briefly and put it in the back of mind. It wasn't until I met a friend who told me a little more about it, and then a couple of years ago I looked even more into it and then I was like oh, this is it." – PV 1

"I think it is ignorance because a lot of people just don't know. I think it's because it's not a super common thing, so your average household is not going to have someone who is trans in it." – PV 7

"I think it is hard for people to imagine something outside of the either or. You either are this, or you are the other." – PV 3

Section 8: Health Care

Theme 1: Needing access to trans-inclusive medical providers

Having informed and caring trans-inclusive medical professionals was seen as a necessity, and they are also rare. Dealing with unsupportive medical professionals was identified as a barrier to good health and self-care.

"If you don't feel like your doctor is going to be nice to you and accept you, and understand that you are trans and not have to explain yourself or defend your position, you are much less likely to go to a doctor. If you don't have a place where you feel that you are safe, why would you go for HIV testing if you are just going to get harassed by the nursing staff and called the wrong pronoun, and treated like a lesser, or if they send you to the bathroom and ask you to do a test for the genitalia you don't have."—KI 2

"There's a great deal of lack of knowledge from post-op providers, that these risks exist. Comprehensive health care for trans individuals, especially when you get into some of the less expensive surgical intervention options, the level of care and after care and education isn't there." – KI 1

"The local pharmacy, almost every time I went to pick it up at least one or two people would ask, what are you using this for? I don't have to tell my pharmacist that. One lady did it a couple of times and I finally said I am taking testosterone because I am transitioning, and then she finally stopped asking. I didn't want to come out to her. There's a lot of weird shame attached to it, it's very daunting." – PV 3

Even when quality health care has been found, it was mentioned that people don't always communicate openly with them for fear of confidentiality laws, or simply because you no longer wish to identify as a member of the trans* community.

"My doctor is incredible...I was her first trans patient about 10 years ago. She has been really helpful. She started me at 15...It's good that there are a lot of good health care individuals out there who can give you the right guidance and the right help, and obviously the right tools for

your medications or your hormones, and it's all about keeping communication. You have to be open with them, talk with them, and let them know what is going on.” – KI 6

“I just know a lot of people on the reservation hate going to the hospitals because of the confidentiality law, and when it is brought up and someone breaks that nothing is done about it. To me that is grounds for immediate termination.” – KI 7

“Look at the transwoman who has been on hormones for the past ten years, has been self-medicating, passes, looks fine, no one knows, they go into their health care provider, they don't tell them they are trans because they don't want to have any issues. They are still male-bodied, they are having sex with a male-bodied partner, but they're not telling their health care provider. They say yes, I am having sex. Is that health care provider ever going to think what kind of sex are you having? Or are they just going to assume that you are having vaginal penetrative sex. But if you aren't divulging that, and you are just conforming and just trying to fit in and hide your identity at that level, then you are just putting yourself at greater risk.” – KI 1

Theme 2: Finding medical supplies

Not all medical providers and pharmacists caring for gender variant individuals are created equal. There was a lot of confusion in the medical settings and among the interviewees about where to get a clean needle supply and how to properly dispose of those needles. In order to get a reliable system in place, people needed to do a lot of research on their own.

“That's the thing that I also try to make people aware of—you don't need a prescription to buy needles. There are a lot of people who just assume well, I don't have a prescription so I can't get clean needles. You can order them on Amazon! I buy cases of needles for hormones. I have six years' worth of needles and syringes in my closet. I kept asking for the correct needle size and it was so hit and miss with my pharmacy that I just said screw it, I'll buy my own!”—KI 1

“When I was doing my last injection, the needle came off halfway through. I was a little upset about that, and went to the pharmacy today actually and asked about getting a better supply with safer tops that actually stay on the needle. They told me I needed a prescription from my doctor for that, who is out of town at the moment for a week and a half, so I'm a little stuck right now where I need better needles and I don't know where to get them.” – KI 6

Some Photovoice participants took a picture of their injection supplies, and discussed their needle disposal techniques. Notice that each of the photos below involves a different disposal technique, and each of these participants live in Missoula County. Also, it was mentioned that it is either too expensive to get testosterone from local pharmacies or they feel too uncomfortable dealing with the pharmacies, and so many people order their testosterone and needles through the mail from pharmacies outside of the state.



“I decided to take a picture of proper supplies that you would need to do your own hormone injections. I think a lot of people, myself included, back before I talked to some other people, I was just tossing them. Wrapping them up in toilet paper and tossing them in the garbage. I mean I know I don’t have any communicable thing or whatever, but imagine if you happened to reach to grab something out of the trash, and you don’t know if that person was safe. So where do I get a sharps container, I don’t want to buy one, and someone said you can use a laundry detergent bottle because it’s roughly the same thickness in plastic as a sharps container. You can do that, put bleach a quarter of the way up the bottle, and duct tape it closed. Don’t make an excuse, be safe about it, have all the right things, your alcohol swab, clean needles.” –PV 7



“Before, I just had a bag in my drawer, and I knew I needed some type of disposal. A friend of mine was just using a laundry detergent thing, so I thought OK, as soon as we are done with this one I’ll use it. I ended up somehow at Curry, and they said we give those away here! I had absolutely no idea. So you take them to Curry, and they give you a new one and take the old one. It’s great that that’s there, but at the same time, I’m in the community, and I do a lot in the community, and I didn’t know.” –PV 6



“This is a bottle of testosterone that I got in the mail. By the way, how difficult is it to turn in your sharps container in Missoula? There is only one place in town that I know that takes them, Open Aid Alliance. I can’t even give them to my own practitioner, because they legally aren’t allowed to take them. Anyway, it is cheaper for me to go to a pharmacy in Portland and have them mail it to me. And trust me, the community that I know has probably tried every damn pharmacy in town. A lot of us pay out of pocket for it, so we switched over to this other pharmacy. And it’s not so easy for people to get, even if you have health care.” – PV 3

Theme 3: Going rogue

It was also mentioned that the Trans* community often needs to be advocates for their own care, and be knowledgeable about the care they require, especially if they have limited access to finding medical supplies or a trans-inclusive health care provider. This self-directed path can lead to dangerous situations when a patient might “go rogue.”

“One of the things we have noticed about trans individuals since they often need to be their own advocates for their own care is that they know an amazing amount about their care. They know more than the majority of doctors do, unless it is a specialist. So there are certain people who are trying new regimens, or new things around their hormones that maybe a doctor has never heard or seen before, and that’s also a reason that a patient might go rogue, if they don’t feel supported in their health care decisions.” – KI 2

“If you look at some of the low-ball black market surgical interventions, or so-called surgical interventions, like pumping parties, or needle-sharing for intra-muscular hormone injections, that puts the community at risk.” – KI 1

“My patient, back in the 80’s, there was no physician up in Kalispell that knew anything about hormones. She finally did find a physician that she could bring the material to. I find that is really common, too, the transgender person bringing the information to the physician. She had to educate him about the latest research, to get these hormones prescribed.” – KI 5

“Around Christmastime I didn’t have a phone, I didn’t have money, I didn’t have money to get my T. I went two months without T...So I was getting pretty ratty about it. It was more mental than physical, because two months isn’t going to do anything, but I felt more feminine, and felt a

little less confident. So my friend was like well, I have T. If you want to come use some of it, and then the next time I need a little bit you'll pay me back.” – PV 6

Section 9: Legal Issues

Theme 1: Experiencing difficulty with gender or name change

Changing your legal name and your gender on various governmental documents can be a complicated process if you don't know where to start. It was also mentioned that if your documentation doesn't match, it can be a barrier when you are looking for work or starting at a new place of employment; if you hand in a driver's license or passport with your old photo, gender, and name on it, and you show up in person asking to be called a different name and gender, you are forced to put yourself in a potentially awkward situation from the beginning. Non-discrimination ordinances are discussed later in this section, which help to protect individuals from the intimidation they can feel when they experience problems with name and gender change on their documentation.

“It's not too bad, but a lot of people don't realize that. It is only about \$200, and if you are broke you can file an inability to pay and it will be covered. People aren't aware of that. You do the paperwork on your own and you print it out and turn it in. But not being aware of that resource, not being aware of how simple that process is, can be extremely intimidating. And then individual states and how they handle trans people. There are states that won't even allow you to change the marker on your driver's license. That's changing fairly quickly. At the federal level, all identification has been changed so that now passports don't require your surgical intervention to change the gender marker on your passport, but social security you still have to have surgery...Just that process of going back to change everything can be super intimidating for many people. Especially people that have been historically told their whole life that they weren't going to amount to anything, because they are trans. Where's the self-confidence.” – KI 1

“I know for work aspects some individuals definitely want to have all of their things changed before you go into a setting where you are not very close with anyone there, and you are already questioned about your ID or something like that, that can be really difficult. The DMV in Butte is absolutely rude. I'm sure it is the same way everywhere because they have to deal with some really stressful people. But, I first went in and tried to change the sex on my ID, and because my birth certificate said male, the woman refused. I asked her why we couldn't change it, because I was going through this transition, and she refused to answer my question. She looked at me really rudely and kept saying you know why, you know why. And I didn't really know why.” – KI 6

Theme 2: Developing needle exchange programs

It was mentioned in Section 8, Theme 2: Finding medical supplies that people don't always know how to find clean needles or dispose of their used needles safely. When discussing HIV transmission in Montana, the need for community needle exchange programs has been discussed in the past. Some of the interviewees discussed their opinion on needle exchange programs in the state, and whether or not they would benefit the trans* community. Some expressed that they think needle exchange programs would

help reduce risk, but others didn't see dirty needle use as a problem within their own communities. One reason for that could be that not all of our interviewees, and not all transgender individuals, utilize needles in their transition.

"We've talked about becoming a needle drop off point here, too. Some people have expressed it's a little bit stigmatized dropping it off downtown at Open Aid Alliance. Many of our client are people who need to use hormones at home. They have trouble getting needles or they have to get them online, and then they don't want to drop them off places because that doesn't help them with passing. 'Oh, I'm here for my hormones, dropping off my hormone needles.' So that is one issue there."—KI 2

"I don't perceive that as an issue. I haven't seen that or heard of it. I don't perceive that as a problem."—KI 4

"As a community organizer, I'm not going to say that needle exchanges in Montana don't exist, because they do. They're not talked about, because yea, there are things that say we can't do it. But that doesn't mean they don't exist. They are all hush-hush, which is unfortunate, because they are all potential resources that hugely impact HIV prevention, by allowing people access to clean needles. Not just with needle use, but hormones, and pumping parties! The whole nine yards."—KI 1

"We need to have centers to inject and dispose needles properly. HIV can be passed through needles, so I think preventing needle sharing is important."—PV 1

Theme 3: Needing non-discrimination ordinances

The lack of a state-wide non-discrimination ordinance is another barrier to practicing healthy behaviors. A non-discrimination ordinance protects people from being fired or denied housing due to their sex or gender orientation. So far, NDOs have passed in Missoula, Helena, and Butte. Activists are currently working to pass one in Bozeman next.

"Law is public policy. It is what the people want. So when you draw the conclusion that what the people want is inherently discriminatory practices, then they've drawn a line. And they put you on the opposite side of that line."—KI 4

"You don't even have to do anything, they can just fire you for being trans. And you have no legal right to say I was discriminated against. Those ordinance don't really stop discrimination, but at least the individual has the legal right to sue that employer for wrongful termination, which goes back to that whole notion of personhood and feeling like a whole person. Even having that recourse is a pretty empowering thing. Not having it is dehumanizing."—KI 2

"Anti-discrimination is the biggest. It effects finances. It effects well-being. If you are constantly being discriminated at your job, it is going to harm your mental well-being. Constantly being turned down at every job interview you went to because you totally pass as a woman, but you haven't had the money to change your name, so you turn in your old driver's license with your old picture and your old name on it."—KI 1

“I think, at a local level, policies that equalize everyone are crucial, I think that helps limit a lot of risky behavior, because then people don’t have to be afraid of who they are and they can be open about what they are. You have to accept others, and you have the same protection as everyone else, and that really helps make a lot of people in the LGBT community feel comfortable.” – KI 6

“Missoula is a lot different. I was always told never to go to Missoula, it’s just the liberal place. Then I started realizing the reason people are telling me that is because of people like me. So I was like I want to go to Missoula. Plus, they have the non-discrimination ordinance in Missoula. So, it was the only place to go.” – PV 9

“He was looking for a reason to fire me. I had problems at the first store, and these guys are brothers. I was a delivery driver, and he would tell me to wait for the other driver to come back, and then that driver would yell at me, tell me I was lazy and stuff. Sometimes I would say I know they need it, and I would take it right away anyway, and the customer would call and say they were happy I brought it. So I was doing a good job but still getting in trouble for it. They would sit around and listen to Rush Limbaugh. One time he was in his office, which is out in the open, and saying how same sex couples shouldn’t have rights, at work!” – PV 6

Section 10: Life in Montana

In general, our interviewees expressed a lot of pride in Montana and the strength of its trans* community and trans-inclusive nature. It was expressed that Montana is on the forefront of the trans* movement, and has an opportunity to be a leader for other states.

“I actually see the community here in Montana stronger than the community in Portland...I think the work being done with the Gender Expansion Project could set the stage for a lot of other states on education for health care people. I think it is a wonderful thing...Montana can be a real example here to other states. You know? Here’s how you do it.” – KI 5

Theme 1: Perceiving a problem in other U.S. states

Occasionally in the interviews topics would come up that did not seem to be a pervasive issue in Montana, but were known to be problems the Trans* community faces in general. It is unknown how largely the community specifically in Montana is affected by these issues. The first issue is violence.

“Transwomen experience an inordinate level of violence, and I think that also ties in to participation in risky behaviors.” – KI 2

“We were dancing, and then I was assaulted for my transgender status. I kind of thought as a society we were pretty much past that, at least for the most part, but I think it goes to show that you need to be safe. You don’t need to disclose your transgender status to everybody. For the most part, for full disclosure and a disclaimer, even if people can tell you are a transgender they aren’t going to come up, most likely, at least I’ve never seen that happen or experience that myself, they aren’t going to go up to you and start physically abusing you. Perhaps some verbal

abuse might happen, but you won't be physically or sexually assaulted just because you are transgender." – PV 2



"That picture was taken at this year's National Transgender Day of Remembrance, and they actually represent lives. There were two tables set up that looked like that, and I don't remember what the count was this year, but it was pretty high. Each candle represents a number, and we had a display, that displayed the person's name and a few more details about the person. So these are people that lost their life because they are transgender. They lost their life to transphobia. And, every year that I go to the TDOR, and I am the organizer here in Billings, and as I prepare for the event, I can't help but to think that could be me." – PV 8

The second issue was sex work.

"One of the biggest ones, not so much in Montana, but outside of Montana, is sex work. The trans community being overtly sexualized by modern society at large is a double-edged sword. It hurts the trans community, but it also present an employment opportunity for a lot of individuals." – KI 1

"It is a problem here. I wouldn't say it is a big problem here, most definitely not. In the larger cities, more so than here. But it's mentioned." – KI 6

"No, not here in Montana that I know of. I know a lot of transgenders, down in Billings and Butte and on the reservations, and none of the ones I know have been sex workers." – KI 7

The third issue was pumping parties.

"Oh, I've heard horror stories of pumping parties ...I'm not sure where or how it goes on. I've heard stories. But I know it is a lot more common out of state, in larger states like Nevada or California. That's where I've mostly heard of girls getting things done. I'm sure things like that are happening in Montana, just few and far between." – KI 6

And finally, discrimination from law enforcement.

"During some of the research that I've done, law enforcement. If you have a problem, where are you going to go? The police. But a lot of people in the transgender community don't believe they

are free to go to the police. Because, again, they have been marginalized, and it has been assumed that they are a hooker, or a prostitute. So again, that's part of the community that should be safe, where you should be able to go, and then you aren't treated safely. That's just one more rejection." – KI 5

"I don't know about that on our reservation, but down in the Navajo nation I knew of some of them that were transgender, there were a lot down in New Mexico that were getting murdered, sex workers, transgender, and native and that was a great big deal going on in Albuquerque. I don't think any of those cases has ever been solved. Oh, it's just another transgender native; we aren't really going to worry about it." – KI 7

Theme 2: Encountering a "live and let live" attitude

Some interviewees expressed surprise at finding a very "live and let live" attitude in Montana, a state in which they thought originally transitioning would be very difficult, making it actually a very positive experience.

"There is another component of Montanans, and some of the older more traditional western people. They have this sense of sort of live and let live, that the work to be done is more important than the individual worker traits...But I've encountered that live and let live attitude. People who in all other respects are pretty doggone conservative." – KI 4

"People are a lot more open than they are given credit for. There seems to be a lot more acceptance than there is hate, at all. I remember the rally we had, PRIDE when we had that here, we had I think a total of one protestor...That live and let live attitude is definitely here." – KI 6

"I think social events are easier here. PRIDE for years has been making it a point to go for years to places that don't have a lot of open diversity and having parades in the middle of their town. Butte this summer, Butte was scary when I first moved here, but it was great, very receptive. The hotel people knocked themselves over to welcome us, best drag show I have been to in years, and you know, it was just no problem." – KI 3

"I'm not scared of walking down main street, Winnett, or Roundup, Jordan, Circle, because nobody really cares. They may stare for a minute, but they won't not treat you politely." – PV 9

Some interviewees mentioned moving to Montana with the specific goal of transitioning here.

"I love Montana. I never want to move." – PV 9

"Three years ago I didn't have any prospect of getting out of the boonies of Georgia. I was stuck there. Every day I am thankful for the friend I met who said, Hey, come to Montana. Just do it. Sure it's going to cost a lot of money, sure it is going to be hard, but just do it." – PV 4



“I think of Billings as my home. I came here about five years ago pursuing a relationship. Although, we are not together at this time we are best friends. I love Billings, I have no regrets in moving here, Billings is my home. People think that it would have been easier to transition in Florida, where I moved from, I don't know; but I do know that Billings has been good to me.”—PV 8

CHAPTER 5: MANUSCRIPT

An Assessment of the Health Needs of the Transgender Community in Montana

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Abstract

The transgender community has been identified as a group at high risk for HIV transmission and increased possibility for poor quality of life. This paper represents the results of a qualitative research study using interviews and Photovoice as methodologies to explore the contextual factors that define and shape the lives of people in Montana who identify as transgender, and specifically to explore factors that influence their risk of infection with HIV/AIDS. Ten major themes emerged from the interviews as well as the discussions surrounding the photographs. Sense of self was identified as a core category related to the overall health and risk behaviour of the transgender community in Montana. The other nine major categories, including 1) age of transition, 2) the importance of love, 3) availability of support, 4) passing as your identified gender, 5) normalization in society, 6) ignorance surrounding gender variance, 7) health care, 8) legal issues, and 9) life in Montana, were seen as contributing to the development of a stronger or weaker sense of self. The findings from this study will be used by the Montana Department of Public Health and Human Services to increase awareness of the lived experience and health needs of the transgender community in Montana.

Keywords: *Transgender; Photovoice technique; grounded theory; HIV; minority stress; gender binary; rural; Montana*

An Assessment of the Health Needs of the Transgender Community in Montana

Introduction

HIV and the transgender community

According to the National Center of Transgender Equality (NCTE) (2009), there is a paucity of information available about the number of transgender people living in the United States. This is due to the absence of a widespread effort to collect this data. Transgender people are not considered in the reporting criteria of the US Census or other agencies, including CDC reporting for HIV/AIDS, and many transgender people choose to keep their identities a secret. Also, because of the perception that the number of transgender individuals living in America is relatively small, there has not been a push to change reporting options to include them in epidemiological data, meaning they often fall into the category of Men who have Sex with Men, but can also fall into homosexual or heterosexual categories. Transgender individuals embody a very diverse range on the gender continuum; it is not unusual for a male-bodied Male-to-Female (MTF) individual to identify as heterosexual and have sex with male partners. Kammerer, Mason, Connors, and Durkee (2001) suggest “that while sex, gender, and sexual orientation are interrelated, they are also separate...Sex is an issue of anatomy, and gender is an aspect of identity, of self. Are you attracted to someone male by sex, male by gender, female by sex, female by gender, or some combination thereof?” This example provides a clear description of the inadequacies of the typical sex and gender reporting options found in epidemiological data.

In 2002, California started to collect epidemiological data regarding its transgender population by creating two new gender reporting options: “FTM” (Female-to-Male) and “MTF” (Male-to-Female). Transgender persons, particularly African Americans, were found to have the

highest HIV diagnosis rate of any group in the state, including MSM, which is traditionally the largest group (Keller, 2009). Herbst et al. (2007) conducted a meta-analysis of 29 research studies from across the US. Their investigation shows 27.7% of MTFs tested positive for HIV infection, and 11.8% of MTFs self-reported positive infection status. Lower prevalence was found among FTMs.

This information tells us a number of things. First, depending on the reporting method used in the study, you can arrive at a vastly different conclusion—if a report relies on self-reporting alone, it is possible to underestimate the population infected with HIV. Second, every study used in the meta-analysis found a different rate depending on location. The following studies all used self-reporting methods: Kenagy and Hsieh (2005) in Philadelphia shows 6% HIV positive rate; Nemoto et al. (2006) shows 26% in San Francisco; and in Minnesota, a less populated state than Pennsylvania and California, Bockting et al. (2005) shows .5% (as cited in Herbst et al., 2007). These three very different locations report very different rates of HIV infection.

Collecting accurate information about rates of infection within the transgender community is important, but it is equally important to collect information about the factors that contribute to infection. Avoiding stereotypic generalizations about the lived experiences of people within the transgender community is critical. Kirk and Kulkarni (2001) emphasize that while there are commonalities across the spectrum, how an individual defines him- or herself and how their life experiences have shaped their opinions is difficult to generalize. It is necessary to acknowledge the importance of individual stories of self-discovery, and accept that there will be outliers from the definitions we seek to create of the iconic transgender experience.

Overall health of the transgender community in Montana

Aside from risk of HIV infection, there are several concerns about the overall social, mental and physical health and wellbeing of the transgender community. The following health problems have been well-documented in the literature, including, but not limited to: social isolation, violence, distal and proximal stress, depression and suicidal ideation, anxiety, stigma, substance abuse, lack of access to trans-inclusive medical professionals, and lack of access to quality care for transition-related medical needs (Snelgrove, Jasudavivius, Rowe, Head, & Bauer, 2012; Kammerer et al., 2001; Testa, Sciacca, Wang, Hendricks, Goldblum, & Bradford, 2012; Grant, Mottet, & Tanis, 2010; Zians, 2006; Kirk & Kulkarni, 2001; and Kenagy, 2005). However, information about the overall health and wellbeing of the transgender community specifically in Montana is limited.

The population of Montana as of 2012, according to the U.S. Census Bureau (2013), exceeds 1 million people, increasing slightly since the last official count in 2010. Montana mostly consists of rural areas. A rural area is described as including all population, housing, and territory not included within an urban area, with a population of less than 2,500 people (Rural Institute of Montana, 2010). Furthermore, almost half of the population in Montana resides in a number of frontier areas, where fewer than six people live in a square mile (Winbush & Crichlow, 2005). Nayar, Yu, and Apenteg (2012) describe frontier areas as having a distinct culture defined by self-reliance, conservatism and religiosity, distrust of outsiders, and individualism, with much value placed on family and work effort. Providing health care in a rural or frontier environment can provide unique challenges, such as: economic disincentives for private providers; reliance on generalists; provider shortages; greater use of subprofessional

staff; geographic isolation; and informal family and community support systems (Nayar et al., 2013; Winbush & Crichlow, 2005).

Living in a rural area affects many aspects of quality of life for a transgender person. Swank, Frost, and Fahs (2012) have found that sexual minorities in a rural community are more likely to endure a history of subtle discrimination over their lifetimes, and that community coping resources are limited in a rural area, leading to an increase in social stress. Willging, Salvador, and Kano (2006b) conducted research regarding attitudes of health providers in rural areas and found that while providers claimed to be accepting of sexual minorities, in reality homophobia, moral and religious guidelines, and lack of education led to increased feelings of social isolation in patients, resulting in patients terminating services. Individuals who self-identified as members of a sexual minority were met with laughter, discouragement, blame for their own problems, resentment for what was seen as “forcing” their lifestyles on their fellow community members, and fear they may convert others to their lifestyles. Issues identified for sexual minorities living in rural communities that can contribute to hesitation toward help-seeking for health care needs including the following:

- Economic insecurity;
- Geographic isolation;
- Perceptions of provider bias;
- Distrust of locally provided services in sparsely populated town/confidentiality concerns;
- Lack of LGBT social networks;
- Ideals of self-reliance; and

- A belief that admitting to any mental illness is a personal shortcoming (Willging, Salvador, & Kano, 2006a; Mayer et al., 2008; Herbst et al. 2007).

While these broad issues provide a framework for addressing the unique health related needs of transgender individuals living in rural areas, localized community needs assessments are important before planning public health interventions. This paper represents the results of a qualitative research study using interviews and Photovoice as methodologies to explore the contextual factors that define and shape the lives of people in Montana who identify as transgender, and specifically to explore the contextual factors that influence their risk of infection with HIV.

Research strategies

The transgender needs assessment team consisted of two co-principle investigators as well as the director of Montana's Gender Expansion Project; a Montana-based non-profit organization dedicated to gender equality. Grounded theory provided a framework for the analytical process of generating propositions or hypotheses that led to a theory regarding contextual factors that influence transgender individuals' risk of HIV infection. Interviews with key informants as well as the Photovoice methodology constituted the first phase in a two-phase study. The second phase will involve the state-wide dissemination of an internet-based survey to the gender variant community in Montana.

Key Informant Interviews

Interviews were conducted with key informants, who were defined as leaders in the transgender community and health professionals experienced with the health care needs of the transgender

community in Montana. Interviews were semi-structured with questions based on the categories outlined in the socio-ecological model in an effort to ensure the broad range of influences on an individual's behaviour were addressed (McLeroy, Bibeau, Steckler, & Glanz, 1988).

Specifically, participants were asked about individual, interpersonal, organizational, community and policy factors that influence the lived experience of transgender individuals and more specifically about how those factors influence risk behaviours for HIV infection.

An initial sample of key informants was identified by our gatekeeper, the director of the Gender Expansion Project, and then the grounded theory technique of theoretical sampling was used to identify additional key informants. Key informants identified a convenient time and meeting place for the interview. Interviewees were provided with a written description of the study as well as the interview questions ahead of their scheduled interview time. An informed consent was provided at the time of the interview. Interviews lasted up to one hour. At the conclusion of the interview, the interviewer completed an interview summary sheet containing general information about the key informant and interview, such as meeting time, date, location, age, gender, qualifications for being included in the sample pool, overall impression of the topics covered in the interview. In addition, the grounded theory technique of memoing was employed after each interview for the purpose of determining information that was still lacking in order to identify future key informants and questions. Interviews were audio-recorded, transcribed, double checked for accuracy, and then the recordings were deleted to preserve confidentiality of the key informants.

Photovoice

Photovoice is a technique based on empowerment theory, documentary photography, and feminist theory. The technique of utilizing Photovoice as a methodology and grounded theory as

an analytical tool in combination is not unprecedented. Lopez, Eng, Randall-David, and Robinson (2005) describe this strategy in a study of African American breast cancer survivors. Their goal was to “provide the means for participants to move beyond merely reporting results to policy and decision makers to suggesting strategies” that are specifically tailored to the conditions of their lived experience (p. 101). Grounded theory provides a framework for identifying areas of intervention and potentially leads to the development of actionable steps toward addressing need (Lopez et al., 2005).

Photovoice was ideal for working with the transgender community because it “engages community members—whose voices are typically not heard—in a participatory process to identify, represent, and change their community through photography, dialogue, and action” (Strack, Lovelace, Jordan, & Holmes, 2010, p. 630). Photovoice methods provided a conduit through which community members could speak to policymakers regarding self-defined concerns.

Photovoice participants were contacted by the gatekeeper and provided with a written description of the project. In turn, participants contacted the researchers via phone or email if they wanted to participate in the project. The only criteria for participation was that individuals identified as members of the transgender community and were 18 years of age or older. No specification as to transfeminine, transmasculine, or gender nonconforming was established. The researchers offered \$100 per participant in order to acknowledge the participant’s time.

The Photovoice method was conducted in three stages. In stage one, participants were invited to a preliminary meeting to discuss 1) the purpose of the study, 2) the timeline of the study, 3) the Photovoice technique, 4) ethics in photography, 5) the proper technical use of the

digital cameras, if the participant requested a camera be provided to them, 6) the constructs of the socio-ecological model, 7) the need for a photo release form for any identifiable person in a photograph, and 8) any related questions. Participants were asked to read and sign an informed consent. Snacks and drinks were provided to those in attendance. A secure web-based platform known as Trello was used to help everyone stay in touch, although it ultimately was used only by the project team.

In stage two, the research assistant contacted each participant a week after their preliminary meeting via email or phone call to check up on how the project was progressing, and whether or not there were questions regarding the project or the use of the cameras.

In stage three, participants identified a convenient meeting time and place for the face-to-face interview where they shared one to five photographs they deemed to be most important. Interviews lasted up to one hour, were audio recorded, transcribed, and checked for accuracy. Some participants requested copies of their recordings, and the others were deleted. In this stage, interviewees were also asked to complete a demographic questionnaire providing basic information such as age, stage of transition, how they identified in terms of their transgender status, whether or not they considered themselves to be a native Montanan, and the size of the population in the community in which they grew up. This questionnaire was reviewed by our gatekeeper and revised based on her feedback.

Data analysis

Data analysis was conducted in accordance with grounded theory. Each interview was analysed and coded prior to embarking on the next. As suggested by Creswell (1998), this analysis took place in three steps. First, the interviews were subjected to open coding. In this step, the

researchers identified categories within the interviews relevant to the phenomenon being studied. This resulted in the reduction of the database to a smaller set of themes or categories that characterized the phenomenon being explored.

Transcriptions of key informant interviews were read by two additional researchers, who identified their own open coding schemes. The researchers met to discuss their individual coding schemes and combined them into one master coding scheme. This process allowed for the coding scheme to be triangulated, reducing researcher bias. After the coding scheme was developed, it was uploaded into NVivo, a qualitative data analysis software package. This allowed for effective organization of the interviews and ultimately showed coverage ratios by theme.

The second step outlined by Creswell (1998) is known as axial coding. In this step, the researchers identified the interrelationship of the categories, specifically “the causal conditions that influence the central phenomenon, the strategies for addressing the phenomenon, the context and intervening conditions that shape the strategies, and/or the consequences of undertaking the strategies.”

Finally, the third step suggested by Creswell (1998) is called selective coding. In this phase, the propositions or hypotheses of the theory was developed by writing a “story” regarding the connections identified through axial coding.

The Photovoice interviews were then analysed in comparison with the final coding scheme. Appropriate adjustments were made when applicable in order to ensure that any themes still emerging from the Photovoice data were considered in the final analysis.

After the final coding scheme was developed, it was emailed to key informants and Photovoice participants in an attempt to further triangulate the data. Feedback was received from two key informants and one Photovoice participant.

Results

Seven key informants were ultimately interviewed for this study. They represented five different counties in Montana, and ranged in age from mid-20s to over 50 years. The key informant interviews ranged in duration from forty minutes to one hour. Six interviews were conducted face-to-face, while one was completed via Skype. All of the interviews were conducted by one of the co-investigators.

Ten Photovoice participants began the project. One person dropped out due to time constraints. Approximately two weeks after the orientation, individual interviews were scheduled for participants to share their photographs and descriptions of their photos. Some individuals chose to share one photograph while others chose to share five. Interviews lasted from 15 minutes to one hour, and participants ranged in age from 19 to 36 years. Six interviews were conducted in person, and three were conducted via phone as the images were viewed on the computer. Six participants considered themselves to be native to Montana and three reported that they had moved from another state. Six individuals reported being from rural communities, which for this study was defined as an area with a population of 2,500 people or less. The other three identified their community as being urban, or with more than 2,500 people.

Five Photovoice participants identified as MTF transgender, three as FTM transgender, and one as FTM transsexual. One MTF participant also chose to write in “woman,” and one FTM participant also chose to write in “gender nonconforming.” The researchers wanted to have a sense for where the participants were in their transition, as our gatekeeper and some key informants had suggested that length of time spent in and after transition had some bearing on a person’s perception and sense of self. The participants were evenly spread in their perception of

their stage of transition (Figure 1). Interestingly, all Photovoice participants believed they would never finish their transition because transition would always be a part of their lives. They recommended adding the option, “I will never finish my transition” to the list of response categories below.

Stage of transition	Number of Participants
I just began	2
I am about ¼ of the way to my end goal	2
I am about ½ of the way to my end goal	1
I am about ¾ of the way to my end goal	2
I have finished my transition	2

Figure 1: Stage of transition

Overarching themes

There were two concepts that ran through all the themes and interviews: the concept of gender binarism and the concept of minority stress. The first concept, gender binarism, is described as the perception in western cultures that gender expression is “temporally and contextually fixed, with prescribed forms of expression—one is born female/male, behaves in a feminine/masculine way at all times throughout one’s life” (Wiseman & Davidson, 2011, p. 529). This phenomenon was described by every person interviewed, and the resulting themes from the interviews should be read with this concept in mind. It was seen to be a primary barrier to positive self-image and a healthy transition experience. One key informant described it in the following way:

You are growing up in this society that constantly tells you that you are this gender, or you are this sex, and sex and gender are one and the same, and any thoughts of variance are wrong. And the entire time you are just thinking well, what the hell is wrong with me? This isn’t how I feel, this isn’t who I am. I know now, I know that I am a woman, but society tells me that I can’t be a woman. So I have to conform to what society thinks or I am going to get outcast. Do 20 years of

that...The problem is that society is enforcing this gender binary, which is in turn causing all of these mental health issues.

The second major concept that was identified as permeating through every other theme was the concept of minority stress and the influence it has on the day-to-day lived experience of the transgender community. According to Effrig, Bieschke and Locke (2011, p. 144), “minority stress theory posits that the increased stress faced by minority individuals leads to an increased level of psychological distress when individuals are unable to successfully increase their level of coping.” Bockting, Miner, Romine, Hamilton, and Coleman (2013, p. 1) state “the stress associated with stigma, prejudice, and discrimination will increase rates of psychological distress in the transgender population...[the stress] is also socially based and chronic.” This concept is seen in the following photograph taken by a Photovoice participant of her gun collection, and the accompanying description (Figure 2):



Figure 2: I do have a target on my head

I knew it was time to get comfortable enough where I could start considering carrying a loaded gun on me. There is this threat upon me being trans. And I do feel a lot of times like I do have a target on my head. So I do carry any time I can carry because of self-protection of me or somebody else, because I do hang out a lot of times with trans people.

Major themes

The themes identified from the interviews fell into ten major categories that described the experience of transgender people living in Montana: 1) sense of self, 2) age of transition, 3) the importance of love, 4) the availability of support, 5) passing as your identified gender, 6) normalization in society, 7) ignorance regarding gender variance, 8) health care, 9) legal issues, and 10) life in Montana. While some themes had a clear connection to better or worse quality of life or becoming more or less likely to participate in a risky behaviour, others were less obviously directional.

Sense of Self: The themes identified in this category were *embracing gender variant identity* and *growing older*. Sense of self was described as being vital for a successful transition in which individuals treat their bodies with respect. The interviewees also described a perception that the length of time from the point where the transition period begins makes it more and more likely for individuals to feel more comfortable in their identity; being more comfortable leads to less risky behaviours because they were no longer feeling the need to conceal who they were.

As one key informant described it, “How self-actualized you become as a transperson has a lot to do with it. For me, as a transwoman, do I accept myself as a woman, am I totally comfortable in my skin as a woman?” Another key informant described it this way, “If someone cares about themselves, they are going to care about their future. They are not going to participate in risky behaviours. If someone doesn’t care about themselves, doesn’t have any self-respect, why does it matter?” Sense of self was identified as the core category in the analysis; it is our perception that a transgender person’s sense of self is shaped and molded by the issues described in the themes below.

Age of transition: The themes in this category were *transitioning at an older age* and *transitioning at a younger age*. The age at which a person transitions was seen as an important factor because, prior to their transition, the older individuals have been established and rooted in their communities and within their families as their prior selves. As one key informant said, “The older group generally tends to be people who entered adulthood following a heterosexual sort of normal life. Many of them already had children and families, even grandchildren, and in one case I know of great-grandchildren, by the time they either became aware or decided to come out about their gender issues.”

Needing to rebuild your identity and feeling a desire to begin experimenting within your expressed gender can also lead to a second adolescence. One Photovoice participant described meeting men she had met online at a series of hotels just to experiment sexually with an anatomical male. However, if a person is able to transition at a younger age, some of these problems could be avoided. Several key informants mentioned that they are seeing younger and younger people transitioning in recent years, as young as elementary school.

The importance of love: The themes identified in this category were *facing rejection or loss* and *searching for love*. The desire to love and be loved was seen as particularly important, which was problematic since transgender individuals often face overwhelming rejection and loss when their families and friends of origin do not transition successfully with them. Describing a photograph of condoms (Figure 3), one Photovoice participant said the following regarding his risky sexual behaviours, his search for love, and how rejection and loss are a factor:



Figure 3: Fear of rejection

I went through a period of time where I was not necessarily being safe when it came to sex because I was thinking well, if I say no, that I want them to use a condom or that they can't not use it or whatever, they probably won't want to sleep with me, and let's be honest I better get it while I can because when I start this transition people are going to look at me weird. I don't think that's only me that has ever thought that. I think not knowing how to talk about it? I learned all about what it's for and why you need to use it, and that it's both people's responsibility. But when you kind of get into that situation, for me I just froze. Because even in times I would tell myself, I'm not going to do that again it's dumb, you need to speak up for yourself, I still would do it a couple times after that. Fear of rejection, I think is the biggest part. I think for anybody, it is hard to be rejected. You need to know that someone is going to accept you. You might have to be more patient than the average person, but you are going to find that somebody and it is more important for you to be safe about it, for you and your body, than to just have those few moments where you aren't afraid of rejection.

Availability of support: Themes in this category were identified as *needing support* and *building a support network*. When people found themselves feeling more supported and less rejected, they were more likely to feel a stronger sense of self and practice less risky behaviours. However, facing rejection from their original support system can lead them to search for new, positive support groups. As one key informant described it,

Going from one support network to another is difficult. A lot of people refuse to change their way of thinking, or they don't want to believe a certain aspect because of religion or whatever, so that can be a lot more difficult. But you do, you have to be more active, you have to be willing to sit and talk with people, or help them understand, the ones you want to hold onto. And you can also give up on them if they turn away from you.

Support systems were seen as friends, family members, community resources or groups, online-based resources and groups, and pets.

Passing as your identified gender: Other themes emerged that dealt with identity in terms of passing and the relationship between going stealth and the transgender movement progressing forward. Specifically, these themes were defined as *going stealth*, *needing active participation*, and *being able to pass*. Passing was regarded as being connected with good quality of life, but a transgender individual who passes and no longer identifies with the transgender community is referred to as being “stealth.” The desire to live in stealth was described as an expression of identifying as your gender instead of transgender, as described via the photograph and description below (Figure 4) of a survey question:

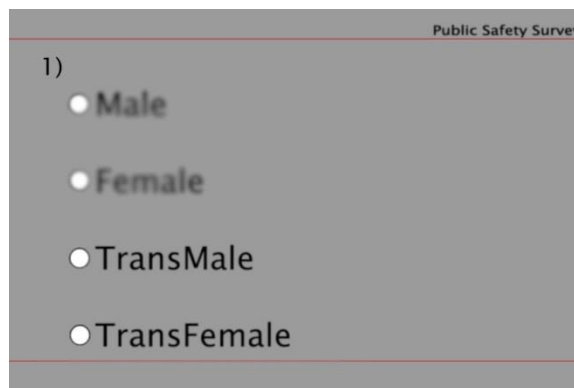
A screenshot of a survey question titled "Public Safety Survey" in the top right corner. The question is labeled "1)" and lists four options, each preceded by a radio button: "Male", "Female", "TransMale", and "TransFemale". The options are arranged vertically on a light gray background.

Figure 4: The idea has always been to become female

The very first question was with which of the following do you most closely identify. There were four choices. And right away, I had to stop and I had to think about that a lot. It left me with the dilemma that even though this was anonymous, I had to make a choice right now to either identify myself as a transgender female or to in a sense lie to the survey and check

myself as female, which I would have liked to do. Because, at no point in my life did I ever say I want to be a transgendered female. I want to be a trans woman. The idea has always been to become a female, to become a woman. Plain and simple, to be a girl.

While most interviewees understood the impulse to go stealth, there was a general consensus that in order to move the transgender community forward, it needed to be strong and visible. Without individuals living openly in their transgender identities, the interviewees felt that the community continues to face marginalization. The following was expressed by one key informant:

It seems to be that people are so concerned with living in stealth, they just don't want to stand up for the community anymore. They stop making the effort. All of a sudden, they are no longer trans. They are just their gender. And I feel like that's not really helping our progression. We need to make a difference for the ones below us, make it easier.

Ignorance regarding gender variance: Themes within the category of ignorance included *lacking comprehensive sexual education, misunderstanding HIV and how it is transmitted, and believing the transgender community does not exist.* Ignorance regarding gender variance and the transgender community was primarily blamed on the lack of comprehensive sexual education. “The fact that there isn't, or hasn't historically been comprehensive sexual education that's gender inclusive—if you're not educating people, they're not going to know.” This not only can lead to difficulty in establishing or identifying one's own gender variance, but it can also lead to misunderstanding what constitutes risky sexual behaviour. As one Photovoice participant explained it, as a result of her lack of access to information on gender variance growing up in rural Montana:

It took me two years to process my identity, and who I am, and my discomfort, just to the point where I felt safe. Telling somebody that I am transgender, and realizing that I can make

changes, that I can change. Before, my perfect answer was joining the army. And then I realized, oh my god, something is wrong.

Another participant told a story about growing up in a rural area and knowing in primary school that there was something different about him, but not realizing what it was until seeing a movie about a phalloplasty in a college class many years later.

Most HIV prevention messages target men who have sex with men, and because that isn't necessarily how a transgender individual identifies, they may not be receiving the prevention messages. "Even now that misconception is still out there, despite huge efforts amongst HIV professionals. You get this interesting misconception where you think 'well, I'm not gay, even though I'm a male-bodied individual having sex with another male-bodied individual, so I'm not at risk.' No, no, no. That's not how things work." Creating comprehensive sexual education programs that discuss gender variance in schools was seen as something that is necessary in helping people become aware of their options much earlier in life, which would in turn lead to less participation in risky behaviours.

Normalization in society: Themes in this category included *wanting to be seen as normal* and *increasing acceptance*. All interviewees mentioned at some point during the course of their interviews that they really weren't so different from everyone else aside from their transgender identity. As one key informant suggested, "People have this idea that trans people are just out there, just really socially outcast. And besides for the fact that I had this particular thing wrong with me, that I had corrected, in all other respects I am pretty socially in the main." One Photovoice participant took a picture of washing his face to convey this concept (Figure 5):



Figure 5: I am really pretty boring

I'm getting ready for the day, washing my face. I just wanted to take some photos of really normalizing things. People ask me all the time, oh what do you do with your day, in your spare time, and I just say you know I am really pretty boring. I don't like to stay out late at night when I work at 7 in the morning. I like to stay home and watch Japanime. That's what is fun to me. It's nice to not feel like you are a two-headed puppy. People say oh how unusual, how unusual that you are trans. You must be a unicorn. No, not really. You would be surprised at how many of us are out there, just washing our faces in the morning.

Being seen as socially outcast was a contributing factor to participating in risky behaviours. Several participants suggested that if the transgender community felt less marginalized, they would feel less compelled to participate in activities they deemed necessary to fit in or find relationships with others.

Health Care: Themes within the topic of health care included *needing access to trans-inclusive medical providers, finding medical supplies, and going rogue*. Risk behaviours related to needle use for hormone therapy were a frequent subject of discussion. Having a supportive and trans-inclusive medical provider was seen as essential to a healthy

medically-supported transition, and also in finding and safely disposing of supplies like needles. Three Photovoice participants from within the city limits of Missoula, MT had three different methods for disposing of their needles. One disposal method was facilitated by a medical practitioner, one utilized a local needle exchange program, and one had no knowledge of where to go in the community and used a laundry detergent container after a friend pointed out that his previous method of throwing the needles into the trash was not sufficient. Transitioning individuals who did not have access to supportive medical resources in the community were seen at greater risk of “going rogue,” or taking their treatment into their own hands, and participating in risky behaviours surrounding hormone therapy and needle use.

Legal Issues: Interviewees identified several legal issues that were hurdles to beginning to transition. These included *experiencing difficulty with name and gender change* on documents such as driver’s licenses and passports, *needing non-discrimination ordinances*, and *developing needle exchange programs*. Although, not every transgender individual utilizes needles for his or her transition, so opinions on whether or not needle exchange services were necessary were mixed. The non-discrimination ordinances passed at local levels in Missoula, Helena, and Butte were seen as an important factor in the overall health and wellbeing of the transgender community in Montana. One key informant explained it this way:

You don’t even have to do anything, they can just fire you for being trans. And you have no legal right to say I was discriminated against. Those ordinances don’t really stop discrimination, but at least the individual has the legal right to sue that employer for wrongful termination, which goes back to that whole notion of personhood and feeling like a whole person. Even having that recourse is a pretty empowering thing. Not having it is dehumanizing.

Life in Montana: Themes in this category included *perceiving a problem in other US states* and *experiencing a “live and let live” attitude*. Overall, the transgender community in Montana was highly praised by interviewees, both key informants and Photovoice participants. One key informant suggested “I actually see the community here in Montana stronger than the community in Portland...Montana can be a real example here to other states. You know? Here’s how you do it.” There were several issues that were defined as problematic issues in other US states, but were not necessarily problematic for the transgender community in Montana. These were issues such as high rates of violence, discrimination from law enforcement, pumping parties, and sex work. Interviewees felt that in Montana they generally encountered a “live and let live” attitude, and some Photovoice participants mentioned moving here from other states with the purpose of transitioning. One Photovoice participant in particular mentioned “Three years ago I didn’t have any prospect of getting out of the boonies of Georgia. I was stuck there. Every day I am thankful for the friend I met who said, Hey, come to Montana. Just do it. Sure it’s going to cost a lot of money, sure it is going to be hard, but just do it.”

Discussion

We were fortunate to be involved with a group of individuals dedicated to increasing understanding and acceptance of the transgender community in Montana. At the beginning of the project, we were skeptical of finding individuals willing to share their experiences. A frequent comment made by people when they heard about the project was “how many transgender people do you think you will find in Montana?” This question shows how limited awareness about the

gender variant community is in Montana—the answer is, we found quite a lot, and they are a strong, outspoken, and dedicated community of individuals.

At the conclusion of each Photovoice interview, we asked the participants how they felt about the project overall and whether or not they found the experience to be worthwhile. The need to speak their mind and share their stories so that others would better understand their lives was a common theme. One participant explained that the name of the project, Photovoice, enticed her because she never felt like she had a voice before, and now we were asking her to speak and show us her life. The excitement in being asked to tell their stories and their passion for educating others may have contributed to key informants' and Photovoice participants' willingness to share openly and honestly about their life experiences and sexual behaviors with the researcher.

During the second and third phases of data analysis, interrelationships among categories were identified and the “story” regarding the connections began to unfold. The importance of self-identity, and the creation of an identity outside of the gender binary system, emerged as dominant themes. In exploring the story that was developing, it was evident that other major thematic categories were contributing to the overall sense of self and strength of self-identity. This concept is illustrated in Figure 6.

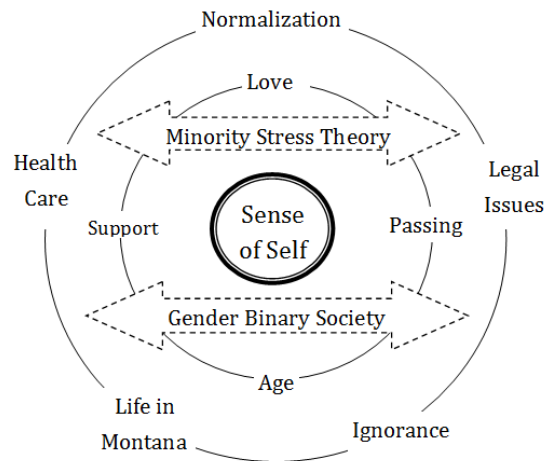


Figure 6: Conceptual framework of factors that influence sense of self and overall well-being of transgender individuals living in Montana

As is illustrated in the diagram, sense of self emerged from the data as the core category when discussing the lived experience of the transgender community in Montana and the contextual factors that could put them at risk for HIV. The next circle represents the first two levels in the socio-ecological model proposed by McLeroy et al. (1988), namely the individual and interpersonal levels of influence on a transgender individual's life. Specifically, this circle represents individual attributes and skills as well as the interpersonal processes that are capable of shaping behavior; the major thematic categories that are primarily represented by these two levels of the socio-ecological model include age of transition, the importance of love, the concept of passing, and the availability of social support.

The outermost circle represents the last three levels in the socio-ecological model, which are the organizational, community, and public policy levels. This circle represents the informal and formal rules and regulations encountered in our workplaces, institutions, communities, and in our local, state, and federal laws. The major thematic categories primarily represented by these

last three levels of the socio-ecological model include normalization, ignorance, health care, legal issues, and life in Montana.

The two concepts that were identified as overarching themes, the gender binary system and minority stress, are seen evenly cross-cutting the layers of the socio-ecological model. These factors all contribute to the development of a stronger or weaker sense of self, which in turn provides one possible explanation for transgender individuals' likelihood for participation in risky behaviors and their overall experience in transition.

These findings are corroborated by several other studies. Bockting, Miner, Romine, Hamilton, and Coleman (2013) found that both distal and proximal stress were positively associated with psychological distress, and confirmed that family support, peer support, and identity pride are protective factors, and negatively associated with psychological distress. Similarly, feeling supported by family and friends of origin leads to less of a sense of rejection, which leads to less vulnerability in the search to love and be loved. Nemoto, Operario, Keatley, and Villegas (2004) found the desire for social affirmation and searching for love contributes to risky sexual behavior among MTF participants in San Francisco, and we have found this to also be the case in Montana. Kosenko (2011a) found that participation in risky behaviors can be thought of as a slow form of suicide, and this concept was identified by our interviewees as well. Emphasis was placed on the importance of respecting your body and your identity, and that when supported by the community around you, you are more likely to find a sense of self-respect and more likely to care about your future.

When our participants felt as if they passed as the gender with which they identified, not only did they find a stronger sense of self within that gender, but they also experienced pride

over their appearance and less fear of violence against them. When a trans-identified individual passes well, they also minimize stigma and the impacts of normalization and ignorance against them, as well as the overall effects of minority stress and the gender binary system. Wilson (2002) conducted a qualitative study regarding the transgender community in Perth, Australia and came to a similar conclusion. “I was told again and again that to be recognized by others as a member of a ‘normal’ gender category and to therefore ‘pass’ successfully as their preferred gender was of great importance for self-recognition” (Wilson, 2002, p. 438). In doing so, Wilson (2002) suggests that the body can be recognized as a legitimate body, capable of acting and appearing according to how others are accustomed.

Being able to successfully pass is partly dependent on having access to health care that is cost-effective, as well as trans-inclusive medical services. Access to quality medical services includes access to a safe method of finding and disposing of injection needles that, for many people, makes the transition possible. This is consistent with observations made by Newfield, Hart, Dibble, and Kohler (2006) and Hancock, Krissinger, and Owen (2011), whereby increases in participants’ quality of life and happiness were associated with receiving hormone therapy and with their perception and likeability of their voices. Another important facet of sense of self is the ability to live legally in the world as the gender with which you identify. Issues such as difficulty in changing your name and gender on your documentation and rejection of non-discrimination ordinances were found to be “dehumanizing,” a word used by a key informant, who went on to describe the importance of developing “personhood.” As another key informant phrased it, experiencing legal issues to fully express your gender identity was problematic because “law is public policy. It is what the people want. So when you draw the conclusion that

what the people want is inherently discriminatory practices, then they've drawn a line. And they put you on the opposite side of that line."

The thematic category of "life in Montana" is especially important for future research as well as contributing to the understanding of the transgender community as a whole. In this category, participants described several issues that are generally understood to have a profoundly negative effect on the transgender community, specifically violence, discrimination from law enforcement, pumping parties, and sex work. However, these issues appear to be far less prevalent in Montana than in other communities across the United States. While many people who initially heard of this project assumed that we would not find many gender variant individuals in Montana, and that Montana would be a difficult place to transition, we found the opposite to be true—in fact, some Photovoice participants reported moving to Montana with the express desire to transition, and none of the participants expressed a desire to move to states that would be considered more favorable, such as California or New York. The strong transgender community in Montana was seen as a key factor in individuals being able to fully express their gender identity, as was the "live and let live" attitude described in several interviews. Despite facing the challenges related to transitioning in a rural state described earlier, including economic insecurity, geographic isolation, perceptions of provider (specifically, pharmacist) bias, confidentiality concerns (specifically when discussing life on the reservations), and lack of LGBT networks in some of the more rural, less densely populated areas, most participants felt safe and supported in their transition in Montana (Willging, Salvador, & Kano, 2006a; Mayer et al., 2008; Herbst et al. 2007).

We would recommend several policy changes to improve quality of life and overall health for the transgender community in Montana. In recent years Missoula, Butte, and Helena

have all passed non-discrimination ordinances to protect transgender individuals from discrimination. However, this should be a state-wide policy. Attempts at passing a state-wide policy have failed thus far, but we feel confident that public opinion is starting to shift. If it is not adopted state-wide, we encourage individual cities to continue thinking progressively and moving the transgender community forward. We also encourage a more comprehensive education plan for health professionals across the state, from doctors to site staff to pharmacists. Across the board, trans-inclusive services need to be made available. While all medical professionals can't reasonably be expected to know the details of the complications that can occur throughout transition, they should be able and willing to work in a culturally competent and respectful manner with all members of their communities, regardless of sex or gender status. Finally, we recommend that a discussion occur surrounding needle disposal in the state of Montana. Clear rules regarding who can collect what types of needles and how to dispose of needles safely and effectively across the state will improve the lives for people who use needles as medical supplies across the state.

Limitations inherent in the design and methodology of this study should be considered when interpreting these results. First, as with any self-reported data, the data collected was limited to the participant's honesty, openness, and willingness to share. Also, due to time constraints of the participants, it was not possible to reconvene as a group once the photographs were taken, which is a key step in most Photovoice projects. While that was the initial intention, it was simply not possible to schedule multiple meetings as many participants were working several jobs, attending school while working, or didn't have reliable access to a computer or cell phone. We also need to acknowledge our convenience sampling. Individuals who served as key informants and Photovoice participants in this project were part of a large network of transgender

individuals who are linked either directly or indirectly to Montana's Gender Expansion Project. We recognize that our findings cannot be generalized to all transgender individuals living in Montana.

The next phase of this study is to develop a more in-depth quantitative survey to be administered across the state of Montana using the information gathered from this qualitative phase. This second phase should devote attention to further investigating the prevalence of social issues like sex work, pumping parties, violence, and discrimination from law enforcement across Montana in order to identify exactly how pervasive those issues are in the state. Contrary to the literature, qualitative data from this project would suggest these issues are of less concern in Montana than they are in larger urban areas. Future investigators should consider stratifying the population according to variables such as age of transition, stage of transition, MTF or FMT transition, and perception of ability to "pass." With the recent explosion of information on the transgender population in particular, it could be easy and potentially dangerous to generalize information about one segment of the community to the community as a whole. The survey should inquire as to whether or not individuals have been tested for HIV in particular, and whether or not they were positive, in order to examine whether or not the needs of transgender individuals in terms of HIV counseling and testing are being accomplished across the state and to also allow for reexamination of HIV reporting methods across the state. The state of Montana will more closely align with national prevention goals such as increasing the number of people in care, reporting accurate statistics of people infected with HIV, providing services in a culturally competent manner, and reducing the number of HIV-related health disparities by using this information to consider adding options to their epidemiological data such as MTF and FTM transgender, and perhaps another question of "what sex were you assigned at birth" in order to

also capture people who identify solely as their gender and not as transgender. The researchers should also consider analyzing the data according to variables such as length of time spent in transition and the degree to which a person is “out” in their community, as conditions such as these can play an important role in a person’s overall health throughout their transition.

Conclusions

This project had two major aims. The first and most important aim was to give voice to Montana’s transgender community and to use our project participants’ own words to describe their experiences of being transgender people living in a sparsely populated state. Ultimately, we hope that by disseminating the results of this study through publications, presentations and websites, we can increase awareness, understanding and acceptance of individuals who do not fit our current gender binary classification system.

Our second aim was to explore the contextual factors that influence HIV risk behaviors. As is true with other groups of people facing minority stress, prevention is inextricably tied to, not only knowledge about HIV prevention, but also to systems of social support, the need to be accepted and loved, and perhaps most importantly, an individual’s sense of self, of being a person who is worthy of the same measure of good health and happiness as people who are not part of a stigmatized minority.

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APPENDIX A: KEY INFORMANT INTERVIEW PARTICIPATION CONSENT FORM

KEY INFORMANT INTERVIEW PARTICIPANT CONSENT FORM

TITLE

An Assessment of the Health Needs of the Transgender Community in Montana

SPONSOR

The Montana Department of Public Health and Human Services – HIV/STD Section

PROJECT DIRECTOR:

Dr. Annie Sondag
The University of Montana
Department of Health & Human Performance
Missoula, MT 59812
(406) 243-5215
annie.sondag@mso.umt.edu

SPECIAL INSTRUCTIONS

The language in this consent form may be new to you. If you read any words that are not clear to you, please ask the person who gave you this form to explain them to you.

PURPOSE

The purpose of this research study is to find out the contextual factors influencing transgender individuals' risk of infection with HIV. By participating in this interview you will help provide valuable information that will be used to develop more clarity regarding the status of the Trans* population in Montana, their health needs, and aid in the creation of better HIV prevention services for the Trans* community in Montana.

PROCEDURES

Interview participation for this study is voluntary. You are asked to read this consent form. If you agree to participate you will be asked to answer a number of questions covering various topics concerning the transgender community in Montana. The interview will take approximately one hour. The session will be audio recorded and transcribed for accuracy of responses.

RISKS/DISCOMFORTS

You may find some of the questions personal, you may feel you do not know the answer, or some of the questions may make you feel uncomfortable. You are welcome to refrain from answering any question for any reason or to discontinue your participation at any time.

BENEFITS

Your help with this study will provide valuable information to the Montana Department of Public Health and Human Services. By participating in this study, your answers will help staff offer services and develop programs to meet the HIV and STD prevention needs of the Trans* community, and offer the MTDPHHS a clearer understanding of the transgender community in Montana.

(continued on back)

CONFIDENTIALITY

All information collected during your interview will be confidential. Interviewers will avoid identifying any of the participants. Interviewers will not use your name or any other identifying information in reports or any other materials related to this study. Specifically:

- The identities of all interview participants will remain confidential and will not be associated with research findings in any way.
- At the conclusion of the study, any and all data containing information about participants will be destroyed.
- All the data collected during this study will be reported and examined as group data.

VOLUNTEER PARTICPATION/WITHDRAWAL

Your decision to take part in this research study is entirely voluntary. You are free NOT to answer any question and to discontinue participation at any time. You also may withdraw from this study for any reason.

QUESTIONS

If you have any questions about the research now or later, you may contact Dr. Annie Sondag at (406) 243-5215 or Anna von Gohren at (240) 925-8862.

If you have any questions about your rights as a research subject you may contact the Chair of the Institutional Review Board in the Research Office at The University of Montana – Phone (406) 243-6670.

CONSENT

I have read the above description of this project. I have been informed of the risks and benefits involved, and all of my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions I may have will be answered by a member of the project team. I voluntarily agree to take part in this study. I am at least 18 years old. I understand this is my copy of this consent to keep.

Printed Name

Signature

Date

APPENDIX B: KEY INFORMANT INTERVIEW RECRUITMENT SCRIPT

Verbal Instructions for Recruiting Volunteers for the Interview

Provide each potential volunteer with an explanation of the interview and a brief explanation of the procedures for the interview.

Purpose: The purpose of this study is to collect information about the contextual factors in Montana influencing transgender individuals' participation in risky behaviors that could lead to infection of HIV. The interview is designed to help gather information for this study to further develop and potentially improve the effectiveness of HIV prevention interventions offered in Montana and provide information regarding a subset of the Montana population that was previously less than visible.

Please remind them:

- The study is completely voluntary and anonymous and they may choose not to answer any of the questions posed at the interview.
- If they volunteer they will be asked to meet with the researcher who will ask them questions about contextual factors that could lead to risky behaviors influencing rate of infection of HIV in the transgender population.
- The interview will be audio recorded, but no identifying information will be transcribed from the interview and the tapes will be erased at a later date.
- By participating they are helping fight the spread of HIV in Montana. The information gathered by the interview will be used to improve HIV prevention programs for the Trans* community in Montana.

If individuals are willing to participate, give them a copy of the interview questions, the researchers' contact information, and ask them if it is okay for the researcher to contact them to set up a time and place for the interview. Collect contact information including: name, phone number, and email address. Remind potential participants that if they have any questions they can contact the researchers.

APPENDIX C: KEY INFORMANT INTERVIEW QUESTIONS

Key Informant Interview Questions

This is a qualitative research study with grounded theory design. Interviews will be loosely formed around the contextual factors leading to risk of infection with HIV in the transgender community in Montana. Allowing the interview structure to be loose benefits the grounded theory design, which is “dependent upon the ability of the researcher to travel a path through the interview with the participant. The greater the level of structure imposed, the less able the interviewer will be to take the optimal route” (Birks & Mills, 2011, p. 75). The wording of the questions may also be slightly altered depending on the professional role of the informant.

Interview questions are structured to reflect the socio-ecological model (SEM) of behavior. This model encourages a broad view of why individuals participate in certain behaviors, and consists of the following levels: individual, interpersonal, organizational, community, and public policy. The interview will last approximately one hour.

1. What individual attitudes, beliefs, knowledge, or behaviors contribute to the transgender community’s risk of HIV infection?
2. How do peers, friends, family, or colleagues (individuals who provide a social network or social support) contribute to the transgender community’s risk of HIV infection?
3. What formal and informal rules and regulations exist in workplaces, schools, institutions, etc. that contribute to the transgender community’s risk of HIV infection?
4. What spoken and unspoken rules and regulations exist within our communities that contribute to the transgender community’s risk of HIV infection?
5. What are the policies or laws at local, state, and federal levels that contribute to the transgender community’s risk of HIV infection?

APPENDIX D: INTERVIEW CONTACT SUMMARY SHEET

Interview Contact Summary Sheet

Interview Date: _____

Interview Length: _____

Interview No.: _____

Interview Location: _____

Job title/Relation to transgender community: _____

1. Physical description/impressions:

2. Main themes and issues:

3. Research question most directly addressed:

4. New working hypothesis or speculations:

5. Problems or questions:

6. Direction of information needed for next interview:

APPENDIX E: PHOTOVOICE PARTICIPANT CONSENT FORM

PHOTOVOICE PARTICIPANT CONSENT FORM

TITLE

An Assessment of the Health Needs of the Transgender Community in Montana

SPONSOR

The Montana Department of Public Health and Human Services – HIV/STD Section

PROJECT DIRECTOR:

Dr. Annie Sondag
The University of Montana
Department of Health & Human Performance
Missoula, MT 59812
(406) 243-5215
annie.sondag@mso.umt.edu

SPECIAL INSTRUCTIONS

The language in this consent form may be new to you. If you read any words that are not clear to you, please ask the person who gave you this form to explain them to you.

PURPOSE

The purpose of this research study is to find out the contextual factors influencing transgender individuals' risk of infection with HIV. By participating in this interview you will help provide valuable information that will be used to develop more clarity regarding the status of the Trans* population in Montana, their health needs, and aid in the creation of better HIV prevention services for the Trans* community in Montana.

PROCEDURES

Participation in this project is voluntary. You are asked to read this consent form. If you agree to participate you will be asked to participate in a 2-week photography project that will involve using a disposable camera to photograph contextual factors in your own life that lead to participation in risky behaviors related to risk of infection for HIV. This 2-week project will start off with a group meeting, to be followed by an optional meeting after the first week and again after the second week. If you are unable to attend the second and/or third meetings, you will be contacted individually by the researchers. Following the completion of the photography portion of the project, the photographs will be developed and returned to you. You will be asked to bring three to five photographs with you to a face-to-face, confidential interview and explain the story behind the photographs and how they relate to risk of HIV infection. The interview will take approximately one hour. The session will be audio recorded and transcribed for accuracy of responses.

RISKS/DISCOMFORTS

You may find some of the questions or activities to be personal, you may feel you do not know or do not want to provide the answers, or some of the questions or activities may make you feel uncomfortable. You are welcome to refrain from answering any question or participating in any activity for any reason or to discontinue your participation at any time.

(continued on back)

BENEFITS

Your help with this study will provide valuable information to the Montana Department of Public Health and Human Services. By participating in this study, your answers will help staff offer services and develop programs to meet the HIV and STD prevention needs of the Trans* community, and offer the MTDPHHS a clearer understanding of the transgender community in Montana.

CONFIDENTIALITY

All information collected during this project, from the photographs to the interviews, will be confidential. Interviewers will avoid identifying any of the participants. Interviewers will not use your name or any other identifying information in reports or any other materials related to this study. Specifically:

- The identities of all interview participants will remain confidential and will not be associated with research findings in any way.
- At the conclusion of the study, any and all data containing information about participants will be destroyed.
- Individual participants will choose which photographs to share with the researchers, and any identifying information from the photographs will be removed according to participant request.

NOTE: *If a photograph that the participant wishes to share contains identifying images of a person, be it you or friends/family members who have been photographed, the person in the photograph will be asked to sign **their real name** to a photograph consent form. These forms will be kept locked in the Principal Investigator's (PI's) office in the University of Montana and will not be shared with the public. This is the only time when a name will be associated with the project.*

VOLUNTEER PARTICIPATION/WITHDRAWAL

Your decision to take part in this research study is entirely voluntary. You are free NOT to answer any question and to discontinue participation at any time. You also may withdraw from this study for any reason.

QUESTIONS

If you have any questions about the research now or later, you may contact Dr. Annie Sondag at (406) 243-5215 or Anna von Gohren at (240) 925-8862.

If you have any questions about your rights as a research subject you may contact the Chair of the Institutional Review Board in the Research Office at The University of Montana – Phone (406) 243-6670.

CONSENT

I have read the above description of this project. I have been informed of the risks and benefits involved, and all of my questions have been answered to my satisfaction. Furthermore, I have been assured that any future questions I may have will be answered by a member of the project team. I voluntarily agree to take part in this study. I am at least 18 years old. I understand this is my copy of this consent to keep.

Printed Name

Signature

Date

APPENDIX F: PHOTOVOICE PARTICIPANT RECRUITMENT SCRIPT

Verbal Instructions for Recruiting Volunteers for the Photovoice Project

Provide each potential volunteer with an explanation of the interview and a brief explanation of the procedures for the interview.

Purpose: The purpose of this study is to collect information about the contextual factors in Montana influencing transgender individuals' participation in risky behaviors that could lead to infection of HIV. The Photovoice project is designed to help gather information for this study to further develop and potentially improve the effectiveness of HIV prevention interventions offered in Montana and provide information regarding a subset of the Montana population that was previously less than visible.

Please remind them:

- The study is completely voluntary and anonymous and they may choose not to answer any of the questions posed at the interview.
- If they volunteer they will be asked to participate in the Photovoice project and ultimately meet with the researcher individually who will ask them to explain the stories behind the photographs regarding contextual factors that could lead to risky behaviors influencing rate of infection of HIV in the transgender population.
- Both the optional final group meeting and the final individual interview will be audio recorded, but no identifying information will be transcribed from the interview and the tapes will be erased at a later date.
- By participating they are helping fight the spread of HIV in Montana. The information gathered by the interview will be used to improve HIV prevention programs for the Trans* community in Montana.

If individuals are willing to participate, give them a copy of the interview questions, the researchers' contact information, and ask them if it is okay for the researcher to contact them to set up a time and place for the interview. Collect contact information including: name, phone number, and email address. Remind potential participants that if they have any questions they can contact the researchers.

APPENDIX G: PHOTOVOICE INTERVIEW QUESTIONS

Photovoice Interview Questions

This is a qualitative research study with grounded theory design. Interviews will be loosely formed around the contextual factors leading to risk of infection with HIV in the transgender community in Montana. Allowing the interview structure to be loose benefits the grounded theory design, which is “dependent upon the ability of the researcher to travel a path through the interview with the participant. The greater the level of structure imposed, the less able the interviewer will be to take the optimal route” (Birks & Mills, 2011, p. 75).

The participant will be simply asked to describe what is happening in each photograph presented in the interview. As needed, probes will be asked regarding each photograph that are structured to reflect the SHOWeD method of questioning common in Freirian literature. This model encourages in depth discussion of each image brought to the interview. The interview will last approximately one hour.

The SHOWeD questioning protocol:

1. What do you See here?
2. What’s really Happening here?
3. How does this relate to Our lives?
4. Why does this problem or situation exist?
5. How could this image Educate others (the community, policy makers, etc.)?
6. What can we Do about the problem or situation?

The interview will end by bringing the focus of the project back to HIV prevention:

1. Do you have anything else to add regarding the project or the experience before the interview ends?
2. Would you like to talk at all about how the issues we have identified in the photographs relate to risk of HIV infection or HIV prevention?

APPENDIX H: PHOTOVOICE INTERVIEW SUMMARY SHEET

Photovoice Interview Summary Sheet

Interview Date: _____

Interview Length: _____

Interview No.: _____

Interview Location: _____

1. Physical description/impressions:

2. Main themes and issues:

3. Research question most directly addressed:

4. New working hypothesis or speculations:

5. Problems or questions:

APPENDIX I: MEMO FORM

Memo Form

Date _____

Memo Title (optional) _____

Current ideas:

Additional comments:

APPENDIX J: PHOTOVOICE PARTICIPANT DEMOGRAPHIC QUESTIONNAIRE

Demographic Questionnaire for Photovoice Participants

1. What age are you? _____
2. Do you consider yourself to be a native Montanan?
 - a. Yes
 - b. No
3. What is the population of the city/town that you lived in before moving to Missoula, which you identify as being the one in which you grew up?
 - a. Urban
 - b. Rural (less than 2,500 residents)
 - c. I have always lived in Missoula
4. If you are not a native Montanan, how long have you resided in Montana?
 - a. Less than one year
 - b. One to two years
 - c. Three to five years
 - d. Five to 10 years
 - e. 11 years to 20 years
 - f. 20+ years
5. Would you like to tell us what state you moved to Montana from?

6. What sex were you assigned at birth?
 - a. Male
 - b. Female
 - c. Intersexed assigned male
 - d. Intersexed assigned female
 - e. Intersexed not assigned
7. Would you consider yourself to be one of the following:
 - a. Cross-dressed
 - b. Transvestite
 - c. Drag queen
 - d. Drag king
 - e. Male to Female (MTF) transgender
 - f. Female to Male (FTM) transgender
 - g. Gender nonconforming
 - h. Other, please describe: _____
8. Where are you in your transition?
 - a. I haven't started
 - b. I just began
 - c. I am about $\frac{1}{4}$ of the way to my end goal
 - d. I am about $\frac{1}{2}$ way to my end goal
 - e. I am about $\frac{3}{4}$ of the way to my end goal
 - f. I have finished my transition

APPENDIX K: PHOTOVOICE CONSENT FORM

The University of Montana
Health and Human Performance Department

Photo Release

I, [print name] _____, hereby grant permission to The University of Montana, Health and Human Performance Department, to use photographs and/or digital images of me provided for use in a Photovoice research project. The purpose of the Photovoice Project is to increase awareness among the general public, health professionals and policy makers, of the health related needs of the transgender population. I hereby release the University of Montana and its agents and employees from all claims, demands, and liabilities in connection with the above. I authorize the use of these images indefinitely without compensation to me. Photographs may be used in the following ways:

***NOTE:** To ensure that privacy rights are protected, individuals whose likenesses are recognizable in photographs to be used by the researchers in this project must give consent for that image to be used. Please only initial next to the terms with which you feel comfortable. Feel free to ask the researchers for clarification regarding any of the conditions.*

____ I agree to have my images included in professional presentations, print or electronic publications, websites, or other electronic communications that will be visible to the general public

____ I agree that my name may be revealed in descriptive text or commentary in connection with the image(s) *note: if this condition is not initialed, researchers will assume that the participant's name may **not** be revealed in any way*

Printed Name

Signature

Date

APPENDIX L: PHOTOVOICE ORIENTATION MATERIALS

Meeting Agenda

** Feel free to get a snack or ask questions at any time!

- Introductions
 - Distribute packets
 - Opening question: What motivated you to participate in this project?
- Explanation of the project
 - Purpose
 - Research questions
 - What is photovoice?
 - Our proposed timeline
- Ethical issues and confidentiality
 - Informed consents
 - Photo release forms
 - Collecting the photographs
- Communication
 - Overview of Trello
- Questions? Clarifications?

At the end of the meeting if there is time, people who wish to communicate through Trello can use one of the computers to set up an account so that we can start using it right away.

Also, there will be an option to set up your individual interview with Anna in approximately two weeks.

THANK YOU FOR COMING!

Health Resources in Missoula, MT

Therapists (provided by the Gender Expansion Project at www.genderexpansionproject.org):

Andrew Peterson
129 West Kent
Missoula, MT 59801
Email: andrewpeterson@montana.com
(406) 531-0659

Andrew Peterson has experience in counseling trans and gender diverse youth.

Anne R. Harris, LCPC
PO Box 17842
Missoula, MT 59808
Email: annerharris@yahoo.com
406-240-9057

Anne R. Harris is a licensed clinical professional counselor in Missoula, Montana, who specializes in working with the transgender community. She has a sliding scale fee based on income, and is willing to work with all of her patients.

Jennifer S. Robohm, Ph.D.
Director, Clinical Psychology Center
Dept. of Psychology
The University of Montana
1444 Mansfield Ave.
Missoula, MT 59812
(406) 243-6890

The University of Montana provides a transgender support group to the Missoula community that is held during Spring and Fall semesters. Contact Nick Heck or Leslie Croot at the Clinical Psychology Center – 406-243-6890.

Linda Kastelowitz, PHD. / Clinical Psychologist
519 S. 4th
Street
Missoula, MT 59801
(406) 327-8830

Lindsey Doe, DHS
Birds & Bees, LLC.
1515 E. Broadway Ste. B
Missoula, MT 59802
Web: <http://www.aboutsexuality.org>
Email: birds@aboutsexuality.org
(406)544-1019

Continued on back

Medical Care/Support (provided in part by the Gender Expansion Project at www.genderexpansionproject.org):

Open Aid Alliance
500 N Higgins, Ste 100
Missoula, MT
<http://openaidalliance.org/>
(406) 543-4770

Montana Gay Men's Task Force- GMTF
PO Box 7984
Missoula, MT 59807
<http://www.mtgayhealth.org>
406-829-8075

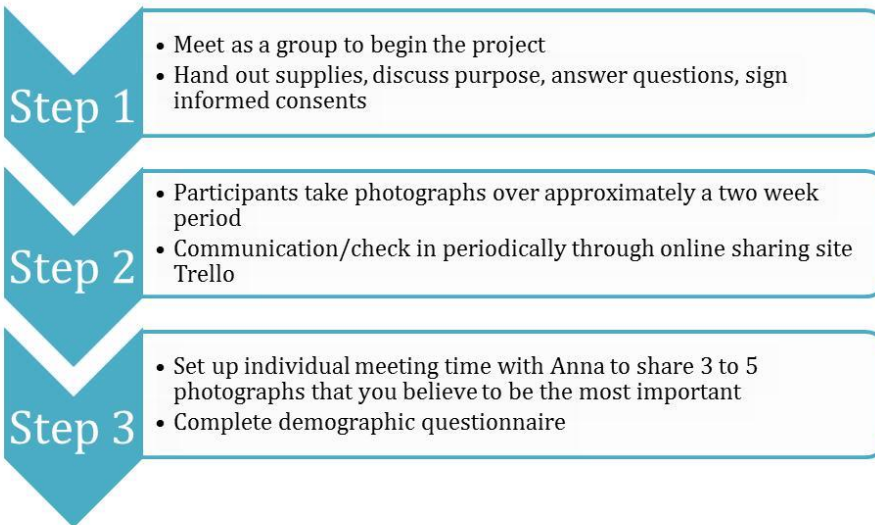
Blue Mountain Clinic
610 N. California
Missoula, Montana 59802
<http://www.bluemountainclinic.org/>
(406) 721-1646

Mary Owens, Nurse Practitioner
Planned Parenthood of Montana
219 East Main Street
Missoula, MT 59802
<http://www.plannedparenthood.org>
406-869-5012

Dr. Jeff Adams & Dr. Mary Kleschen
Curry Health Center
The University of Montana
634 Eddy Ave.
Missoula, MT 59801
contactcurry@mso.umt.edu
<http://www.umt.edu/curry/>
(406) 243-2122

Photovoice Timeline

Project starts at introductory meetings on Tuesday, January 21 and Saturday, January 25



Attempt to conduct individual interviews approximately 2 weeks from start, from February 5 to February 17, 2014.

Have questions, comments, or concerns? Feel free to share through Trello to the group, or contact Anna [(240) 925-8862, agvongohren@gmail.com]

or

Annie [(406) 243-5215, annie.sondag@umontana.edu].

thank
you!

Need help deciding what to photograph?

Purpose: The Montana Department of Public Health and Human Services (MTDPHHS) would like to know more about how to effectively include the trans* community in HIV prevention and education programs. So, we would like to explore factors that may influence trans* individuals' social, mental, and physical health, and more specifically their risk of infection with HIV.

So, what influences our behavior and the decisions we make?

It is believed that our behaviors can be influenced on **five** separate levels. The **individual** level, the **interpersonal** level, the **organizational** level, the **community** level, and the **public policy** level. If you are stuck when you are thinking of what to take pictures of, it could possibly help to think about this model of behavior.

The **public policy level** considers policies and laws that regulate or support (or fail to support) healthy behavior choices at the local, state, or federal levels.

The **community level** explores the formal and informal social rules that we all encounter within our communities, for example the city or neighborhood where we live.



The **organization level** examines the formal and informal social rules that we all encounter at our workplaces, schools, and other social institutions like local businesses.

The **interpersonal level** looks at how our social support systems affect us, for example how do our peers, friends, family, or colleagues contribute to our behaviors and the decisions we make.

The **individual level** contains our individual beliefs, attitudes, knowledge (or lack of knowledge), behaviors, and skills (or lack of skills), as well as self-efficacy, or the belief that we will be successful in accomplishing a certain task.

Ethical Considerations in Photovoice

Personal Safety

Key concerns include (among others):

- Potential risks to photographers from putting themselves in dangerous settings or situations
- Potential risks to photographers from photo subjects
- Potential risks to photographers from being identified in connection with their photos and stories
- Emotional or psychological risk from photographs taken or shared within the group by other photographers

Possible solutions:

- Give careful thought to the context and content of your photographs, and consider the communities you will be in before putting yourself in a dangerous situation
- Use your street sense
- Remember that **no** photo is worth personal danger
- There are alternative ways to present issues (like through abstract representation)
- Take photographs in public spaces instead of private property to avoid trespassing

Subjects in Photographs

Key concerns include (among others):

- Potential risk to photo subjects from being identified in connection with particular situations or activities in photos

Possible solutions:

- Respect the privacy of others; if they don't want their photo taken, don't take it
- Photo subjects must sign a release form
- Emphasize to photo subjects that the photos will be disseminated
- Consider alternate ways to present issues that don't require identifying individuals

Impact on the Community

Key concerns include (among others):

- Potential risks to your community as a whole through generating conflict around issues or negative images

Possible solutions:

- Show both strengths and weaknesses of the community
- Include your stories with the photographs to help avoid misrepresentation

Continued on back

Acceptance of Each Other and of Images Presented

Key concerns include (among others):

- Making a photographer feel uncomfortable about sharing images and starting a discussion or asking questions

Possible solutions:

- Remain open-minded
- Set ground rules as a group
 - What could some ground rules for our group be?

Participation and Ownership

Key concerns include (among others):

- Feeling disconnected from the end goal of the project
- Feeling confused about where the images will end up
- Feeling forced into sharing information that you don't want to share

Possible solutions:

- Ask questions at any time to the whole group or the facilitators about eventual sharing of photographs
- Strive toward clarity over any confusion in regards to the photovoice project
- Keep in mind that you are in complete control over the images that you choose to share and how you choose to describe them

Can we think of any other ethical considerations?

Are there any questions?