2018

A Phenomenological Study of People Living with HIV in Montana

Mary E. Parrish
University of Montana, Missoula

Recommended Citation

Parrish, Mary E., "A Phenomenological Study of People Living with HIV in Montana" (2018). *Graduate Student Theses, Dissertations, & Professional Papers*. 11211.
https://scholarworks.umt.edu/etd/11211

A Phenomenological Study of People Living with HIV in Montana

BY

MARY E. PARRISH

Bachelor of Arts, Anthropology, The University of Chicago

Chicago, Illinois

2008

*

THESIS

presented in partial fulfillment of the requirements

for the degree of

Master of Science in Community Health and Prevention Sciences, The University of Montana

Missoula, Montana

May 2018

*

Dr. Annie Sondag, Chair

Health and Human Performance

Dr. Blakely Brown

Health and Human Performance

Dr. Kimber Haddix McKay

Anthropology

Abstract

Parrish, Mary, E., M.S., Spring 2018 Health and Human Performance

A Phenomenological Study of People Living with HIV in Montana

Chairperson: Dr. Annie Sondag

Rural states like Montana (MT) have unique considerations related to health care. Barriers to care, diagnostic testing and treatment, and availability and accessibility to timely care are of concern in rural areas. These considerations may be exacerbated for someone living with a chronic condition like HIV. Consequently, the primary purpose of this phenomenological study of people living with HIV (PLWH) in MT was to deepen understanding of their lived experience as it relates to the HIV health care continuum. This study captured the experience of PLWH in MT through in-depth qualitative interviews. A phenomenological approach allowed for an understanding of the essence of the lived experience of the interviewee and the opportunity to assess shared experiences across all participants. Interviews were conducted with 10 participants representing the northwestern and south-central regions of the state. Audio recordings were transcribed, reviewed and discussed between two qualitative researchers until consensus was met regarding the essence of all interviews. Member checking with nine of 10 project participants validated accurate representations of each participant's experience of LWH and confirmed broader thematic categories. Participant experiences clustered into nine descriptive categories including: defining experiences, vulnerability, diagnosis, disclosure, health care, supports, education, processing LWH, and experience of LWH. Several insights regarding the health and well-being of PLWH in MT were identified. The value of mental health services to PLWH cannot be diminished: all participants that were linked to mental health care indicated that this aided their healing process. Many participants suggested that peer supports were critical to maintaining a positive outlook and easing the burden of LWH. Engaged case managers, housing liaisons, and coordinated health care teams were beneficial to all participants. It is also imperative to note the need for sensitive health care practices including options that recognize and acknowledge the dignity of each individual, which is crucial during the testing, treatment, and on-going care related to PLWH.

Table of Contents

Chapter 1: Introduction

HIV in the United States

HIV is now characterized as a manageable, chronic condition; however, people living with HIV (PLWH) have a lower life expectancy, and are more susceptible to comorbidities, functional decline, and faster aging than the general United States (US) population (Chu & Selwyn, 2011; Langebeek et al., 2017; Nasi et al., 2017). The Centers for Disease Control and Prevention (CDC, 2017b) reports that, in the US, more than one million people aged 13 and older live with HIV. Between 2010 and 2014, the annual number of new HIV diagnoses decreased by 9%, with 39,513 new cases reported in 2015 (CDC, 2017b).

HIV is disproportionately represented across demographic and sexual transmission categories. Demographically, infection varies by: age; sexual orientation; gender, racial, and ethnic identity; socioeconomic status; and, geographic region. African Americans, representing approximately 12% of the US population, accounted for nearly 45% of all new infections in 2015 (CDC, 2017b; CDC, 2017c). Young people also experience disproportionate infection rates. CDC data indicated that young people aged 13-24 comprised approximately 16% of the US population in 2015, but represented nearly 22% of all new HIV infections in the same year (CDC, 2017b). The highest HIV and AIDS incidence rates are concentrated in the southern US, while the northeastern US exhibits the highest prevalence of PLWH (CDC, 2017b). Diagnoses of HIV infection by sexual transmission category reveals that male-to-male sexual contact, or men who have sex with men (MSM), remains the highest disease transmission category accounting for 70% of all new HIV cases, or 26,200 of all new HIV diagnoses, in 2014 (CDC, 2017b).

Although HIV is a manageable disease today, it is still a pressing public health concern with different considerations by sex and gender, racial and ethnic group, age, socioeconomic status, and/or geographic location. Several studies indicate that PLWH in rural and urban areas experience disparate health concerns such as access to care, availability of treatment, quality of care, delayed diagnosis, and stigma (Costelloe et al., 2015; Kalichman, Katner, Banas, & Kalichman, 2017; Pellowski, 2013). Stigmatization, for example, contributes to social distancing, avoidance, prejudice, discrimination, and self-devaluation (Kalichman et al., 2017). Research indicates that PLWH that experience greater stigma have poorer mental and physical health outcomes, and decreased medication adherence (Kalichman et al., 2017). Although stigma only represents one component of living with HIV, it illustrates the complex relationships that need to be addressed in an integrated manner to effectively reduce HIV transmission, and prevent and treat HIV infection.

HIV in Montana

Montana (MT) is a rural state in the northwestern US with just over one million residents (United States Census Bureau, 2017). In 2015, the MT Department of Health and Human Services (DPHHS) reported 595 PLWH in the state, which included people living out of MT at the time of diagnosis who later became state residents (MTDPHHS, 2016). Most cases (68%) are from the six most populous state counties, including Missoula, Flathead, Gallatin, Cascade, Yellowstone, and Lewis and Clark (MTDPHHS, 2016). Similar to MT state demographics, most new infections are among non-Hispanic, White males (MTDPHHS, 2016). Since 2000, 14-32 new cases are reported annually in the state. In 2015, men accounted for 17 new HIV cases, while there was one new infection among MT women (MTDPHHS, 2016). Paralleling US trends, HIV in Montana is primarily transmitted among MSM, while female infection is largely due to high-risk heterosexual contact (MTDPHSS, 2016).

Purpose of Study

The purpose of this phenomenological study was to explore the experience of living with HIV in MT through qualitative, in-depth interviews with HIV+ individuals living in the state, without regard to their place of diagnosis.

Statement of the Problem

Rural states like MT have unique considerations related to HIV prevention and treatment. Much of the scientific literature focuses on the rural southeastern US where incidence rates are highest (Costelloe et al., 2015; Kalichman et al., 2017; Pellowski, 2013). Although these studies cannot be generalized to a different geographic area with divergent demographics, their findings might illustrate possible concerns for PLWH in MT. In a systematic review assessing barriers to care for rural PLWH, Pellowski (2013) identified 27 different, yet integrated barriers to care including: transportation, provider stigma and discrimination, confidentiality concerns, and affordability or lack of health insurance. Pellowski (2017) also found that PLWH in rural areas typically initiate treatment later than PLWH in urban areas, a delay which often leads to more advanced stages of the disease. Nelson et al. (2016) analyzed CDC surveillance data for care continuum outcomes across rural, urban, and metropolitan settings. Findings indicated that although rural residents experienced the greatest linkage to care (84.3%), they also experienced lower level of care retention (46.2%) and lower levels of viral suppression (50%) compared to their urban and metropolitan counterparts (Nelson et al., 2016). Additional studies reported a geographic displacement after diagnosis, with PLWH moving away from their place of diagnosis (Kalichman et al., 2017; Nelson et al., 2016).

Limited MT specific research indicates that individuals that do not conform to hetero-normative standards may experience loneliness, isolation, and fear related to their sexual or gender identity (Schwitters and Sondag, 2016). In-depth qualitative interviews with closeted, self-identified MSM in MT revealed that affective characteristics, such as loneliness, isolation, and fear of alienation, fostered unhealthy behaviors including engagement in risky sexual encounters, a reluctance to communicate or disclose sexual health with sexual partners, limited interactions with healthcare providers, and an unwillingness to get tested for HIV (Schwitters and Sondag, 2016). Unhealthy behaviors like these likely create an unnecessary burden on individual and public health in the state. Schwitters and Sondag (2016) recommended developing more immediate changes to healthcare settings such as improving access to health services where men feel safe, prior to cultivating more long-term cultural changes that will be necessary to transform seemingly entrenched conservative attitudes toward non-traditional lifestyles.

Significance of the Study

Capturing the lived experience of PLWH in MT by listening to individual stories as they relate to factors like barriers to testing or treatment, or navigating the rural healthcare continuum, could enable the development of targeted health care practices improving health outcomes and quality of life for this demographic including long-term care and positive self-image.

Information from this study fostered understanding and created awareness about the lived experience of PLWH in MT. Findings may help improve patient outcomes, inform population specific interventions, enhance quality of life, and give voice to an under-studied demographic living in a rural state. Results will be shared with MT DPHHS and the MT State HIV Planning Group to enhance provider knowledge and develop strategic healthcare interventions.

Research Questions

- What is the experience of living with HIV in MT?

In the spirit of phenomenological methodology, the research question was broad and open-ended allowing for each participant to share what they considered to be most relevant to their experience of LWH. This strategy allowed each participant to guide the conversation and let information related to HIV testing, treatment, medication adherence, etc. arise more naturally. Extending control to each participant granted them the opportunity to share their authentic voice and their unique experience in their own way and in their own time. In addition to asking about each participant's experience of LWH, everyone was asked what was most beneficial to their health and well-being via the question, 'What works for you?' (*See Appendix for Interview Prompts*.)

Limitations and Delimitations

Delimitations

1. The study was limited to PLWH in MT.
2. Data was collected through in-depth, qualitative phenomenological-based interviews.
3. Data collected was self-reported.
4. Participants were volunteers who could exit the interview at any time for any reason.

Limitations

1. Data collected was limited to the experiences and recollections of each participant.

Definition of Terms

- **ARV:** Antiretroviral viral drugs used to treat, not cure, HIV.
- **cART (HAART):** Combined Antiretroviral Therapy (Highly Active Antiretroviral Therapy) used to treat, not cure, HIV.
- **High-risk heterosexual contact:** An HIV transmission category relating to persons who had heterosexual contact with a person known to have, or to be at high risk for, HIV infection.
- **HIV:** Human Immunodeficiency Virus, typically now a manageable disease.
- **HOPWA:** Housing Assistance for People Living with HIV, a federal housing assistance program.
- **IDU:** An HIV transmission category relating to injection drug use.
- **LWH:** Living with HIV.
- **MSM:** An HIV transmission category relating to men who have sex with men.
- **Out of Care:** People living with HIV that are not currently in medical care or are sporadically in medical care, which could be indicated by not having a viral load detection within the past six to 12 months.
- **PEP:** Post-exposure prophylaxis can be used after potentially being exposed to HIV; it must be taken within 72 hours after the potential exposure for maximum efficacy.
- **PLWH:** People living with HIV.
- **PrEP:** Pre-exposure prophylaxis can be used by people at very high risk for HIV to reduce their chances of getting infected; typically taken daily if someone is perpetually at a high risk for developing HIV (i.e. sexual partner is HIV+).

Chapter 2: Research Perspective and Review of Literature

Phenomenological Research Perspective

Phenomenological analysis explores the lived experience of a shared phenomenon through open-ended interview questions (Padgett, 2012). Husserl described this analytical approach in the early 20th century, which was later refined by Giorgi (1985) and Moustakas (1994), and then applied to healthcare settings by Benner (1994). Phenomenology has roots in psychology and applications in nursing (Padgett, 2012). Padgett (2012) notes that guidelines for qualitative phenomenological studies are among the least explicit, which is reflective of the perspective's philosophical origins. Through in-depth interviews of PLWH in MT, important information was learned about what individuals experienced before, during, and after HIV diagnosis, including the situations and conditions of those experiences.

Phenomenology is both a philosophical perspective and a qualitative research method (Creswell, 1998). This method explores the structures of consciousness in human experience and unravels how individuals construct meaning (Creswell, 1998; Moustakas, 1994). Information about experience and meaning is elicited through long interviews, augmented with researcher self-reflection and secondary literature (Creswell, 1998; Moustakas, 1994). While phenomenological interviews are perhaps less formal and more conversation-oriented than a structured interview, they allow for a more complete exploration of how an individual's thoughts, feelings, emotions, and perceptions are evoked into consciousness and constructed into meanings (Moustakas, 1994). Multiple interviews with diverse individuals experiencing the same phenomenon can be reviewed and synthesized, identifying common themes, shared meanings, and/or divergence from normative categories.

Creswell (1998) states that phenomenology allows the researcher to understand how an individual's subjective experience mediates their objective understanding. "From individual descriptions, general or universal meanings are derived" and the essence of experience is better understood (Moustakas, 1994, p. 13) This phenomenological research approach fostered a more holistic understanding of people's experience of the life-changing event of receiving a positive HIV diagnosis and LWH in MT.

Review of Literature: HIV

HIV-related research is extensive. Today, the scientific literature regarding HIV in the US predominantly focuses on the southeastern US, where incidence rates are highest among Black men and women (CDC, 2017b; CDC, 2017c). Surveillance data demonstrates that a disproportionate number of PLWH reside in the south where HIV incidence and mortality rates are higher than any other region of the country (Reif et al., 2015). For example, in 2010, approximately 38% of the US population lived in the south, while nearly half of all PLWH were diagnosed there in the same year (Reif et al., 2015).

Research for the current undertaking was restricted by several parameters for the purposes of exploring the experience of living with HIV in MT. Research published in peer-reviewed journals within the last 15 years was evaluated with a focus on barriers, risk behaviors, health problems, quality of life, treatment, interventions, and health policy and health care systems with specific regard to rural populations. Each of these topics is explored in more detail below. Although HIV-related research is limited in MT, when possible and relevant, MT-specific studies were included in the following discussion.

Barriers

Barriers to care, treatment, and medication adherence continue to affect quality of life for PLWH (Eastwood et al., 2015). Barriers vary across demographic factors including sex, race, ethnicity, age, and place of residence. In a systematic review, Pellowski (2013) identified 27 barriers to accessing care and remaining in treatment. Barriers varied by geography, social support, culture, and community (Pellowski, 2013). The most pressing barriers were transportation to and from health services, provider stigma and discrimination, confidentiality concerns, and affordability or lack of health insurance (Pellowski, 2013).

Barriers create different health care considerations for rural and urban populations. Eastwood et al. (2015) compared urban and rural barriers to HIV care for 921 women of color located at six urban sites and three rural locations in the US. Findings indicated that urban women were less likely to live in their own home and more likely to report using public assistance than rural participants (Eastwood et al., 2015). Additionally, urban women reported more frequent use of injection drugs or cocaine than their rural counterparts. In the same study, nearly 40% of all women reported intimate partner violence, a dynamic that compromises an individual's ability to effectively self-advocate for sexual health and wellness (Eastwood et al., 2015).

While it is important to note that barriers differ across urban and rural regions, it is critical to focus on rural barriers for understanding quality of life for PLWH in MT. Pellowski (2013) found that PLWH in rural communities initiated treatment later than PLWH in urban settings, while Nelson et al. (2016) reported that although rural PLWH were more frequently linked to care, they were less likely to remain in care than their urban counterparts. Barriers to care for rural residents included: decreased access to services; isolating stigmas related to sexual orientation, HIV status, confidentiality, and substance abuse; less HIV testing; and, more late HIV diagnoses (Nelson et al., 2016). Some research also suggests that PLWH in rural areas at time of diagnosis move to urban areas due to fear, stigma, and confidentiality concerns (Nelson et al., 2016).

Although HIV is considered a chronic, manageable condition today, barriers to testing, care, and treatment remain a concern particularly for people of color, low income, or geographic or social isolation. Barriers need to be carefully evaluated and addressed in a strategic and integrated manner specific for each HIV subpopulation (Pellowski, 2013).

Risk Behaviors

Substance abuse and unprotected sex are recognized risk behaviors for HIV transmission in the US (CDC, 2017e). Sondag and Epperson (2012) and Schwitters and Sondag (2016) identified risk behaviors prevalent among PLWH in MT and closeted MSM in MT respectively. The 2012 Assessment of Prevention Needs of PLWH in MT surveyed 168 PLWH about quality of life, health problems, preferred prevention and treatment services, and barriers to care (Sondag and Epperson, 2012). The most prevalent risk behaviors were substance abuse, including sharing needles, and unprotected sex, including multiple sexual partners (Sondag and Epperson, 2012).

Qualitative interviews with MSM on the down low in MT reinforced Sondag and Epperson's (2012) findings for the state, suggesting that closeted MSM in MT feel lonely, isolated, and fear alienation, often leading to unhealthy behaviors such as limited interactions with health care providers, unwillingness to get tested for HIV, engagement in risky sexual encounters, and a reluctance to communicate with sexual partners (Schwitters and Sondag, 2016). Although Schwitters and Sondag's research (2016) was not tailored to PLWH, similarities exist among MSM and PLWH in rural states like MT where the stigmatization of non-heteronormative lifestyles perpetuates silence and secrecy about sexual health. Reducing risk behaviors will likely require both short-term and long-term solutions including improved access to social and mental health services where MSM and PLWH feel safe, as well as transforming the seemingly entrenched conservative attitudes toward non-traditional life-styles (Schwitters and Sondag, 2016).

Health Problems

PLWH have a lower life expectancy than the general population, and exhibit comorbidities at higher rates and at younger ages (CDC, 2017g; Langebeek et al., 2017; Nasi et al., 2016; Chu & Selwyn, 2011; Vyavaharkar et al., 2010). Combination antiretroviral therapy (cART) has improved the quality of life and life span of PLWH; however, at least one third of PLWH concurrently live with at least one additional health condition that needs to be co-managed with HIV infection (Salters et al., 2017; Vyavaharkar et al., 2010). Some of these health comorbidities can be compounded in rural locations where PLWH may be far from care and have fewer social supports than PLWH in urban and metropolitan settings (Vyavaharkar et al., 2010).

Nasi et al. (2016) reported PLWH experience chronic inflammation and activation of the immune system, affecting their general health and quality of life. Some research suggests that PLWH prematurely age and experience functional decline earlier than the general population. Examples of functional decline in PLWH include: higher bone fracture rates, decreased bone mass, higher risk of developing cancer and cardiovascular disease, and overall frailty (Nasi et al., 2016). In a comparative study of PLWH (n=541) and individuals without HIV (n=542) aged 45 and older, Langebeek et al. (2017) found that PLWH reported worse physical and mental health-related quality of life and a higher likelihood of depression than people without HIV. Specifically, participants living with HIV in this study exhibited lower grip strength, lower walking speed, higher Hepatitis C infection, and more comorbidities than participants without HIV (Langebeek et al., 2017).

Research indicates that social supports are correlated with overall physical and mental health (Vyavaharkar et al., 2010). Consequently, it is critical to cultivate support systems in rural areas where PLWH may have fewer resources and more health problems than the general population.

This could be a practical way to improve quality of life, effectively decreasing and managing HIV-related comorbidities.

Treatment

Medications are available for managing existing cases of HIV and reducing disease transmission (CDC, 2017d; CDC, 2017f). When properly used, Highly Active Antiretroviral Therapy (HAART) effectively manages HIV by promoting continued health and reducing an individual's viral load. HAART requires at least a 95% medication adherence to be effective (Vyavaharkar et al., 2007). Medications are also available to reduce HIV transmission rates for individuals consistently or sporadically exposed to HIV risk. An individual at a high risk for developing HIV, such as a regular sexual partner of someone living with HIV, can take PrEP daily to reduce transmission (CDC, 2017i). The CDC (2017i) reports that routine PrEP use can reduce sexual HIV transmission by nearly 90% and IDU transmission by 70%. PEP, which is better suited to emergency use, can be taken within 72 hours after a possible HIV exposure (CDC, 2017h). Like HAART, both PrEP and PEP, need to be taken as prescribed to be effective.

Medication adherence, or how well a patient takes their prescription medications, continues to be a problematic issue in health care including the effective management of HIV (Rathbone et al., 2017). In a systematic review of medication adherence literature, Rathbone and colleagues (2017) suggest that adherence can be better understood as a social interaction between patient identity and patient medication, which are both mediated by social interactions. This nuanced perspective helps illuminate how barriers to medication adherence affect quality of life for PLWH (Flash, Dale & Krakower, 2017; Vyavaharkar et al., 2007).

Flash et al. (2017) report that behavioral and structural barriers affect medication adherence. Unstable employment or housing, existing mental health disorders, and history of trauma are some common obstacles affecting routine medication adherence (Flash et al., 2017). Vyavaharkar et al. (2007) identified that nearly 60% of 224 women living with HIV participating in a longitudinal, peer-based support intervention for medication adherence in the rural southeastern US did not adhere to their prescribed medication regimes. Further research suggested that women in this study population missed medication due to denial and avoidance (Vyavaharkar et al., 2007). Additionally, researchers identified a correlation between number of children and adherence, with medication compliance reducing as number of children increased (Vyavaharkar et al., 2007). These findings suggest that targeted and tailored programs need to be developed and delivered to PLWH that might be more susceptible to decreased medication adherence. Community-based organizations could be one platform for creating awareness, increasing knowledge, and reducing stigma related to HIV management and sexual health (Flash et al., 2017).

Quality of Life

A positive HIV diagnosis has significant psycho-social consequences: it disrupts an individual's life trajectory and goals, including dramatic shifts in sense of Self, personal relationships, and participation in social activities (Macapagal, Ringer, Woller & Lysaker, 2012). The narrative a person living with HIV tells themselves and others may indicate how well they are adjusting to their diagnosis and treatment (Mazanderani and Paparini, 2015; Macapagal, et al., 2012; Ezzy, 2000; Sowell et al., 1997). For example, in a US-based study, Macapagal and colleagues (2012) captured and analyzed narratives from 26 Black and White men LWH in the Midwest. Findings from this study suggested that a more coherent HIV narrative correlated with self-reported positive, adaptive behaviors and increased social contacts, which are crucial to psychological and physiological well-being (Macapagal et al., 2012).

Narratives are often complex and can reveal an individual's world view and anticipated health outcomes when they are faced with illness. Ezzy (2000) conducted qualitative interviews with 46 PLWH in Australia and assessed their narratives regarding religious beliefs, future planning, and CD4 (T-cell) counts. Within this study sample, Ezzy (2000) identified three different narrative types (Linear Restitution Narrative, Linear Chaos Narrative, and Polyphonic Narrative) that demonstrated how differently PLWH perceive their diagnoses. Linear Narratives presume that the future can be controlled through human action; therefore, hope hinges upon concrete outcomes like improved health or material possessions (Ezzy, 2000). In a Linear Restitution Narrative, life mirrors the narrative, while in a Linear Chaos Narrative, life diverges from the narrative. Consequently, individuals that framed their stories with a Linear Chaos Narrative idealized the past and often expressed anger or experienced depression and social isolation. The Polyphonic, or Many Voiced, Narrative is oriented toward the present: hope is more abstract and arises from new insights from their illness, community, and spirituality. While each narrative was represented in the study group, the Linear Restitution Narrative was more prevalent (38%) than Linear Chaos Narrative (27%) or Polyphonic Narrative (31%) (Ezzy, 2000). (Note, 4% of study participants were excluded from analysis due to pre-existing health conditions that impacted the HIV narrative (Ezzy, 2000).)

Stigma is a pressing public health issue that creates negative self-perceptions, lower rates of disease disclosure, decreased healthcare utilization, limited testing, and reduced medication adherence (Colbert, Kim, Seraiki & Erlen, 2010). Stigma related to HIV status both reflects and catalyzes other stigmatized categories such as social class, gender identity, sexual orientation, and ethnicity, which compounds quality of life for the populations most affected by HIV (Chollier, Tomkinson & Philbert, 2016). Whether perceived or real, stigma interferes with HIV prevention, screening, routine testing, and medication adherence (Kalichman et al., 2017; Chollier et al., 2016; Costelloe et al., 2015).

Considerable research indicates that HIV-related stigma affects PLWH differently across their sexual orientation, gender identity, race, ethnicity, income, and place of residence. For example, in a secondary data analysis assessing stigma across genders (n=183), Colbert et al. (2010) found that women scored disproportionately higher than men on the stigma scale with females reporting both higher rates of personal stigma and negative self-image than their male counterparts. A cross-sectional survey of men and women LWH in urban and rural Georgia revealed that women LWH in rural communities experienced greater concerns about diagnosis disclosure than urban female participants (Kalichman et al., 2017). Coleman (2013) identified a difference in perceived stigma between heterosexual and homosexual participants in a descriptive, cross-sectional study examining the relationships between spirituality, sexual orientation, mental well-being, and functional health in HIV populations. Among 117 Black men and women LWH, heterosexual participants reported poorer mental health and physical functioning than homosexual participants, suggesting that perhaps there are different coping mechanisms across different sexual orientations (Coleman, 2003). Finally, in a comparison of stigma and depression among rural and urban PLWH in North Carolina (n=200), Costelloe et al. (2015) found that rural participants reported more concerns about diagnosis disclosure than their urban counterparts.

The stigmatization of HIV/AIDS contributes to social distancing, avoidance, prejudice, discrimination, and self-devaluation (Kalichman et al., 2017; Kelly, Langdon, and Serpell, 2009). PLWH or AIDS who experience greater HIV/AIDS-related stigma have poorer mental and physical health outcomes, and have decreased medication compliance (Kalichman et al., 2017; Corless et al., 2013). Kalichman et al. (2017) reviewed three types of stigma: internalized, anticipated, and enacted. Each type of stigma has negative health consequences. Internalized stigma, or a feeling of being less worthy than others, is associated with poor mental health outcomes (Kalichman et al., 2017). Anticipated stigma refers to how a person expects to be mistreated or discriminated against, which may affect medication compliance and medical adherence (Kalichman et al., 2017). Finally, enacted stigma captures the internalization of previous stigmatized experiences, which are reinforced with each new stigmatizing experience (Kalichman et al., 2017).

Research demonstrates that HIV-related stigma is a complicated and pressing issue that affects quality of life for PLWH (Kelly et al., 2009). For example, an Interpretative Phenomenological Analysis of gay men LWH in London (n=10) assessed an individual's experience of LWH with special regard to body image (Kelly et al., 2009). Kelly et al. (2009) state that HIV places an increased risk on certain subpopulations that are already highly vulnerable to body dissatisfaction and disordered eating. Semi-structured interviews revealed that participants had discordant ideas of thinness and health that could be addressed through coping strategies related to understanding how the body changes with time, age, and disease (Kelly et al., 2009). A more recent phenomenological study of indigenous populations diagnosed with HIV during their youth (n=21) sought to understand participant experience of LWH from each individual's frame of reference (Woodgate et al., 2017). Woodgate et al. (2017) found that a positive diagnosis during youth for members of this indigenous subpopulation created isolation, and fear of discrimination and stigma at a time when individuals were already struggling to form their personal identity, cultivate a social identity, develop interpersonal relationships, and consider their future. Consequently, these youth reported a reluctance to seek health care and an avoidance of health services (Woodgate et al., 2017). The diversity of HIV research clearly indicates that sub-populations experience stigma differently. As such, interventions will need to be carefully crafted for specific populations addressing each population's unique needs.

The normalization of HIV is a more recent phenomenon that Mazadrani and Paparini (2015) examined through 76 interviews of PLWH in England. Characterizing HIV as 'just another' chronic condition may inhibit the healing process for PLWH (Mazadrani and Paparini, 2015). For example, economic hardship, treatment side effects, social stigma, and discrimination are barriers to normalizing HIV status. During interviews, Mazadrani and Paparini (2015) noted a performative approach to talking about HIV, where individuals are encouraged to speak ‘the right’ way to the ‘the right’ people. Narratives from PLWH in the study indicated that PLWH both contradict and reproduce the wider discursive normalization of HIV; PLWH feel pressured to continue normalizing the disease as a chronic condition, which perhaps incorrectly diminishes the severity of diagnosis as a life changing event (Mazadrani and Paparini, 2015).

Interventions

Structural Interventions

Vulnerability to HIV transmission is a function of structural barriers including social, economic, and legal circumstances that increase susceptibility to infection, heighten risky behavior, and decrease seeking health care (Hardee, Croce-Galist & Peltz, 2014). Although these circumstances are well known and discussed in the scientific literature, Hardee et al. (2014) contend that HIV prevention does not typically invest in structural interventions related to legal reform, education, gender norms, violence, or economic concerns. While these factors affect all PLWH, they are compounded for women LWH who may face a double stigma relating to their health status and childbearing ability, the latter of which is the only route to social status or economic support in some cultures (Hardee et al., 2014).

Hardee and colleagues (2014) conducted a systematic review identifying methods for strengthening the enabling environment for women and girls LWH world-wide. Some successful interventions consisted of: peer and partner discussions; community-based participatory learning approaches with men and women; abolishing school fees; and, increasing employment opportunities (Hardee et al., 2014). Although Hardee et al. (2014) explored interventions on an international scale, some of their findings could be applied to managing HIV in the US. For instance, gender or sexual norms that cultivate sexual ignorance, submissiveness and codependency may disproportionately affect women LWH, MSM, or men on the down low, while violent and abusive relationships decrease an abused partner's ability to negotiate safe sex (Hardee et al., 2014). Structural factors like these affect PLWH's quality of life, possibly reinforcing culturally established vulnerabilities in an already vulnerable population.

Disclosure Interventions

Addressing structural barriers to health and wellness are necessary, however, targeted interventions might be more realistic in the short-term. For example, some HIV research suggests that diagnosis disclosure reduces stigma, facilitates medication adherence, and promotes safer sex practices among PLWH (Teti, Conserve, Zhang & Gerkovich, 2016; Teti, Pichon, Kabel, Farnan & Binson, 2013; Teti, Murray, Johnson & Binson, 2012; Palacios et al., 2015; Hardee et al., 2014; Gordon and Miles, 2011).

Teti and colleagues (2016; 2015; 2013; 2012) developed Photovoice interventions for PLWH to explore diagnosis disclosure. Over several years, Teti et al. (2015; 2013; 2012) implemented and evaluated pilot Photovoice projects among women and men LWH in the US. In addition to intervention development and evaluation, researchers conducted qualitative interviews with project participants to better understand opportunities and challenges for PLWH. Photovoice provided participants a visual opportunity to achieve empowerment, cultivate social justice, and redefine the Self, suggesting that patient disclosure, exposure, and ownership of HIV status can be beneficial for some subpopulations living with HIV (Teti et al., 2013; Teti et al., 2012).

In additional studies, women LWH identified challenges and opportunities regarding patient well-being (Teti et al., 2013; Teti et al., 2012). Challenges included stigma, isolation, mental health, personal violence, trauma, and physical illness, while opportunities for transformation included healthfulness, spirituality, and self-acceptance (Teti et al., 2013; Teti et al., 2012). In a project with men and women, Teti and colleagues (2015) identified disclosure themes which ranged from fearfulness and reluctance to openness.

Contrary to Teti et al.’s findings (2015; 2012), other research indicates that disclosure has varied outcomes (Vyavaharkar et al., 2011). For example, in an exploration of the relationships between disclosure, social support and depression among 340 Black women LWH in the southeastern US, Vyavaharkar and colleagues (2011) reported that disclosure can be a stressor, increasing the vulnerability of an already at-risk population. Factors affecting diagnosis disclosure for this study population included: degree of personal illness or progression of HIV; strength and type of relationship with whom a PLWH might disclose their diagnosis; and, personal belief systems (Vyavaharkar et al., 2011).

Diagnosis disclosure may have positive health effects for some PLWH and should be discussed as a method for improving quality of life. Photovoice only represents one technique of diagnosis disclosure; however, it appears to be effective in some HIV subpopulations, particularly among the minority women in Teti et al.’s studies (2015). However, not all forms of disclosure are appropriate for each subpopulation. Ideally, different disclosure methods should be reviewed and discussed with HIV subpopulations, collaboratively identifying effective and empowering disclosure processes, so that PLWH might benefit from fostering an open dialogue about their disease status.

Health Policy and Health Care Systems

The 2020 World Health Organization (WHO) HIV targets indicate that 90% of PLWH will know their status, 90% of all cases will receive sustained treatment, and 90% of all people receiving treatment will reach and retain viral suppression (MacDonald, Verster & Bagley, 2017). Although these goals are commendable, they are not realistic since key populations continue to be disproportionately affected by HIV. Sex workers, transgender individuals, people living in prisons or closed settings, and IDUs are examples of subpopulations that historically and currently are unduly affected by HIV. MacDonald et al. (2017) suggest that structural factors compound subpopulations' vulnerability, stigmatization, and exclusion from health care services. As such, differentiated and integrated healthcare delivery systems like community-based testing services, peer support, and self-testing, could benefit these populations by alerting them to their status, linking them to care, and retaining them in care (MacDonald et al., 2017). Case management and peer navigation systems appear to improve care retention and enhance individual functioning; however, their cost effectiveness remains understudied (MacDonald et al., 2017).

In alignment with WHO goals, the 2015 National HIV/AIDS Strategy outlined a five-year plan to guide response to HIV in the US (Albritton, Martinez, Gibson, Angley & Gradnelski, 2017). US priorities included: fewer new infections, increased access to care, improved health outcomes, fewer health-related disparities, and a coordinated response (Albritton et al., 2017). Albritton et al. (2017) report that strategies developed to meet these priorities (i.e. expanding outreach efforts in high risk communities, supporting individuals with coinfections, and meeting basic housing needs) have been problematic due to flat federal funding: financial resources have remained the same, while there continue to be more cases of HIV. Historically, rural communities have received less health funding, and therefore, may stand to lose the most regarding national targets (Albritton et al., 2017).

Albritton and colleagues (2017) conducted qualitative interviews with 11 HIV case managers working with seven different agencies located in one northeastern and one southeastern state to better understand HIV policy, planning, and management. Grounded Theory analysis of interview transcripts identified common themes among case manager participants. Topics consistently addressed by case managers included: Ryan White budget; AIDS drug resistance programs; syringe exchange programs; ancillary services; housing services; substance abuse assistance; home visits; financial assistance; transportation; and, HIV/AIDS prevention outreach (Albritton et al., 2017). Case managers also reported that policy changes and budget cuts increased barriers to care, prevention, and all ancillary services. It was noted that rural communities might achieve more effective program integrations because there are fewer stakeholders with competing interests (Albritton et al., 2017).

Research suggests that policies should be sensitive to place (physical location) and to the social determinants of health present in each place (Albritton et al., 2017). For example, rural areas may have concerns specific to accessing quality care where there are typically fewer health centers and limited health specialists (Albritton et al., 2017). In addition to tailoring place-based policies, case managers, PLWH, and care providers need to navigate changing federal funding guidelines regarding the HIV continuum of care.

People Living with HIV Out of Care

A discussion of health care systems would be incomplete without considering PLWH that are out of care. PLWH that are out of care are more likely to transmit HIV to others and more likely to have poor health outcomes than PLWH engaged in continuous care (Dombrowski et al., 2017). Current public health efforts target PLWH out of care; however, if these individuals are not out of care, but rather lost in data surveillance systems, then health efforts or federal funding could be better targeted elsewhere (Dombrowski et al., 2017).

In a 2017 study, public health researchers analyzed out of care HIV statistics across six states in the Pacific Northwest (Dombrowski et al., 2017). More than 3,800 patient cases were identified that lacked a viral load or CD4 count in the 12 months or more between 2012 and 2014 (Dombrowski et al., 2017). No recent viral load was used as an out of care indicator because it suggested that a PLWH was not recently seen by a care provider. After patient follow-up, Dombrowski and colleagues (2017) classified a PLWH as: moved; deceased; in care, but unaccounted for; out of care during the surveillance period with evidence of care after the surveillance period; out of care during and after the surveillance period; data error; or, not locatable. Prior to analysis, researchers estimated that 25% of the 3,866 cases would be out of care; however, after investigating all cases, they determined that only 8% of the total sample was actually out of care (Dombrowski et al., 2017). MT specific data indicated that there were 582 PLWH during the 2012-2014 study period (Dombrowski et al., 2017). Of the 582 PLWH, 110 people (or 19% of all PLWH in MT) did not have a viral load or CD4 count (Dombrowski et al., 2017). After follow-up, it was determined that 74 people moved; 13 died; 11 were in care; 11 did not have evidence of care; and, no one was lost to data error (Dombrowski et al., 2017). These findings indicate the need for refined data collection and surveillance systems with data systems sharing relevant patient information across health districts.

Moving Forward: Continuing to Address HIV in MT

The most recent assessment of the prevention needs of PLWH in MT collected information regarding demographics, quality of life, risk behaviors, barriers to care, unmet needs, and preferred services from 168 individual surveys and four focus groups comprised of 22 PLWH from across the state (Sondag and Epperson, 2012). Qualitative data from the focus groups added depth to survey data indicating that PLWH in MT continue to feel stigmatization and isolation due to their HIV status (Sondag and Epperson, 2012). Additional findings paralleled trends from the scientific research relating to risk behaviors (i.e. substance abuse and unprotected sex), health problems (i.e. comorbidities related to mental health and side effects from medication), and barriers to treatment (i.e. transportation, fear of disclosure or lack of confidentiality, and distrust of health care providers) (Sondag and Epperson, 2012).

Although the scientific literature suggests that more research needs to be conducted about the efficacy and cost effectiveness of case management, the most recent MT assessment indicated that PLWH held their case managers in high regard and nearly 95% of all study participants were linked to care at the time of their participation in this assessment (Sondag and Epperson, 2012). Poverty is closely associated with HIV status in MT: more than half of all participants reported an income of less than $20,000 per year and one-third of all participants were receiving housing assistance (Sondag and Epperson, 2012). At the time of this assessment, participants reported several unmet needs including: health education related to HIV and sexuality; personal empowerment; peer advocacy; physician expertise; addressing comorbidities; and, knowing how to navigate changing healthcare systems (Sondag and Epperson, 2012).

The current research undertaking sought to enhance both awareness and knowledge of people's experience of LWH in MT with the intent of informing health professionals of an insider's perspective of LWH and of tailoring health services for this population. A qualitative, phenomenological inquiry, while small in scale, provided a more nuanced understanding of LWH in a rural state in the intermountain west. Community-based participatory research suggests that targeted, collaborative research in specific populations might reveal relevant localized health issues within the context of the immediate culture (Hinkler & Wallerstein, 2003). While the existing scientific literature is beneficial to understanding the experience of PLWH in general, more targeted research conducted where the people are, should enrich the development of accessible and efficacious local health programming in the state.

Chapter 3: Methodology

Introduction

This phenomenological study explored the experience of LWH in MT through qualitative, in-depth, open-ended interviews with PLWH in the state, without regard to their place of diagnosis.

Description of the Target Population

The target population for this study consisted of PLWH over the age of 18 who currently reside in MT.

Protection of Human Subjects

This study was conducted with approval from the University of MT Institutional Review Board (IRB#24-18, Approved February 1, 2018; *See Appendix*).

Study Design

This phenomenological study captured the experience of living with HIV in MT through one-time qualitative interviews with PLWH. Qualitative research was well-suited to exploring this complex topic of emotional depth from an insider's perspective (Padgett, 2012). A phenomenological design allowed for understanding the essence of the lived experience of the interviewee and the opportunity to assess shared experiences across all participants (Padgett, 2012).

Each participant was interviewed once, in-person with follow-up for clarification and member-checking to validate findings. Although the study consisted of one-time interviews, the research process sought to identify and explore the holistic experience of each participant: while the interview occurred once, an individual could discuss any component of their experience from any time in their life.

Procedures

Instrument Development

Following established guidelines for phenomenological studies, the interviews were open-ended allowing for participants to elaborate upon their experience of LWH in the manner that they chose. The interview consisted of one opening question: What is your experience of living with HIV in MT? Prompts were developed to assist participants who may have had difficulty responding to this broad question; however, these prompts were not needed (*see Appendix for Interview Prompts*).

Expert Assistance

Prior to conducting interviews, the researcher met with case managers, clinicians, and health professionals familiar with PLWH to better inform the interview process. This prepared the interviewer for discussing what is considered a sensitive topic with a vulnerable population.

Pilot Testing

Pilot testing did not occur since this was an open-ended interview process without an established questionnaire. However, prior to formal interviews, the researcher practiced and refined interview techniques such as active listening, including reflection of content and reflection of emotion, such that she was better prepared for the data collection process.

Sample Selection

PLWH in MT were accessed through passive purposive sampling (Padgett, 2012). Given the sensitive nature of HIV and ethical considerations for privacy, study participants were passively recruited by partnering with clinicians, case managers, and nonprofit resource centers that serve this population across the state. These specialists and organizations privately shared project information with qualified candidates, and interested parties contacted the researcher for more information about participation. Ideally, a racially and ethnically diverse sample would have been identified, however, participants paralleled the larger state demographics, and the demographics of PLWH in Montana, which are predominantly male and White.

Data Collection

Data was collected through informal open-ended interviews with 10 individuals whereupon saturation of themes was realized (Padgett, 2012). Interviews were conducted in-person, in private spaces at Open Aid Alliance in Missoula and Riverstone Health in Billings. All interviews were audio-recorded and transcribed verbatim. Interviews varied in length from 60-120 minutes with approximately 350 pages of transcription. As described by Padgett (2012), the researcher retained a personal field notebook to ensure best practices. The notebook captured the researcher's personal reflections and perceptions before, during, and after interviews, and as needed when analyzing findings, which helped reduce bias and improved the research process. Padgett (2012) suggests the following guidelines for maintaining a field notebook: (1) avoid inferences; (2) distinguish between first-order and second-order data, such as verbatim conversation(s) or paraphrasing; (3) record observations of self; and (4) strive for balance. Keeping an accurate and timely record produced invaluable raw data and refined the research process, while offering a private space for researcher reflexivity (Padgett, 2012) (*see Appendix for Field Notebook Guidelines*).

In addition to the qualitative interview, participants were asked to complete a brief demographic questionnaire regarding: age; sex; race/ethnicity; socio-economic status; educational attainment; and, year of HIV diagnosis (s*ee Appendix for Demographic Questionnaire*).

Upon arriving for the interview and providing verbal consent, participants received a $50 monetary incentive for their time.

Data Analysis

A phenomenological perspective suggests that human experience makes sense to those who live it and that that meaning can be consciously expressed (Creswell, 1998). The goal is to understand experiential matters from the perspective of participants, or those who experience the phenomenon most personally (Creswell, 1998). This research approach requires extensive self-reflexivity of both researcher and participant: reflexivity involves researchers thoughtfully recording their reflections relating to personal biases so that they may more deliberately set aside preconceived notions about what will be found in the study, while the participant is expected to carefully reflect upon their experience of living with the phenomenon.

Raw interview data was reviewed and transcribed verbatim for each subject. Individual interview transcripts were reviewed repeatedly until a deep familiarity was acquired for them. Multiple interviews were reviewed and synthesized, identifying common themes, shared meanings, and divergence from normative categories (Padgett, 2012). Significant statements were extracted from individual interviews that directly pertained to LWH (*horizontalization* of the data) (Creswell, 1998). Meanings were derived from repetitive contextual reading of selected statements across distinct interviews. This meaning could not be separated from its grounding in the experience of LWH. Once individual meanings were identified for each participant, clusters of themes were organized and aggregated across all interview data. Textural and structural data interpretation led to an understanding of the essence of the experience (Padgett, 2012; Creswell, 1998). Textural description answered, "what happened," while structural description answered "how" the phenomenon was experienced (Creswell, 1998, Table 8.2). Once the data was texturally and structurally organized, an essence become evident, for each individual participant and the larger participant pool.

An exhaustive description of the essence of the phenomenon resulted from the aggregate data (Padgett, 2012). Two readers trained in qualitative research methods reviewed all data and reached consensus on meanings and themes to ensure reliability of findings. This study was undertaken with a collaborative, social justice-oriented approach that sought to give voice to PLWH in MT. Therefore, the meanings and themes identified by the researchers were validated with interviewees to reduce potential errors or misunderstandings. Two to four-page member summaries were written for each individual, capturing general themes of the conversation and the essence of their experience of LWH. All participants were contacted to review these summaries with the researcher with an offer of a $10 incentive for follow-up. Secondary meetings with nine of the 10 participants served as member checking, validating research findings.

Chapter 4: Results

Interview Process

Ten individuals participated in the project. Participants were recruited through passive purposive sampling with assistance from Open Aid Alliance in Missoula and Riverstone Health in Billings. Additional recruitment strategies were implemented including a partnership with the Gay Men's Task Force in Missoula and direct outreach to all Ryan White case managers across the state. Interested participants LWH contacted the researcher to learn about the project and schedule an interview.

All interviews were conducted in person, in private spaces at Open Aid Alliance and Riverstone Health. Although the researcher and interviewees met privately, safety was ensured for all participants by holding interviews during regular business hours at each organization when other individuals were present at each facility. Interviews lasted 60-120 minutes, ending when each participant felt that they had fully shared their experience. Interviews in Billings were shorter due to participant time constraints; often these participants were at Riverstone Health to tend to healthcare needs in addition to meeting with the researcher.

Demographic Data

Participants were from the northwest and south-central regions of the state, with seven participants representing northwestern MT. Ages ranged from 24 to 64 years old, with participants LWH for 3 to 31 years. Interviewee race/ethnicity paralleled both state demographics and PLWH in MT: six people identified as White/non-Hispanic, three identified as American Indian/Alaska Native, and one indicated a preference for "Other." Six participants identified as male and four as female. There was a diversity of sexual identities represented including four heterosexual women, five gay men, and one bisexual man. Most participants had some exposure to college-level education but did not complete their degree. Two participants completed college and one attended a trade/vocational school. All participants indicated that they earned less than $20,000-$35,000, suggesting that they were at or below the poverty level. All participants received federal and/or state assistance either currently or previously.

Thematic Categories

Interview transcriptions were read and re-read until a deep familiarity was gained and the essence of each participant's experience was understood. Thematic categories evolved with each reading until topics accurately captured both the individual and the group experience of LWH. Categories were reviewed and discussed between two qualitative researchers until consensus was met.

During theme development, the primary researcher wrote individual interview summaries, one for each participant, attempting to capture the essence of each person's experience. Summaries were written in plain language as if writing a letter to each person. All participants were contacted to review member summaries with the offer of a $10 incentive to follow-up with the researcher. Six of the 10 participants met with the researcher a second time, at a private setting at Open Aid Alliance. All six people indicated that the summaries accurately and authentically captured their experience and their voice. Participants noted that they felt heard and were grateful for the opportunity to contribute to the project. Three additional participants representing the south-central region of the state reviewed summaries remotely and confirmed that their summaries accurately represented their experience.

Member checking served two purposes: verification of both individual and group experience related to LWH. Participants acknowledged the value of each thematic category and noted that the categories described their overall experience. Consequently, theme consensus was reached by triangulating with participants and a second qualitative researcher. After agreement was reached, all interviews were coded using NVIVO qualitative data analysis software. Coding was reviewed by both researchers until consensus was met regarding the accuracy of each thematic category and representational quotes from each interview. (*Refer to Appendix for Member Summaries and Coding Tables*.)

Nine thematic categories were derived by organizing similar individual experiences into broad categories that attempted to accurately capture the essence of those similar, shared experiences. Categories included: defining experiences, vulnerability, diagnosis, disclosure, health care, supports, education, processing LWH, and experience of LWH. Descriptions of individual categories with representative quotes follow. Participant names have been changed to protect identity and retain confidentiality.

Defining Experiences

Defining Experiences captures significant events directly or vicariously experienced by an individual. These events could have occurred during childhood, adulthood, or both. Most defining experiences were related to traumatic events including, but not limited to: emotional, psychological, physical, or sexual abuse. All but one participant reported memorable defining experiences related to adverse childhood events, and/or intimate partner abuse and violence. Examples of defining experiences included: growing up in the foster care system where abuse was prevalent; growing up in a home where they and/or their siblings were molested; growing up in a one-parent home with significant instability related to substance abuse, mental health issues, and/or unemployment; intimate partner abuse and/or manipulation; homelessness; and, forced prostitution. Often, adverse childhood experiences continued through adulthood, where the cycle of trauma persisted until an individual started taking steps to process those experiences, regain their self-worth, and practice forgiveness.

Susie, a middle-aged woman, described growing up in the foster care system and later living with her aunt and uncle who raised her. She shared that she experienced physical and verbal abuse in both environments, a trend that continued into adulthood. Susie acknowledged the role that this abuse played in fostering unhealthy co-dependent behavior that presented itself in each of her five marriages.

“I never had a normal childhood. And into my adulthood… abuse was still there.”

Michelle, a woman in her mid-30s, discussed the cycle of abuse and trauma that she is now trying to break. She was molested by her father at a young age and was subsequently raised by her alcoholic mother. Michelle shared she never had to go to school and she moved from place to place throughout her childhood. She married in young adulthood and quickly entered parenthood helping raise more than 10 children. Michelle described her marriage as a complicated relationship where she learned how to take care of herself and others, while simultaneously being undermined by a husband who would diminish her worth and make her feel incapable of being a good parent without him. The relationship became even more strained through bouts of shared drug abuse. Michelle also revealed that one of her step-sons molested her children, and later her husband molested her daughter. She shared that she is now taking steps to address and improve her self-talk, however these experiences remain with her today affecting her perception of her self-worth.

“You don’t understand the things that were put in my head.”

Vulnerability

Vulnerability is distinct from Defining Experiences, such that Vulnerability captures on-going, dynamic processes affecting quality of life. Information related to this thematic category consisted of: drug and alcohol abuse; drug and alcohol addiction; poverty; lack of family or social supports; risky sexual behavior, both chosen and coerced; codependency; and, unhealthy peer supports.

Nearly all the participants shared that they had an addiction, several of which were addicted to methamphetamine. The remaining two participants, while not necessarily abusing substances, intimated that they were often in environments where drugs and alcohol were abused. These individuals experienced verbal and physical abuse because of those environments.

All women described various levels of co-dependency that affected their feeling of self-worth and their ability to live independently. Although these participants may not have described themselves as co-dependent, they related stories of intimate partners manipulating them, diminishing their worth, and/or withholding resources like food and money. Today, the women described a sense of coming back into their own by improving their sense of worth and self-esteem.

All participants, particularly those in recovery from substance abuse, discussed the importance of positive social supports, like fostering relationships with like-minded peers. Individuals often described the idea that ‘you are who you hang out with,’ and the need to remove negative influences to promote healthier lifestyles. About half of the participants were in recovery and acknowledged both the pride and vulnerability of that state: they are proud of the changes they have made but recognize that recovery is an on-going process requiring daily attention.

> Jaime, a woman in her early 20s, talked about her drug addiction that escalated when she was forced into prostitution. This addiction later intensified when she learned of her HIV diagnosis. She indicated that she went through bouts of trying to sustain healthy behaviors, however, those well-intentioned efforts were short-lived due to the severity of her addiction and her feelings of

hopelessness at the time. She noted that she had several legal issues related to her risky behavior: she was arrested and had time to withdraw from drug use and enter treatment, which may have been the best thing for her health today.

> *"I couldn't really stop using drugs until I finally got caught with drugs."*

Matt, a middle-aged man, shared his on-going battle with alcohol abuse and risky sex related to a sex addiction. He described having sex with multiple unknown partners, sometimes having upwards of 15 encounters in a day. Of all participants, Matt has been LWH for the shortest amount of time. Although he appears to be in shock over his diagnosis, he seemed to recognize the intricate and complex connection between his unhealthy behaviors and his current physical, mental, and emotional condition. Matt's words illuminate an experience common to many PLWH that engage in high risk sexual contact and substance abuse behaviors.

> *"To me, sex with multiple men always started with drinks, and then it would just get out of control."*

Diagnosis

This thematic category describes HIV testing and diagnosis, including initial thoughts, feelings, and reactions to a positive diagnosis. All but one individual who engaged in risky sexual behavior and/or injection drug use seemed to know that something was just not right with their health, sensing that they would be HIV positive prior to confirmation from a test. All but one of the female participants were entirely blind-sided: two unknowingly contracted HIV from ex-husbands and one participant engaged in a one-night stand where contraceptives were used. All participants, even the participants that knew they would be HIV positive, felt a range of negative emotions including shock, fear, sadness, and loss of the life they once knew. Participants described their positive diagnosis similarly, stating that they felt 'marked,' 'tainted,' and as if they had been given 'a death sentence.'

Participants in the study had been LWH for three to 30 years. Individuals that were diagnosed in the late 1980s and early 1990s, described changes in HIV health care, noting that testing, diagnosis, and medications have significantly improved with time. Tom was diagnosed during the height of the HIV/AIDS epidemic and shared that his positive diagnosis came with the advice to prepare to die. He sold his pets and belongings, which affected his quality of life for several years until he decided to live his best life since his medication seemed to be working. He now has a dog and chickens that bring him great joy.

> *"And back then, you know they told you, 'You better make your arrangements'."*

Michelle shared her reactions to a positive diagnosis. Like all participants, she felt a range of emotions wondering how her life changed in that moment. She questioned if she would lose her family, thought about how long she had left to live, and wondered if she would be single and unpartnered for the rest of her life.

> *"I felt like I was going to be forever alone."*

Alexander, a young, gay man, has been living with HIV for several years. He intimated that he was and continues to be afraid not just of LWH, but of the implications of LWH. He described a cycle of loss that is difficult to navigate: he lost friends, jobs, and a career which he attributes to his status. His fear seems to be connected to feelings of hopelessness that are continually compounded by detrimental experiences related LWH.

> *"I'm just so afraid."*

Disclosure

Disclosure refers to transparency and honesty with health providers throughout the care process, as well as sharing one's status with family, friends, and/or intimate partners. Typically, participants with substance abuse issues and/or risky sexual behaviors shared that they were not immediately forthright with their health care providers, perhaps due to shame, perhaps due to knowing they were not ready to address their behaviors, or possibly due to wanting to protect themselves from additional hurt and pain. It seemed that with time, trust, and processing, many participants realized the importance of honest interactions with health providers, noting that the relationship with their health care team was critical to maintaining their well-being. Almost all participants sought out mental health care, which helped them start processing defining experiences, including their HIV diagnosis.

Sharing one's status with loved ones is an important decision that each participant carefully considered. All but one individual shared that they disclosed their status to intimate partners; however, almost everyone that did so experienced at least one shift or loss of a relationship, which caused them to be more careful with future disclosure. Many participants shared their status if they knew it could compromise other people's health, for instance letting children or coworkers know that if an accident or injury occurred that they should take precautions. All individuals shared the sentiment that they 'found out who their real friends were' when they attempted to share their status. Often, individuals were surprised by who remained in their lives and who left them; however, all were thankful for the support they now have. Many individuals sought help from family with mixed outcomes: several people who had tenuous family relationships to begin with were rejected and scorned, while others who had strong family connections were supported.

> Gary, a middle-aged man, described the importance of talking about LWH with someone. Like other participants, he shared that he initially concealed his status, holding all thoughts, feelings, and emotions within himself, until he broke down. Gary found great relief and significant healing

from connecting with a mental health counselor where he engaged in beneficial dialogue about past experiences, current behaviors, and healthy coping mechanisms.

> *“Important to not be alone and talk to someone about it.”*

Matt described leading divergent lives: he had one identity with his conservative family, another with his friends and coworkers, and still another with his sexual partners. He tried to retain these distinct identities to protect himself and his family. Matt became extremely sick over the course of two years, ultimately close to death when his mother called an ambulance to address his emergency care needs. Matt became unconscious in the hospital and required consent to care, whereupon doctors disclosed his HIV status with his family. He would not have told his family had he had a choice. He feels that he lost all respect from the people he thought loved him. He lives near family and tries to maintain a familial connection, but often feels isolated even in group settings where he is talked about and talked over despite his physical presence at gatherings.

> *“Now they all look at me differently. That’s probably the hardest thing.”*

Education

Education is three-fold and refers to self, others LWH, and the general population. All participants shared that they knew very little about HIV prior to their diagnosis and that they had since learned a lot about the disease. This limited knowledge extended across all individuals regardless of when they were diagnosed: individuals that were diagnosed in the late 1980s and within the past five years thought they would die from the disease, even though medication and understanding has significantly improved with time. While each person has since learned a lot about HIV, there still seems to be some misunderstandings. For instance, on several occasions, participants related that they were undetectable, and they were told that they could not transmit HIV to anyone, but they were ‘not sure’ if that was accurate.

Each participant intimated that they wanted to contribute to this current project to share their experience with other PLWH that might be struggling with their diagnosis. Many people recognized the importance of sharing their story and how it fosters healing. They wanted to ensure that PLWH not be afraid and know that they are not alone. Several individuals wanted to engage in a peer support or mentoring role; however, some of those people that would like to do so also acknowledged that they need more time to heal and process before being able to support others.

All participants described the need for more HIV education for the general population. Participants shared that it felt like many people still have misconceptions about HIV, often incorrectly stereotyping what someone with HIV 'looks like.' Participants discussed the need for general education within the context of family members not wanting to share things like utensils or coworkers assuming HIV affected their ability to effectively complete their job. There were different views about the need for education in general and the need for education in a rural state like MT. Regardless, all participants stated that 'no one is safe' and people need to know how to protect themselves and how to treat PLWH with respect and dignity.

> Susie was diagnosed with HIV while living in the Southwest. At the time of diagnosis, she was leaving her fifth husband. She reached out to family in MT, thinking she would receive love and support while transitioning to a new place, processing her diagnosis, and evaluating care plans. Susie intimated that she was not welcomed when she moved to MT more than a decade ago. She relates this behavior to misinformation and misunderstanding that could be rectified with education and compassion.
>
> > *"My family was scared to death of me; they still are."*
>
> Jaime discussed a steep learning curve: prior to her diagnosis she knew little about HIV, because it did not directly affect her. Upon receiving her diagnosis, however, she became an informed

patient and continues to learn about HIV to be her best advocate. She recognized that lack of knowledge fosters stereotyping that she feels is prevalent in MT. She cautioned that some people do fit 'the mold', while others certainly do not.

> *"That's another thing people don't understand. There's people that fit the stereotype and then there's a lot of people… that don't."*

Health Care: Providers & Medications

Health Care describes experiences with care providers and HIV medications.

Relationship with Care Providers

Although all participants seem to have strong relationships with their current health care providers, a few participants shared that they had bad experiences along the way. A few individuals were immediately connected to care and providers that they felt comfortable with engaging in the healing process. Other individuals shared that their confidentiality was breached either in the health care facility and/or in a public location causing them to mistrust the health care system and creating a need to find new providers at a different, safer location. Most participants felt that trust and honesty were critical components of doctor-patient interactions, and that that trust and honesty was required of both individuals in the care giving relationship. Most participants related that they saw a mental health professional, which helped with their healing process. It seemed that finding a mental health professional was a turning point for people: they acknowledged that although it required vulnerability, healing became more possible with an open discourse in safe space. Another individual did not discuss seeing a mental health professional, but intimated that he was connected to a spiritual and peer mentor for more than ten years, which helped his recovery process. Another individual who was recently diagnosed understands that a counselor could be beneficial but notes that he is not ready to take that step.

Only one person related that he was afraid of seeing a mental health professional indicating he has always had a fear of people in authority.

> Jaime, like other individuals struggling with addiction in the project, described the endless support from her HIV case managers. Jaime's drug addiction and alcohol abuse intensified immediately after her diagnosis. She noted that she consistently went to her medical appointments, but she was not happy to be there. Despite her anger, her case managers consistently met her with kindness and compassion. Both the availability and authenticity of support helped Jaime process her diagnosis and heal.
>
> *"They were just very kind, until I was ready to be kind."*

Medication

Individuals had a variety of feelings and attitudes about medication. A handful of people were immediately compliant to their prescribed medication regime. Other participants, particularly those with substance abuse issues, described taking medication inconsistently, which they acknowledged was a result of their struggle with addiction. With time, it seemed that almost all participants became compliant, however, they noted that sometimes they occasionally missed a dose due to stress. One participant shared that he gets tired of taking meds and goes on 'pill vacations' sometimes upwards of six months. Another participant seemed to be the least adherent, which he recognized was due to his addiction and fear of what the pills did to his body. Another person identified a critical insight regarding her journey toward medication adherence: she intimated that she was not initially compliant to her med regimen because when she was in her addiction she was still surrounded by unhealthy individuals who engaged in risky behavior and would not be above stealing pills. This awareness meant that she did not want to pick up medications from a facility, risk having them stolen, and possibly compromising her HIV status in the process.

It is also important to note that nine of the 10 participants have non-detectable viral loads.

> Tom provides an example of the complex relationship PLWH might have with their medication. He has an undetectable viral load, indicating that he continues to adhere to his medication regime. However, he also casually shared that he often takes ‘pill vacations.’
>
> > *“I went for like six months this last time without taking them [meds] just because I was just tired of pills. But I also know that I want to be here ... I need to keep taking them.”*

Supports

Supports encompasses both what is beneficial and what is needed to live a healthy life while LWH.

All participants shared how integral their case managers were to their healing process. Individuals struggling with addiction particularly noted the importance of their relationship with their case managers, noting that they were always available, caring, and non-judgmental. Housing assistance was also important: not only does a safe, clean space foster a positive outlook, but it also recognizes the dignity of each person. Participants noted that they found benefit from support groups or regular gatherings with other PLWH, family and friends, and healthy outlets like walking and hiking. A few individuals shared that their faith became stronger after their diagnosis and that their spirituality continues to be a great comfort.

What was most beneficial for all participants was a safe space, like Open Aid Alliance in Missoula, where PLWH could find security, compassion, and friendly faces. It seemed critical for PLWH not necessarily to talk about their HIV, but to see other PLWH, knowing that they were not alone in their experience. While individuals in Missoula felt that support from Open Aid Alliance, they identified the need for additional support groups, perhaps even for friends and family of PLWH. Participants from Billings emphasized how beneficial Yellowstone AIDS Project was when it was open: it was that safe space where PLWH could freely come and go, take respite, use the internet, get food, and reassess. It seemed like PLWH in Billings would find great value in a space like Yellowstone AIDS Project if it were made available to them. Currently, participants acknowledged that the lack of that space is noticeable throughout the community and many people are wondering where they can go and who they can turn to in times of need.

> Preston, a middle-aged man, is in recovery from drugs and alcohol. His experience of LWH is intimately tied to his spirituality. Although he is very guarded with his status, he finds strength to live a healthy life from within, an ability that is likely related to his deep connection with his American Indian/Alaska Native culture including daily prayer and ritual.
>
> > *“I think I find strength within myself knowing that no one is going to do it for me, I've got to get out there and do it myself. I quit, cleaned up.”*

> Alexander, a native Montanan, was diagnosed with HIV in the Portland, Oregon area. He severed all connections with friends in Oregon and returned home to MT where he had family and what he thought would be beneficial supports. Alexander shared that he and others found great refuge at Yellowstone AIDS Project, where like-minded people could find comfort in a safe space. He seems to have lost hope and feels defeated, not necessarily from HIV, but from his experience of LWH and society’s negative reactions toward the disease. He noted that his day-to-day life is difficult and thought it would be a great benefit to the community if something like the Yellowstone AIDS Project were available.
>
> > *“They [Yellowstone AIDS Project] were always there, not to be that crutch, but to be that helping hand when I needed it and now it's--I know people just being like, ‘Now where do I go? What do I do?’"*

Processing Diagnosis

Processing Diagnosis refers to the changing mental, emotional, and physical processes related to understanding, accepting, and LWH. Adjustments took a variety of forms for all participants. Several of the individuals that acknowledged they struggled with addiction, shared that they immediately returned to their abusive drug and alcohol behaviors, sometimes with more intensity than before their HIV diagnosis. One individual noted that once they recovered from the shock of the initial diagnosis and regained their physical health that they returned to drinking and risky sexual behavior, often having multiple partners in a day, however, now using contraceptives. Two of the female participants who were initially blindsided by their diagnoses, recalled moving from feeling like they had to explain themselves to everyone on their care team to acknowledging that their care team was non-judgmental, understanding, and there to help them. For example, one participant said they felt 'tainted' and used that descriptor for several years, before finally letting it go. It seemed that almost all participants had accepted their status, a process that appeared to evolve with time, sometimes taking several years before reaching acceptance.

> Meredith described how she processed her diagnosis. She experienced shock and disbelief, which may have been compounded by the way she contracted HIV: her second husband, who she 'lowered her standards for,' transmitted the disease to her, which developed only after having separated from him. Meredith felt 'tainted' for several years, however, she seems to have stopped describing herself that way, often finding perspective from focusing on the positive parts of her life and practicing gratitude for what she does have.
>
>> *"I think mentally too my outlook, you know when you say, 'Oh, that's not going to happen to me or this won't?' That's wrong. I was a grandmother of seven grandkids in my 50's, and I find out I have HIV. Yeah, I felt tainted, but then I just kept telling myself, 'No, you're not tainted. This happens. Things happen. There are worse things.'"*

Jaime, like other participants wrestling with addiction, discussed how and why her addiction intensified after her diagnosis. She felt hopeless, worthless, and lost, sentiments that encouraged negative coping mechanisms.

> *"I want to try using the needle because I feel like... I would like it and I feel like it is pointless not to now because I'm already ... I've already caught something [HIV]. So I was just like, I don't give a fuck. I just want to blow my mind out."*

Experience of LWH

This category captures overarching experiences of LWH, specifically the words used to describe life after HIV. Common descriptions depicted HIV as a journey, an on-going process that improves with time, sometimes people forgetting that they even have it. People seemed to become more aware of their mind-body-spirit needs because of LWH, and they were more attuned to how stress, diet, exercise, and medication adherence affected their daily lives. Today, people described LWH as 'not a death sentence, but something I live with' and something that is 'a part of me, but doesn't define me.'

Susie recognized that LWH is an on-going process, one that will never end as long as she continues successfully managing the disease.

> *"I've been on a very long journey, and I don't believe it's ever gonna be over."*

Preston talked about finding hope and healing amidst very trying circumstances. He finds great support from within himself and from his nieces and nephews. He loves being an uncle. He continues to surround himself with positive supports that nurture and sustain his quality of life.

> *"The road that I took to almost dying, to finding a hope; that I didn't have to die with a mark saying HIV. There's been people that have said to my face, 'Oh, you're just a faggot,*

> *you're going to die.' There's two of them that have said that that I've outlived them. Not saying that it's good or bad, it's just a fact."*

These nine thematic categories are not intended to be exhaustive, describing every detail of every interview. Rather, the categories capture the general experience shared by all project participants at a particular time in a specific setting.

Chapter 5: Discussion, Implications, Limitations, & Conclusion

Discussion

The purpose of this undertaking was to learn about the experience of LWH in MT through one-on-one, in-depth interviews with the intention of better understanding both the life changing event of receiving a positive HIV diagnosis and how to better serve this population. A phenomenological research perspective met this purpose with empathy and kindness, which was crucial to establishing trust and initiating an authentic dialogue. Each interviewee led the direction and scope of the conversation, while the researcher listened with a curious compassion. With one question, 'What is your experience of LWH in MT?' participants described several facets of interest that directly related to the scientific literature surrounding this topic. However, instead of the researcher eliciting or extracting information from individuals through a line of questioning, each participant shared only what they wanted to in their own terms and in their own time. It is critical to emphasize that phenomenology hinges upon the relationship between two individuals, such that each person continuously mediates the other's experience. While this is certainly a subjective endeavor with non-generalizable findings, it does not diminish the efficacy of the research or, perhaps more importantly, the validity of each person's experience. Arguably, this strategy honors the humanity and dignity of each individual, while also illuminating commonly shared experiences of people living with the same phenomenon.

Current findings related to the scientific literature both reinforced existing knowledge, while sometimes also providing divergent insights. Results will be discussed with regard to the literature review provided in Chapter 2, which will contextualize the current undertaking within the broader research available at this time. Topics include: barriers, risk behaviors, health problems, treatment, quality of life, interventions, and health policy and health care systems with specific regard to living in a rural setting like MT when appropriate.

Barriers

Individuals living in rural settings or places with low population density commonly experience barriers to HIV care including testing, diagnosis, and routine check-ups. Nelson et al. (2016) indicated that limited access to services may be a result of living in a rural setting such that fewer resources are available, or it may be a result of individual vulnerability related to isolating stigmas including divergent sexual or gender identity, addiction, or LWH. These stigmas may delay testing and affect health care engagement and medication adherence. Participants in the current study did not explicitly link their level of care engagement to living in a rural setting like MT. Most participants that knowingly engaged in risky sexual behavior and/or drug behavior seemed to know that they had HIV before an official diagnosis; however, that knowing did not delay their testing. All individuals were immediately linked to care, which some met with immediate engagement, while others took months to years to fully commit to. The delay in committing to care seemed to be an artifact of processing a positive diagnosis, rather than a consequence of living in a rural setting.

Self-advocacy is a critical component of health and healing. Eastwood et al. (2015) reported that women who experience intimate partner violence have a compromised ability to self-advocate, not only during sexual interactions, but also in other relationships including patient-provider interactions. Participants in this study, men and women, that had experienced intimate partner violence and/or abuse seemed to have different perceptions of the patient-provider relationship. For example, a woman that experienced childhood trauma resulting in co-dependent behaviors intimated that she had difficulty asserting herself with men. She also shared that a male health care provider molested her, which compounded previous trauma and affected her health care engagement: now she will only see female health professionals.

Breaching confidentiality was a third barrier to care. A few participants indicated that their status was disclosed either in a clinic setting or a public place. This gross violation of patient-provider trust caused some participants to be more cautious about disclosing personal, vulnerable information. One participant shared that he even tried to file a law suit against a health care organization for this blatant disregard of client-patient confidentiality, but he met too much resistance, and instead found care elsewhere. While this breach could cause issues in any setting, it is distinctly possible that stigmatizing effects are compounded in rural places where familiar faces are often seen regularly.

Risk Behaviors

Previous health assessments of PLWH in MT revealed that substance abuse and unprotected sex with multiple partners were prevalent risk behaviors for contracting HIV in the state (Sondag & Epperson, 2012). More specifically, Schwitters and Sondag (2016) found that MSM engaged in high levels of risky sex were reluctant to communicate with their sexual partners.

Similarly, substance abuse, both drug and alcohol addiction, were common among the project participants. Most people interviewed related that they struggled with addiction, including injection drug use, which often put them in unhealthy situations. All participants that knowingly engaged in risky behaviors seemed to understand that drug and alcohol are closely connected to risky sex. Most participants knew exactly how and when they contracted HIV, whether through injection drug use with a shared needle or unprotected sex. The remaining participants, two women, were completely blind-sided: they thought that they were in safe, committed intimate relationships with their significant others, when in fact their partners were not monogamous and often engaging in risky behaviors.

Health Problems

PLWH often have comorbidities at higher rates and younger ages than the general US population, with at least one-third of all PLWH living with at least one additional health concern (Chu & Selwyn, 2011; Vyavaharkar et al., 2010). Nasi et al. (2016) reported that PLWH often have chronic inflammation and an over-active immune system affecting general health and quality of life. Project participants in the current undertaking described living with multiple comorbidities, which were either a result of LWH or unrelated health issues that compounded their HIV. Some comorbidities described by participants included: Hepatitis C, poor liver health, leg and back pain, lethargy, anxiety, depression, and heart problems. Participants related that they took extra caution to not get sick, because when they did, they often experienced extreme illness due to their compromised immune system. For example, one participant shared that when he last had the flu he developed pneumonia and was in the hospital for several days.

Treatment

Medication adherence is a critical component of LWH: with consistent medication, PLWH can attain and maintain undetectable viral loads so that they are unlikely to transmit the virus to another person. Medication compliance, while crucial for disease management, is a complex issue related to social, behavioral, and structural factors (Rathbone et al., 2017; Flash et al., 2017).

Rathbone and colleagues (2017) suggested that medication compliance is better understood as a social interaction between patient identity and patient meds, which is further mediated by social interactions. This dynamic relationship was illustrated through project participant’s stories regarding their medication regimes. A few individuals, primarily women, were immediately adherent and maintained a routine. The majority, however, described a complicated relationship with medication, where it took months or years before they were compliant. It seemed that for most participants, particularly those with addiction, unstable housing, a history of trauma, and a lack of social supports, took more time to reach adherence. Part of this was likely due to processing and accepting the life changing event of a positive HIV diagnosis. For instance, some participants shared that their substance abuse increased in severity after their diagnosis, which they recognized affected their ability to be adherent. Almost all participants have an undetectable viral load today, indicating that despite the length of time it took to incorporate a medication routine, the meds were and continue to be effective.

A few participants described medication adherence techniques. One individual who continues to struggle with addiction related that he uses a pill delivery service through his mental health support system: someone delivers his meds each day. This not only improves his chances of remaining adherent, but also serves to hold him accountable, as well as provide a daily social support. Other participants described using mail order prescription services to retain their privacy, however, even this could be problematic. For instance, a male participant who admittedly has a hard time with meds, explained that he takes three sets of medications to manage HIV, but often does not receive a complete set in the mail. This demonstrates that people may need to explore what will most effectively help them manage HIV.

Quality of Life

While HIV is a manageable, chronic condition, it is still a life-changing event that should not be diminished. Macapagal and colleagues (2012) stated that a positive diagnosis disrupts an individual's life trajectory, shifting their relationship with self and others, often affecting their involvement in social activities. The narrative an individual LWH uses may illuminate how they are adjusting to their diagnosis. Research suggests that a more coherent narrative is indicative of positive self-adaptive behaviors and positive social supports. The importance of narrative became evident through conversations with different participants. It seemed that PLWH for longer periods of time were more accepting of their status, presumably because they have had more time to process and negotiate their new life than PLWH for less time. The participants that appeared to be more accepting of their HIV shared a more coherent story about coming to terms with their status than individuals that are still struggling to find their way today. For example, the participant that was diagnosed most recently, within the past two years, appeared to still be in disbelief despite his self-described reckless lifestyle. Of all participants, he seemed to have the most discordant narrative, often appearing to exhibit cognitive dissonance between his behaviors and outcomes, stating that if he knew he were at risk he would have made different decisions related to sex and alcohol, while simultaneously acknowledging that he is not ready to shift his risky sexual behaviors toward healthier behaviors.

Interventions

Disclosure was a prominent component of the HIV intervention literature. Sharing one's status may reduce stigma, increase medication adherence, and improve safe sex practices (Teti et al., 2016, Teti et al, 2013, Teti et al. 2012). Through Photovoice projects with women LWH, Teti et al. (2013, 2012) demonstrated that some participants found disclosure to be an opportunity to redefine the self and change their personal narrative, an empowering process for a vulnerable population.

Other research indicated that disclosure needs to be carefully evaluated because it could create additional stress. Since disclosure inherently increases someone's vulnerability, considerations that may affect sharing information with others includes: an individual's progression of HIV, the type and extent of relationship between people, and individual personal belief systems (Vyavaharkar et al., 2011).

Participants in the current project had a variety of experiences related to disclosure, whether it was about sharing their sexual identity with loved ones, or relating their HIV status to family, friends, or intimate partners. All participants described carefully considering sharing their status, often losing family or friends in the process, which compounded their vulnerability and increased their self-protective behaviors. Several participants clearly indicated that they always disclose their status with intimate partners, while others choose to practice safe sex instead of divulging their disease, particularly if they continue engaging in risky sexual behavior like having multiple unknown partners. Many individuals shared that through disclosure they 'found out who their friends were.' While this greatly affected them at the time, these participants now seem to be at peace with that loss, acknowledging that they only want to nurture positive, supportive relationships.

Findings from the current study underscore the complexities of disclosure, illustrating that while it may be beneficial, it may come at the loss of some personal relationships. Despite the possible costs, participants stressed the importance of sharing with someone—a friend, family member, mental health professional, or spiritual mentor—to ease the burden of LWH, reduce the shame of a positive status, and process an HIV diagnosis. Disclosure is unique to each individual: while sharing can shed a light on grieving and create a space for healing, it should be approached with care, compassion, and thoughtful consideration for the benefit of the PLWH.

Health Policy and Health Care Systems

Differentiated and integrated health care systems like community testing centers, self-testing, and peer supports could be beneficial to an individual's health, particularly for someone LWH (MacDonald et al., 2017). MacDonald and colleagues (2017) indicated that case management and peer navigation systems appeared to improve care retention and quality of life for PLWH, however, little research has been conducted on the cost effectiveness of these kinds of integrated approaches. Although cost considerations are an integral component of public health, it is difficult to disregard the benefit of integrated care.

All participants that contributed to the current study described the importance of engaged case managers and discussed the need for more social supports, particularly from peers LWH. Individuals with addiction emphasized the benefit of having consistent and nonjudgmental support from their case managers, who often encouraged them to take their meds without pressing them to quit their risky behaviors. Knowing that that support was available was a great boon to each participant: it was beneficial to know that support and compassion was there, even if they were not initially ready to receive it. Several participants indicated that it would be helpful to regularly meet other PLWH to foster a sense of community and increase social supports. Additionally, participants related that they would like to act as peer mentors, helping ease someone else's diagnosis so that they might not have to struggle in the same way.

Other participants described their immense gratitude for Open Aid Alliance and Yellowstone AIDS Project (now closed): these safe spaces with caring people offered a refuge from daily life. Again, knowing that a space existed for like-minded people with similar struggles eased the process of LWH. Often people did not necessarily need to talk about their HIV with other PLWH, but rather, needed to be able to see PLWH, which cultivated solidarity and improved optimism, critical aspects promoting health and well-being.

LWH in Montana

The current project provided depth and understanding to previous findings from the most recent health needs assessment of PLWH in MT (Sondag & Epperson, 2012). Results from the 2012 assessment suggested that PLWH in MT are linked to care at high rates and that they hold their case managers in high regard. A notable portion of PLWH in MT that contributed to the previous assessment experienced economic hardship: nearly half earned less than $20,000 per year and almost one-third received housing assistance. Significant unmet needs included: education, personal empowerment, peer advocacy, and physician expertise.

Participants in the current study highlighted several needs, which while identified in 2012, appear to still be unmet today. Education was frequently mentioned both for PLWH and the general population. Stigma and discrimination, while less common today, is still present. Participants that have been LWH for 20-30 years indicated that while society's impressions have improved, they still experience prejudice through harassment and discrimination. It seemed that physician expertise has generally improved, with more and better-informed health care providers available. It is still disheartening to note that some participants have had their status inappropriately disclosed by health providers in health care settings and in public places.

Few participants discussed LWH in MT and arrived at divergent conclusions. One participant wondered, 'What does MT have to do with it [LWH] – you live with it anywhere,' while another interviewee noted that she's experienced stereotyping from misinformed community members, which she attributes to the small-town feel of MT. One individual described how difficult it is to LWH in MT in comparison to their former residence in the Portland, Oregon area where he felt there was more diversity, resources, and cultural understanding benefiting the quality of life of PLWH.

Limitations

The current study has several limitations related to time, participation, representation, and methodology. Although the study met established criteria regarding participant contribution such that saturation of themes was realized, time constrained the number of participants that could contribute to the study. Small sample sizes are expected in phenomenological research; however, among the ten participants there was a diversity of race/ethnicity, sex/gender, and sexual identities represented. The participants were from the two most populous areas of the state and the two areas with the highest rates of HIV. While these individuals' experiences are significant, they may not capture what it is like to LWH in more rural areas of MT where there are potentially fewer health resources and more barriers to care.

Participant descriptions were restricted by recall bias: although individuals shared significant life events it is possible that they did not include other relevant information. Additionally, the findings cannot be reviewed without considering the phenomenological research perspective and the interviewer-interviewee relationship. Phenomenology requires extensive self-reflexivity of both participants: the interviewee is required to carefully reflect on significant experiences and consider how they affected their life, while the interviewer is required to recognize her biases, withhold judgment, and listen with compassion. As a result, the findings cannot be viewed without considering the distinct exchange of two individuals with unique life trajectories: each reflecting on their own lives, while reflecting one another.

Qualitative research such as this provides depth to the breadth of existing health assessment data. It is crucial to note that these findings are not generalizable; however, that does not diminish the importance of the shared experience or the significance of the research.

Implications

While study findings are not generalizable, there are a few specific insights that should be discussed, because they might provide direction for adapting, developing, and/or implementing integrated healthcare for this population. First, the value of mental health services for PLWH cannot be diminished: all participants that connected with a mental health professional described how crucial that relationship was to their healing and processing, not only regarding their diagnosis, but their lives prior to that point. Most people emphasized not only the usefulness of mental health services, but the importance of nurturing a quality relationship between patient and provider: those with a ‘good fit’ with their clinician found healing more quickly than those who tried several mental health providers prior to finding a healing connection.

Second, many participants indicated the importance of peer supports, whether social supports from the community or other PLWH. Sustaining friendships improved quality of life and seeing other PLWH helped ease the burden of LWH. Consequently, it seemed that PLWH would benefit from more safe spaces like Open Aid Alliance or regular gatherings, not necessarily to talk about HIV, but to foster community with people that are intimately familiar with HIV.

Participants repeatedly recognized the value of engaged case managers, housing liaisons, and health care teams. Particularly, participants managing addictions shared that they knew they could and would fail before they were ready to enact and maintain healthier behaviors related to recovery and healing. Over and over, individuals noted that knowing that there were people that cared about them, even when they were not ready to accept support, benefitted their healing process.

Finally, it is imperative to discuss the need for sensitive health care practices. For example, an American Indian/Alaska Native participant related that he felt more comfortable with a Native mental health specialist. Another individual noted that he felt great benefit from incorporating his spirituality into his healing through daily prayer and smudging and sweating when needed. He also stated that he preferred less invasive, more holistic techniques provided by Native health providers that treat the whole person. Similarly, care providers should be aware of participant trauma, both recent and historical. For instance, several people shared that they had been abused or molested, which affected their health care practitioner choices. Having a dialogue about provider gender preference should be within the scope of health care practice.

These insights, while not exhaustive, will be shared with the state DPHHS and the MT HIV Planning Group with the intention of cultivating understanding, improving patient outcomes, and improving quality of life for PLWH in MT.

Conclusion

This project sought to implement a research approach that fostered participant healing and engendered understanding of the experience of LWH in MT. This thoughtful approach met people where they were spatially and temporally: the researcher met project participants at a familiar, safe location which helped establish trust, and the researcher strived to listen with care and compassion, joining each person where ever they were in their experience. Research transparency was maintained at all times and findings were shared with participants, allowing them an opportunity to review and validate their words, and the chance to see how their individual conversation contributed to the project as a whole. The depth of findings generated from this research demonstrates the usefulness of the phenomenological perspective for understanding what it is like to LWH. Participants stated that they were grateful for the opportunity to share, intimated that they felt heard, and acknowledged that sharing helped them heal. In addition to engendering positive personal outcomes for each participant, all individuals provided significant insights into the experience of LWH in MT: through their courage and vulnerability may they help others heal.

References

Albritton, T., Martinez, I., Gibson, C., Angley, M., & Grandelski, V. R. (2017). What about us? economic and policy changes affecting rural HIV/AIDS services and care. *Social Work in Public Health, 32*(4), 273. doi:10.1080/19371918.2017.1282388

Benner, P. (Ed.) (1994). *Interpretive phenomenology: Embodiment, Caring, and Ethics in Health and Illness.* Thousand Oaks, CA: Sage.

Centers for Disease Control and Prevention. (2017a). About HIV/AIDS. Retrieved from https://www.cdc.gov/hiv/basics/whatishiv.html

Centers for Disease Control and Prevention. (2017b). HIV in the United States: At a glance. Retrieved from https://www.cdc.gov/hiv/statistics/overview/ataglance.html

Centers for Disease Control and Prevention. (2017c). HIV in the United States by geographic distribution. Retrieved from https://www.cdc.gov/hiv/pdf/statistics/cdc-hiv-geographic-distribution.pdf

Centers for Disease Control and Prevention. (2017d). HIV Basics. Retrieved from https://www.cdc.gov/hiv/basics/index.html

Centers for Disease Control and Prevention. (2017e). HIV Transmission. Retrieved from https://www.cdc.gov/hiv/basics/transmission.html

Centers for Disease Control and Prevention. (2017f). Living with HIV. Retrieved from https://www.cdc.gov/hiv/basics/livingwithhiv/index.html

Centers for Disease Control and Prevention. (2017g). Opportunistic Infections. Retrieved from https://www.cdc.gov/hiv/basics/livingwithhiv/opportunisticinfections.html

Centers for Disease Control and Prevention. (2017h). PEP. Retrieved from https://www.cdc.gov/hiv/basics/pep.html

Centers for Disease Control and Prevention. (2017i). PrEP. Retrieved from https://www.cdc.gov/hiv/basics/prep.html

Chollier, M., Tomkinson, C., & Philibert, P. (2016). STIs/HIV stigma and health: A short review. *Sexologies, 25*(4), e75. doi:10.1016/j.sexol.2016.03.005

Chu, C., & Selwyn, P. (2011). An epidemic in evolution: The need for new models of HIV care in the chronic disease era. *Journal of Urban Health, 88*(3), 556-566. doi:10.1007/s11524-011-9552-y

Colbert, A. M., Kim, K. H., Sereika, S. M., & Erlen, J. A. (2010). An examination of the relationships among gender, health status, social support, and HIV-related stigma. *Journal of the Association of Nurses in AIDS Care, 21*(4), 302-313. doi:10.1016/j.jana.2009.11.004

Coleman, C. L. (2003). Spirituality and sexual orientation: Relationship to mental well-being and functional health status. *Journal of Advanced Nursing, 43*(5), 457-464. doi:10.1046/j.1365-2648.2003.02743.x

Corless, I. B., Voss, J., Guarino, A. J., Wantland, D., Holzemer, W., Jane Hamilton, M., . . . Cuca, Y. (2013). The impact of stressful life events, symptom status, and adherence concerns on quality of life in people living with HIV. *The Journal of the Association of Nurses in AIDS Care, 24*(6), 478-490. doi:10.1016/j.jana.2012.11.005

Costelloe, S., Kemppainen, J., Brion, J., MacKain, S., Reid, P., Frampton, A., & Rigsbee, E. (2015). Impact of anxiety and depressive symptoms on perceptions of stigma in persons living with HIV disease in rural versus urban North Carolina. *AIDS Care, 27*(12), 1425-1428. doi:10.1080/09540121.2015.1114993

Creswell, J. (1998). *Qualitative Inquiry and Research Design: Choosing from Among Five Approaches* (Second Edition). Thousand Oaks: Sage Publications.

Dombrowski, J., Bove, J., Roscoe, J., Harvill, J., Firth, C., Khormooji, S., Carri, J., Choi, P., Smith, C., Schafer, S., and Golden, M., (2017). “Out of care” HIV case investigations: A collaborative analysis across 6 states in the northwest US. *Journal of Acquired Immune Deficiency Syndrome*, 74(2), S81-S87.

Eastwood, E. A., Fletcher, J., Quinlivan, E. B., Verdecias, N., Birnbaum, J. M., & Blank, A. E. (2015). Baseline social characteristics and barriers to care from a special projects of national significance women of color with HIV study: A comparison of urban and rural women and barriers to HIV care. *AIDS Patient Care and STDs, 29*(S1), S10. doi:10.1089/apc.2014.0274

Ezzy, D. (2000). Illness narratives: Time, hope and HIV. *Social Science & Medicine, 50*(5), 605-617. doi:10.1016/S0277-9536(99)00306-8

Flash, C. A., Dale, S. K., & Krakower, D. S. (2017). Pre-exposure prophylaxis for HIV prevention in women: Current perspectives. *International Journal of Women's Health,* , 391-401. Retrieved from https://doaj.org/article/81a190396dc34129b91e5ead090f0eb2

Hardee, K., Gay, J., Croce-Galis, M., & Peltz, A. (2014). Strengthening the enabling environment for women and girls: What is the evidence in social and structural approaches in the HIV response? *Journal of the International AIDS Society, 17*(1), n/a. doi:10.7448/IAS.17.1.18619

Giorgi, A. (Ed.) (1985). *Phenomenological research methods*. Thousand Oaks, CA: Sage.

Kalichman, S., Katner, H., Banas, E., & Kalichman, M. (2017). Population density and AIDS-related stigma in large-urban, small-urban, and rural communities of the southeastern USA. *Prevention Science, 18*(5), 517. doi:10.1007/s11121-017-0761-9

Kelly, J. S., Langdon, D., & Serpell, L. (2009). The phenomenology of body image in men living with HIV. *AIDS Care, 21*(12), 1560-1567. doi:10.1080/09540120902923014

Langebeek, N., Kooij, K., Wit, F., Stolte, I., Sprangers, M., Reiss, P., & Nieuwkerk, P. (2017). Impact of comorbidity and ageing on health-related quality of life in HIV-positive and HIV-negative individuals. *AIDS, 31*(10), 1471-1481. doi:10.1097/QAD.0000000000001511

Macapagal, K. R., Ringer, J. M., Woller, S. E., & Lysaker, P. H. (2012). Personal narratives, coping, and quality of life in persons living with HIV. *Journal of the Association of Nurses in AIDS Care, 23*(4), 361-365. doi:10.1016/j.jana.2011.08.011

Macdonald, V., Verster, A., & Baggaley, R. (2017). A call for differentiated approaches to delivering HIV services to key populations. *Journal of the International AIDS Society, 20*, n/a. doi:10.7448/IAS.20.5.21658

Mazanderani, F., and Paparini S. (2015). *The stories we tell: Qualitative research interviews, talking technologies and the 'normalisation' of life with HIV*. Amsterdam [u.a.]; Jena: Elsevier.

Minkler, M. & Wallerstein, N. (Eds.). *Community-Based Participatory Research for Health*. San Francisco, CA: Jossey-Bass.

Moustakas, C. (1994). *Phenomenological Research Methods*. Thousand Oaks, CA: Sage.

Montana Department of Health and Human Services (MTDPHHS). (2017). HIV and Hepatitis C Infections: Montana, 2010–2014. Retrieved from http://dphhs.mt.gov/publichealth/cdepi/diseases/HIV_HCV

Nasi, M., De Biasi, S., Gibellini, L., Bianchini, E., Pecorini, S., Bacca, V., . . . Cossarizza, A. (2017). Ageing and inflammation in patients with HIV infection. *Clinical & Experimental Immunology, 187*(1), 44-52. doi:10.1111/cei.12814

Nelson, J., Kinder, A., Satcher Johnson, A., Hall, I., Hu, X., Sweet, D. … Harris, J. (2016). Differences in selected HIV care continuum outcomes among people residing in rural, urban, and metropolitan areas-28 US jurisdictions. *The Journal of Rural Health*, 00, 1-8.

Padgett, D. (2012). *Qualitative and Mixed Methods in Public Health*. Los Angeles, CA: Sage.

Palacios, J. F., Salem, B., Hodge, F. S., Albarrán, C. R., Anaebere, A., & Hayes-Bautista, T. M. (2015). Storytelling. *Journal of Transcultural Nursing, 26*(4), 346-353. doi:10.1177/1043659614524253

Pellowski, J. A. (2013). Barriers to care for rural people living with HIV: A review of domestic research and health care models. *The Journal of the Association of Nurses in AIDS Care: JANAC, 24*(5), 422-437. doi:10.1016/j.jana.2012.08.007

Rathbone, A. P., Todd, A., Jamie, K., Bonam, M., Banks, L., & Husband, A. K. (2016). A systematic review and thematic synthesis of patients' experience of medicines adherence. *Research in Social and Administrative Pharmacy,* doi:10.1016/j.sapharm.2016.06.004

Reif, S., Pence, B., Hall, I., Hu, X., Whetten, K., & Wilson, E. (2015). HIV diagnoses, prevalence and outcomes in nine southern states. *Journal of Community Health, 40*(4), 642-651. doi:10.1007/s10900-014-9979-7

Salters, K. A., Irick, M., Anema, A., Zhang, W., Parashar, S., Patterson, T. L., . . . Hogg, R. S. (2017). Harder-to-reach people living with HIV experiencing high prevalence of all-type mental health disorder diagnosis. *AIDS Care, 29*(6), 696-704. doi:10.1080/09540121.2016.1227763

Schwitters, A., & Sondag, K. A. (2017). The lives and sexual risk behaviors of rural, closeted men who have sex with men living in Montana. *Culture, Health & Sexuality, 19*(1), 121-134. doi:10.1080/13691058.2016.1211739

Sondag, K.A., & Epperson. (2012). An assessment of the prevention needs of people in Montana who are living with HIV/AIDS. Report prepared for: The Montana Department of Public Health and Human Services HIV/STD Section. Available upon request.

Sowell, R.L., Seals, B.F., Moneyham, L., Demi, A., Cohen, L. & Brake, S. (1997). Quality of life in HIV infected women in the south-eastern United States. *AIDS Care*, 9(5), 501-512.

Teti, M., Conserve, D., Zhang, N., & Gerkovich, M. (2016). Another way to talk: Exploring photovoice as a strategy to support safe disclosure among men and women with HIV. *AIDS Education and Prevention*, 28(1), 43-58. doi:10.1521/aeap.2016.28.1.43

Teti, M., French, B., Bonney, L., & Lightfoot, M. (2015). “I created something new with something that had died”: Photo-narratives of positive transformation among women with HIV. *AIDS and Behavior, 19*(7), 1275-1287. doi:10.1007/s10461-015-1000-7

Teti, M., Pichon, L., Kabel, A., Farnan, R., & Binson, D. (2013). Taking pictures to take control: Photovoice as a tool to facilitate empowerment among poor and racial/ethnic minority women with HIV. *The Journal of the Association of Nurses in AIDS Care: JANAC, 24*(6), 539. doi:10.1016/j.jana.2013.05.001

Teti, M., Murray, C., Johnson, L., & Binson, D. (2012). Photovoice as a community-based participatory research method among women living with HIV/AIDS: Ethical opportunities and challenges. *Journal of Empirical Research on Human Research Ethics, 7*(4), 34-43. doi:10.1525/jer.2012.7.4.34

United States Census Bureau. (2017). *Quick facts: Montana.* Retrieved from https://www.census.gov/quickfacts/table/PST045216/30.

Vyavaharkar, M., Moneyham, L., Corwin, S., Tavakoli, A., Saunders, R., & Annang, L. (2011). HIV-disclosure, social support, and depression among HIV-infected African American women living in the rural southeastern united states. *AIDS Education and Prevention, 23*(1), 78-90. doi:10.1521/aeap.2011.23.1.78

Vyavaharkar, M., Moneyham, L., Corwin, S., Saunders, R., Annang, L., & Tavakoli, A. (2010). Relationships between stigma, social support, and depression in HIV-infected African

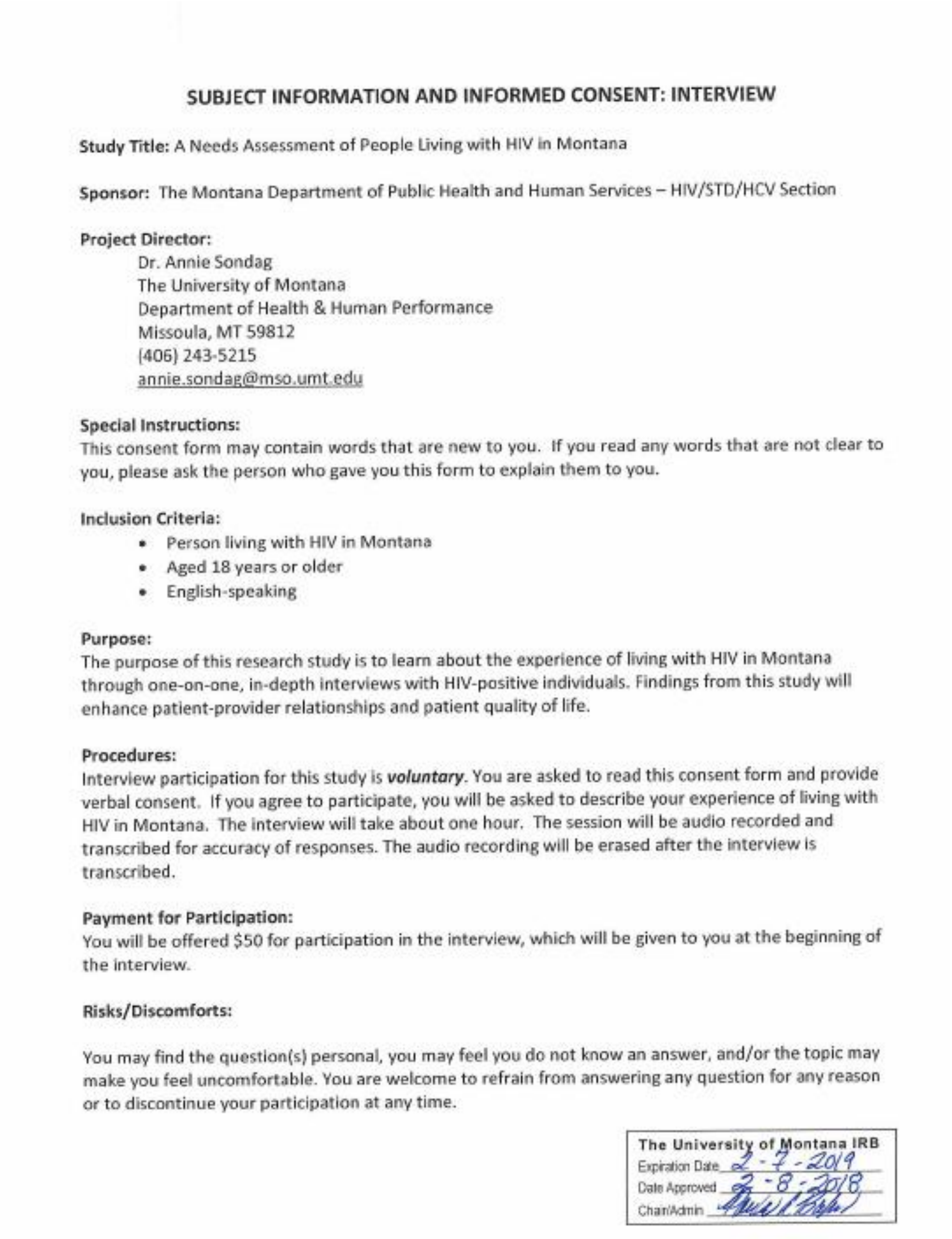
American women living in the rural southeastern united states. *Journal of the Association of Nurses in AIDS Care, 21*(2), 144-152. doi:10.1016/j.jana.2009.07.008

Vyavaharkar, M., Moneyham, L., Tavakoli, A., Phillips, K. D., Murdaugh, C., Jackson, K., & Meding, G. (2007). Social support, coping, and medication adherence among HIV-positive women with depression living in rural areas of the southeastern United States. *AIDS Patient Care and STDs, 21*(9), 667-680. doi:10.1089/apc.2006.0131

Woodgate, R., Zurba, M., Tennent, P., Cochrane, C., Payne, M., & Mignone, J. (2017). A qualitative study on the intersectional social determinants for indigenous people who become infected with HIV in their youth. *International Journal for Equity in Health, 16* Retrieved from https://search.proquest.com/docview/1925848099

APPENDIX

IRB Approval: Subject Information and Informed Consent: Interview



SUBJECT INFORMATION AND INFORMED CONSENT: INTERVIEW

Study Title: A Needs Assessment of People Living with HIV in Montana

Sponsor: The Montana Department of Public Health and Human Services – HIV/STD/HCV 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:

This consent form may contain words that are 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.

Inclusion Criteria:

- Person living with HIV in Montana
- Aged 18 years or older
- English-speaking

Purpose:

The purpose of this research study is to learn about the experience of living with HIV in Montana through one-on-one, in-depth interviews with HIV-positive individuals. Findings from this study will enhance patient-provider relationships and patient quality of life.

Procedures:

Interview participation for this study is ***voluntary***. You are asked to read this consent form and provide verbal consent. If you agree to participate, you will be asked to describe your experience of living with HIV in Montana. The interview will take about one hour. The session will be audio recorded and transcribed for accuracy of responses. The audio recording will be erased after the interview is transcribed.

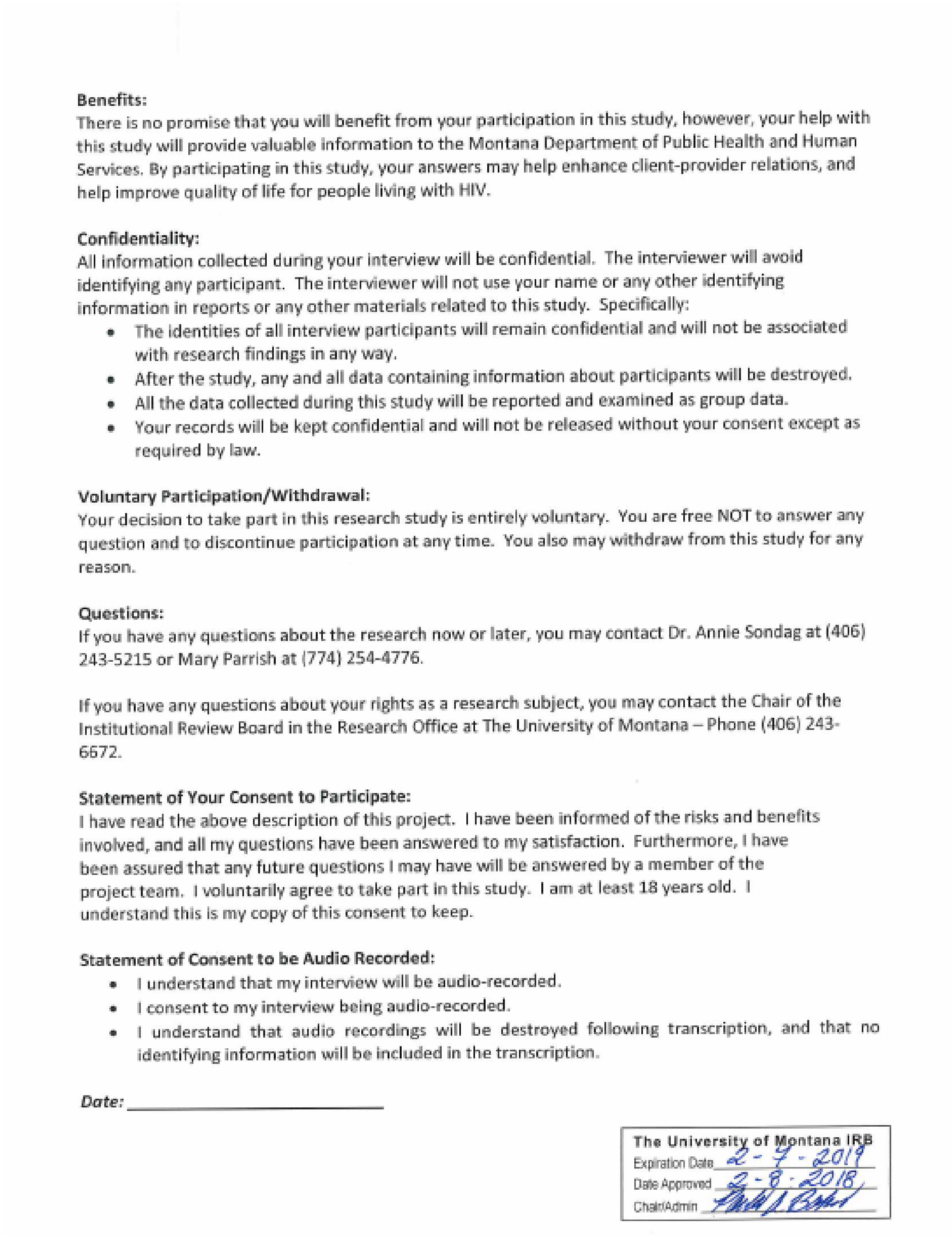
Payment for Participation:

You will be offered $50 for participation in the interview, which will be given to you at the beginning of the interview.

Risks/Discomforts:

You may find the question(s) personal, you may feel you do not know an answer, and/or the topic 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.

The University of Montana IRB
Expiration Date 2-7-2019
Date Approved 2-8-2018
Chair/Admin



Benefits:
There is no promise that you will benefit from your participation in this study, however, 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 may help enhance client-provider relations, and help improve quality of life for people living with HIV.

Confidentiality:
All information collected during your interview will be confidential. The interviewer will avoid identifying any participant. The interviewer 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.
- After 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.
- Your records will be kept confidential and will not be released without your consent except as required by law.

Voluntary 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 Mary Parrish at (774) 254-4776.

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) 243-6672.

Statement of Your Consent to Participate:
I have read the above description of this project. I have been informed of the risks and benefits involved, and all 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.

Statement of Consent to be Audio Recorded:

- I understand that my interview will be audio-recorded.
- I consent to my interview being audio-recorded.
- I understand that audio recordings will be destroyed following transcription, and that no identifying information will be included in the transcription.

Date: ____________________________

The University of Montana IRB
Expiration Date 2-7-2019
Date Approved 2-8-2018
Chair/Admin

Demographic Questionnaire

The purpose of this questionnaire is to collect information about people living with HIV in Montana. By participating in this brief eight question survey, you will help provide valuable information that will be used to develop better HIV prevention services for people living with HIV in Montana. **Participation in this survey is voluntary, anonymous, and confidential.** You are welcome to refrain from answering any question for any reason or to discontinue your participation at any time.

---

1. What age are you? ___________

2. What is your gender?

☐ Female	☐ Transgender
☐ Male	☐ Other: _______________________

3. What is your race/ethnicity?

☐ Native American / Alaska Native	☐ White (non-Hispanic)
☐ Asian / Pacific Islander	☐ Hispanic
☐ African American	☐ Other: _______________________

4. How would you identify yourself?

☐ Heterosexual / Straight
☐ Gay
☐ Lesbian
☐ Bisexual
☐ Other: _____________________

5. What is the highest level of education you have attained?

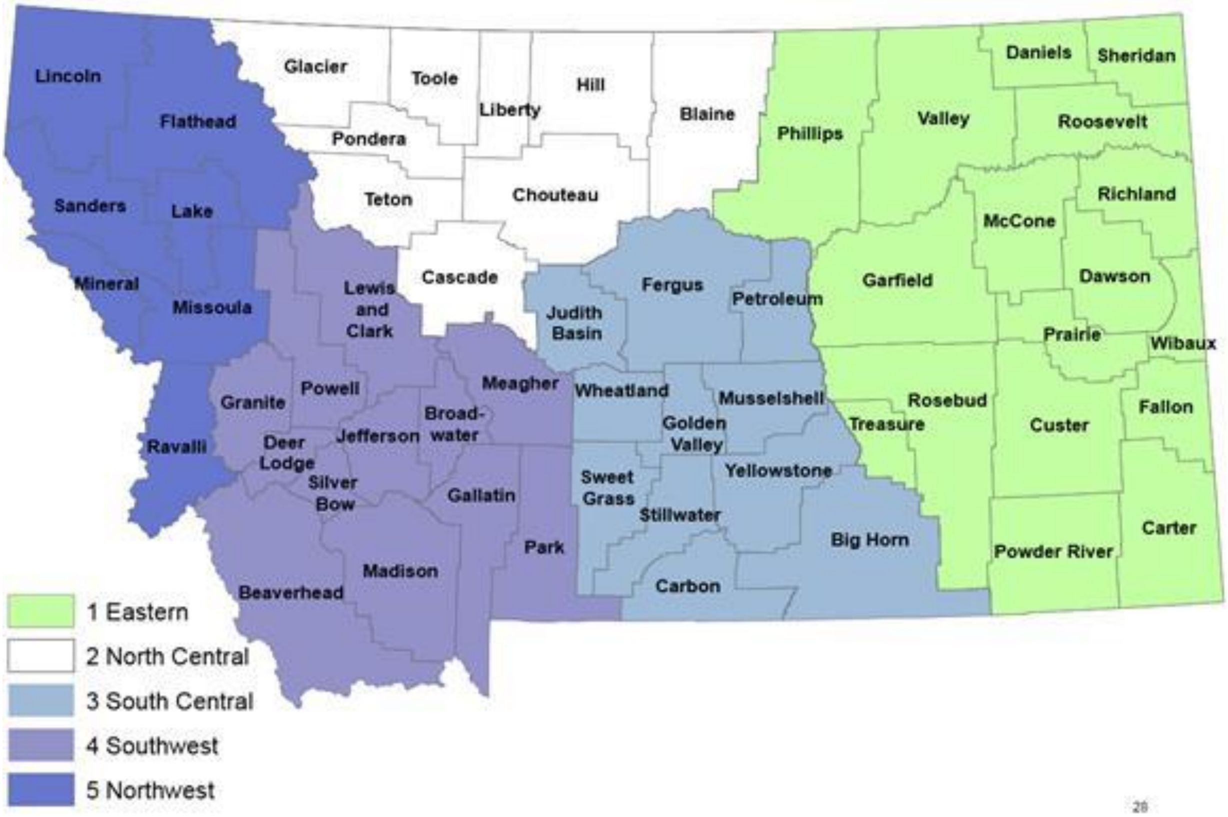
☐ Less than high school
☐ Some high school, but did not graduate
☐ High school / GED
☐ Trade or vocational school
☐ Community college graduate
☐ Some college, but did not graduate
☐ College graduate
☐ Graduate or professional school

6. Approximately how much money to you make per year?

☐ $100,000+
☐ $75,001 – 100,000
☐ $50,001 – 75,000
☐ $35,001 – 50,000
☐ $20,001 – 35,000
☐ $10,001 – 20,000
☐ $6,000 – 10,000
☐ Less than $6,000

7. About what year were you diagnosed with HIV? ________________________________

8. Using the map below, in which region do you reside? ____________________________



Thank you for participating in the survey.

Interview Prompts

If needed, perhaps due to reluctance, timidity, or a need for more clarity, one or more of the following prompts could be used to initiate the interview.

- What made you decide to get tested for HIV?
- What was the experience of HIV testing like for you?
- What happened after you received your HIV test results?
- What was your life like before your diagnosis?
- What was your life like after your diagnosis?
- How has your life changed since you were diagnosed?

Field Notebook Guidelines

Field Notebook

Items to be considered by the interviewer before any interview and as needed throughout the research process. Guidelines revised from Padgett (2012).

1. Try to avoid any inferences, whether your own or volunteered by others. Aim for specific and concrete descriptions of behaviors or events.

2. Distinguish between different types of observational data such as first order verbatim data or second order paraphrasing.

3. Record observations of yourself including impressions, feelings, and/or concerns. Bracket this information in field notes or create a separate field notebook. This will serve as a personal, emotional outlet reducing bias. This also provides a healthy method for internal processing.

4. Strive for balance throughout the research process.

Interview Contact Summary Sheet

To be completed by the interviewer immediately after each interview.

Interview Date:________________Interview Length: ________________

Interview No.: ________________Interview Location: ________________

1. Physical description/impressions (including interview setting and interviewee appearance):

2. Experience(s) discussed the most:

3. Thoughts moving forward:

Interview Summaries

Interview summaries are presented below with names changed to ensure participant confidentiality. Summaries were composed as if writing a letter to each individual. Efforts were made to contact each participant to review their individual summary for accuracy and authenticity. Six of the 10 participants met with the researcher within the allotted time frame and provided feedback. No one suggested revisions or the need to clarify or redact information. All participants indicated that the summary accurately captured their experience of living with HIV.

Participant 1: Cliff

Defining Experiences

You shared that you left home as a young man, stating that you are ‘from all over,’ because you spent about ten years of your life hitch hiking. It seems like you would not trade those hitch hiking experiences for anything, because you enjoyed the freedom of those adventures. Hitch hiking brought you across the country, eventually to Montana, where you are laying down roots for the first time.

It sounds like you were promiscuous with both women and men, until you finally felt comfortable with your sexual identity in your mid- to late-20s. You mentioned that you addicted to drugs and alcohol, though you are trying to stop. You shared that the first time you tried meth was with a needle and you were hooked. It seems that you continued to use meth for several years and drink too much too often, until ‘enough was enough’ and you were ‘tired of playing the game.’ You have taken big steps in the past year to clean up, surround yourself with good friends and good supports. You would be ‘heartbroken’ if you lost your housing and that is a big motivation for staying clean and taking your meds.

You mentioned that you are proud of yourself and your friends are proud of you, too.

Diagnosis / Processing

It sounds like you ‘just knew’ you contracted HIV before you were tested and diagnosed. You mentioned that you think you contracted it at a party where people shared needles. Although you were diagnosed in 2005, you did not seek treatment or take your meds regularly until the past five months. It sounds like after you were first diagnosed, you continued to hitch hike and move around, but noted that you were slowing down.

You mentioned that, ‘before I had HIV, I didn’t have a family,’ which suggests that you have now taken steps to find and keep good friends that hold you accountable and good supports like Open Aid that care for you. It sounds like you might see HIV as something that helped you change your ways; you were almost ‘glad that happened’ because you were ‘tired of living that lifestyle.’

Health Care

Although you described yourself as ‘lazy,’ it sounds like you have taken big steps to help you take your meds and keep clean. For example, you use a daily medication delivery service to make sure you take your pills each day. It sounds like you see your doctors about once per week and have spent time off and on seeing a mental health counselor. When we spoke, you seemed happy, though shared that you continue to easily feel tired or worn out, and do not have much of an appetite. You have taken your medication consistently for the past five months and your viral load is undetectable.

Education

It sounds like you think people need to be more educated about HIV, sharing that ‘it’s been out there for so long and people are still afraid.’ You mentioned that you like to educate people, too, sharing your story and information with others.

Supports

It sounds like you have several good supports right now: friends, doctors, and case managers. It seems like you made a choice to protect yourself and only surround yourself with good, clean people. Your friends hold each other accountable and support one another. You mentioned that folks at Open Aid are your ‘angels’ and you’re very thankful for them and what they do for you and others. You mentioned that you have ‘been to a lot of different HIV places and they don’t provide anything’ like Open Aid does.

Housing is also huge for you. You are working very hard every day to make good choices and ‘staying out of trouble’ to keep your house.

Sharing Your Status

After arriving in Missoula and spending several months here, you now seem to be open about your status. You described yourself as ‘very open’ and that you usually get good responses. You noted that you learn who your friends are when you share something like that. You said that you actually ‘wouldn’t trade any of this for the world,’ that you ‘worked so hard to get here’ to a healthier place.

Participant 2: Susie

Defining Experiences

It sounds like you experienced abuse as a child, which continued into adulthood, because you “didn’t know any better” or any differently. You shared that you spent time in and out of foster care until an aunt and her boyfriend took you in; however, you experienced abuse in this house that continued into adulthood. You shared that although you have trouble remembering things, you are slowly starting to recall your past. For example, you shared that you wrap yourself tightly in blankets to sleep at night, which you compare to when your sister would wrap you up in blankets and lay on top of you to protect you as a child. You also shared that your aunt and her boyfriend manipulated and drugged you when were pregnant.

Vulnerabilities

It seems like abuse was present throughout most of your life. Because you “didn’t know any better” you felt “unworthy” and experienced abuse in intimate partner relationships. You have been married several times, and while you were able to assert yourself and stop physical abuse, you still experienced emotional / verbal abuse from different men.

You also shared that you have mental health and physical health issues (i.e. schizophrenia, memory trouble, several surgeries, CPAP machine, etc.) that affect your day to day life.

Diagnosis / Processing

It sounds like you were shocked when you first learned of your diagnosis. You were very sick and not expecting that it would be HIV, which you apparently contracted from a previous husband. You decided to leave Arizona, where you were at the time, and move to Montana, where you were expecting to have help and support from family.

You described HIV as a continuous journey, one that you will always be on. Today, you consider yourself a “survivor” and are now confident and content. You appear to be coming out of your shell. You seem to recognize that ‘we all have our things’ and HIV is just one of those things.

Health Care

It sounds like you were linked to care before you even moved to Montana and were immediately able to meet with doctors, care providers, and case managers that helped you with health and housing. You mentioned that when you first got to Montana, you often helped educate your doctors since you were the first HIV positive patient they had. You take your medication as best as possible. In the early days, bubble packs were delivered to you; now you pick up a 90-day supply on your own.

You shared that you were molested by a male doctor in Arizona. Now you only see female doctors.

Education

It seems like you learned a lot about HIV after you contracted it and continue to learn about it.

You shared that education could reduce ignorance and stigma. For example, you said that although you moved to Montana to be with family, they would not support or help you, which you attribute to not knowing enough about HIV. It also seems like you think that that education would help people understand that 'no one is safe' and there are 'no excuses' to not get help because there are so many resources available today.

Supports

Although your family, including your daughter, do not seem to support you, you have a strong faith that keeps you going. You do a lot with your care provider and have a dog that keeps you company and brings you joy. You also enjoy renaissance fairs and the friends you've made through this community.

You mentioned that you are still seeking community, both in the church and with other HIV positive individuals. It seems like you would like a safe space with helpful resources (i.e. classes, computers, etc.) for like-minded people to meet, or a place where monthly gatherings could take place. It sounds like you don't need to sit and talk about your HIV, but rather be in the presence of people that have experienced similar things. You said that there needs 'to be more and more things that people with HIV can do together' to foster community.

Sharing Your Status

You mentioned that you would like to "reach out" and help people with HIV. You want to let people know that even though HIV is 'scary,' you don't have to be scared. You believe that it is helpful to talk about HIV and share with people you trust.

Participant 3: Gary

Defining Experiences

You shared that you and one of your sisters were adopted into a large, white, Christian family when you were nine months old. It sounds like you and three other children in the family were molested by your step-dad and step-brother. You shared that you 'don't want to blame anyone,' but you were abused, and no one believed you until you were an adult. For example, you said that you tried to approach your mom when you were a little bit older but 'she couldn't believe it… she wouldn't listen… and that really hurt.' It sounds like you wonder how the abuse affected your sexual identity and you wonder if that was what made you sexually active at a young age. You also seem to think that this may have affected your ability to open up to males. To this day, it sounds like some of your family has accepted you for you, while others can't because of their religious beliefs.

You shared that you found your biological parents when you were old enough. You noted that your biological father was an alcoholic and died of cirrhosis of the liver and that you only saw him when he was in and out of the hospital. You mentioned that you are treated like an outsider by most of your biological family and relatives, that you don't blame them or resent them today, but they won't look at you eye-to eye. They seem to think you are looking down on them, when you are only trying to establish a relationship and help them.

Diagnosis / Processing

You shared that you were young when you were first diagnosed with HIV. You described yourself as 'careless' for not using protection and you 'just knew something was going on' because your partner at the time suddenly disappeared. You described that you had to wait a long time to get your results back, losing sleep while you waited for answers, but you 'just knew it' would be positive because you 'just felt you had it.'

You described being in shock and disbelief when you learned of your diagnosis. You felt depressed, you cried, and you blamed others and yourself. You felt that you had been 'given the death sentence' and it seems like you didn't know who to trust or how to handle this new, life-changing information.

It sounds like it took you a few years to process your diagnosis and start taking your medication regularly. You mentioned lying to providers early on about your medication adherence and that you felt sorry about it, but you just didn't know what to do at first. Looking back, you noted that you 'had to be honest' but you weren't. It sounds like during those first years you would find a healthy pattern, think you were ok, and then got off track. You mentioned that it took you 2-3 years to find a counselor, which helped you very much. You now know that talking about it with people you trust is helpful and not talking about it is a mistake.

Health Care

It sounds like you had trouble finding good health care providers, but you now have a doctor and care team that you love. You mentioned that you had bad experiences with Partnership Health. For example, too many people are in the waiting room overhearing what you might be there for; the doctors change all the time; and providers inappropriately disclosed your status in a public place. It sounds like after trying to hold people accountable at Partnership and not getting anywhere, that you stopped going there and drove to Kalispell for care for two years. Today you attend Providence where you feel safe and cared for.

You mentioned that you have seen a mental health counselor in the past, which was very helpful for processing not only HIV, but also childhood experiences. It sounds like you haven't seen your counselor in a while, but that you know that it is helpful for you and you will try to reach out again soon.

You also talked about how far health care for HIV has come. Testing is faster, medication is easier, and there are so many resources available. You mentioned that when you were first diagnosed in the 90s things were a lot different and you didn't have the support cast that you now have. You have been taking your meds consistently for ten years.

Education

It sounds like when you felt comfortable opening up to some friends that they wanted to learn more about HIV, how you got it, and how you were feeling. It seems like you learned and shared information with them, noting that it was 'good to talk about it.'

It seems like if you could share advice with someone you would let them know that it's important to not be alone, to not isolate yourself, but to find someone to talk with about it. You also noted the importance of having a good one-on-one with your doctor.

Supports

You mentioned that there are a lot more supports available today than when you were first diagnosed. Some supports you talked about were your volleyball team, the food bank where you now volunteer, Open Aid that offers lots of educational information, and support groups like the Gay Men's Task Force. You admitted that you do not like to go to AA often because you know too many people there.

You shared that it seems like a lot of people might not know that these resources exist, and you wonder what can be done to change that. For example, it sounds like a lot of people think the Gay Men's Task Force outreach programs, support groups and camps are only for young people, when they are actually for everyone.

Sharing Your Status

It sounds like you have moved from not being able to talk about HIV to being able to talk about it with friends you trust. You mentioned that you shared your status with some family members and some family friends; some believed you and some didn't. You also mentioned that you 'learn who your friends are' when you try to share something like that, and it sounds like around ten years ago some of them started coming around. It seems that you have worked a lot on forgiveness, realizing that 'it's an easy out to blame someone' and that you can't take on other people's problems. You seem to be open about your status and your identity with your nieces and nephews, trying to help them practice safe sex and understand what could happen if they don't.

Participant 4: Preston

Defining Experiences

It sounds like you were raised Catholic, and although you've always believed in the Catholic church, your Native religion seems to overtake that because it's simpler. For example, you know that 'whatever is in your mind and on your heart' will be carried up by sweet grass and sage. You seem to be a very spiritual person and you pray daily.

You mentioned that your father died when you were ten years old and that affected you greatly. It seems like you are working through resentment you held toward him and now starting to understand more about addiction and understand more about your father.

You shared that you used to use meth and alcohol often, which seems to have affected your personal life and your professional life. You mentioned that a cousin first turned you onto injection drug use. You later used off and on with a boyfriend and eventually used on your own. You noted that things got out of control and you eventually went cold turkey with meth. It sounds like you have had several DUIs, spent some time in jail, and attended recovery programs that have helped you to varying degrees. You mentioned that you are on probation now and working on your sobriety.

Diagnosis / Processing

You have been living with HIV since the mid-80s. You think you contracted HIV in Philadelphia, when you lived there for two years, trying to attend college and see what life was like in a big city. You mentioned that you returned to Montana to take care of your mother when you started getting sick.

It seems like you 'felt something in your body telling you that something wasn't right' and you seemed to know what was happening. You described HIV as a 'death sentence' and you experienced 'all of the emotions' when you were first diagnosed. You seemed to question if your promiscuity was 'worth it,' and if you'd be 'marked' for the rest of your life.

It sounds like you became reclusive when you learned of your diagnosis and you felt like you had no one to turn to and nowhere to go. During this time, you lost your mother to cancer and you said that 'you lost it' as well; feeling like you had nothing left to live for you decided to let HIV 'run its course.' You described this time as being off meds, drinking to excess, and putting yourself into dangerous situations. Eventually, your sister reached out to you, offered help, and 'saved your life.'

It seems that you have had trouble taking your meds regularly, noting that you would often fall into old habits with old friends. Other times you would take your meds, but you did not know if they were working or not because of your drug and alcohol use.

Health Care

You mentioned that in addition to HIV, you have Hep C and thyroid issues. You described two bad experiences with the flu in the past year, one that put you in the hospital with pneumonia.

It sounds like you are cautious about who and where you get your health care. You would very much prefer culturally sensitive health care. For example, you shared that you would like to go to the native center for testing 'where they do it spiritually' with 'smudge and sweat,' and not just picking your mind causing you more turmoil.

You also noted that even though it's been 20 or 30 years, you do not want to receive health care at IHS, because someone would say something and 'that's supposed to be confidential.' As a result, you get your care in Missoula.

Education

It sounds like you have learned a lot about yourself and about HIV. For example, you mentioned having to learn about the numbers and counts and what that means for your health.

You seem to recognize that a lot has changed since you were first diagnosed, saying that 'now people are more informed, but then you still have, maybe the younger generations that don't know the facts'. You shared that HIV 'is not going to go away and they need to know about it.'

Supports

You seem to find great strength from within yourself and from your family. You know that 'no one is going to do it (get sober) for you.' You described your family as being one of the big reasons that you want to stay alive. 'It's so good to be called 'uncle,'' and have nieces and nephews that check in on you. Your family is a big reason for taking your meds regularly.

It sounds like you are trying to set yourself up for success: you will turn friends away if they are not sober when they come to see you; you attend meetings when you can; you pray daily; and you eat right.

Open Aid has assisted you with housing and bills here and there, which is very helpful.

Sharing Your Status

You seem to be a very reserved person, but some family knows that you are gay and that you have HIV. You shared that when you first opened up to your family about your sexual identity, you felt like that 'was enough' and that it took you time to open up about your health. You shared that in the early days when you had to take so many pills you would play it off as something else, like heart medication. To this day 'a lot of people don't know that you are HIV positive' but there is always 'talk.'

You noted that you hope our conversation can help somebody out there and you'd like to share that 'HIV isn't a death sentence. It's manageable… get in focus and get the right circle of people and you can make it.'

Participant 5: Matt

Defining Experiences

You described yourself as the ‘odd,’ ‘liberal’ in a very religious and conservative family. You explained that your mother remarried when you were 12 or 13 and that changed a lot of things for you. Church and discipline became prominent. It sounds like you don’t think you were ‘abused’ as a child, but that you often took beatings when you did something wrong or when you stepped in to protect your sister or mother.

You mentioned that you have been drinking since you were seven years old and learned early on how to be private and sneak around. It sounds like this privacy continued into young adulthood, when you started exploring your sexuality. It seems that prior to your diagnosis, you led very separate lives, separating your personal, sexual life from your friends, family, and co-workers.

It sounds like you recognize how present drugs and alcohol are in the gay community and that ‘drinking has always been a big force in your sexuality,’ describing that alcohol was the ‘kindling to the fire.’ You mentioned it was common for you to have 10 or 12 partners in a day and described this time as being ‘with a lot of people but with no one’ at the same time. You said that you think you have a sex addiction that propelled your ‘reckless’ behavior. You noted that that is something that you would like to address now that you are working on being sober.

Prior to your diagnosis, it sounds like you were very active with work and you exercised often. You felt healthy most of the time. Now it sounds like you are having trouble adjusting to not working and that you have many health problems that affect your daily life, health problems that arose when your HIV progressed undiagnosed.

You shared that you often struggle with feelings of worthlessness and that you sometimes ‘fantasize’ about being ‘heterosexual’ or ‘normal.’

Diagnosis / Processing

You shared that you were diagnosed in 2015 and have been living with HIV for about 2 ½ years. You now think that you were probably sick for about two years before you were hospitalized. You seem to think that you were ‘indestructible’ and that nothing like HIV could ever happen to you. You mentioned that even though you don’t like doctors, you felt so bad you tried to figure out what was going on, but no one could figure it out.

Your time in the hospital was traumatic and you nearly died. You said you spent 17 days in a coma and couldn't walk for several weeks after you were released. You now have several health issues related to how serious your HIV was at the time of your diagnosis. For example, you mentioned you have heart and lung issues.

It sounds like when you were in the hospital, your health status was shared with your mother who had to make a life and death decision for you while you were unconscious.

Health Care

It sounds like you have been taking your meds regularly for about two years, but are detectable, which is frustrating. You mentioned that after you were first diagnosed and regained your strength, you returned to your old habits, this time using protection. However, it seems like you noticed that drinking affected your ability to take your meds regularly, which was one of the reasons you decided to stop drinking.

It seems like you have ok relationships with your health care providers, although you question if your primary care doctor believes you when you say you are taking your meds regularly. It sounds like you are hesitant to 'bother' your doctor with other questions you have, like about anxiety you've been experiencing since you were diagnosed.

You mentioned attending intensive outpatient treatment of your choosing to help you get clean and sober. This was when you started learning about your behaviors and started thinking about why you were acting the way you were acting with alcohol.

You've been sober for several months and occasionally attend AA.

Education

It sounds like you have learned a lot about HIV during this time. You wonder how you never received any messages about HIV or PrEP until it was too late; however, you also seem to acknowledge that you were perhaps 'naïve' and 'tricked yourself' into thinking you were indestructible in spite of your 'dangerous lifestyle.'

You seem to hope that participating in things like this interview will help other people. It sounds like you want to spread the message to others that you did not receive: practice safe sex, get tested, get checked, etc. You also noted that ‘this day and age, no one should ever get like that,’ get as bad as you did.

Supports

It sounds like you have a few supports like your roommate and your good friend who are not judgmental. You seem to find some help and answers in online blogs, where you can often find answers before a doctor can get back to you.

You noted that you found out who your friends were during this time, and that ‘it’s not the one you think it is that’s your real friend. It’s the one you never really talk to that will surprise you.’

It seems like your family is not particularly supportive of you regarding your sexual identity or your health care. You said that your mom is harsh and judgmental, but that is ‘just her condemnation of the lifestyle that she believes is wicked and evil… she’s old school.’ It sounds like you feel that you lost any respect that you might have had with your family. You shared that you love and care for them despite that.

It sounds like you’ve found some healing in nature, walking in the woods, and practicing coping.

Sharing Your Status

You seemed to be very private before your diagnosis and you continue to be private now. You mentioned that ‘people finding out has probably been the biggest struggle… but it’s getting better’ and you’re adjusting. Although you are cautious and reserved, you also acknowledge that ‘when you’re open about things, you’re more likely to stay on a path and be more responsible,’ which might be why you’ve started trying to open up about your experience.

Participant 6: Alexander

Defining Experiences

It sounds like you are working through several challenges related to the loss of dreams you had for yourself. It seems like you feel that you have lost your sense of purpose and waver between good days and bad days. You seem to have a history of alcohol and drug use, which is something that has gotten you into trouble from time to time. You shared that are now on probation and are looking into rehab options.

Despite these challenges, you have found jobs here and there to get you through, discovering that you love working with your hands and gardening. However, you also shared that even then you would use drugs to get you through the work day.

It seems like you have become more aware of your feelings and actions (i.e. why you feel the way you feel and why you do the things you do) and are trying to take steps to get into a healthier place. You seem to have trouble trusting people, because you have been burned so many times.

You seem to feel isolated and secluded, feelings that are worsened because Montana still seems ‘stuck’ and ‘close-minded.’

Diagnosis

You shared that you were diagnosed with HIV while you were living in Oregon. You mentioned that you were aware that you ‘weren’t living in a good, healthy environment’ and that you started to sense that something was wrong with your health. It took you a few months to get tested, because even though you had a sense of what was going on, you weren’t ready to face it. When you first learned of your diagnosis you, ‘kind of died,’ and you ‘vanished’ because you just couldn’t face anyone. It sounds like when you learned of your diagnosis, a lot of other things weren’t going well in your life. For example, you mentioned having car trouble, work trouble, and not being able to afford much more than pasta and butter for meals. It seems like all these things happened at once and you left Oregon to return home to Montana.

It sounds like you haven’t been clinically diagnosed with depression, but you are aware that it ‘ebbs and flows’ and that this ‘got worse after your diagnosis.’ You seemed to notice a shift in yourself, moving from a happy, social, fun-loving person to someone that wants to be alone.

You describe your experience of living with HIV as a ‘mountainous region… always up and down.’ You acknowledge that you’ve shut parts of yourself off, perhaps as a protective measure, perhaps because you feel defeated. Most days you feel set-backs.

Health Care

You seem to struggle with health care in different ways. You are happy to have resources like Riverstone and Rim Rock available, but you seem to want to go to these places on your own terms and in your own time.

You seem to recognize that you have conflicting feelings about meds and you know that you struggle taking them, saying, ‘I am not adherent by any means. It’s been like that since day one, that first year.’ You don’t seem to like taking any meds or pills and have experienced side effects from HIV meds when you’ve taken them regularly. It sounds like you don’t like to think about how ‘toxic’ the meds are and what they might be doing to your body. You also shared that you’ve tried mail delivery, but pills would not always arrive on time.

Education

It sounds like you wish people knew more about things like sexual identity and HIV to reduce stigma in your home community. You shared that even though you are getting comfortable with your status and do not feel shame about it, ‘unfortunately, society still does look at it like that… there’s always going to be a hang up.’

Supports

It sounds like you wish there were more supports and resources available to people living with HIV. You shared that the Yellowstone AIDS Project was very helpful when it was around. It sounds like it was helpful to ‘see a familiar face’ and now you don’t have that since YAP closed. You described YAP as ‘always there, not to be that crutch, but to be that helping hand when you needed it.’ Now you and other people are wondering ‘where can we go, what can we do?’ You also noted that not having a vehicle is a huge set-back and it was great when YAP had a van.

You seem to know that there are some supports available and that it is up to you to put in the effort, however, it sounds like you are not ready to do that just yet.

Sharing Your Status

It seems that many people have burned you, either at work or in your personal life, and you are very cautious about who you trust. It sounds like you have a few good friends, but you ‘miss having friends’ that might understand what you are actually going through. You mentioned that you are ‘just so afraid’ and that it is ‘so hard to again try to get to know people and see if you can trust them enough.’ You continue to feel ‘disheartened’ and ‘damned by everyone in the world’ by something that you didn’t choose.

Participant 7: Tom

Defining Experiences

It sounds like you had an ‘excellent upbringing’ with very supportive parents. You opened up to them about being gay when you were in your 20s and they accepted and loved you just the same. You have a love for animals and spent years working as a dog groomer. You mentioned you had a cocaine addiction in your 20s, which got you into trouble, saying that you ‘lost everything’ (i.e. house, car, etc.) when you turned to drugs. You sought treatment and tried to clean up. However, it sounds like you have spent significant time with peers with substance abuse issues, including your long-time partner. You mentioned that being around your partner helps you keep yourself together.

Diagnosis

You’ve been living with HIV for more than 30 years. It sounds like when you were first tested you had to take a retest and you just ‘knew right then and there’ that something wasn’t right. You were told to ‘make your arrangements’ and you got rid of all of that animals you were caring for at the time, which was very difficult for you to do.

Although you were upset and blaming at first, you now acknowledge that you ‘cannot blame anybody’ because you were ‘having unprotected sex’ and using drugs. You sound like you have taken responsibility for behaviors that put you in situations where you contracted HIV.

You described how much things have changed with HIV from medication to information about the disease. You seem to be open and honest with your care providers, and you expect them to be ‘discreet,’ although you shared that other people have had their health information shared in the hospital.

Health Care

You seem to have good relationships with your care team. You mentioned that you sometimes get ‘tired’ of pills and will go on a ‘pill holiday.’ The most recent pill holiday lasted six months. You seem to know that even though you go on mini vacations you need to take your meds because you ‘want to be here.’

It sounds like you have other health issues that cause you trouble including your heart health, ulcers on your leg, thrush from HIV, and syncope that prevents you from driving.

When speaking about other people you indicated that they seem to not want to be honest with themselves or the lifestyle they're choosing, which might affect their ability to take meds regularly.

Supports

You seem to surround yourself with people that could have good and bad influences on your health. For example, you described having a good support in Sister Mary for many years. However, you also described previously living with three roommates with substance abuse issues, and now living with and supporting your partner, who is also has substance abuse issues. You also noted that your family is a big support for you and that they are 'very protective.'

You mentioned that now that Yellowstone AIDS Project is closed, 'most of the clients (at Riverstone) are unhappy about not having resources.'

You also shared that you now must rely on others to get you around and that not having a vehicle can be very difficult.

Sharing Your Status

You seem to be open and honest about your status if it comes up. Early on, you volunteered for speaking and educational events, however, it sounds like you stopped when the focus of the talks shifted from HIV to your sexual identity.

Participant 8: Michelle

Defining Experiences

It sounds like you experienced a lot of instability during your childhood. You shared that your mom and dad separated, and you lived with your mom while your brother lived with your father. You shared that your father abused you as a child, but your mother, who is an alcoholic, did not believe you or know what to do about it.

It seems like you moved around a lot with your mom, and because of her addictions and lifestyle, you did not learn how to be responsible (i.e. go to school, budget money, clean a home, etc.).

It seems like when you met your husband (who you are now separated from), you started to learn how to be responsible (i.e. how to care for yourself and others) and you became a strong, caring mother to your children.

Vulnerabilities

You mentioned that you have been addicted to drugs and alcohol for most of your life, which you attribute to following your mom around and not knowing anything different. Addiction has been something you struggled with but are now taking steps to manage.

It seems like although you love your husband, you had/have a complicated relationship. For example, he showed you how to be a good parent and encouraged you to attend school, but he also emotionally/verbally abused you and made you feel unworthy. It seems like you felt like you had to continue to be with him even when it didn't feel right, because you did not want to lose your children.

You shared that your children were molested by your step son, and later you found out that your husband molested your daughter. It seems like you want to break this cycle of abuse, clean up, and provide a loving, stable home where your children feel safe.

Diagnosis

It sounds like you were in shock and fear when you first learned you 'caught HIV'. For example, you 'never would have expected this' and you were afraid that you would lose your family. It seems like you felt hopeless and, as a result, your relationship with drugs and alcohol intensified. You felt like you had no one to turn to and were afraid that you would be alone forever. You shared that you separated from your husband and family, describing these first few months as ‘slowly committing suicide’ because you ‘just didn’t care.’ You also shared that you were hesitant to pick up medication, because ‘people often steal’ and you did not want to compromise your HIV status.

Health Care

Today, you are taking steps to manage your use of drugs and alcohol, and your HIV care. It sounds like your children are your motivation for living a healthy, full life. You are clean, in recovery, take your meds, eat well, and use alternative medicine to heal your body and spirit.

Education

It sounds like you learned a lot about yourself and about HIV after you contracted the disease. For example, you ‘didn’t realize that you got PTSD out of it (i.e. childhood, relationship with husband) until you started getting help for yourself.’ You also share information with your children about safe sex.

Supports

It sounds like River Stone has been a great support for you, even when you were not ready to accept their help. You noted that the case managers there were/are ‘very engaged’ and it was very helpful to know that you could ‘fail ten times and they’d still be there’ for you. You shared that your stepson telling you that you ‘didn’t need to be married to be his mother’ was a turning point for you; it helped you know that you could leave your husband, clean up, and still have the family you love.

It seems like you’ve found some supports from women friends during your prerelease program, and you have also started a relationship with a loving, caring, supportive boyfriend that you trust.

You discussed how helpful Yellowstone AIDS Project was when you first got HIV, again noting that even though you weren’t ready to use their resources, it was a comfort to know it was there. It seems like you would really like a place like YAP to come back so that you and others would have a safe space to go to, noting that sometimes you just need to know that you’ve got that ‘extra spot’ where you can find understanding people, lay down on a couch, grab some food, and just be.

Sharing Your Status

It sounds like you are very careful about who you share your status with. You initially described it as a ‘secret’ to your boyfriend, before fully sharing it with him. You also mentioned telling your older daughter, because you felt that she needed to know, and you needed someone to talk to at the time. It seems like each time you shared your status with these people, you felt love, support, and acceptance.

It also sounds like you are careful with your home community. You mentioned that you do this to protect your children, who are still there while you are in recovery and taking steps to secure a home and a job before getting them back in your life.

You'd also like to be able to share with other people who might be in a similar situation, perhaps as a peer mentor, but you acknowledge that you are not ready to do that just, yet.

Participant 9: Meredith

Defining Experiences

You shared that you are one of ten children. Although you were taken care of as a child, you felt lost in the shuffle of your large family, which you think may have affected your self-confidence and self-esteem as a child.

Vulnerabilities

It sounds like you have a big heart and tend to put others needs and interests before your own, even when it is not healthy for you to do so. This big, caring heart may have caused you to try to endure emotional abuse in your relationships with men when you wish you had protected yourself and your heart. You may also attribute your unconditional love and tendency to see the best in everyone as the reason you contracted HIV from your second husband, who you described as ‘a liar’ and a ‘drug addict’ and ‘someone that you wished you could have helped’ at the time.

You shared that your daughter struggles with drug addiction. You stepped in to help care for her children while she seeks treatment, and you are legal guardian to one of your granddaughters. While your granddaughter brings you great joy, it is an unexpected responsibility after raising two children of your own.

Diagnosis / Processing

It sounds like when you were first diagnosed you were in shock and disbelief. You shared that you felt “tainted” and “marked” for a very long time and were afraid that your life was over. When you first started seeking care, you were afraid of being judged for having HIV by your health care providers. With time and practice and patience, it sounds like you have allowed yourself to take responsibility for your part in contracting HIV (i.e. ‘lowering your standards to feel less lonely’). You continue to find the positive side of any situation, have accepted your status, and are “ready to get back into the world.”

Health Care

You shared that your health is a priority for you. It sounds like you are afraid to miss your medication. For ten years, you have taken your medication as best as possible, only missing a dose once or twice when you were stressed out caring for your grandchildren. You noted that although the doctors you see change often, you have only had good experiences with your care providers.

Education

It sounds like you learned a lot about HIV after you contracted it. Learning more about the disease helped you manage and understand it.

It also sounds like you think that there is a need for the public to be educated about HIV. You noted that people often stereotype or think that someone with HIV looks a certain way, but the reality is that anyone can get it. You shared that you can attest to this through your own experience. You also shared that you do not want people to feel sorry for you. It sounds like perhaps if people knew more about HIV, then they would understand that it is a manageable condition and not something to be afraid of.

Supports

It sounds like you have many strong supports that help you live a healthy life. Your faith, which was always important to you, became stronger after your diagnosis. It sounds like you attribute your strong faith to your ability and willingness to find the positive in any situation.

You shared that when you were first diagnosed, most of your family was supportive of you. However, your mother never really accepted it, even suggesting that you change your last name at one point. Today, most of your family is supportive of you, including your brother, your son and his fiancé, and even your granddaughter.

You shared that you are very grateful for Open Aid and not only the resources they provide (i.e. housing, safe space), but also for the people that work there and go out of their way to help you.

It sounds like having good housing helped and helps you stay healthy. You said, “you may have HIV, but you’re a human being” and that proper housing helped you feel better about yourself, which made you want to take care of yourself.

Sharing Your Status

You shared that you no longer explain to doctors how you developed HIV, knowing that they are there to care for you without judgment. You can and have talked about having HIV, however, you do not want to ‘wear your status on your sleeve.’ You shared that you take precautions as needed, for instance explaining to your granddaughter how to be safe around HIV.

You also shared that that you are no longer seeking romantic relationships. It sounds like you chose to do this to protect yourself and potential intimate partners.

Participant 10: Jamie

Defining Experiences

It sounds like you grew up in a one parent home with a mother that struggled with significant mental health issues that affected her ability to successfully parent you. For example, you mentioned that you were used to being left unsupervised and alone at a very young age with your mother's boyfriend(s) entering and exiting your lives. You shared that you spent time in foster care—something your mom unknowingly initiated due to her concerns for your safety and wellbeing. While you acknowledge your physical needs were met in foster care, you never felt particularly nurtured or comfortable in that home. As childhood continued, you started to rebel: you dropped out of high school and started engaging in risky behaviors like drugs, alcohol, and sex. You shared that you left home as a teenager, hoping to reconnect with your father and attend college; however, you were not welcomed in his home and were left alone and vulnerable in an unfamiliar setting.

Vulnerabilities

You shared that you are recovering from drug addiction and alcohol abuse. You acknowledged that you were hanging around with a lot of unhealthy people as a teenager, both when you moved away from Montana and when you returned home before your diagnosis. When you were not welcomed in your father's home, you didn't know what to do or where to go, so you returned to the only people you knew who happened to be drug dealers. Although these individuals took care of you (i.e. shelter, protection, food, clothes, drugs, etc.) they also took advantage of you and your vulnerability (i.e. young and alone without support). While you tried to hold out as long as you could from prostitution, you eventually felt pressured to give in because the people that were taking care of you threatened to stop. You shared that you moved from the southeastern US to the northeastern US during this time, continuing to use drugs and alcohol, and continuing sex work. You shared that you think you contracted HIV during a sexual encounter in the northeastern US, prior to returning home to Montana.

Diagnosis / Processing

Before your diagnosis you described becoming very sick: you lost weight, had a sore throat, and your teeth hurt. You said that you became so sick that you did not even go out with your friends. At first, doctors could not figure out what was causing your illness. You mentioned that while they were ruling things out like strep throat, you started to freak out because you had a strong feeling that you knew you had HIV because you knew the severity of the situations you put yourself in. You described your diagnosis as "the worst day of my life." You were in shock and thought you were going to die. After your diagnosis, you started using injection drugs, thinking that nothing could be worse than HIV. It seems like while you were processing your diagnosis, your relationship with drugs intensified and changed. During this time, you shared that you also had legal troubles and spent time in intensive supervision probation. Eventually, you were able to clean out in jail and attend a treatment and recovery program. You shared that you now have a different perspective about HIV, that it does not define you and that it isn't the end of your life, but that it changed your life forever.

Health Care

You shared that you have always had a supportive health care team that you trust. Even when you were first diagnosed and using drugs more often, your support team was kind and nonjudgmental: they just wanted you to take your meds. You also shared that even though you were struggling, you still said, 'yes,' to care providers' suggestions (i.e. met with a peer mentor) and you always took your medication the best that you could. It seems like, much like your relationship with anyone else, you have been and are always honest with your care providers. Today, you continue to take your meds, attend care appointments (physical and mental health), attend NA meetings, and continue to work on yourself.

Education

Education relates to self and others. During this process, it seems like you learned a lot about HIV that you would not have known had you not contracted the disease. For instance, you did not know that you could be undetectable. In addition to learning about HIV, you have also learned how to be healthy and be responsible. You now feel like you have the tools and supports and information you need to live the life that you always wanted but didn't know how to get there otherwise.

You also shared that there is a need for public education around HIV. You noted that there are still stereotypes and misunderstandings around HIV, which might be intensified because Montana is a conservative, rural state. It seems like you think that people need to start having difficult conversations to increase understanding and reduce stigma.

Supports

Helpful supports for you include your boyfriend who you trust fully, your care providers, housing assistance, and the good, clean, caring people that you surround yourself with.

You also mentioned that you would like to have more support groups for people living with HIV, because it is helpful to connect with people that know what it's like to have HIV.

Sharing Your Status

It seems like you are a very open and honest person, and you share your status with anyone that it might directly affect, like your boyfriend. You offer information and resources to the people you share your status with, like making your doctors available to your boyfriend to answer any questions or concerns he might have. Otherwise, you do not feel like your status is something you need to share with everyone.

Themes

The following tables present themes and representative quotes along with an approximate estimate of total time dedicated to discussing each topic. Percentages were derived through coding with NVIVO qualitative data analysis software. Percentages represent the total time across all interviews, not individual participants.

Theme	% Coverage	Quotes
Defining Experiences	31	*I was adopted when I was nine months old…. I was adopted into a White family. It was a Christian home. I don't want to blame anyone, but I was molested when I was a kid.* *The way I was raised, you know, I never had to go to school. My mom was an alcoholic. I never had a home. I've been addicted all my life.* *My stepson was raping my three kids.* *My husband got charges of sexual assault on our nine-year-old.* *Their father, the man that I married, he after seven years of marriage, told me that he was gay.* *I have a lot of memory loss. Short-term memory loss where there's stuff… I have so many blanks in my lifetime, it's just ... I don't know if I unconsciously just didn't want to, but I know I've been through a lot of major, major stuff when I was younger… abuse, trauma.*

Theme	% Coverage	Quotes
Vulnerability	37	*My husband, there's been emotional abuse and stuff there, so I didn't think that I was going to be able to take of my kids or myself.* *I couldn't really stop using drugs until I finally got caught with drugs.* *I don't do drugs, never have really, but I do drink. I don't drink anymore. I used to drink. To me, sex with multiple men always started with drinks, and then it would just get out of control.* *"Whenever they told me that about some of the things I was doing when I was drunk… I was so, so ashamed of myself and I, I don't want to be that person.* *"My family when I got here, they were all scared to death of me, they still are."*

Theme	% Coverage	Quotes
Diagnosis	25	*I just knew it when I went back to get the test results that I just felt that I had it.* *I think that was the day that just totally changed my life... I knew it was a new avenue that I had to take, that if I wanted to stay alive I would have to take the medication.* *I came home and that’s when I felt something in my body telling me something is not right.* *I was diagnosed in 2015, from waking up in intensive care, that's how I found out. I was very sick and just thought it was something else. It's been traumatizing because of the way I found out, almost dying from it.* *I used to use the word I feel tainted, I feel tainted.* *Yeah. And back then, you know, they told ... "You better make your arrangements."*

Theme	% Coverage	Quotes
Disclosure	25	*I don't feel like that is something I need to disclose to everyone… unless I am putting them [someone] in a situation where they could get it.* *I was afraid to tell anyone, even my close friends, which was a mistake because you need to talk about it. You can't just leave it inside locked up.* *I mean eventually, like one day I wouldn't mind coming out. I wouldn't mind, because what bugs me a lot, is like when I first caught it [HIV] in the little town that I was in or whatever and just being known or whatever, it just was really hard to ... It was just a lonely feeling of knowing that I had contracted what I had contracted, and I had nobody to talk to about it.* *This is the first way it affected me, every new nurse I met or doctor, whoever I saw, right away I felt compelled to tell them how I got HIV because I didn't want to be looked down upon. Was she a drug user? Was she sleeping around? I didn't understand all of it so I told them all how I got it, from this terrible person that lied to me.*

Theme	% Coverage	Quotes
Education	15	*I'm looking at it from the perspective, [that] I was there too. I was completely uneducated about it [HIV] when I found out that I had it. I didn't even know, like, I can have children and they [might] not have it. I didn't even know that was a thing.* *Society has that image that people see when they hear HIV or you try to talk about it. It's just disheartening that I feel so damned by everybody in the world for something that unfortunately I didn't choose.* *I have people always tell me, "You look healthy. You look healthy." Then you wonder, well, what is somebody with HIV supposed to look like?* *But yeah, it almost killed me not getting checked. That's the message, I hope I get to people.*

Theme	% Coverage	Quotes
Health Care	18	*I'm just really grateful… that I had the doctors and everyone, the team that was willing to help me. Willing to deal with my high emotions at that time and really just encouraged me to take my medicine.* *Two or three years later, I reached out to a counselor and that just totally took everything off my shoulders.* *I was taking my meds and doing drugs and not knowing if it was working.* *I went for like six months this last time without taking them [meds] just because I was just tired of pills. But I also know that I want to be here ... I need to keep taking them.* *My addiction has come into play, and so that's the main reason why it was hard for me to stay on my medications or anything, because of my addiction and the problems that I was going through in my life.*

Theme	% Coverage	Quotes
Supports	31	*Riverstone Health, they were just very kind until I was ready to be kind.* *They [my case managers] knew about my drug problem. It didn't get better, it got worse for a long time. They never pushed treatment or anything on me, which, I feel like was helpful.* *I only have good people, clean people that care about me in my life today. People I can rely on if I need anything.* *I think I find strength within myself knowing that no one is going to do it for me, I've got to get out there and do it myself. I quit, cleaned up.* *My family is a big part of my wanting to stay alive.* *Now I know that I can fail ten times and they'll still be there. Because they know and understand that.* *AIDS Alliance, wonderful support. The group of people, the love and the kindness and no judging, helping, giving you references. When I come in here, I just feel safe.* *One thing I wish that Montana had, or Missoula, would be more, even Montana, more support groups for people.* *They were always there, not to be that crutch, but to be that helping hand when I needed it and now it's--I know people just being like "Now where do I go? What do I do?"*

Theme	% Coverage	Quotes
Processing Diagnosis	7.5	*I want to try using the needle because I feel like... I would like it and I feel like it is pointless not to now because I'm already ... I've already caught something [HIV] anyways. So I was just like, I don't give a fuck. I just want to blow my mind out.* *It was just really hard but the more I've gotten comfortable with it, there is nothing to be ashamed of per se. Unfortunately society still doesn't look at it like that so it's a daily process, it still is.* *I think mentally too my outlook, you know when you say, 'Oh, that's not going to happen to me or this won't?' That's wrong. I was a grandmother of seven grandkids in my 50's, and I find out I have HIV. Yeah, I felt tainted, but then I just kept telling myself, 'No, you're not tainted. This happens. Things happen. There are worse things.'* *It's been traumatizing, the three years. It's not even been three years. It's been two and a half, so I've had a lot of getting used to it. People finding out has probably been the biggest struggle for me. But it's getting better.* *HIV isn't a death sentence. It's manageable. You can get… in focus and get the right circle of people and you can make it.*

Theme	% Coverage	Quotes
Experience LWH	15	*Just a mountainous region and it's always up and down.* *You lose all respect, if you had any, from these people. You don't have any. I don't have any respect, to this day nobody respects me in my family.* *I've been on a very long journey, and I don't believe it's ever gonna be over.* *It's what I always wanted my life to look like, but I didn't really know how to get there.* *I think it's just really important for people who are HIV positive to take care of themselves and to respect other people that aren't; even if it is painful.* *The road that I took to almost dying, to finding a hope; that I didn't have to die with a mark saying HIV. There's been people that have said to my face, "Oh, you're just a faggot, you're going to die." There's two of them that have said that that I've outlived them. Not saying that it's good or bad, it's just a fact.* *Sitting here sober, clean and being able to share is ... It means a lot.*