

COUPLES LIVING WITH HIV: GATHERINGS, DIALOGUE AND COMMUNITY  
ACTION

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# Couples Living With HIV: GATHERINGS, DIALOGUE AND COMMUNITY ACTION

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# Couples Living With HIV: GATHERINGS, DIALOGUE AND COMMUNITY ACTION

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## Gratitude

One does not enter and come to understand a community of people without some sort of opportunity. The opportunity that came to me was through the Southern Alberta Clinic and Alberta Health Services, and through my work as a social worker within the Calgary Health Region. Being a social worker allowed me to enter people's lives in the dual role of helper and advocate for persons living with HIV. I thank the profession of social work for giving me a professional framework in which I could work towards bettering people's lives.

The leap of faith I took to start my PhD and tackle a qualitative research project was greatly supported by Dr. John Gill, Clinical Director of the Southern Alberta Clinic. He trusted me to conduct research that would benefit the larger community of persons living with HIV; for that trust, I am forever grateful. To the HIV patients and their partners who trusted me to gather them into a community and engage in dialogue - I thank you for your bravery and for placing your trust in me. The voice of your community will forever change how the world understands your experience, individually and collectively.

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Lastly, in a recent *Macleans* article, Payam Akhavan (the UN's youngest-ever war crimes prosecutor and human rights scholar) stated that “paying the price can mean many different things: emotional, psychological or material...But we must sacrifice something in order to make the world better” (Bethune, 2017, para. 2). The multiple

## Couples Living With HIV: GATHERINGS, DIALOGUE AND COMMUNITY ACTION

sacrifices that my family and I endured through this seven-year process were necessary; so that it becomes better for others who do not have the same chance.

### **Abstract**

The initial idea to gather together sero-discordant couples (i.e., when one partner is HIV-positive and the other is HIV-negative) to learn about their experience of living with HIV was generated from conversations that I had with couples at the Southern Alberta HIV Clinic. Beyond the world of HIV medical care, many sero-discordant couples are unable to share personal experiences that might range from travelling and taking their medications, separation due to HIV and exposure, welcoming a child with negative HIV status, and the many other aspects of couples' lived experiences. My observation was that many sero-discordant couples felt invisible or silenced due to HIV's social stigma, and perceived that they fell outside of the North American society's dominant, socially-constructed couple narrative.

Multiple services – Alberta Health Services, the Conjoint Ethics Committee, HIV Community Link, the Taos Institute and other community professionals – were engaged to create a community space that would allow sero-discordant couples to come together to share their experience of living with HIV. The aim of this collaborative practice of community engagement was to develop an inclusive, collaborative agenda that would protect and provide a safe space for sero-discordant couples to gather and dialogue.

This study was conducted as a participatory action research process that included an initial process of community gathering for sero-discordant couples. The aim was to foster dialogic processes that could be woven together to empower couples to break through the stigma that has kept them marginalized through and after the AIDS epidemics of the 1970s and 1980s. The gatherings were intended to be a first step towards understanding the experience of these couples, which is often invisible, by lifting the veil of marginalization and isolation that has socially permeated their lives since being diagnosed with HIV.

This study was conducted over six years. The research phases included the initial gatherings and dialogues, the development of an action-oriented agenda by the sero-discordant community, an engagement of the action phase, and finally the creation of a fully funded, peer-support model that provides individual and group support to the sero-discordant community. This peer support model, as initiated by the action-oriented research process, is now provincially, nationally and internationally recognized as a working model for other oppressed groups of people living with chronic disease (Miller, 2017).

### **Abstract in Dutch**

Tijdens gesprekken gevoerd met Sero discordante echtparen op de Southern Alberta HIV Clinic ontstond het idee om deze type paren bij elkaar te voegen in groepsverband. Buiten de HIV-medische wereld delen deze paren namelijk vele problemen die variëren van medicatie op reis; scheidingen als gevolg van HIV en blootstelling eraan; het verwelkomen van een HIV negatief kind, en de vele andere aspecten van de door deze paren (al of nog niet) meegemaakte ervaringen. Mijn observatie was dat veel Sero discordante paren zich onzichtbaar of de mond gesnoerd voelden door het sociale stigma rondom HIV. Ze hadden het gevoel buiten de Noord Amerikaanse samenleving te vallen.

Meerdere diensten – Alberta Health Services, the Conjoint Ethics Committee, HIV Community Link, the Taos Institute en andere maatschappelijk-werk professionals—associeerden zich t.b.v. het creëren van een gemeenschappelijke ruimte waarin Sero discordante paren samenkomen om hun ervaringen over het leven met HIV te delen. Het doel van deze samenwerking was om een zo volledig mogelijke agenda te ontwikkelen dat uiteindelijk een veilige plek zou bieden voor Sero discordante paren: ook om bij elkaar te komen voor dialoog.

Deze studie is uitgevoerd als een participatief actie-onderzoeksproces, inclusief een kennismakingsproces t.b.v. de onderlinge ontmoetingen van Sero discordante paren. Het doel was om de processen voor dialoog te bevorderen die samen geweven konden worden om de mondigheid van paren te vergroten zodat ze het stigma konden doorbreken die hen na de AIDS epidemieën in de jaren '70 en '80 aan de kant doen bleven zetten. Deze bijeenkomsten waren bedoeld als een eerste stap naar het begrijpen van de vaak onzichtbare ervaringen van deze paren; door het marginaliseren en isolatie weg te halen dat onbedoeld hun sociale leven is binnengedrongen nadat ze met HIV zijn gediagnostiseerd.

Deze studie is uitgevoerd over een periode van zes jaar. De onderzoeksfases behelsden initiële bijeenkomsten en dialoog; de ontwikkeling van een actie-georiënteerde agenda door de Sero discordante gemeenschap; het aangaan van de actie fase; en tenslotte de creatie van een volledig gefinancierde peer-support model die voorziet in individuele en groepsondersteuning voor de Sero discordante gemeenschap. Dit peer-support model, zoals geïnitieerd door het hier gedocumenteerde actie-georiënteerde onderzoeksproces, is nu op provinciaal, nationaal en internationaal niveau erkend als een goed werkend model voor andere onderdrukte groepen mensen met een chronische ziekte (Miller, 2017).



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## **CHAPTER ONE: INTRODUCTION**

### **The Need for Contemporary Knowledge for Couples Living with HIV**

“Nothing is nothing, until someone gives it some meaning.”

(field notes, P. Miller, 25 February 2012)

### **The Lived Landscape Behind the New Narrative**

UNAIDS (2016) states that HIV continues to be a major global public health issue. In 2015, an estimated 36.7 million people were living with HIV (including 1.8 million children), which corresponds to a global HIV prevalence of 0.8% (p. 2). As HIV-positive children grow up to become adults who seek to live well, prosper, and to engage in relationships with HIV-negative partners, they need new narratives that provide enriched opportunities and allow them and others to better understand their circumstances; this helps them live free of misunderstanding, discrimination, stigma and violence. The prevalence of HIV warrants an immediate response that uses knowledge and community building to support couples as they live with HIV over their lifetime.

In the first 10 years of the 1970's Canadian HIV epidemic, social workers were primarily engaged with men identifying as gay and with gay men's families and communities. Most social work support revolved around emotional events for gay male couples, such as death, dying, grief, multiple losses, financial crises, and care for sick and hospitalized individuals. Initially, it seemed that gay and bisexual men, as well as partners of intravenous (IV)-drug users, unknowingly found themselves in relationships with HIV-positive partners (Harmon & Volker, 1995). The lack of information regarding how the virus was spread, coupled with the relative certainty of death for the HIV-positive partner, left the HIV-negative partner in a fog of judgment and loss.

Because of the low survival rates associated with HIV at the beginning of the HIV epidemic of the 1970s and 1980s, it would be easy to assume that many sero-discordant couples did not get the time needed to experience the full impact of living with this now chronic disease. Twenty years ago, HIV-positive and HIV-negative partners mainly existed in the gay community, and HIV-negative partners only found out their partners were HIV-positive once they had developed symptoms of AIDS (Harmon & Volker, 2008). Social work services were primarily concerned with managing diagnosis-oriented crises, or with addressing concerns about end-of-life preparations; as a result, social workers came to know their clients through issues related to dying and the preparation for being widowed.

In 1996, the introduction of protease inhibitors in combination with reverse transcriptase inhibitors (Highly Active Antiretroviral Therapy, or HAART) resulted in significantly reduced AIDS mortality rates (Beckerman, 2002). With the introduction of HAART, HIV went from being a death sentence that brought grief and suffering, to a medically-defined chronic disease that could be managed across a patient's protracted lifespan. The emotional issues of sero-discordant couples changed into "how ongoing uncertainty has affected the identities and life ambitions of both—their choices around work, career, friendships, children—and changes in the epidemic forced them to reinvent themselves and their relationships together" (Beckerman, 2002, p. 504).

As social narratives developed and HIV-positive partner stories emerged, these stories were sometimes overshadowed by larger, socially constructed narratives that stereotyped people living with HIV and emphasized the dangers of having a relationship with someone who was HIV-positive. Many sero-discordant couple narratives were not heard due to social barriers such as biased health protocols, insurance rejections, lack of support to live well as a couple, and uncertainty about whether it was safe to talk to others about their HIV-discordant status.

Not only did sero-discordant couples have to work through concerns that affect all long-term partnerships (e.g., general life transition issues); they also had to deal with the fear of HIV transmission, coping with uncertainty of potential illness, shifts in emotional and physical intimacy, and dilemmas regarding how HIV might impact their reproductive well-being (Beckerman, 2002). As HIV has changed into a diagnosis of a *chronic* disease, it has become important that couples find some sort of acceptance of their new reality as a sero-discordant couple and talk about what co-existing together means (Persson, 2008).

Persson (2008) further discussed that both sides of serostatus are legitimate, and that both people deserve equal recognition, when developing a relationship and seeking to understand the lived experience of a couple living with HIV. This information acknowledges how inclusive recognition of each person's experience needs to be acknowledged as interesting and informative, while not being prescriptive nor determinative of the importance of one rather than the other as they both cohabitate with HIV.

One study revealed that the most important issues to sero-discordant couples were the prevention of HIV transmission and the uncertainty that HIV adds to their life (Beckerman, 2002). Such concerns highlight the need for clinical practitioners, social workers, psychologists, and other support persons to be equipped with tools and techniques to reduce bias and build professional capacity to empathize with the persons living with HIV. Seeking to empower clients around communication, while helping them to build dialogues that allow for the open discussion of issues relating to sexual intimacy, sexual health, emotional well-being, emotional merging, and trust within the couple's relationship becomes paramount as they uncover their relational truths.

Relevant information (which includes all new knowledge) as socially constructed by the couples can inform practitioners of the contemporary and changing needs of sero-discordant couples. Through qualitative, semi-structured interviews, Persson (2008) found that the following issues are informative to our understanding of the experience of couples living with HIV: prior knowledge of HIV; impact of HIV on everyday lived experience; disclosure and impact; stigma and discrimination; relationships, intimacy and sex; family and children; social connectedness; and contact with services and with other HIV-positive people. From the lack of current research, there appears to be a multitude of couples' concerns within the sero-discordant couple's experience that have had little exploration, critical inquiry, or active dialoguing, devoted to the social construction of self, couple, world and HIV to date.

Current sero-discordant couples' issues situate within dominant social discourses of contemporary times – medication adherence, safe sex, aging, and other concurrent mental and physical health issues – while still being submerged within the historical social phenomenon (HIV diagnosis and preparation for death) that came with the AIDS epidemic of the 1970s and 1980s. As Gergen (2009) has discussed, the potential of constructionist dialogues, to co-create the future and bring a new understanding about people in general, would allow this community of sero-discordant couples narrative space to generate a new understanding of their lived experience, firstly for themselves. There is a lack of social representation for couples living with HIV, due to the silence and shaming within the social stigma of living with HIV. The sero-discordant couples in the research project required a formal opportunity for gatherings that would generate conversations, as well as multiple

conversations to undo the socially structured, relational patterns that had systemically reduced their self-determination. These opportunities allowed them to define their own needs and understandings, beyond medical and social prescription.

### **Background and Purpose**

Working within Alberta Health Region as a social worker at the Southern Alberta Clinic gave me access to a plethora of stories that wove themselves through the professional-patient relationship that we developed under the umbrella of medical care. The lack of understanding of the sero-discordant couples' experience was of great interest to me due to the invisibility of partners, except when they joined a medical session and were extremely grateful to be included. After these medically-oriented dialogues with sero-discordant couples, I would formulate questions in my mind about what their experience was like as they wove themselves through the day-to-day fabric of our society that is biased and infiltrated with social stigma against those who live with HIV and those who love the HIV-positive person.

These brief encounters challenged me to bring the unspoken into the spoken realm due to what Gergen (2009) describes as bringing understandings that would open up new paths. Opening new pathways of understanding could bridge qualitative research understandings and therapeutic support work in the larger helping professions, as the new information would prepare the platform for generative dialogues between sero-discordant couples and professionals who provide therapeutic support and general care.

Wanting to create open working relationships with the sero-discordant couples' community, I began to envision a participatory action research project that applied a post-modern feminist theoretical lens. I sought to ground my ideas and curiosity in a theoretical framework that would encourage me to invite in voices that had not been heard. Post-modern feminist theory provided the impetus to invite in people who had not been visible and to understand their experience of living with HIV. The politics of interpretation and representation are particularly vexing for feminist researchers because they so often hope to empower the people they study and to improve the conditions of their lives within a social landscape that denies them the right to do so as discussed by Bulter (1988) and Kirsch (1999). The process of trying to create a safe space for sero-discordant couples to co-mingle with each other through generative dialogues would be perplexing due to the intensity of stigma and the prevalent issue of confidentiality that co-existed with the medical issue of HIV and a positive status.

The gathering of sero-discordant couples would bring an opportunity for social change by giving these couples a chance to gather, dialogue, and decide whether or not to take on action, while being heard as a legitimate voice on their experience. I started to develop a research idea that fit particularity well with a participatory action methodology in order to give sero-discordant couples a chance to define their own agenda. The opportunity to gather sero-discordant couples arose at the Southern Alberta Clinic where I was employed as a social worker, and was supported by its Clinical Director, Dr. Gill. PAR as a research methodology was true to social work practice, as it would empower the couples to define what they needed versus being researched and further oppressed through expert-driven methodologies; concurrently, disenfranchised by the knowledge that they represented.

Given that there had been little opportunity for sero-discordant couples to tell their stories and clearly identify their unique experience, I had a sense that the couples would need multiple gatherings to shift discourses and understand their own individual and collective experience of living with HIV. I had worked with this community of people through the clinic for approximately five years and had not clearly understood the sero-discordant couples' stories. Was this because I had not paid attention? Perhaps the medical system had not scheduled regular appointments with couples because of a bigger social issue related to stigma? Were sero-discordant couples seen as less understood and not needing couples support as they navigated the lived experience of HIV? My sense was that all of these factors had contributed to my impaired understanding. It was the latter issue, however, that evoked my interest in constructing a research methodology that would reduce barriers, increase participation, and allow for empowerment of this invisible community of couples.

For more than twenty years, I had engaged various forms of social work practice to understand and address the diverse forms of societal oppression that people might face due to difference. Through social work practice, I learned that many groups of people do not have equal access to resources and they live in an inequitable world where some are privileged and others are not. Many groups of people face barriers such as social stigma, racism, sexism, classism, ableism, ageism, homophobia, and the many other forms of social injustice. These barriers become layered onto peoples' experiences and lives as they are deemed different from those who hold dominant status and control the discourse and resources with which others live.

It was this process of working closely with the larger HIV medical community, and my own curiosity to understand the stories of this group of couples, that led me to seek a new way to look at stories (or the lack thereof) through a social justice lens. As I found myself deeply connecting with the primary ideals of social constructionism that invite us to rethink everything that we have been taught or not taught, I felt compelled to relate to these couples and to understand their stories. I not only wanted to understand their stories, but also why they did not have a dominant health story like other couples facing chronic illnesses such as cancer, kidney disease, and heart disease – all of which are served by the same medical system as HIV. I suspected that there were many reasons why the sero-discordant couple story was invisible and I wanted to understand the “why” and the “what”.

In the seven years that I worked directly with the HIV medical community, I worked alongside various professionals who were actively engaged in caring for this community of people. Their commitment to direct medical care was outstanding. People overcame medical crises because of the rigorous work of these medical professionals, the advanced medications that were available, and the ongoing research to understand how to improve the quality of medical care to HIV-positive individuals. The research done at the clinic focused on direct medical care and the ongoing advancement of treatment. We did develop an interpersonal violence screen that became a mandatory screening tool to reduce the impact of IPV on the lives of persons living with HIV. However, this screen was the closest that we got to hearing their story of living with HIV; it did not go beyond acquiring quantitative data on adherence, reduction and the identification of IPV in their lives.



The process of wanting to relate to the rich descriptions of the social world of sero-discordant couples goes beyond quantitative research that aims to be nomothetic (i.e., generalizable to a broader population) and is immune to the unique narratives of the everyday social experiences of people. Qualitative research as described by Leavy (2009) “is a process of composing, orchestrating, weaving rather than gathering data and writing a summary” (as cited in Gibson, 2012, p. 30). The opportunity to facilitate a meaning-making process, within a series of gatherings for couples who were seeking to be heard (through relational discussions about their lived experiences with HIV) was true to the process of qualitative research.

Frustrated by the medical research focus from a nomothetic perspective, I pushed forward with the development of a PhD research project that sought to unveil and understand the narratives of sero-discordant couples. After careful consideration of the deficiencies in sero-discordant discourse, I decided that I wanted to shift the quantitative medical research agenda to one of qualitative research. I sought to understand the narratives that were submerged under the dominant medical story of number of visits, demographics, adherence, lost to follow-up, hospital admissions and death. Dr. Gill accepted this new direction, and immediately I began to develop a rigorous process that would introduce the qualitative research project to the Conjoint Ethics Committee (CHREB) at the University of Calgary, the appointed committee which held the authority to accept or deny the research.

Awareness regarding the potential disclosure risk and the rigorous commitment to preventing harm was paramount in all steps taken in developing the sound academic process surrounding my participatory action research. The couples made an informed decision to disclose their HIV status by committing to being participants in the gatherings. The risk of engaging in the research process was of the utmost concern to the ethics committee; they were concerned about undue harm that might come to participants through disclosure of their HIV status in research gatherings, and about the lack of guaranteed confidentiality.

Seeking to engage a theoretical framework that addressed the perplexing issue of confidentiality, it became of primary importance to my research proposal to invite a group of sero-discordant couples to gather and dialogue about their lived experience with HIV. Post-modern feminist theory called me to action to unpack the unknown parts of the sero-discordant couples’ story, while also allowing for discussion of issues related to disclosure, risk and confidentiality – the primary concerns that have plagued all policy and action related to people’s HIV positive status in the Alberta Health Region. In this context, the couples would have to be the experts in their own decision-making, holding the tension of entering into the research or choosing not to engage the research. Their participation or lack thereof was not a decision that I would make for them. As stated by Kirsch (1999), the feminist theoretical lens invites its users to sit within the vexing practice of not being an expert on someone else’s life and notably invites the user of this lens to seek new understanding, ideas and knowledge about oppressive situations for action and further research. My role was limited to inviting couples to participate in the research; it was up to them to decide whether the benefit of sharing their story with others would outweigh the risk of disclosure.

PAR methodology became a primary choice for this research process because of its ability to allow a collaborative research agenda that would invite participants to

become co-researchers in the research process and define their action agenda. This transformative art of researching was key to exploring the lived experience of sero-discordant couples' because their marginalized stories were not visible due to the dominant medical discourse and larger stigma-infused social discourse. Co-creating a research experience with the participants themselves challenged me as the lead researcher. My lack of definitive control further detracted from my expert stance, as I did not have expertise on the primary experience of living with a HIV diagnosis. PAR as a research methodology would challenge the professional status that I had experienced as a social worker at the clinic. This methodology would ask me to step into a researcher role that would define itself through a collaborative relationship with the participants as they sought to empower themselves through the initial gatherings.

As I further understood the politics of doing research, it became integral to my research practice that I be reflexive. Nancy Scheper-Hughes referred to this role as the cultural self, and described it as something "that all researchers take into their work (1992) [which] is not a troublesome element to be eradicated or controlled, but a set of resources" (Olesen, 2005, p. 250). The act of reflexivity invited me to be an active participant in the co-construction of the new knowledge, while acknowledging my limitations around understanding the participants' lived experience with HIV.

The cultural self is the identity that the researcher herself brings into the research process. The meaning of the research participants' stories would challenge my own social experience as a heterosexual, HIV-negative female who had never had an intimate relationship with a HIV-positive person. This lack of lived experience being HIV-positive or being in a sero-discordant relationship automatically meant that I was less knowledgeable as a participant in the gatherings and the larger research project. In the initial gatherings, I had to accept that I was an outsider – a participant that would have a limited role in shaping the collective dialogue about what it is like to live with HIV.

Gergen (2009) used the word "co-action" (p. 97) to describe the basic constructionist premise that the world becomes meaningful in relationships. I considered reflexivity, with its inherent nature of reflection, as important in co-mingling with full awareness of my lack of personal knowledge about the lived experience of being HIV-positive. This brought co-action into the research process, allowing me to create meaningful relationships with the participants. Co-action included stepping into the relational-research arena with sero-discordant couples, a relational-action that allowed participants to build relationships as they developed their dialogic agenda. The couples themselves dialogued and I witnessed, which I assert was a response-based action that was integral to the overall empowerment of the participants as they sought to occupy an expert stance on their lived experience. I choose to play a less vocal role, due to understanding the systemic oppression that the couples had experienced. The couples would vocalize their needs and be the experts on their lived experience in order to break the legacy of HIV-infused oppression.

I had to situate my lack of knowing and choose to respond to the greater collective commitment to bring to fruition a participatory research project that would create a collaborative agenda to move new knowledge into co-action with the co-researchers (i.e., the couples living with HIV). True to PAR methodology, co-action was to happen naturally through the series of gatherings, whether the participants chose to pursue a formal action agenda or to end the process after the initial gatherings. I was also aware of

the blurred action boundaries that can arise between the researcher and the researched when a PAR agenda is set and all committed parties act upon it.

I was naïve to the radical change that would come from immersing myself in a community of sero-discordant couples as they shared their fundamental human experiences and their experiences living with HIV. Social constructionist thinking helped me bridge the many layers of human experience that I encountered; it allowed me to relate and knowledge-build in order to pierce through the social-relational dynamics that had historically rendered this group of people as stigmatized, silenced, and socially disempowered. Social constructionist thinking gave me a social-relational cognitive construct in which to situate and develop the participatory action methodology. This methodology provided a way of creating social action through relationships, which in turn empowered a displaced community to find their social position by bringing their experience forward into authoritative voice. Postmodern feminist theory fit philosophically with the social constructionist paradigm of thinking because it brought in displaced voices through relationships that would foster understanding and active inclusion of their lived experience.

### **The Writer within the Written**

One of my goals as a postmodern feminist researcher was to ensure that there was validation, support and recognition of sero-discordant couples' voices as authoritative. As a postmodern feminist researcher, I wanted to empower a community of people that seemed to be invisible, in that their individual and collective stories rarely entered the public arena beyond a therapy session or a regular medical appointment. The unspoken had become the new normal for this group of couples, and social stigma had rendered them unworthy of having their story validated. I related to these couples as someone who had grown up poor in a motherless family and who had struggled with the harsh reality of life. Often, the narratives of those who are underrepresented in society become submerged under the dominant story of those who appear to have greater resources, ideas and socially constructed aspects of their being (e.g., educational or class status).

During my Bachelor of Social Work degree, I took some women's studies courses. I learned about postmodern feminist theory and earlier feminist writings, like Virginia Woolf's "A Room of One's Own" (2011), which taught me that "my" life had meaning beyond the socially scripted identity of being a poor woman who would face too many barriers to live an empowered and meaningful life. My knowledge of postmodern feminist theory has enabled me to pay attention to that voice which is most dominant and to understand why. Over time, I learned that my voice was important. When engaging in academic work, I recognized the value in externalizing the oppression that I had internalized from dominant social discourse and its associated structural oppression. Ultimately, facing my own self and deconstructing the dominant stories that sought to define me brought a deeper purpose to my own life and writings.

### **Witnessing Self Within the Written**

As a postmodern feminist researcher, I have learned that knowing my own social location in this research and sharing the marginalized experience based on class and gender has given me some perspective on the marginalized experience, which I call the “submerged self.” As I listened to the submerged personal stories of sero-discordant couples – and noted their need for a safe and dedicated process to continue their conversations – my personal perseverance was ignited to support the sero-discordant community in Calgary. Their personal narratives became a political project for me, and so I began this doctoral research to help them become visible by allowing a space for them to narrate their own stories, and, in turn, deconstruct the historical legacy of cultural inequity regulated through the dominant medical, social, and legal histories that have oppressed them.

Throughout the research process I had to continue to fight for the worth of its content; within PAR methodology, this is referred to as a social-academic fight in which science opposes science in action. The traditional social sciences are often at odds with PAR, which seeks full engagement of participants in sociopolitical changes. PAR liberates research from its conventional practices and embraces the act of social engagement and change (MacDonald, 2012; Marshall & Rossman, 2006; McNiff & Whitehead, 2006). Experienced with overcoming barriers, I was able to accept multiple rounds of academic rejection and become introspective. With the help of my dissertation supervisor, Dr. Wulff, I was repeatedly able to reengage my academic process and push forward with this important research.

The potential for new knowledge to be developed by the sero-discordant couples’ community reflected science in action, and was a form of sociopolitical action for the larger HIV community and the profession of social work. As noted by Maguire (1987) and MacDonald (2012), PAR requires a cyclical process that simultaneously engages critique and challenge of dominant social sciences research processes as the only legitimate and valid source of knowledge. The resistance to PAR methodology as an appropriate and scientifically rigorous approach was a good indicator of the structural oppression that housed quantitative, academic research processes within the primary health care system.

### **Dialogue Within the First Relationship**

In my social work practice within the Southern Alberta Clinic, I heard multiple dialogues in therapy and in the initial couples group of 2009 that indicated that sero-discordant couples were struggling to be heard and to have their voices validated as important. My recognition of these oppressed voices led me to passionately pursue a doctoral research project on behalf of this collective group of oppressed couples. Gilbert (2001) described this process, where qualitative researchers aspire to uncover the world through another’s eyes through discovery and exploration, as one that is deeply experienced.

Once the sero-discordant couples asked for more space to talk after the initial couples group, I knew that I could not choose to ignore them. They inspired me to be a co-researcher within a PAR process, as they needed someone to begin a process that would eliminate their sense of isolation. I knew that the research methodology had to be

rigorous enough to be accepted as an academic research project, and humanistic enough to overcome the isolation and stigma that marginalized this group of objectified people.

The postmodern tradition within research allows for shared realities and multiple experiences, and it embraces a dialectic shifting of understandings, whereby objectivity is not a reasonable goal (Kelly, 2005). In this research, no single story adequately represents the sum of all the research participants' stories. Instead, this thesis weaves together stories that highlight the diversity, adversity, diversion, and aversion of understanding that resulted when couples from all sexual orientations, ages, cultures and class backgrounds came together to discuss their experiences of living with HIV (whether newly diagnosed or having had longer-term discordant status).

The primary goal of qualitative research is to interpret and document an entire phenomenon from the viewpoint of someone else, and to understand the meaning that this experience brings to their day-to-day world (Creswell, 1998; Greenhalgh & Taylor, 1997; Leininger, 1985; Mason, 1997). Couples were chosen to participate in this research based on two inclusion criteria: they were people living with HIV, and they were in an enduring relationship of at least one year. The primary goal of this qualitative research project was to understand the experience of living with HIV.

### **Diversity as a First-Person Right**

As Sands and Nuccio (1992) explain, "Diversity is a special concern of postmodern feminists, who highlight/foreground/emphasize/insist on differences" (p. 492). My goal for this final dissertation document, as supported by PAR methodology, is that it should be a summary of all stories, woven with themes and words that represent the participants' experiences. This summary addresses the participants' significant differences in social location and offers a reflexive understanding of these narratives within the larger socially constructed experience of living with HIV. The social construction of diversity for this group of people is that diversity somehow brought them together around a common health issue – a positive HIV diagnosis. The HIV virus itself was not diverse, but the parameter of being a person living with HIV did invite diversity.

In the context of postmodern feminist theory, I functioned as a co-facilitator in creating a safe forum that allowed discordant couples to discuss their couple experiences of living with HIV. The interplay of a social constructionist paradigm, which allows for exploration on how lived experiences are produced and reproduced in relationship, and the development of a participatory action research project that followed postmodern feminist theoretical principles, aligned with what social constructionists call being a multi-dimensional being (Gergen, 2009). My current understanding is that a multi-dimensional being is able to intersect the layers of discovery that occur when we accept a paradigm of thinking, to incorporate this knowledge into a theoretical framework that guides our thoughts, and finally to act through a methodology. This series of steps invites us to move beyond the ordinary thoughts and actions of the day and make meaning out of multidimensional experiences that co-exist within the lived experience of being a sero-discordant couple.

Postmodern feminist theory invites me to be a medium of support, an engaged advocate, as well as a critical thinker to gather participant stories and put the unwritten into writing and the unspoken into some sort of formal action. Participatory action

research is intimate by nature, and requires that the community of participants and I engage in the research process as equals. Our relationship then takes on a “power with” stance rather than a hierarchical “power over” stance (where one person has greater say on another’s experience). Baum, MacDougall, and Smith (2006) state that “the process of PAR should be empowering and result in people having increased control over their lives” (p. 854).

This process of understanding and developing relationships with others is identified as important by Narayan, a researcher quoted by Bishop (2005):

What we must focus our attention on is the quality of relations with people we seek to represent in our texts: are they viewed as mere fodder for professionally self-serving statements about a generalized other, or are they accepted as subjects with voices, views, and dilemmas—people to whom we are bonded through ties of reciprocity. (p. 672)

The research relationships that are shaped through the relational dynamics of community research practices require constant reflection by the researcher, who is committed to relating to her participants as relational beings that will provide their own stories. The participants bring their own understandings and their own reflective processes, and simply need a safe space and fluid structure in which to act. It is important not to impose too much systemic structure so that the participants are viewed as people in their own right. The research relationships are a form of social action – a ‘doing with’ as described by Gergen and Gergen (2003). The generative discourse that develops from these relationships represents a step towards radical social action.

### **Diverging Truths**

Postmodern critique as explored by one of the leading postmodern thinkers, Michel Foucault, emphasized the inadequacies of metanarratives and the need to examine the specificities of power and its relation to knowledge (Marchand & Parpart, 2003). Through an exploration of local and ad hoc narratives, we sought to support the participants to create discourse that would challenge the notion of universal knowledge, while at the same time committing to social justice. As a postmodern researcher, I recognized that: “There can be no objective standards of truth or morality, because there is no distinction between the external world and what’s in our mind” (Rubin & Babbie, 2005, p. 36). I acknowledged that being a subject rather than an object would be key to allowing the research participants to come to their own understanding of their lived experience and to develop alternative discourses to explain their reality.

After consultation with the sero-discordant couples as group members in initial gatherings, it became evident that they felt invisible, both individually and collectively. They perceived the virus as being more important than their existence and its impact on their lives. The advancement of HART medication had given these couples the time to create lived experiences that reflected a different truth, one that was no longer marked by fear and death. Instead, these discordant couples share other common truths and engage in their lives in common spaces: schools, restaurants, public service realms, policy arenas, health care facilities, and various spaces that provide resources that support day to day living.

When people are diagnosed with HIV, they must face the socially constructed stigma that accompanies the disease and figure out the meaning of their personal story. At times, these people are forced to own a dominant discourse, a medical discourse, or a stigma-infused discourse, until they construct their own script and externalize their oppression enough to allow for authentic identity reconstruction. These discourses, such as medication adherence and non-compliance status, relegate the person living with HIV to a good or bad status through medical dialogue and service pathways. Denial of the opportunity to donate blood out of concern for infecting others brings an inherent structural stigma that further magnifies the intentionality of medical discourse to exclude those who live with HIV. The collective response to the dominant medical and stigma-infused discourse, which is perceived to be socially important, is to assert power and control mechanisms in the larger medical system through public health legislation; the system seeks to find and charge those who do not adhere to the regulations of the medical system for the greater good of society.

The couples in this study did not feel acknowledged within the experience of HIV primary care, nor did they feel that their voices mattered in academic literature. There seemed to be a collective sense that they were not heard and an understanding of themselves as separate, unique individuals. Through this research, I had the opportunity to hear and document their experiences as they chose to disclose them. We dialogued together about their world of relevant concerns and co-constructed a plan for social co-action and change. This process was led by the magnetic couples themselves as they empowered themselves through dialogue, creating a space that would allow for the exploration and emergence of multiple, previously silenced truths and the generation of new, valuable knowledge.

### **Phoenix Rising: Silenced Truths Must Emerge**

Postmodern feminist theory deconstructs the layers of oppression experienced by groups of marginalized people. Social stigma around HIV and AIDS, and its attending oppression, has marginalized sero-discordant couples' needs, experiences, and personhood. As a result, their personal authority has been diminished, and their right to have and make choices relevant to their couple identity has been limited. From a postmodern perspective, "everything is subjective; no points of view about reality are superior to others" (Rubin & Babbie, 2005, p. 36). A postmodern perspective in social work practice creates a space for voices to be heard, needs to be acknowledged, and sero-discordant couples to be validated as identifiable couples with powerful stories that deserve to be understood.

Postmodern feminism is highly compatible with research in the social work fields and with a social constructionist paradigm; "it recognizes the diverse constitution of client populations and their unique needs" (Sands & Nuccio, 1992, p. 292) while seeking to relate to the experience of the client through relational dialogues. Furthermore, the use of deconstruction, which unravels the power relations of knowledge within relationships and uncovers the suppressed voices of a marginalized population, provides a means through which social workers can work in concert with client groups to promote social co-change. Social action and change driven by those who are most marginalized by stigma may bring truths that have not been heard before, as well as change to systems and

social norms that keep people caught in an invisible state where dominant discourse defines their being.

Postmodern feminist theory allows for a construction of a new discourse and a deconstruction of the dominant ideals that are, “shaped by class, race and other historical forces and how these are disseminated through ‘discourses’ that are structural and symbolic” (Olesen, 2005, p. 246). The collective dialogues and new discourse fit within the theoretical framework of postmodern feminist theory, and in turn allow the social constructionist paradigm to co-exist with postmodern feminist theory. A social constructionist paradigm is a philosophical lens that invites relational dialogues to be at the center of knowledge expansion (Gergen, 2009).

Postmodern feminist theory is an ally of the social constructionist paradigm. It focusses on inviting in voices that have not been heard, it reconstructs relationships, and it undoes historical dogma; giving power to relational dynamics becomes the priority. As couples dialogically collaborate while remaining within their own experience, they relate to each other and share their collective story without giving up their unique voice. The interplay of postmodern feminist theory and social constructionist paradigm invites the “unique” story to become visible and the relational dynamic to become an important framework of discovery. If the relationships are aligned with a postmodern feminist stance, the relationship dynamics will be saturated with the “power with” stance where no one identity dominates another.

The postmodern feminist theoretical framework allowed for the generation of new knowledge within this PAR research project. Together, these frameworks engaged the client population in initial gatherings and discussions, while shaping future co-action agendas. If any imminent issues were brought to the table and were of significance to the larger community of participants, then these issues were subject to follow-up discussions, further research, or co-action. Sands and Nuccio (1992) state that “the linkage between theory and practice (or ‘praxis’), with the demands of practice (everyday considerations) predominating over theory, distinguished postmodern feminism from postmodernism” (p. 492). Generative and inclusive dialogues have the potential to identify the need for, and subsequently to provide, other general health resources that sero-discordant couples need.

### **The Awakening of an Oppressed Personhood**

PAR is also referred to as the “enlightened and awakened of the common people” (Fals-Borda & Rahman, 1991, p. 4). PAR has the potential benefit of being an action-oriented process that allows for praxis in action to be a mutual inquiry of significance in social-relational exchange; it invites discordant couples into a community of people living with the confounding and compounding reality of HIV. The “in action” was a paramount social engagement that required all couple participants to bring their relational understanding of the lived experience of HIV into the collaborative dialogues of the gatherings.

Through the gatherings, differences in the lived experience of HIV were supported by guidelines of respect, while potential conflicts of perspective were seen as important in order to gain a better understanding of the various experiences of HIV and its meaning to couples’ lived experiences. In some cases, the in action inquiry instigated an emotional upheaval, leading couples to recognize that their differences were unique;



these couples decided that did not want their diverse voice to be integrated into the collective story. The unique structure of PAR methodology allowed the science-in-action format to support each of the participants' unique needs and to hear each and everyone's experience. At the same time, it created an active forum for storytelling that carefully considered context and relational dynamics, allowing participants to maintain their dignity in the midst of diversity.

PAR is considered a significant player in community-based research. Briefly, Israel, Schurman, and Hugentobler (1992) describe PAR as:

- participatory;
- cooperative, engaging community members and researchers in a joint process in which both contribute equally;
- a co-learning process for researchers and community members;
- a method for systems development and local community capacity building;
- an empowering process through which participants can increase control over their lives by nurturing community strengths and problem-solving abilities;
- a way to balance research and action. (p. 77)

The process of participants being co-actors in creating new knowledge within the framework of relationships (i.e., marriage and companionship) gives merit to all primary components of PAR methodology, postmodern feminist theory, and a social constructionist paradigm. It is a merged experience that allows discordant couples' personhood to be valued as they are invited to disclose their lived experience together and yet maintain the multiple dimensions that confound their existence with HIV and its significance in their lives (separate and together).

### **Knowledge Built by Whom?**

As noted by Foucault (1982), power is developed through knowledge-building; all people exercise power, albeit in different ways. Power is a relational dynamic that can only exist in relation to another. The hope was that the merging of new, unique stories would provide new knowledge that would empower couples as they built their narratives. Knowledge that is socially constructed by those who have an expert or social-cultural notion of those groups which are more susceptible to HIV infection can be oppressive (e.g., it can influence immigration status and access to health and intervention resources). According to Foucault (1994), "what defines a relationship of power is that it is a mode of action that doesn't act directly and immediately on others. Instead, it acts upon their actions: an action upon an action, on possible or actual future or present actions" (p. 340). The way in which people are spoken about as "other" in the media and within academic circles results in the marginalization of people's personhood and impairment of their right to define their authentic identity.

Postmodern feminist theory can challenge the oppression within personal, social and cultural domains by making the personal political, and by deconstructing knowledge and de-pathologizing difference in order to allow a safe space for narratives to be received and respected for their unique perspective (Besley, 2002; Brown, 1994; Dietz, 2000; Sands & Nuccio, 1992; White & Epston, 1989). For the community of sero-discordant couples, the process of de-pathologizing difference is important because the

medical profession has held power over the HIV story, which has primarily emphasized that HIV is a disease from which the partner should be protected.

Persson (2008) has argued that, “perhaps more than any other contemporary disease HIV/AIDS has served as a powerful signifier for a range of cultural anxieties around ‘otherness’ and invasion, sexuality, and deviance, contagion and death” (p. 238). For the sero-discordant couples being brought together to experience some sort of oneness—while recognizing their diversity and unique experiences specific to their induction of HIV—an action-oriented research process may be potentially cathartic and empowering. Up against the odds, the research project prevailed – gatherings were constructed within a system that denounced its validity, space was created, and participants’ voices and stories were recorded as valid data which was an accurate reflection of their constructed narratives. Young (2006) identified that one of the most frequent criticisms of PAR is that it is a “soft” method of research. However, social justice was embedded in every step of the project; postmodernism invited critical processes to this research in order to provide a space that valued alternative forms of knowledge (such as emotions, imagination, and experience) (Neuman, 1997)

Ultimately, this research project transformed into a two-stage process that was defined by the participants themselves; not only did it support research and knowledge-building – it also became an active peer-support group for couples, companions, and those interested in having a sero-discordant relationship. The larger HIV community has funded the group, which is now recognized as a valuable way to support their members living with HIV. Sherman, Mosier, Leszcz, and Burlingame (2004) discussed how cancer and HIV are the two medical conditions in which group support is scientifically proven to be essential to a patient’s well-being.

Some of the additional benefits of support groups for persons living with HIV are those of reduced isolation, decreased depression, improved coping strategies, an increased ability to adjust to the health and social concerns, and an increased adherence to pertinent medical/social resources (Walch, Roetzer, & Minnett, 2006). The power of the peer-support process provided an ongoing space for the couples to meet monthly in order to support each other to live well and sort through the many active facets of their lived experience. It also provided participants with additional health benefits that continue beyond the group meetings.

This research project was designed to help the community identify the resources needed to support, sustain, and allow for a further understanding of the merging of contemporary issues with the underpinnings of historical HIV/AIDS care. PAR offers a radical alternative to knowledge development – it provides a collective, self-reflective mode of inquiry aimed at improving the conditions of a community or a marginalized group of individuals, whom have invited in some sort of change (Koch, Selim, & Kralik, 2002). This radical research approach has the people resource power to bring change to the community itself, as well as to the researcher in her many roles.

This chapter has presented many aspects of my process as I sought to connect my journey with the HIV community. I have aimed to highlight the desire for sero-discordant couples to gather, to be heard and to be understood in the context of their experiences of living with HIV. I have also aimed to describe the approaches that I took to understand the needs of these couples. The next chapter presents the various theoretical and academic frameworks that I drew on to inform this work. I will provide a theoretical

perspective that situates this research within theory and knowledge that supports the process of participatory action research and social constructionism. After presenting a theoretical and philosophical grounding for my work, I will describe the action-oriented process and the work that was done with this resilient community of people living with HIV.

**CHAPTER TWO: CONTEXTUALIZING OUR RESEARCH AMONG THE  
AUTHORITATIVE STUDIES THAT HAVE DEFINED THE SOCIAL  
LANDSCAPE OF KNOWLEDGE BUILDING**

“It is the meaning we make out of our experiences that defines both who we are, who we ultimately were, and who we will become and this has the potential to redefine our world.” (field notes, P. Miller, 25 February 2012)

## THE OVERVIEW OF LITERATURE

### Conjoint Experiencing: The I & Professional Affiliations

I will reflect on my professional self as it is deeply embedded in my writing, while hopefully not dominating the collective process of research and knowledge building. As qualitative researchers, we are situated in frameworks of understanding and practice. Davidson (2004) has discussed the paradox of qualitative research: the researcher reaches feelings of empathy and emotional resonance, yet also experiences the vulnerability of distress from the client population's expressed duress. In engaging PAR methodology, I mentally held a frame of reference that brought me somewhere between the paradox of empathically relating to the stories of the sero-discordant couples and being a co-researcher. Similar to my role as a social worker (although as a social worker, I am required to be more therapeutically responsive than in my role as a researcher), reflexivity as a researcher allowed me to sort through the blurred boundary between co-researcher and co-leader.

Qualitative research is often not viewed as an authentic style of research. This can, at times, be politically challenging when academic audits and authoritative voices fail to recognize the good that comes with community engagement versus expert knowledge production. Davidson (2004) describes that the qualitative researcher weaves through the ethical complexity of working with populations of vulnerable and disadvantaged people whose experiences can invite us into an abyss of emotional response and potential risk of our own emotional anguish. Engaging populations that have lived marginalized lives can transfer feelings of powerlessness to the researcher; alternatively, the researcher may counter-transfer their own marginalization, and a plethora of emotional discord may arise for the researcher.

To prevent burnout or a lack of awareness related to their experience, the researcher must recognize the need to share its impact – either with supporting colleagues or by writing down their internal processes so that they are externalized. A standard debrief protocol has not yet been created. Tenets of an informal process would be discussion with external advisors, written notes shared with trusted academic colleagues, or debriefs with supervisory teams and other PhD students who might be experiencing the same sense of isolation and emotional countertransference.

Gibbs (2001) has explored the changing nature of social work research by analyzing the influence of the wider economic, political, theoretical, and practice changes that are occurring in social work practice and research. This movement within social work practice, and specifically in social work research, is clearly influenced by the sociocultural needs of a larger society. Gibbs has noted that present-day research practice standards and processes are quickly being impacted by the global issues of oppression and bias. This force, which ebbs and flows with some momentum, is shifting the paradigm of research from taking a “power over” stance to a “power with” stance, and creating a “co-empowering” movement.

Gibbs (2001) also noted that the profession of social work has become less homogenous in its research practices and more open to postmodern theoretical movements, including feminist, anti-oppressive, and anti-racist theory. This movement is people-driven and no longer relies on a dominant researcher's voice. Any movement that

challenges the structure of traditional research (i.e., the research framework) that others will follow has the potential to bring social action and/or advocacy to those whose voices are marginalized and not heard. Research for social workers, as Gibbs noted, is becoming less ethnocentric and more inclusive of engaging multicultural perspectives, empowerment models of practice, and women-centered practice methods. This creates greater acceptance within the profession of participatory action research methods that engage community members as co-researchers. PAR creates pathways for diverse experiences; marginalized people telling their own story while defining their action agenda provides a movement outside of ethnocentric and/or traditional Eurocentric expert-driven methodologies.

### **Action Research: Does it Have Merit?**

It is important to acknowledge that participatory action research is sometimes not seen by the scientific community as having merit. But why is this the case? Traditionally, research legitimacy has been established through numbers to secure funding for research purposes in hard science research. For example, the Southern Alberta Clinic received funding for research into pharmaceutical driven drug testing and HIV virus suppression. Downie and Cottrell (2001) have argued for the importance of recognizing that community-based research is not only conducted for the sake of new knowledge, but for the purposes of finding a practical solution for an identified need. The authors further elaborated the differences between community-based research and research that is linked formally to universities or hospitals. The top-down research approach that is engaged by universities and hospitals brings expert opinion, but does not incorporate the action component of PAR (although the research can be used for action); alternatively, the collaborative development process of PAR includes the community and its members. There is a need for community-based research resources because research within the community seeks to provide an equitable counterpart to university-based research (Downie & Cottrell, 2001).

Downie and Cottrell (2001) discussed how the community-action component of research brings a co-constructed, collaborative dialogic process to its members, who ultimately build knowledge that is more responsive, accurate, and representative of the reality of the participants' lived experience and needs. Ethically, community-based research challenges practitioners to be present and mindful of their commitment to equality and equitable practice that engages community members and stakeholders, as well as develops knowledge that is not expert-led. The experts are those who voice their experience and share the action component of living with HIV, otherwise known as advocacy in action (living with HIV and overcoming social stigma every day).

The interplay of voices within the experience of HIV/AIDS might be one of the most prevailing factors that can break through the isolation that comes with living with HIV/AIDS (versus other chronic disease conditions). This stems from the diversity of experience that living well with HIV can bring across the lifespan. Kesby (2000) discussed how the benefits of participatory research in the context of HIV allows the individuals who are engaged in the research to become agents who have much to say about HIV/AIDS and have the experience of living with it. This bottom-up approach incorporates the views, needs, and ideals of those who are living with HIV, and allows

the constructs of their reality to share space while still giving an authentic voice and personal agency to participants. The participants become actively engaged in the research process and learn about the problems and strengths embedded within the lived experience of HIV as it socially interplays with social relations (both dominant and submissive, chosen or not) that are in praxis (the act of practicing ideas) with reflection and action as enacted within PAR.

There is also praxis (the realized process) within the action component of the research as it bridges and relays the expression, experience, and action needed to formulate new ways of living with the experience of HIV. Heslop, Elsom, and Parker (2000) showed how a participatory action research framework was used to present the concerns of emergency department nurses who had significant insight into how to provide appropriate and coordinated care for patients seeking mental health services. The authors discussed how the inherent process of using a PAR methodology allowed the nurses to be active participants in developing the research, running the focus groups to discuss the concerns, and implementing recommendations from the focus group into hospital settings. This action framework purposely blurs the line between the researched and the researcher.

Ochocka, Janzen, and Nelson (2002) have outlined how the PAR methodology allows for knowledge to be created (through participants' telling their stories) and community built (by collaborative commitment to relationship-building and co-action). This action-oriented process provides more potential for empowerment of the consumer/survivor (participants understanding their own needs and making decisions to participate or not), as well supportive relationships and a component of social justice. Their article highlights the values that are central to the research process in order that it benefits the consumer/survivor researcher (in this case, specific to mental health systems). These values have core principles about engagement, empowerment, and a building of knowledge that is driven by those who have the lived experience.

Ochocka et al. (2002) also discussed the importance of building relationships and identified this as being integral to the balance of power and control. These relational dynamics allow the participants (or the co-researchers) to know the people who are working on their behalf and to recognize the relationships that allow for power-with relational dynamics (in which participants would participate actively in knowledge construction). These dynamics foster co-empowerment of all people involved and encourage the development of an action community. Furthermore, Evans and Jones (2004) noted that the PAR researcher has multiple roles: ally, advisor, enabler, and, if possible, partner to the participants or users of the researcher process. The community of participants might be one of the most overlooked pieces of a traditional or scientific research project where the researcher is given priority, authority, and God-like status, which ultimately limits the contribution of the participants.

### **The Synthesis of Education, Action and Potential People Movements**

There is a human ecology that exists within every common human lifespan. Healy (2001) explained that PAR synthesizes investigation, education, action, and a potential personal political movement. She noted how practitioners of participatory action research emphasize liberating dialogue with impoverished and oppressed people, and merge power and knowledge. Healy's article highlighted the need for collaborative relations with each other and with the wider human ecology. Her work also invited participative approaches that merge various worldviews and foster a collective humanitarian quest to reformulate knowledge, and ultimately the lived experience, while shaping a history that remaps the direction of care, opportunity, viability (or destruction, if it is not done with equality).

Healy's (2001) critical reflections on PAR and its historical roots are consistent with progressive forms of social work—both situate the original causes of oppression in macro-social structures (such as those associated with capitalism). Second, PAR draws on the conflict theory position as identified by two sets of people: the haves and the have-nots. Third, the researcher and the researched are encouraged to develop an egalitarian relationship wherein power is shared. Lastly, PAR is intended to empower participants to take control of the political and economic forces that shape their lives, and to engage social action strategies, such as consciousness-raising and collective action. Collective action can be perplexing to those who seek domination and submission. PAR seeks to deconstruct the inherent patterns of power that control those who are trying to gain true identity within their experience. Within PAR methodology, the diversity of participants is an important element of attention, as HIV does not discriminate. Notably, the participants in this study came from diverse populations, which reflects the fact that HIV impacts all people (although some populations might be more at risk).

### **Participatory Action Research: Collaboration in Action**

Traditional forms of research sometimes lack insight into the lived experience of people living with HIV. HIV patients are often defined by their symptoms or other categorical data that describes their medical prognosis; consequently, patients become statistics that are entered into databases and numerically analyzed. Rempfer and Knott (2001) explored the idea that a lot of traditional mental health research has been conducted exclusively by professionals who have little experience living with a mental health illness themselves. As experts, researchers become knowledge developers – traditional research gives the researcher the dominant voice. Alternatively, PAR research methodologies allow participants to have a “voice” that is neither dominant nor passive, but one that is collective and that allows people to put forth communications that will provide structure for further thought, dialogue, and action.

Additionally, Rempfer and Knott (2001) argued that PAR methodology allows for research participants – who also function as co-researchers – to have the lived experience of a mental illness and to work collaboratively together. This creates a union, a movement that actively defines next steps, and potentially empowers the whole. In their final argument, the authors postulated that a PAR approach is advantageous because it increases the scope and relevance of the research by including many people with diverse



experiences, therefore more accurately reflecting the underlying knowledge that needs to be developed.

This idea of a PAR union is much more subjective than the authoritative approach of researcher and researched. The risk is that PAR will induce skepticism in those who claim that this approach is invalid or lacks reliability. When there is a union between the co-researcher and the participant who has the lived experience, validity is addressed as the authentic voice meets authentic action. Reliability is found in acceptance and encouragement of the community to be a community. This community is able to define, push back, re-develop, and ultimately reconstruct itself as it moves forward in the process together. At the same time, the community acknowledges that it is not homogeneous and strives to stay true to its diversity, which brings with it the greatest amount of authentic change.

### **LGBTQQ2: The Call for Greater Understanding**

LGBTQQ2 is an acronym that describes people who are lesbian, gay, bisexual, transgendered, queer, questioning or two-spirited. Lesbian, bisexual, gay, and transgendered persons are recognized as sexual and gender minorities who have unique health needs. This provides an opportunity to seek a greater understanding of the nature of these unique needs. Creating a safe space for discussion that allows the community to voice their needs is important as minorities become more visible in all domains of society. Mayer et al. (2008) described the crisis that is emerging around LGBTQQ2 health issues, and argued that clinicians and public health professionals must work to reduce the barriers that prevent LGBTQQ2 persons from receiving adequate health care. The authors articulated how the AIDS epidemic brought forth a discussion about the lack of appropriate health resources for the LGBTQQ2 community. Mayer et al. (2008) also referred to the Kinsey report, which discusses how sexual expression is important and must not be suppressed; otherwise, homophobia or other phobic expressions that extend beyond mainstream stereotypes of gender identity and sexual orientation arise. Homophobia or other phobic-oriented stigma create marginalization of these unique groups of people. A lack of HIV resources and other sexual health services often accompany this marginalization.

The article by Mayer et al. (2008) is important because it identified the LGBTQQ2 community as unique and dynamic, while arguing that the larger medical and public health systems should become more sensitive to their needs. The authors describe how the ethos of community activism, which was first stimulated by the feminist movement, helped challenge the mainstream thinking of male domination in health services. This activism formed from within the community. A partnership between the LGBTQQ2 and non-LGBTQQ2 communities has the potential to create space, bridge ideas, and reform health care systems and its professionals.

The initial AIDS epidemic primarily affected the gay, lesbian, bisexual and transsexual community; therefore, gay, lesbian, bisexual and transsexual partners became acute caregivers to their friends or partners. During this time of significant loss and trauma, these caregivers took on additional roles: as advocates for the development of more resources, as partners to medical professionals, and as activists working to highlight the unique needs of this population. A significant action-oriented movement was created by the LGBT community during the AIDS epidemic of the 1970s and 1980s.

### **Ageism and LGBTQQ2: A Perfect Storm**

There is a significant recognition of the marginalization and intersectionality that has occurred in the LGBTQQ2 community that, when merged with the social inequity of ageism, creates a socio-cultural storm consisting of social stigma and a lack of sensitivity to the unique needs of this aging population. Fredriksen-Goldensen, Hoy-Ellis, Goldsen, Emler, and Hooyman (2014) acknowledge that this aging population is not fairing as well in the areas of mental health and disability compared with their heterosexual peers. This socially constructed, arbitrary and interdependent relationship between age and LGBTQQ2 issues needs to be deconstructed. Moreover, voices that authentically represent the lived experience of this intersectional identity need to define the agenda for better access to resources for both mental and physical health care pathways.

Fredriksen-Goldensen et al. (2014) noted that members of the LGBTQQ2 population face increased barriers as they age, especially in regards to health resources. The authors speculated that the historical oppression and disparity that has plagued the LGBTQQ2 community intensifies as they age due to a dominant oppressive stance that exists for all people as they age (which stratifies the concurring oppressions). This perspective acknowledges the need for sensitivity and generative dialogue with sero-discordant couples. The transgendered population is at greater risk than other members of the LGBTQQ2 community; they must overcome many barriers when seeking health care resources and they experience the highest rates of victimization (Fredriksen-Goldensen et al., 2014). Although the transgendered population is known to create community support networks through family and peers, they are also recorded as being the population group facing the largest amount of isolation and loneliness. Living alone and being lonely becomes a risk factor for concurring mental health and other physical ailments.

Fredriksen-Goldensen et al. (2014) also discussed the concerns around aging and living with HIV for the LGBTQQ2 community. Within the next few years, there will be a wave of people living with HIV and identifying as LGBTQQ2 who will turn 50. This increase in survival can be attributed to the effectiveness of the medications used to treat HIV. Although this advance in treatment has positive implications, there are hidden costs to living longer. Aging HIV-positive LGBTQQ2 persons who experienced loss at the beginning of the AIDS epidemic must also face the intersectionality of being LGBTQQ2 and aging; aging increases their risk of being alone and being discriminated against, which may put them at increased risk for mental health concerns and/or victimization.

### **Uninformed: Transgendered Persons - "It's Not About What's Between My Legs"**

The merging of genders that comes when sexual identification blends biologically defined men and women into one status promotes something more diverse than man versus woman. Mallon (2000) described how an understanding of the destructive relationships that exist between transgendered persons and social environments focused on an "either/or" male or female gender constructions is integral to the process of developing practice knowledge when working with transgendered persons as clients. He emphasized the importance of understanding current and relevant knowledge that represents the lived experience of this diverse population group in order to practice with transgendered persons, amidst the social oppression that this population faces. Within the

social work professional literature, Mallon identified an urgent need to develop a more accurate, professional dialogue regarding practice knowledge to replace the existing, very circumscribed discussion of transgendered practice issues. Mallon has advocated for the social work profession to quicken their building of knowledge specific to the transgendered community and its relevant social issues. He challenges his readers to understand that contemporary social work practice needs to merge, transcend, blend, and blow-through un-diverse ideals – something that many people might struggle when trying to work with this diverse-marginalized population group.

### **AIDS: A Gay Man's Issue - The Emergence of Social Stigma**

Historically, AIDS, which brought significant loss to the larger gay community, was accompanied by the social stigma that HIV-positive gay persons were to blame for the illness. Courtenay-Quirk, Wolitski, Parsons, Gomez, and the Seropositive Urban Men's Study Team (2006) addressed the social stigma that continues to oppress gay men who live with HIV – a concern that has largely been overlooked. In their article, Courtenay-Quirk et al. (2006) identified important historical content to remind readers of the importance of naming the initial inception of the AIDS epidemic as “the gay-related immune deficiency” (p. 2). The authors identified how the stigma for gay men is different than it is for heterosexual men because it is a socially located perceived risk. Gay men who are HIV positive have also encountered social stigma from within the gay community, an experience that can increase their risk of depression and other mental health concerns (Courtney-Quirk et al., 2006).

Courtenay-Quirk et al. (2006) suggested that gay HIV-positive men who experience social stigma are more likely to engage in sexual practices that have non-emotional attachments (such as those encounters that occur in private sex parties, sex clubs, and other anonymous settings). The belief is that HIV-positive men seek sexual experiences that do not require emotional involvement in order to further protect themselves from the impact of social stigma (because the social stigma is also pervasive within the gay community). Oppression is stratified as structural oppression against gay HIV-positive men in how it is internalized and then acted out within the community through their interpersonal and sexual relationships (Courtney-Quirk et al., 2006).

### **Merging Social Constructivist and Attachment Theory: Couples & Affairs**

It is daunting to run a couples' group that seeks to blend the world of couples' lived experiences around affairs. Knowing that neither person can be the ultimate dictator of the whole of the couple experience brings many emotional dynamics when trying to support the couple to dialogue through their lived experience after an affair. Reibstein (2013) identified how a combined social constructivist and attachment theory approach can help in work with affairs. She made the case that a vulnerability to affairs derives primarily from pressures on partnerships stemming from the dominant discourse of modern relationships. Reibstein then invites the reader to think about a discourse that exalts sharing and joining, rather than limiting dialogue, the latter of which is a more common contemporary experience of couples. Reibstein also acknowledges that affairs

may be viewed as attempts, albeit misguided, to address the untenable goals of dominant discourse.

Reibstein (2013) merged the social constructionist paradigm and attachment theory to explain both the need to be in a variety of relationships (normally within a hierarchy with multiple attachments) and also the extreme wounds that attend the discovery of secret affairs. Exploring the social constructionist explanation of affairs can become an important precondition to embarking on therapeutic work because it replaces potential blame with compassion and reframes secrecy as an imperfect strategy to spare heartache. Reibstein (2013) also noted that the therapist offers an empathic bridge for the couple to provide understanding and help bypass the quagmire of condemnation and contempt.

When dialogic commitment is achieved, it provides a talking framework for the oppressed couple to break out of blame and move into generative dialogue and acceptance. This allows each person to participate in healing and growth. It is a relational experience that merges tension and hope with love, betrayal with rebuilding, and fracture with reintegration. It puts an end to the way a couple was and urges them to determine whether or not they will move forward together. For some, the constructed experience around an affair is not necessarily an ending, but instead can be viewed as a rebirth within a betrayal and an acknowledgement that something was not working. Because there is likely to be a multitude of couples experiences for gay, lesbian, transgendered and straight couples, it is essential that all experiences are explored through a relational dynamic that allows them be heard without shame and judgment.

### **HIV, Sex and its Relational Dynamic**

Why, with so much knowledge, do people continue to risk another's well-being and health? Alternatively, why would a person living with HIV choose not to tell their partner about their status and therefore rob their partner of their choice? Kalichman, Rompa, Luke, and Austin (2002) found that as many as one in three persons living with HIV/AIDS continue to practice unprotected sexual intercourse with people who are HIV sero-status. This knowledge informs and potentially scares helping professionals into acknowledging that not all couples practice "safe sex", or sex that prevents transmission. Currently, there is a lot of speculation about why so many couples do not practice "safe sex"; ultimately, this knowledge can be used to support couples. For example, this knowledge can be used to inform how we discuss the dangers of unsafe sex, and it also acknowledges that people are human and that judgment around the risks associated with sexual interactions has many layers and dynamics. Kalichman et al. (2002) reflected on the possible reasons why risky behaviours persist in HIV-positive populations, and also explored how persons living with HIV/AIDS could be supported in order to reduce transmission. This generative thinking encourages us to sit outside of right or wrong, good or bad, and consider the many medical directives that come with a virus that has the potential to kill people; it seeks to understand the people who live with and/or expose themselves to risk.

Kalichman et al. (2002) noted that counseling is recognized as one of the most important forums to discuss risk reduction interventions, and that group interventions are a valuable therapeutic tool. The value of discussion about risk and prevention regarding

HIV transmission brings us back to the importance of sharing knowledge and providing opportunities for people, couples, and companions to be engaged in the description, explanation, and design of their HIV-specific risk reduction strategies. A protective factor within a peer-support gathering is the idea that all topics can be talked about as desired by the participants, which allows for the reformulation of ideals related to sex and wellness within their relationships.

### **HIV is Not the Only Issue: Is Interpersonal Violence an Ally?**

The need to talk about the intersection of HIV and interpersonal violence (IPV) is a part of the social experience that comes with living with HIV. Siemieniuk, Hartmut, Gish, and Gill (2010) have identified a strong association between domestic violence and HIV infection. This research acknowledged that the association between these comorbidities can lead to poor health outcomes, including mental health disorders and reduced access to care. As the interaction between HIV and its impact on peoples' lives continues to evolve with advances in treatment, the risks imposed on mental health must be considered. When bringing together couples who are living with HIV, it is important to consider the many other experiences that contribute to the couples' total experience of living with HIV.

HIV caregivers must be aware of domestic violence so that they can create and optimize safety plans for HIV patients experiencing domestic violence in their primary relationships (Reed, Krentz, Gish, & Gill, 2010). Because the community-action component of this research is key to its long term vitality, all relational dynamics are integral to generating rich dialogues within the couple dyad and within the community of sero-discordant couples. It is possible that bringing couples together might prompt a new disclosure of interpersonal violence that has existed within the couple relationship. How to respond, if needed, in a relational manner is not clear. However, some clarity around other resources and potential referrals is necessary when bringing couples into a couple forum, especially when this group has a high prevalence of IPV.

It is important to note that IPV often co-exists with other potential risk factors. Reed et al. (2010) separated IPV from various other variables such as previous abuse in childhood, culture, gender, sexual orientation, income status, and compounding issues such as mental health. The socially constructed reality for couples living with HIV brings multi-faceted oppression such as class barriers, sexism, ageism, and racism. This systemic discrimination accentuates the risk associated with lack of disclosure of violence within relational situations. This lack of disclosure may result, for example, from HIV-related stigma and its intersection with social processes and structural inequalities. It is important to recognize that the positioning of power and control relational dynamics within the lived experience of HIV is not unique to this virus and its concurring social processes. A couple's relational experience inherently brings with it a power and control dynamic, but it is the toxicity of the power imbalance that blurs the line of power and control and leads to interpersonal violence that has the potential to destroy the unique couple's experience.

### **Peer Support: The Road Less Travelled**

Davidson, Chinman, Sells, and Rowe (2006) have discussed how peer support is supported by the belief that people who have faced, endured, and overcome adversity can and will be useful in offering support, hope, and mentorship to those who have faced similar experiences. Peer support is a unique model of relational support that allows people a chance to relate to others that share common experiences. The relational dynamic allows all individuals within the agreed upon peer relationship to receive and give to each other. This releases them from all limits and isolation, which further “liberat[es] the human dream of self-advocacy” (Cyr, Mckee, O’Hagan, & Priest, 2016, p. 10). The giving aspect of a relationship, through the peer support model, is important because it has the exponential potential to develop a community of people who have not been visible because of oppressive socio-political agendas.

According to Gartner and Riessman (1982), “Peer support is social emotional support” that is different from traditional therapeutic relationships; it is more mutual and reciprocal in nature, and can include friendship, equal power and sometimes bring about a desired personal and/or social change (as cited in Cyr et al., 2016, p. 10). The self-advocacy that comes with living within the experience and sharing the experience with others through supportive relational dynamics has the potential to invite social change and social movement. This sharing can further undo some of the oppression and stigma that attends the lives of those with HIV. This impactful empowerment has the underpinnings of all great social movements, where folks gather, discuss, and align with an agenda that serves the greater good of those with whom they self-identify. This allows the group to move from being the oppressed other to a group of people who matter, and who have needs, wants, and the right to ask for and receive care.

According to Muise, “Peer support is ‘the process by which like-minded individuals with similar experiences—who have travelled or are travelling the road—encourage and assist each other to continue the healing’” (as cited in Cyr et al., 2016, p. 11). Research by Mead, Hilton and Curtis illustrated that healing that comes through shared dialogue and “a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement on what is helpful” (as cited in Cyr et al., p. 11). A healing relationship that values safety and excludes judgement allows for vulnerability and the ability to relate; this benefits those who have committed to a system of giving and receiving for the benefit of the whole.

People who provide peer support also experience relational dynamics that reflect their own experiences and the societal interpretation of their experience. Peer support workers who have had a particular experience are therefore in a unique position to offer support to others to improve the quality of their lives and the lives of others (Cyr et al., 2016, p. 11). The giver and the receiver of an experience can realize mutual benefits when an experience is normalized and when those new to the experience are supported by those who have faced a similar issue.

The ideology around peer support involves a relational dynamic that is fluid; it is people-driven rather than power-driven, and operates within a layered relational responsiveness. This relational peer dynamic embeds a sense of experience that is driven not by research and expert relational dynamics but by the most intimate interaction; it sits within the human vulnerabilities of being with peers that redefines each person. Peer

support subjects you to the human condition of having a relationship with your own understanding of others, just as they do with you. As noted by Dennis, the people-driven movement around and within peer support is similar to “this self-help movement, [which] specifically incorporates peer lay individuals with experiential knowledge who extend natural (embedded [i.e., family, friends]) social networks and complement professional health services” (as cited in Cyr et al., 2016, p. 11).

It is the sense of people leading and engaging within a social-relational movement that fluidly defies and redefines what and how people will relate to the experience of living with HIV. The peer support definitions have some similarities to those that have been socially constructed through the process of people sharing their experiences and developing relational dynamics; ultimately, these practices co-create and co-construct a new truth about living with HIV. The reciprocity that occurs within a peer support relationship brings participants out of isolation and reduces suffering, while at the same time improving their wellness and the quality of their lived experience.

Peer support allows for peer-intersectionality. It permits culture, gender, sexual orientation, age, ability, class, HIV and oppression to blend with the ravaging historical violence against HIV-positive individuals. It also supports the psychological adjustments that must be made as people live longer with HIV. Collectively, peer support is key to establishing and maintaining relationships across a lifespan. By incorporating the significant loss that came with the AIDS epidemic with more progressive research alternatives such as PAR, this research has the potential to create a new social-relational movement for couples as they live with HIV. It also acknowledges the right of couples to define their personhood within a peer support relational model. The biggest social issue that this population faces is still, by far, endemic stigma and discrimination from a society that has silenced and marginalized them.

The numbers of people affected by HIV are too large to ignore, and it is of paramount importance that this segment of society be heard. The merging of a postmodern research process (such as PAR) has the potential to engage a population of people who have been oppressed by social stigma and discrimination under a blanket of dominant discourse and relational dynamics. By providing a space for HIV-affected people to tell their authentic stories (in dialogue and action), this research has the potential to validate their truths, which society has not wanted to hear.

**CHAPTER THREE: RESEARCH METHODOLOGY, SCIENCE-IN-ACTION**

**(with people) RATHER THAN RESEARCH (on people)**

“Walking with people, feeling with people, acting with people, science and the story of the collective soul”. (field notes, P. Miller, 3 April 2012)



## RESEARCH DESIGN

Chapter 3 includes a description of the research methods and design framework, discussion about ethical considerations for this study and how they were addressed, and a description of the participants and the gathering settings that were established for the safety of the participants. There is a thorough discussion about the methods of data collection, the limitations of the study, and the significance of the study in terms of the new knowledge that it brings to sero-discordant couples. Data analysis was reviewed with the couples and generative discussions were used to explore the appropriateness of the data analysis methodology that was chosen (which is congruent with a PAR methodology). This study was a qualitative research project that relied on participatory action research as a methodology within the stance of social constructionism.

This chapter will describe how the qualitative research approach used in this study was concerned with curiosity and inquiry and was grounded in postmodern feminist theory. This reinforced the requirement to acknowledge multiple truths, multiple roles, and multiple realities. In this way, no single story was considered to adequately represent the story of all study participants. The study was also approached through the lens of social constructionism – the concern that all knowledge is created through how we make meaning and how multiple realities compete for truth and legitimacy (through interactions between and among social agents).

This current research was designed to support the community of sero-discordant couples that found themselves without a safe and validating space to share their stories. The aim was to provide a forum to encourage the sharing of couples' narratives, which we hoped would foster empowerment and reduce HIV-induced stigma. Much of the work in this research project was action-oriented, and was carried out with the community of couples themselves. My initial relationships with the clinic director, Dr. John Gill, and my PhD. supervisor, Dr. Dan Wulff, were key to its successful inception.

### Objectives

1. To gather together sero-discordant couples in Calgary, Alberta in a participatory action research process as a way of developing relational dialogues with the couples, in order to gain a better understanding of the contemporary needs of this community of people.
2. To co-create an action process within a participatory action research methodology that allows sero-discordant couples to be co-empowered as active co-researchers in the development of action-oriented processes that benefit community of people.

### Research Questions

The primary research questions in this study were as follows:

- a) What are the predominant contrast experiences that will contribute to the development of new knowledge?
- b) How can we understand the collective needs of diverse couples as they live with HIV in Alberta, Canada?

The secondary research questions in this study were as follows:

- a) What is the role of the researcher in participatory action research when they have not had the lived experience of living with a HIV diagnosis?
- b) How does postmodern feminist theory and participatory action research methodology allow for the empowerment of a silenced and marginalized social

group, and how does it allow the group to evolve and develop into a visible, action-oriented community?

## **RESEARCH METHODOLOGY**

### **Participatory Action Research: The Science of Persons in Action Versus Written Action About People**

This research will employ a PAR (participatory action research) methodological approach to qualitative data collection, analysis, and utilization. In PAR, “participants (called ‘subjects’ in traditional research) decide the research objectives, research question, methodology, are involved in data collection and analysis, reporting, and determine the uses of the research” (Morris, 2002, p. 10). The first phase of the research process included generative discussions between Dr. Gill, the Conjoint Ethics Review Board, Dr. Wulff and myself. The second phase involved the participants themselves. In this phase, the sero-discordant couples and myself engaged in generative dialogues that fit methodologically with PAR.

Because of the flexibility needed to implement PAR methodology and to sustain a co-research relationship with the sero-discordant couples, it was necessary to be open to adapting the process to include the voices of the members. This was not an easy task because the issues of relationship building and confidentiality situated themselves alongside the medical research ethics agenda that had significant expectations regarding how to format the initial invitation into the research and gatherings in order to safeguard participants. Because of the participatory nature of PAR methodology, complete confidentiality could not be guaranteed; in fact, the first method of action was to engage gatherings with sero-discordant couples.

Multiple conversations occurred between Dr. Gill, Dr. Wulff and myself. These conversations clarified roles, expectations and responsibilities in order to develop our relational commitment to each other (i.e., what we could expect from each other) and to the larger research project. True to the philosophical nature of the social constructionist paradigm, the ongoing relational dialogues were essential to evolve the potential of the researcher/supervisor/community relationships. This initial series of relationships set the stage for the relational dynamics (regarding respectful communication, responsibilities and roles) alongside the informality of the PAR research process (allowing the participants to define what they needed and how that information would be communicated to supervisors and community members). A web of relationships, both formal and informal, co-existed, which allowed for a plethora of dialogical relationships around the research participants.

Miller and Salkind (2002) have supported the need for a “power-with” relational approach in order to allow for an epistemological perspective that focuses on the ways that we know things versus what the things are. The social constructionist paradigm employs postmodern principles that invite in diverse dialogues with diverging realities (multiple representations of truth); this creates social negotiations amidst tensions in discourse that foster the creation of knowledge (Gergen, 2009) while being woven within a PAR methodology (encouraging collaborative action with diverse people). With the attention in PAR research methodology shifted from method to process, it became

apparent that there was a significant focus on relational dynamics and on the authoritative voice coming from the participants themselves. This created a fluid atmosphere of openness that brought forth actions that were initiated by community members.

The research relied heavily on the works of Bishop (2005), Davidson (2004), Downie and Cottrell (2001), Morris (2002), Olesen (2005), and Reason and Bradbury (2008) to emphasize the scholarly importance of co-operative inquiry as a scientific methodology of research-in-action (rather than research *about* action). Research-in-action takes time and requires the organization of people, resources, critical analysis, reflective processes, and documentation of process. The outcomes are significant for the participating community of people as they develop their identity together with meaning and collaborative empowerment.

Qualitative research, and specifically PAR methodology, tends to attract comments that critique its focus on action-oriented processes. Critics fail to recognize that the act of gathering participants for the co-action of generating dialogues gives back to the community through research as praxis (McTaggart, 1997). The act of initiating data collection without tape recording all dialogues (as decided by the research participants due to concerns over confidentiality) is an action-oriented agenda that reflects the participants' need to talk together, build community, and identify who they are beyond recordings that justify data. As intended in this project, conversations are data, even when they are not tape-recorded; as noted by shame researcher Brene Brown, "stories are just data with a soul" (Brown, 2010).

The discovery of voices is essential to PAR. Reason (1994) pointed out that "sometimes in action research, what is most important is how we can articulate voices that have been silenced" (as cited in Fournier, Mill, Kipp, & Walusimbi, 2007, p. 16). PAR methodology is an action-orientated methodology; it is science-in-action that favours the process of gathering people, and not just the documentation of themes that render a series of stories worthy or not. In truth-seeking forums with marginalized groups of people, the act of standardized questions or expert-driven knowledge development can disempower the group of individuals that one hopes to know better. It is critical that the researcher recognize that they hold power over marginalized populations and that they take steps to mitigate this power (Letherby, 2003).

In employing PAR methodology, we co-created action frameworks for co-action, which we negotiated. The negotiations were fluid and unfolded in different ways depending on whether the participants had ideas to lead or sought my ideas to initiate moving forward into some formal or informal action process. Because of the need to dialogue with my co-researchers (the research participants), however, I was not able to provide concrete steps to be taken beyond the initial gatherings. A "power-under" stance was taken, which was supported by postmodern feminism and by the work of Foucault, who maintained that scientific knowledge often has little relevance in people's everyday lives and instead serves to maintain existing structural oppression that limits power to members of economic, social, and political elites who have historically held power (Rodwell, 1998). PAR methodology requires flexibility in the methods and process of the research project, which cannot be clearly defined until the greater collective of participants give voice to their experience and, in turn, identify if they require an action response to their collective needs.

According to PAR methodology, the couples involved in this study were “not only the ‘subjects’ but also the researchers, as the participants ‘own’ the research” (Morris, 2002, p. 10). My ultimate goal was that the sero-discordant couples become co-owners of this research project and develop an authoritative knowledge base that allowed them to take co-action to improve their situation within the larger health care community. According to Reason (1994), there are two objectives of PAR: to produce knowledge and action directly useful to a group of people, and to empower people at a deeper level through the process of constructing and using their knowledge to better the community that they are representing.

PAR is an approach that guides the research process but does not prescribe its methods; therefore, a variety of approaches are used in relation to the participants that co-create the outcome as defined by its transformational aims (Seng, 1998). Kimjin Traver (2004) explained that PAR is a form of research that generates knowledge for the express purpose of taking action to promote social change and social analysis. PAR aims to increase the ability of the involved community or organization to control their own destiny more effectively and to improve their capacity to do so through praxis (merging theory and practice) and action-oriented processes (building trust and developing action steps).

When this research project was conceived, it was not known what might evolve from the engagement of the participants in a collective dialogue of their experiences. The ultimate goal, then, was to create a space in which sero-discordant couples could dialogue and explore their relational dynamics so as to allow them to define their collective reality. The relational context is emphasized throughout this dissertation because of the commitment to a social constructionist paradigm, in which relational dialogues are required to co-create a collective outcome that benefits the sero-discordant couples as they aspire to relate to each other (Gergen, 2009). The constructionist paradigm in this research study allows a set of orientating principles to guide the thinking and construction of the written work.

## **SAMPLING PROCEDURES AND SELECTION PROCESS**

Because this research project was designed to identify the significant experiences of sero-discordant couples, I employed a selection process that was aligned with a non-probability sampling process: the sero-discordant couples, who were participants gathering at the initial sero-discordant couples group, would be invited to participate, as would other couples who were identified by the Southern Alberta Clinic. The initial sero-discordant couples group requested more opportunities to have their voices be visible within the HIV and non-HIV communities. The sero-discordant, psycho-educational group at the Southern Alberta Clinic, run by myself as an employed social worker in the Alberta Health Services, and by another social worker, brought forth requests from discordant couples for more counselling support. The discordant couples quickly acknowledged that they felt that the once-a-week, 6-week, psycho-educational group was not enough and that they wanted more space to talk, learn, and develop into some sort of informal or formal community.

As the research took shape, non-probability sampling was used to assemble the gatherings, which allowed participants to be chosen based on particular features or groups

within the sample population (Ritchie & Lewis, 2003). For the purpose of this research, the sample population was persons living with HIV, and more specifically, sero-discordant couples within this group. Potential participants were those who had identified themselves as belonging to a sero-discordant partnership, or those who were identified by staff at the Southern Alberta HIV Clinic. This sampling had natural limitations, as previously noted. In initial research gatherings, two groups were assembled that were limited to 10 members (five couples in total), bringing the total number of participants to 20.

### **Developing Engagement Methods**

I was asked by the Conjoint Ethics Board to create a mail-out letter of invitation and a telephone script to guide the engagement of sero-discordant couples. Prospective participants were given the letter by the co-researcher to invite them to participate in the initial meetings. As the organizing co-researcher, I then contacted the patient and his/her partner by phone, using the phone script to invite the couple to attend one of the two gatherings. As the gatherings continued to occur over a one-year period, new couples accepted invitations into the formal gatherings through referral (by staff) at the Southern Alberta Clinic. The empowerment process that the couples went through allowed them to decide that they wanted to share their safe and non-judgemental community with other sero-discordant couples.

The letter and phone script met the needs of the Ethics Committee and also invited a dialogue that felt respectful and evoked curiosity from the sero-discordant couples. If the sero-discordant couple did not feel comfortable coming to a gathering of other discordant couples for the dialogue process, then they were acknowledged for engaging the conversation. In these cases, an open-ended invitation was extended for future gatherings. Every choice was respected, and no couple was made to feel that had made the wrong choice if they decided not to participate.

### **Informed Consent: Clarity in Action**

As the initiator of the research, I was committed to ensuring that all research participants who were involved in the initial gatherings followed procedures of informed consent and confidentiality. Because I had a professional social work relationship with some of the participants, the participants needed to feel that they were voluntarily participating and that no feelings of gratitude or obligation were impacting their choice to participate in the research (Holloway & Wheeler, 1995). Any other person having direct or indirect contact with research participants and/or any of their personal information were asked to sign a confidentiality consent form at the beginning of the group. All forms were given to the couple participants and clarification of the consent content was provided by the primary researcher as needed. Each member of the couple dyad signed a form on their own behalf.

Because of the group format of the gatherings, I could not guarantee anonymous participation of the research participants. As the consent form explained, anonymous participation could not be guaranteed, an issue that participants had to consider for themselves and collectively discuss if they chose to participate in the group. I took confidentiality seriously, especially when critically reflecting on the disclosure of HIV-

positive status and the social stigma that is attached to this virus. As a co-researcher, I was as clear as possible with the participants regarding the limits of absolute confidentiality, both for direct (names) and indirect (collection of specific characteristics) attribution.

In my own mind, confidentiality was a barrier to navigate with the couples because the impairment around social stigma seemed equivalent to social exclusion and character assassination. As discussed by Rintamaki, Davis, Skripkauskas, Bennett, and Wolf (2006), the hysteria and lack of education surrounding HIV has led to victim-blaming and social repudiation of those who live with the disease. This, in turn, has led to stigma being the most important social and psychological issue of the HIV experience. People living with HIV must navigate, on a daily basis, the potential risks within their personal relationships, and at the same time decide if they will disclose their status amidst fear of shame and/or fear of persecution (Rintamaki et al., 2006). To bring couples safely together for the gatherings, the psychological risk associated with stigma had to be aligned as closely as possible with protocols that addressed this risk, and there had to be complete acceptance of a participant's right to withdraw without embarrassment or shaming.

### **THE INITIAL GATHERINGS: STARTING TOGETHER**

Ten couples were invited to participate in initial gatherings, which allowed the five couples in each of two groups to selectively choose dates that worked for them to meet. The first gathering had only six people (three couples) and the second gathering had eight people (four couples) because some couples were unable to come due to changes in their schedule. As the original two gatherings cross-pollinated as per the couples request, the couple numbers increased to seven couples (or fourteen people) per group. Cross-pollination became my word for the process of bringing together the two separate gatherings with the couple's permission and creating a new diversity among the participating sero-discordant couples.

I purposely kept the gatherings small because of the significant concerns with confidentiality. Kimjin Traver (2004) stated that "her PAR research used focus groups drawing on Mullender and Ward's (1991) argument that groups best facilitate empowerment" (p. 9). As a postmodern feminist researcher (who strived to include and hear all diverse voices), my secondary goal was to encourage and support empowerment of my research participants throughout the research process. The initial gatherings appeared to be a positive forum in which the couples felt engaged and were empowered to be active co-researchers with myself.

The Ethics Board did not prescribe a protocol for developing an atmosphere of safety, respect, and an acceptable level of comfort for the gatherings. There was, however, a clear protocol on how the consent forms should be reviewed with each participant within the sero-discordant couple dyad before the gatherings began. The initial gatherings were conducted at the Sheldon Chumir Medical Building in one of the community group rooms on the third floor. To accommodate the participants' schedules, meeting times were 7:00 p.m. to 9:00 p.m. during the evenings, or Saturday afternoon from 1:00 p.m. to 3:00 p.m.

The first gathering was held on February 25, 2012 – a beautiful, sunny but cold Saturday afternoon. The second gathering was held on March 14, 2012 on a Wednesday

evening. The third gathering was April 9, 2012, again on a Saturday afternoon. There were six participants at the first gathering. Two other couples had committed to come but were unable to attend because of other commitments. The six attending participants consisted of one gay couple and two heterosexual couples from diverse backgrounds. At the second gathering, there were eight participants including one trans-gay couple, two heterosexual couples and one gay couple, again from diverse cultural and class backgrounds. Only three couples were able to attend the third gathering. The couples stayed for the two hours in each initial gathering and actively engaged in dialogue with myself and each other. Multiple members indicated that the two hours was insufficient. A sense of ease filled the room as the group progressed in their dialogues and spoke openly with each other, which reduced the fear and uncertainty that was palpable in initial moments of meeting.

In the initial groups, the participants were asked to openly discuss their experiences of living with HIV as a couple. Richie and Lewis (2003) have discussed how, in a very exploratory study, a key objective is to understand the ways in which participants' values and conceptions emerge through their narrative (and that data emerges through their interactions). The participants were invited to dialogue about their lived experience and ask questions of each other (which they could leave unanswered) as they began the process of using "reflexivity" on their lived experience of HIV within the framework of PAR. The exploratory nature of the gatherings allowed the couples to merge their narratives, which in turn allowed them to be "reflexive" with each other as their topics evolved out of group responses.

The goal of PAR methodology is to create empowerment by "including members of the population under study throughout the process that in turn would make research empowering" (Massat & Lundy, 1997, p. 44). The openness of the discussions was pivotal to the development of a collective agenda. The approach that would be used to follow-up on the information and ideas from the two groups was also developed during the initial gatherings. As a co-researcher, it was decided that I would be responsible for following through on any requests coming from the two separate groups' agendas, and would collaborate with the groups to create a collective or collaborative agenda that would invite further action or bring some closure to the initial gatherings.

As the co-researcher, I believed that we could further reduce the potential for harm to our research participants by "subject-empowering strategies that reduce a participant's sense of exploitation and repair experiences of exploitation" (Massat & Lundy, 1997, p. 36). The PAR methodology offered a framework that allowed the collective to define what they deemed as important in further exploration and possible action. I then employed an initial discussion of the rules regarding confidentiality as another safeguard. Light snacks and beverages were provided to enhance the atmosphere of the meeting.

### **Understandings, Action and Analysis**

Because this study engaged a PAR methodological approach to qualitative data collection, analysis, and utilization, the first phase of the research process needed to include the intensive development of a research process, ethics review, and initiation of the groundwork for the gatherings. Kemmis and McTaggart (2005) have discussed how it is up to the researcher to decide how much emphasis is placed on collaboration. They

also noted that even funders for health care research require the involvement of service users. According to Bergold (2007), being that participatory action is an extensively involved people process, it can evoke the empowerment of a group of marginalized people as they collaborate and develop a knowledge production process (as cited in Bergold & Thomas 2012). This potential is inspirational and possibly cathartic for a community of people such as sero-discordant couples because it offers the opportunity to unveil their unique couples' narratives and invite new ways to interpret their reality – possibly leading to a paradigm shift.

To allay concerns about confidentiality in this marginalized group of participants, there was no formal tape recording of the initial gatherings or subsequent meetings. An analysis of data was also not performed as the science of “bringing people together” was broadened into something called “research-in-action,” which means making the world visible through a set of interpretive practices (Denzin & Lincoln, 2003). Denzin and Lincoln (2003) also highlighted how qualitative research methods turn the world into a series of practices that include field notes, interviews, conversations, photos, and memos to self. The initial gatherings generated data that was analyzed and led to a documentation of the themes of discussion. Ritchie and Lewis (2003) discussed how group discussion involves four to ten participants who come together to talk about a research topic or a common issue, and that this provides an opportunity for people to gather, discuss and hear others talk about an issue of interest (e.g., the experiences of couples living with HIV).

As the co-researcher and at the groups' request, I did capture the participants' words on paper, which is considered a form of data. Whyte (1991) outlined how participants actively participate in collaboration with the professional researcher throughout the entire research process (from the initial design, to the dissemination of information, to the ensuing action that may occur), and in this way act as co-researchers in the project. When requested, the participants' words were recorded as themes that highlighted which topics were important to them. The group decided how to finalize the information from the meetings and how it was to be distributed for follow-up.

If there were any incongruencies between the two groups and what they needed, I, as co-researcher, requested an opportunity to phone the other group members for follow-up. All contact with the group members was authorized and whole-heartedly agreed upon by all participants. No one had access to members' direct personal information unless the couple participants decided that they wanted to disclose their last names, personal location, or other demographic information. All information was data, but how this data was used was decided upon by the group. It was important that the researcher and participants collaborated regarding which methods of data collection were relevant to the situation or the issue at hand (Gillis & Jackson, 2002; McNiff & Whitehead, 2006; Stringer & Genat, 2004). All words became data, which fed into a collaborative need to manage the outcome of that data with the participants themselves.

The collective action-agenda was developed by the sero-discordant couples themselves during group discussions. They decided whether direct research or some other modality of expression would be pursued, and what mode of data analysis, if any, would be utilized. In keeping with PAR methodology, at this stage there was no preconceived notion of the actions that would be taken after the initial generative dialogues. One of the primary goals during the dialogues was to create a safe space that Wicks and Reason



(2009) and Kemmis (2001) described as being essential to deliberations, where “domination-free” discourse happens within a communicative space (i.e., a transition zone between system and life world). The generative dialogues had an indefinite agenda, in that the primary action for the couples was to describe and explain their understanding of who they were and what they wanted to dialogue about, with a focus on their current reality as well as their understanding of their experience in the context of the AIDS epidemic of the 1970s and 1980s. The potential for a collective agenda was not given priority, and the couples living with HIV were left to fashion their own futures.

### **Risk Analysis: The Potential Harm**

The probability of harm to participants resulting from this research was, in my clinical experience with this client population, moderate. There was a chance that participants might feel embarrassed, ashamed, or sad, or that they may experience stress due to difficulties with their diagnosis or being identified as a sero-discordant couple. If the research participants exhibited any signs of emotional distress and required support, as planned in the research proposal, I was to provide phone numbers for additional support through the Southern Alberta Clinic and/or other community-based resources. All participants had access to information about additional support resources.

If any participant exhibited signs of distress after a meeting, I was to meet with the participant to assess if there were any immediate safety concerns regarding the participant’s emotional and/or mental state. If I deemed that there were safety concerns for the participant, I implemented a crisis intervention plan, taking into consideration all of the couple’s resources. As discussed by Gilbert (2001), boundaries must be negotiated and renegotiated as an ongoing part of the research process. There needs to be a balance between the dangers and benefits of being too far in or too far out of the lives of the participants. All crisis intervention was to be carefully considered and referrals to other professionals were to be given at the participant’s discretion to use.

If a participant continued to experience unmanageable distress, I was to co-ordinate a follow-through plan within the Sheldon Chumir Health Centre in the Urgent Care Department. If a participant wanted to withdraw from the process at any time due to personal reasons, they were permitted to do so at their discretion. The principal researcher was then to follow-up with the participant to make sure they were okay and to determine whether they were in need of support from other professional resources. Lee and Renzetti (1993) discussed how qualitative researchers need to situate their “sensitive” research even more closely in developing communities that are identified as being marginalized and potentially have not been able to discuss sensitive issues before. Because of the nature of potential disclosure of sensitive phenomena, all participants were informed of the potential risks and were advised clearly about protocols for psychological safety, as noted in the confidentiality agreement.

### **Benefits: Social Change Agents**

My intention in holding the initial gatherings was not only to have the participants share their prevalent couples' experiences and further link them into a more collective dialogue with other discordant couples; I also hoped to develop a community of support and co-action as "creative actors in the world" (Maguire, 1987, p. 30). PAR, as discussed by Reason and Bradbury (2001), is a participatory, democratic process that is concerned with developing practice knowledge in the pursuit of worthwhile human purposes. I view social action as one of the potential benefits of this research project.

PAR facilitates the empowerment of the participants while also creating potential for action and change at the personal and structural level (Maguire, 1987). One of the distinguishing factors of PAR methodology is that community members themselves may develop community relationships that foster an agenda of collective, beneficial community action. This action can strengthen the identity of the collective while at the same time addressing social issues, challenging political and legal agendas that disseminate discrimination and stigma, and creating new knowledge for others (about who they are, what they need, and what they want).

I heard from the initial psycho-educational group for sero-discordant couples (who met in the Health Region prior to the research gatherings) that they felt isolated, and that the medical system and other support relationships misunderstood their couples' experience around HIV. It seemed imperative that a supportive community be developed for this marginalized group. Lenz (2012) and Götsch, Klinger, and Thiesen (2012) explained that the social concept of democracy needs to be engaged when considering a PAR methodology that empowers a disempowered group of people. The concept of social democracy serves as a litmus test for society to see how it supports its most marginalized people to be visible and empowered to reconstruct an outcome for their benefit.

The goal of the initial meetings of sero-discordant couples was to engage their collective dialogues and create empowerment through the generation of new dialogues. The hope was that this act would impact and transform the social stigma that silences and isolates this group of people around their HIV experience, and that relational empowerment would replace the isolating relational power of stigma. Power and knowledge building can be provocative in that they have relational pull into certain empowerment dynamics beyond those enforced by social structures that have previously impaired them.

### **Confidentiality: Secrecy and Story**

As the primary researcher in this research project, I could not maintain absolute confidentiality of the participant identities due to the nature of the gatherings and the necessity of face-to-face contact. Building a trusting relationship between the researcher and the co-researchers (participants) is an essential component of qualitative research, and this makes an important contribution to the authenticity of a study (Hennink, Hutter, & Bailey, 2011). Trust and authenticity, in turn, allow for narratives to be woven with transparency by the participants themselves. For any participants requesting a one-on-one meeting, confidentiality was managed by allowing those couple participants to have an in-person discussion with the primary researcher only.

In these one-on-one meetings, the confidentiality of the information that was discussed, and how to dispense the information to the other participants, was agreed upon. The participants were also given the option of reviewing their dialogue and its meaning before it was included with the other couples' information, as agreed upon by all members. This step built trust within the research process. Wiles, Crow, Heath, and Charles (2008) have argued that any changes in raw data should be explained in a research report to ensure that the integrity of the research is maintained. Although time consuming and onerous, this stage was important for the building of trust and for consistency in the research process. As Karnieli-Miller, Strier, and Pessach (2008) have postulated, the way in which permission is gained from participants in the research process—through building rapport and transparency around the issue of confidentiality—helps develop a sense of trust. The issue of the limits of confidentiality were clearly addressed in the initial letter inviting couples to participate in the study, and also in the phone call script and the consent form that all participants signed when attending the gatherings.

Because many of the study participants indicated that they were concerned about confidentiality and the larger issue of HIV's social stigma, I made myself available by phone to dialogue about any concerns the participants had, both before and after gatherings. The issue of confidentiality was also part of many of the formal discussions that I had with the conjoint Ethics Board director. These generative conversations shaped my academic process within PAR methodology. I recognized that the ethical standards of "science-in-action" must be equivalent to those to which laboratory-based research projects must comply. Even though no definitive method can unequivocally prevent participants from knowingly sharing information about another participant's status, I tried to safeguard confidentiality and its conjoint issue of disclosure of another's HIV status in multiple ways. This multifaceted approach received final approval from the Ethics Board.

Issues around confidentiality changed as the research project progressed. The approaches that were used to protect confidentiality in the beginning became less relevant as the peer support model gained strength. Initially, confidentiality had to be addressed specifically with each participant; however, as participants immersed themselves in peer support gatherings, the issue of confidentiality was discussed through peer support volunteers and the community agency that housed the ongoing support program. As the relationship dynamics changed and became less intrusive, the confidentiality expectations within the group were renegotiated.

### **Provision of Results to Participants**

After the initial meetings, the ten couples decided how the data would be distributed to the group members. As identified by Selenger (1997), if PAR is to serve social change, then democratic forms of interaction and decision-making that lead to empowering the marginalized must be dialectically discussed. The ultimate decision-making process remains with the co-researchers (i.e., the participants). While differences of opinion and a divergence of perspectives, values, and opinions (Gillis & Jackson, 2002; McNiff & Whitehead, 2006) may prevent research from being a straightforward process, true to the inclusiveness of PAR and postmodern feminist theory, all voices and opinions matter. True to the nature of PAR, there were inclusive and collective dialogues,

and, in turn, co-action that met the needs of most of the participants. If some of the participants were not satisfied with a plan of action, they had the opportunity to further talk through their decisions.

The inclusive participatory component of the research brought forth a generative dialogue that gave meaning to the needs of this group of isolated and marginalized people living with HIV. This process was not about meeting consensus, but instead focussed on generative and transformative contemporary dialogues with conversational holding space for tension, difference, constraints, and the unfolding of constraints. Conflict and a narrative shift about the interpretation of data and its meaning were allowed to occur, but all perspectives were heard (Wadsworth, 1997) in order to deal with the uncertainty of not knowing or not being able to come to some formal, agreed upon understanding.

As the co-researcher, I thoroughly followed the directives of the collective to disperse the data between the two groups. The groups easily engaged this idea of allowing their stories to be a collective review process. As the co-researcher, I had not imagined what would need to happen as my primary focus was to understand the needs of the sero-discordant couples. MacDonald (2012) emphasized that participants must be informed that PAR is time-consuming and requires the commitment of the research team. In this project, the research team included the participants themselves, who were charged with making inclusive decisions about data sharing. In keeping with PAR methodology, the timeline for data sharing was flexible, and was responsive to the needs of the collective of sero-discordant couples. It was paramount to support personal agency in this research project because the participants needed to be able to define their own set of choices in relation to their time, participation, and commitment to the research process; otherwise, there was a danger that they would feel further marginalized by having traditional academic research dogma imposed upon them.

### **The Action Phase: Decision Making in Action**

The action phase of any PAR project brings different needs to the table. In addition to Paulo Freire, Kurt Lewin was one of the other well-known originators of PAR methodology. Lewin, a Jewish refugee and psychologist, advocated the philosophy that people would be more willing to participate in research if they were allowed to take part in the decision-making process (McNiff & Whitehead, 2006). For the couples living with HIV, PAR was a cumulative process that benefited them and instilled trust that they were the priority. They knew that their needs were primary to all discussions and movements forward (or even the need to stay stuck). They were able to talk through different perspectives and experience difference in a safe forum; this safety allowed them to acknowledge difference without feeling silenced or marginalized within their own community. The conversations that took place were significant. They provided much needed validation to this community of people living with HIV with its unique needs and contemporary stories – stories that had been submerged within the historical and current discrimination and marginalization that society had enacted upon it by silencing or “othering” its members into isolation.

This deconstruction of oppression was apparent as the couples sorted through what they needed for next steps of action. Consistent with the origins of PAR, Lewin’s form of action research addressed problems of segregation, discrimination, and

assimilation, and assisted people in identifying and solving issues that would further impede their development as an empowered community (Stringer & Genat, 2004). There were different needs amongst the members of the sero-discordant groups because of their diversity, including concerns that arose from their community. As a facilitator within their action phase, I was there to support their process and witness them discuss their differences without interfering or solving their issues.

There was a clearly identified need to attain safety and belonging in their communal relationships, which further helped to enhance the facilitation of their community development in the action phase. This was a compounding issue that renegotiated itself throughout the ongoing gathering(s) as new members were invited in and new guidelines for emotional safety were established. There became a clear need for participants (or *Plus Friends of Calgary* as the group named themselves) to commit to the ultimate goal of building a positive-blended-discordant community for and by the couples.

Empowered to do so, the group's commitment extended beyond the research goal of gathering and dialoguing in order to achieve a new understanding of their lived experience with HIV. There is often a significant shift in tone when people move from an individual goal to a community goal; this shift brings forth a contemporary, conscious truth regarding their lived experience that empowers formal action. As acknowledged by Stringer (1996), PAR is a democratic process that enables the participation of all people, is equitable, values all people's worth, liberates (as it provides freedom from oppression), and enables the expression of people's full liberation.

### **Confidentiality Within a Peer-Support Model**

What is confidentiality within a peer support model? There is scant literature that defines the line that weaves itself through the layers of confidentiality and peer support. The peer support facilitator and I established the confidentiality clause by consulting the participants about what they felt they needed for ongoing confidentiality. There were multiple discussions regarding what confidentiality might need to be, and how to bring some sort of knowledge into creating a line driven by the participants, but guided by the multiple and diverse needs of the peer support participants. As noted by Lewin, the cycling of processes is important in the critical reflection of implementation of action (McNiff & Whitehead, 2006). Furthermore, what is needed through the cycles of action must be further defined by the group in action. Power in the relational dynamics of the group, mitigated through the group's co-action, must happen concurrently within the context of the environment and other socio-economic processes to ensure that confidentiality is developed through a support process rather than a mandated set of rules.

The peer-support confidentiality guidelines for the initial peer support groups were as follows:

- The peer support facilitator will only ask for your first name when they are attending to your e-mail or phone request to attend a peer support gathering;
- No identifying information will be requested beyond your first name;
- Only first names will be used in group;
- Diverse couples are welcome;

- No identifying information will be shared unless the person speaking chooses to do so;
- The peer support facilitator is the only person who will know the full names of people interested in the group;
- The group members agree not to try to get additional information from the group participants;
- The initial confidentiality expectations will be established by the peer support facilitator;
- The participants will sign a confidentiality guideline sheet to show their commitment to the guidelines;
- The ongoing gatherings will follow guidelines that include respect for the emotional safety of the participants and their partners;
- No dating will happen within the group;
- Participants can stop attending the group at any time;
- Any abuse will not be tolerated in the group process;
- Fun, friendship, and food are the main needs of group.

### **Community Engagement: Science-in-Action**

Community action is an effective way to rebuild identity, primarily when the action comes from the community itself. Science-in-action is not kept in the lab—it is moved into the playing field of life itself. Selenger (1997) discussed seven different components that are embodied in PAR methodology (as cited in MacDonald, 2012). These five components according to Selenger (1997) are:

1. “Acknowledge that the problem originates in the community itself and is defined, analyzed, and solved by the community.
2. The ultimate goal of PAR research is the radical transformation of social reality and improvement in the lives of the individuals involved; thus, community members are the primary beneficiaries of the research.
3. PAR involves the full and active participation of the community at all levels of the entire research process.
4. PAR encompasses a range of powerless groups of individuals: the exploited, the poor, the oppressed, and the marginalized.
5. PAR has the ability to create a greater awareness of one’s own capacity and mobilizing the members for development of their resources”. (p. 39)

The participants from the gatherings gained clarity through the process of generative discussion, and sought to develop gatherings and/or supportive groups that could meet regularly in a safe place, and thereby inspire them to provide mutual support to each other and bring in new members. This participatory action was their collaborative, science-in-action agenda. MacDonald (2012) identified PAR as more than scientific method, because participation in the PAR process allows for a more appropriate analysis of what needs to be done for the long term empowerment of the community. The couples themselves sought positive input from each other while looking to expand their gathering process to all couples (whether they were sero-discordant couples or couples where both members of the relationship dyad were HIV positive).

As the community of discordant couples built trust with each other and their community of discussion and action evolved, they were better able to develop the many layers of sustainability that they needed in order to address issues of significance concerning the flourishing of human persons, the community and a greater ecology in which their community participates (Chandler & Torbet, 2003; Kelly, 2005). Participants formed working narrative discussions in the monthly gatherings that helped build physical and psychological infrastructure, so that new couples could enter the working ecology for longer-term support. As noted by McTaggart (1997), the ultimate goal of PAR is to empower a group of oppressed individuals. Empowerment allows the group to engage social change, which encourages capacity building in all individuals that participate. Capacity building would enable group members “to be creative actors on the world”; the empowered group of couples living with HIV would be active participants in meaningful decision-making around a natural outcome (Maguire, 1987, p. 30).

In a PAR project, the goal is not to achieve closure. As relationships change in PAR, there is a shift towards new psycho-social relational dynamics, and the group of individuals is able to organize and then re-organize as needed. The oppression of individuals living with HIV is rooted in 30 years of historical and social dialogue that has marginalized their identity by characterizing them as the other, the not as good, the potentially dangerous, or those who have put themselves at risk for getting HIV. Actions that arise from PAR have the capacity to encourage psychological prosperity in these individuals by fostering empowerment, capacity building, and conscious self-reconstruction of their individual and collective identity. Paulo Freire (1970) identified engaged psychological co-action as important, and highlighted the need for critical consciousness in marginalized persons as essential to their capacity to bring about social change.

The initial gatherings created a different form of relational dynamics in the community that was based on a new conscious awareness of the need for a peer-support model of gatherings that excluded professionals from being directly involved. It better suited the people involved, and shaped future ideas around embracing diverse relationship structures, such as gay and transsexual couples and companions that live with HIV within diverse political, social, economic, and familial contexts. McTaggart (1991) explained that PAR was developed to improve social, economic, and cultural practices in order that those marginalized – who come with differing levels of power, status, and influence – would collaborate in relation to a theme or concern; for this group of couples the theme was their experience of living with HIV as a couple.

The new definition of need in this community of couples allowed meaningful relationships to develop that were inclusive, empowering, and validating; they benefitted those who committed themselves to conscious dialogue, social investigation, and action around the social-political issue of HIV. This new relational construction allowed for a dialectic shift of understanding, new knowledge, and a way of being together with the larger society. It freed participants from traditional dominance and power relationships, and merged individual experience with the collective experience of HIV. Relational dynamics were negotiated through interactive dialogue that formed as the couples found new meaning with each other and their new collective identity. Conscious of their individual and shared experiences, their social action agenda became organized under their own control. As discussed by Kelly (2005), consciousness allows a community to

collaboratively come to an agreed upon goal that then moves them into their social action phase. There is no need to define an ending or a formal closure; instead, there should be an allowance for next steps into community building that will continue to evolve with the community's consciousness of what it needs.

The edge of meaning is not always closure; meaning can come from the redefining of relationships situated within a community of participants, from growth and negotiating for many years and within many dynamics, and may also be embedded in formal and informal relationships. MacDonald (2012) described how the professional PAR researcher can become a committed participant, facilitator, and learner in the research process, roles that require attentive attachment rather than detachment. Six years on, the meaning of this research has come from the participants who have walked directly with it and have embraced the PAR research process, as well as those who have chosen to exit. All participants, whether they matured through the research or deemed it unnecessary, helped to develop a vibrant, inspirational and meaningful community of action that continues to exist and thrive within the larger Calgary community and in a national peer support movement.



#### **CHAPTER FOUR: BEING THEIR OWN EXPERTS**

“They spoke, they found, they roared, they soared.” (field notes, P. Miller, 25 April 2012)

### **THE INITIAL GATHERINGS IN-ACTION**

At the first group gathering, even I did not know whether this project would succeed or fail. It is not often that a researcher brings people together without a predetermined agenda, aside from some guidelines for confidentiality and emotional safety. Moving straight into dialogue when people are extremely afraid can be quite limiting, but these gatherings quickly ignited a sense of shared knowing. Each couple had been living a silo-type existence where people around them did not know of their sero-status. Their fear was real. The internalized fear dialogue had developed its own consciousness, due to the larger social construction of the couples' story that situated itself amongst the medical discourse and the historical chapter of AIDS. The current sero-discordant couples' narratives somehow still merged with contemporary social narratives, due to the threat of the virus or the threat of how people treat those who are diagnosed with HIV. The couples brought with them a plethora of experience; a dominant sentiment was that disclosure of their HIV status was equivalent to death in a society that socially judges those who live with HIV.

There is a privileged discourse around who is healthy/who is not, who is infected/who is not, and who is at risk for infection/who is not. Yes, there is fear about the impact of the virus on the health of those who live with it. How does a virus socially marginalize those who live with it, especially when placed within a chronic disease model in which symptoms can be managed? When situated within a society that holds biases and stereotypes that demonize those that live with its burden, HIV still evokes a dominant story that benefits those who are not positive at the expense of those who are. The gatherings shifted the discourse – and therefore lifted the veil of stigma – from those who were infected and contagious to those who live well and love those who are HIV-positive, or are HIV-positive and love those who are HIV-negative.

### **Conversations Woven into Actions**

A major accomplishment of the first gatherings was that they supported the participants as they externalized conversations that had previously only existed inside the partnership. The exchanges among the couples at the first gatherings foreshadowed the needs of the group members that had never been identified outside the micro-unit of the sero-discordant couple. Within the gatherings, there were many insightful comments that formed larger narratives and assembled into collective conversations. As the couples engaged a process of asking each other questions and sought to understand each unique experience, trust was built and a shared experience of living with HIV began to emerge. Laughter replaced awkwardness, a sense of knowing replaced difference, humanness replaced stigmatized silence. The gatherings took on a life of their own.

### **Initial Gatherings: History-Making in Discourse Exchanges**

The unique social constructionist framework and discourse exchange that emerged in the first two gatherings was a major accomplishment. The externalizing of individual narratives (within the initial gatherings) set the stage for whether or not the couples would choose to continue to gather or accept the gathering as a one-off

experience. Participants could decide whether the empowerment that they would gain from externalizing their stories and contributing to the collective dialogue outweighed the cost of disclosing their HIV status. This choice of whether or not to continue to participate was not only pertinent to the ethics requirement of the project (that research participants could choose to withdraw at any time), but was also integral to alleviating any oppression that might arise from participants perceiving that they did not have the right to choose.

The main themes that emerged through the initial gatherings came from the sero-discordant couples' dialogues. The topics that were discussed were identified by the couples as having meaning in their lives. Several different perspectives were explored, in keeping with the diversity of people who attended. The unique experiences that each couple brought – which were dependent on sexual orientation, age, class, race, ability, inception of HIV diagnosis, how people became positive, where they lived, what they did, how they adjusted to the diagnosis, who in their family and community of people knew or did not, whether or not they had AIDS – formed the collective narrative. These robust dialogues generated a significant shift towards personal empowerment and allowed the invisible couple narratives to be seen as data. More importantly, their lived experiences, when externalized, were no longer silent, allowing the participants to move beyond HIV-infused stigma.

### **Narratives to Science-in-Action**

Listed below are the main narratives that came out of the gatherings, in no specific order. They are the words used by the participants themselves as put into field notes dated February 25, 2012, March 14, 2012, and April 7, 2012. In the following themes you will find the original data from the sero-discordant couples' dialogues as they penned their unique history together as active participants in this science-in-action research. At the outset of these dialogues, I sought to understand the conversations as laying the foundation for future discussions that would emerge as participants found a safe dialogic space to understand each other in current tensions and affinities. Amidst the vulnerability of being exposed as a sero-discordant couple, concurrent experiences existed around the longstanding vulnerabilities that comes with using language to formulate expression of the lived experience, particularly when language has been used to suppress their actual experience through HIV-infused stigma. Nelson (2001) proposed that people construct effective counter-stories to undo the oppression that impairs the identity of those whose identity is embedded into the dominant narrative. The following segments of discourse can be understood as holding the tensions and affiliations within words that represent experiences, within the lived experience of being a sero-discordant couple.

The initial question used was:

What matters to you in your lived experience as a sero-discordant couple?

**Female Speaker:**

*The issue of trust is potentially a part of culture and to break out of traditional cultural stigma around HIV is difficult and it's difficult to reach out to other couples living with HIV; more so, it's really difficult for an immigrant couple to reach out for help.*

**Male Speaker:**

*Sometimes, family members isolate couples when they find out that they have a HIV diagnosis. Sometimes people are very open to hearing that you are living with HIV and they do not judge you as a person; while it's scary to have your partner's parents find out that you are HIV-positive.*

**Male Speaker:**

*Being on TV to tell people about my HIV status was okay to do and I started to educate my family on HIV, what it means, and how its transmission through blood and bodily fluid works. There were lots of questions regarding aging and HIV.*

**Male Speaker:**

*I was interested in how to be an emotionally healthy couple around HIV and illness, not just AIDS. Sero-discordant couples can end up living in isolation due to HIV-infused stigma. This is a significant anxiety within the experience of living with HIV regarding dying.*

**Male Speaker:**

*In the larger gay community, I know people that are positive but they do not want to talk about it as fear still pervades the gay community due to the historical experience of the AIDS epidemic of the 70's and 80's.*

**Female Speaker:**

*There are complicated couples' experiences that come with living with HIV that cannot be talked about with other couples that do not live with HIV. Intimacy changes HIV. Age is a significant factor in living with HIV.*

**Male Speaker:**

*Always having to think about using a condom as protection from infecting my partner. Sometimes I ponder as the partner of the positive partner, if it would be easier to be positive too. Sometimes I take risk in intimacy as I think it would be easier to be positive with my partner.*

**Male Speaker:**

*HIV jaded intimacy, intimacy never the same after being diagnosed with HIV. Once virus managed with medications, then couples can have safer sex such as oral sex with no protection.*

**Female Speaker:**

*Once being diagnosed with HIV, feeling asexual and loss of desire. Sex drive being impacted by living with HIV, as virus makes you tired and aging also plays out.*

**Male Speaker:**

*Finding intimacy beyond sex, looking for ways to increase intimacy without being sexually active. Sometimes wondering if my non-positive partner will leave me.*

**Male Speaker:**

*Fear of infecting negative partner is always there.*

*(field notes, February 25, 2012)*

In reflection, these comments were lived experience stories that would allow the couples to sort through the tensions of their private experiences within their larger lived experience of HIV. By sharing their truths, the HIV-infused stigma that had overwhelmed

the experience of the couples living with HIV was lifted. This allowed the couples' voices to be heard; they became an eager audience for the unravelling of each story.

Stories of sex, lived experience, age, living well, family, and a plethora of other lived experience factors, embedded themselves in the general discourse that fermented within the gatherings. The lifted veil of stigma allowed for the expression of experience ([within the limitations of language], within the tensions of emotions) that sat within the breaking out of dominant discourse that had defined their experience as a sero-discordant couple. As the second gathering began, sero-discordant couples were nervous and filled with tension about being seen, not saying enough, talking too much, being too emotional and feeling vulnerable within the group. The following are experiences of the participants, in their own words:

**Female Speaker:**

*We had a hard time talking about living with HIV and how my partner got infected. Telling our story is hard to do as there is so much shame, guilt, fear and so much unknown.*

**Male Speaker:**

*Family members who knew our status betrayed us by telling other family members. We were psychologically attacked by family members, due to the fear for their one family member, who could become infected.*

**Male Speaker:**

*We are telling family members of other health conditions but not ready for full disclose, preparing them that maybe someday I may need to tell them.*

**Female Speaker:**

*His sperm is poisonous for me. Betrayal a big issue, being preoccupied with how the other person got the virus, have to remember no one is perfect as a way of letting go of anger towards partner. We are living with a "secret".*

**Male Speaker:**

*What is the benefit of telling people, why do they need to know?*

**Female Speaker:**

*We are living a lie. If you tell family will it benefit your couple relationship, will they pressure you to leave your HIV-positive partner?*

**Male Speaker:**

*Telling the family, can be the biggest gift to the next generation of people as it challenges HIV-infused social stigma.*

*(field notes, March 14, 2012)*

The voiced experiences were diverse - intimacy and betrayal, sperm now experienced as a weapon, sexuality changed into something not wanted, continued (albeit changed) desire and intimacy. Conversations about how to talk about the diagnosis with other family members was potentially problematic because a predefined script could lead to rejection, shame and further judgement. Some participants believed that family discussions should be an act of social activism – a coming out or a standing tall with no shame – that challenges the current dominant discourse that “others” or disenfranchises them. There were also overlapping conversations about the range and combinations of lived experiences with HIV. Because nothing was mandated or fixed during the

gatherings, all dialogues were allowed and each member of the group could identify their point of vulnerability and share it with the group.

As the gatherings merged into their third session, there was an elevated emotional difference in the room; people now greeted each other, there was a sense of familiarity from previous gatherings, and many smiles were shared. Although some members were new, there was more ease to discussions, which seemed to come more naturally. Participants looked to each other for engagement, rather than to me, the co-researcher. The easy laughter, shared sadness, tears, tension, and peacefulness were evident. The groups initiated discussions with each other immediately, reintroducing themselves and reaching out to get to know the new members. The participants carved out an informal agenda that summarized what they wanted to achieve – open spaces for peace, justice, equality, safety, inclusiveness and reduced isolation. The group emphasized the need to hear all voices, and to validate stories as unique and representative of their lived experience. The third meeting turned into a dialectic movement that released participants from HIV-infused stigma, and allowed HIV-defined discourse to be validated and less isolating.

The following dialogue came out of the third gathering of sero-discordant couples:

**Male Speaker:**

*If we inform people of our HIV-positive status they can make a better decision in their own sexual lives, if we are to share out sexual practices.*

*We have lots of history around being sexually active. Our history of how HIV has changed us as a sexually active couple. Maybe we could have infected out partners without knowing that we had. I feel bad for that, if it happened.*

**Male Speaker:**

*Waiting for partner test results, highly fearful and worried about the results. The days of waiting seemed like years. Wanting to talk about it with my partner but not wanting to. More tension in the relationship while we wait.*

**Female Speaker:**

*Being sexually active before the relationship and choosing to get tested. Not positive at that time and then positive when I did not expect it.*

**Male Speaker:**

*Couples not being sexually active, one person went outside the relationship and brought back HIV. Now navigating (not that successfully) open versus closed relationships. How to address the fluidity of boundaries, sex and safety?*

**Male Speaker:**

*Being happy together with no sex. How to handle the truth of temptation, it is intense.*

**Female Speaker:**

*Many stories of living in the present and letting go of the past, always remembering their partner loves them, though love should not hurt.*

*Shared experiences around finding out they are HIV-positive, difference and commonality in emotion and adjustment. Now feeling blessed, talking about who we are and who we were.*

**Female Speaker:**

*Feelings of embarrassment, guilt, shame and being depressed after the initial diagnosis. Other people generalize how you got it, the HIV diagnosis, usually that we were sexually deviant. Feeling like I am being punished, based on being Catholic. There is not punishment due to being HIV-positive, the New Testament talks about a loving God that does not judge.*

**Male Speaker:**

*Having HIV is not only a gay disease, it can happen to anyone. Multiple disclosures around CD4 counts being monitored as a way of understanding the process of diagnosis, how long they were infected might define how it happened.*

**Male Speaker:**

*Immigration needs to know so much information about my HIV status.*

**Female Speaker:**

*Feeling caught and cannot tell others about our HIV-positive status as it is complicated when deciding who to tell, not being told who to tell about your diagnosis. We needed lots of rebuilding of the relationship after a HIV-positive diagnosis.*

**Male Speaker:**

*The HIV diagnosis has been in the gay community longer and in turn is more acceptable.*

**Female Speaker:**

*Family issues are a significant concern, who to tell, who knows, who are they telling or not. We experienced family rejection; though they said they loved me, I guess only conditionally. We are more mindful in relation to developing community.*

*(field notes, April 7, 2012)*

The couples mingled after the sessions closed and appeared more connected and less afraid. They participated in deeper conversations, they no longer feared disclosure and they requested more gatherings; they seemed to want something real with each other, and transformed the conversation space into a safe place to externalize the lived experience of living with HIV. Different experiences translated into a bond of shared experience with divergent translations of emotions, thoughts and actions. Fals Borda (2013) described how authentic participation aims to shorten the relational distance between the superior and subaltern, oppressors and oppressed, exploiter and exploited, roles that contain and limit people in to dominance and submission standpoints. The couples had authentically participated within an action-oriented research process. The sero-discordant couples activated their own empowerment in order to engage a community process, through generative dialogues that enhanced their ability to develop inner courage and self-efficacy. Collectively, this deconstructed the historical-cultural myths that had disempowered and marginalized them.

My role shaped into taking the data and making sure that everyone in the gatherings had a chance to see and review the themes, as discussed in the initial guidelines. Field notes became important as they were now representative of the history of the group's conversations. However, the participants were not interested in reviewing

the field notes. Instead, they clearly and unanimously articulated that they wanted more gatherings in order to further establish a safe space to continue to understand their discourse around lived experiences of living with HIV. Gergen and Gergen (2003) argue that discourse itself is a form of social action – a doing with in the world. These couples discovered the intrinsic benefit of social action by creating meaning through the sharing of discourse in their gatherings. They rose into dialogue from places of vulnerability and redefined the landscape of their lived experience; in this way, they transcended the experiences that had previously been prescribed through HIV-infused stigma.

The couples continued to meet monthly through the spring and into summer. During this time, the enlightened participant conversations shifted the larger sero-discordant couples' discourse. The couples, as a community, were evolving their story together, and repetitive multifaceted exchanges allowed the community to shift their story without the aid of myself as the co-researcher. Freire (1970) argued that PAR has an authentic and organic nature as an approach that allows community members to name and conceptualize their own problems and then co-enact searched for solutions or resolutions. Organically, the sero-discordant couples created community through dialogue, and through generating discourse that would best represent a formative outcome that enabled them to feel empowered to continue with each other, while shaping the future of the group process.

### **INTIMATE DIALOGUES: KNOWING THE UNKNOWN**

As the couples continued to gather, a few of the sero-discordant couple participants wanted to share their story directly for the purposes of this written dissertation. Wade (1997) discusses how, in response to violence and oppression, people will engage in conversations that bring forth the details and implications of their own resistance. For these sero-discordant couples, their data – the story of their lived experience – offered an opportunity to better understand their history as it relates to the collective history of the AIDS epidemic, HIV-infused stigma, loss of lovers, estranged family and isolation, and discrimination. These conversations would form an act of resistance. As the couples found strength in their gatherings, they sought to share with the world the contemporary dialogue that defines their inner self – a dialogue that is submerged under stigma, isolation, and the significant relational dynamics that so many sero-discordant couples know and in turn resist. Wade (1997) described how people will engage in conversations that bring forth the details and implications of their own resistance to various forms of humiliation, racism, and exclusion based on disability or sexual preference, which are defined by the dominant group. These conversations form articulate actions (a meaningful dialogues) that become written words (i.e., data) within the world of research. They also form an act of resistance (i.e., response-based theory) for groups who are mistreated because of oppressive social stigma.



### **The Invitation: Data Sharing Without a Condom**

Some sero-discordant couples offered to place their stories in a written document (i.e., this thesis) so that those who seek to understand them outside of the veil of oppression and stigma might come to understand some of the contemporary issues faced by sero-discordant lovers and relational partners. Wade (1997) described how any mental or behavioural action through which a person attempts to expose, withstand, stop, strive against or oppose any form of violence or oppression, may be understood as a form of resistance. These courageous couples signed over their stories for those who have never known the lived experience of someone who is HIV-positive or is a lover to someone who is HIV-positive. Each couple reviewed their own story and these stories became reflective of their relational process; the review became a way of ensuring that the words truly reflected their ideas and actions, and were as accurate as possible. The couples were given the choice to remove their stories at any time before the publication of the final dissertation.

The following stories come to us from couples who define themselves as lovers, friends (and enemies at times), soul mates, and partners. Sexuality is expressed differently between two partners who share the virus and its sero-status permutation. Whether the partnership was formed amidst a betrayal by the partner who knew they were HIV-positive but did not share their status, or whether the partnership formed under less hurtful circumstances, these couples now embark on their shared journey with HIV. The generative dialogues tentatively evolved in the beginning from being uncomfortable to being openly expressed invitations to enter into an intimate disclosure of their lived experience. Themes evolved into many common moments of understanding between the couples with myself as their witness, protected in a stigma-free relational dynamic that was free from the oppression.

### **THEIR STORIES: HIV, RELATIONAL WORDS AND THE LIVED EXPERIENCE**

Some couples who shared their stories were willing to reveal their identity despite being sero-discordant lovers in this harsh, heterosexist world with all its oppression towards gay couples, transgendered persons, and persons living with HIV. What makes a couple ready to share their sero-discordant status with others who will never know the lived experience of living with HIV beyond the dominant, medialized, whitewashed story? According to response-based theory, the open sharing of their story is an act of resistance that allows sero-discordant couples to initiate a discourse concerning the healthy resistance to oppression. These conversations require multifaceted exchanges that prioritize dialogue that has never been heard before. They provide an urgent facelift to the lived experience of being a sero-discordant couple and encourage progress on the continuum of resistance to HIV-induced stigma.

The word “story” comes from the Latin words “storia” and “historia”. If one looks to its origins in history, “story” provides a marriage between story and history, and one does not exist without influencing the other. As one brings forth another’s story into a document for the purpose of knowledge-building, they must do so with great care and regard for the author’s words as they describe the lived experience. These words reflect

the beauty and sorrow of the lived experience of HIV and the relational dynamic of living with a partner who is HIV-positive. The narratives shared below are provided by three sero-discordant couples (one gay couple, one heterosexual couple, and one gay and transgendered couple) who seek to establish a life grounded in respect and equality.

### **Me, the Researcher: Questions around Consensual Data**

As a co-researcher, I created some questions to invite the couples into dialogue about their lived experience of being a couple and living with HIV. I met with each couple separately in an agreed upon space that was either a quiet coffee shop or an office space. These dialogues were separate from the main scheduled gatherings, as the couples wanted to provide intimate details of their lived experience as a way of further contributing to this significant piece of new knowledge. Their responses were shaped by being asked questions that aimed to understand how their experience of living with HIV had been shaped by social stigma.

The two main questions were as follows:

- a) What are the themes, the lived experiences that define, influence and matter in your sero-discordant relationship?
- b) How did the group benefit you as a sero-discordant couple?

### **Contribution # 1 - A Lover's Generative Dialogue**

As the first gay couple, Mark and Blaine (real names), shared their dialogue with me, they did so with great openness and a willingness to bring forth their full lived experience. They had few reservations or concerns about sharing their names, their relationship duration, or their age. The words of this couple flowed freely in animated discussion. With great enthusiasm they shared their experience of living together as a sero-discordant couple.

#### **Mark and Blaine:**

*Both men discussed how they feel they have sexuality and emotional barriers with other people beyond the relationship, specific to the isolation and stigma that comes from living with HIV. We did not choose the barriers that society places on us – they chose us. It's the barriers through HIV-induced stigma imposed on a couple that become internalized and then are, in turn, self-imposed and become our reality. Sero-discordant couples keep things from each other. The benefit of the group is that it allows a space to share things with other couples and my partner. Communication is important for sero-discordant couples as they can lose respect for each other and how to articulate your needs, and create safety; life is not black and white.*

I reflected on the barriers that this gay couple identified – isolation, stigma, inequality, homophobia – all of which are socially constructed as people create relationships through words, knowledge, experience, power, and all of the experiences that align with humanity. There are systemic perpetrators of social injustice that are not black and white. Namely, social stigma and oppression feed into the anarchy of discrimination and social isolation, which creates a divide between those who are HIV-positive and those who are not. The personal resistance that Blaine and Mark discuss is how they freely bond beyond the stigma that impairs the HIV discourse. Through the

impact of stigma, sero-discordant couples align and disalign with each other. Many types of stigma – including perceived, interacted, layered, symbolic and enacted stigma – highlight differences that create social separateness, and in doing so label difference as bad. The resistance to this oppression is to embrace, to love, to understand each other fully, and to create space with others to develop capacity within the HIV community.

The narrated insights by the sero-discordant couple highlight the politics of HIV-infused social stigma, with its implicit oppressive agenda (which takes an “us” versus “them” stance). Because HIV is medically defined as an infectious disease that one must be diagnosed with and that must be managed to prevent its spread into the non-HIV community, those living with HIV have little control over the greater HIV narrative. Loutfy et al. (2012) argued that “HIV-related stigma remains one of the greatest barriers to the health and well-being of people living with HIV” (p. 1). HIV-related stigma is complicated by its intersection with the structural inequalities and social processes that are often internalized by couples themselves; as a result, stigma is often unconsciously played out through their interpersonal relationships.

Creating safe spaces that nurtured the ebb and flow of conversation was integral to foster the well-being of the couples as they shifted through their lived experiences and re-experienced what it was like to live outside of the isolation that exists in an HIV-stigma infused, discriminatory society. Loutfy et al. (2012) explained how disclosure of one’s HIV-positive status to friends, family, social support networks and health care providers can lead to higher rates of marginalization, isolation and social exclusion (p. 1). These barriers and relational losses lead sero-discordant couples into isolation and increase the risk of deterioration of their emotional well-being. Wade (1997) explained that the precise form that resistance takes depends upon the unique dangers and opportunities that exist within any given situation. Because an HIV diagnosis can render a person unfit for healthy relationships by those who proclaimed their love pre-diagnosis, resistance might be an act of isolation that protects against rejection; the choice not to be in relationship allows more control over the experience of loss.

**Mark and Blaine:**

*The couple discuss how the experience of being in the gatherings has allowed there to be space to overcome some of the challenges of living with HIV in our day-to-day lives. A space that allows lives to touch each other through relationships developed, that give a connection to the stuff that each couple is living with. The gatherings bring forth an experience in which the dynamic forces that cause us to live in isolation are mediated and reduced so that there is more openness. HIV disconnects us from others, communities, church, families, and the relations that we need to stay healthy.*

It is remarkable that, as the world gets smaller through the advancement of technology, we as a larger community create isolation in the HIV-positive community through stigma. In first world countries, most people have access to diverse technologies. The internet connects people across the world and provides an opportunity for diverse individuals to relate to each other. Despite these advances, social stigma around HIV still creates barriers between people. HIV-related stigma is a dynamic and powerful force that negatively isolates sero-discordant couples from their families, their resources and their community by shaming and silencing them. HIV-infused stigma determines their lack of

worth, which psychologically injures them and disarms their innate ability to respond to that which is dismantling them.

As Mark and Blaine describe, this sense of pervasive isolation separates those who live with HIV from those who do not. HIV-related stigma has the power to harness the social standard of “deviant sexuality” as a cause of HIV, and in doing so it dehumanizes those who live with it; it labels HIV-positive individuals as “bad”. In turn, this stigma-infused process creates a fear of those who are HIV-positive. In turn, this prompts fear-fuelled guidelines to avoid infection, such as not to share toothbrushes, drinking cups, or hot tubs, to always use condoms, and to immediately clean up blood when injured. From the human apocalypse of HIV and AIDS arose the need to segregate and keep away those who might bring destruction to HIV-negative people; this represents a contemporary version of George Orwell’s (1949) classic novel *1984*, but without the screen playing the script. In today’s world, social discourse holds the script of othering.

**Mark and Blaine:**

*Words that come from lived experience are those of: do not stop living, your day continues, it has been in my life as a gift that is HIV. Life is about bumps and bullshit, guns and roses. It’s the old versus the young. In openness we have each other and the general public, we take the risk to talk but you have to take it, we are the hero, we accept it and we bear it.*

Where does truth start and end? “Bumps and bullshit,” according to Mark and Blaine, are the main ingredients to resistance against the dominant discourse and stigma-infused isolation. The sharing of a life story, specific to the sero-discordant couple’s journey with HIV, comes with trials and tribulations but also with the wisdom of knowledge gathered through the experience of living with HIV. As this sero-discordant couple discusses, the bullshit part is the messiness that co-exists with most meaningful moments in which people must sort through the bumps of living with something that renders them oppressed, marginalized, disenfranchised and othered.

Externalizing the bullshit part of their couple experience allows this couple to label the oppression that wreaks havoc in their day-to-day life. The resilience of who they are and their commitment to living well with HIV breaks through the barrier of being powerless to the greater HIV-related stigma that permeates the society in which they live. It is important not to romanticize this form of resistance. It is painful and prudent, and highlights the determination of those who consider it to be the only way to live with meaning beyond oppression. The “mind” is vulnerable to inscription as written by the dominant dogma within HIV-infused stigma and socialization processes. Externalizing the bullshit and roses of living with HIV allows for the deconstruction of truths. The new awareness empowers people living with HIV to cognitively choose different social scripts, even when they are not sure on what script will work better. Choice itself is an act of resistance.

**Mark and Blaine:**

*If we think about what we hope for, it’s that there would be housing to meet our needs, and health care that will continue to support us throughout our lifetime. World peace and an ongoing movement to continue to break through the barriers that force us into isolation.*

Where does hope fit in for all people living with HIV? Why does hope, or the search for a hopeful process, connect us as human beings and as people living with HIV?

Knowing that one's primary needs will be met – such as shelter and food – and also knowing that one's life matters, provides a sense of hope and comfort. There is a dependency on the larger ecosystem called life, and also a dependency on others, to overcome the stigma and oppression that accompanies HIV. This gives meaning to the lives of those who live with the daily epidemic of HIV.

This incurable virus has brought the world to its feet and continues to erect barriers for those who live with HIV. From a constructionist perspective, the meaning of this couple's observations is made within historical relations of power, many of which pre-existed before the current observer (Winslade & Monk, 2008). The inheritance of a history that defined HIV and AIDS as being an epidemic to fear continues to plague the world and its human relations.

Beyond the initial momentum that came from the relational dynamics of AIDS and death, there is a new tension that arises out of hope and the desire to live well with HIV. We are now in our third generation of HIV – one that lives with hope and transcends HIV's inception in the first generation and the experience of AIDS and death in the second generation. There is now an opportunity to invite constructionist dialogues that contain seeds of alternation as a mode of nurturing a new relational humanity that co-exists collaboratively with HIV.

### **Contribution # 2 - Another Lover's Generative Dialogue**

The next couple, Rose and Eddy (not their real names), were a heterosexual African couple who had been together for 15 years. Rose has two adult children and one grandson from a previous marriage. They generously shared their story with all of us as a lived testament of the way that couples merge, blend, and give meaning to the ongoing experience of living with HIV and AIDS. Loutfy et al. (2012) discussed how the intersection of race and gender can exacerbate HIV-related stigma, which further compounds the risk of isolation and marginalization. This story highlights the intersectionality of race, gender and HIV.

#### **Rose and Eddy**

*Rose talks about how Eddy is her best friend, he is good and has helped her to overcome the stigma that comes with living with HIV. As well, he helps her to get through the many challenges that life brings as they stay together. Eddy talked about how Rose is a strong woman, whose strength gives Eddy strength. He notes that if Rose was not strong and if she had given up after her diagnosis, he would not have been able to stay with her for so long. She is open and not afraid to express her strength.*

Rose and Eddy found a strength that instilled itself into their psyche and into the ecology of their relationship. Eddy, a committed partner, felt honored to accompany his lover in her battle with HIV and its long-term implications. Rose and Eddy, amidst much chaos and trauma from the initial diagnosis, found that each other's strength provided a calm in the storm. As committed partners, they faced the consequences of living with HIV and vowed not to be beaten by AIDS. Together, they negotiated moments of not knowing what the future had in store beyond a positive HIV diagnosis. They tried to focus on healthy living, despite the shadow of death that lurked behind Rose's persistently low CD4 count. Both Rose and Eddy displayed great bravery through their choice to be "all in", even amidst the real possibility of death.

Eddy's story of watching his partner, Rose, come close to death and yet find ways to keep living was an act of resistance. Their story is closely linked with the AIDS epidemic of the 1970s and 1980s. Acts of courage, strength, cradling death, and walking towards life co-mingle with the virus; HIV has the potential to define the couple experience. Vulnerability (i.e., the willingness to be "all-in") arises from the dance called life. It reflects a range of evolving feelings and states – deceased, dying, (not) fighting the virus, recovering, worrying, being afraid, being hopeful (Brown, 2017). Collectively, these descriptive words form a discourse that brings fear and hope to the life of a sero-discordant couple. This allows the couple to transcend death and pursue a life together beyond AIDS. It establishes a relational dynamic that bridges all intersectionality and allows the couple to find empowerment and meaning together.

**Rose and Eddy:**

*When Rose was diagnosed, she was very ill. Death seemed imminent with fevers, lack of eating, deteriorating in the hospital, no long-term memory. The health crisis took all of our energy and it helped us to know that we could get through anything. We understood that this health crisis had prepared us to get through life, to pass through such difficulties that basic living was like being on a holiday. We are now living beyond crisis and we are in heaven. Each day is a gift and we honor that we are alive and together.*

Rose and Eddy honored each other and found love within and beyond Rose's health crisis. The sero-discordant couple had glimpses of both heaven and hell as HIV progressed to AIDS and back again. There is no remission in sight for Rose - just a medically managed virus. Eddy and Rose's love faced the ultimate sacrifice of letting go; each partner encouraged the other to let go and move towards something more or different. Rose was strong in her encouragement of Eddy to let go and continue life without her. In this way, Rose provided a gift to Eddy in the form of resistance to the impact that the virus would have on both of their lives. Wade (1997) explained that resistance can fall between the extremes of open defiance and completely disguised activities. Rose's encouragement of Eddy to let go could have been her way of trying to encourage him to choose to leave to reduce the impact of her suffering on him.

The dyad experienced sanity and insanity all in one gesture, merging the unknown with the known – all this within one relationship that had the common ingredients of HIV, intimacy, strength and resiliency. Rose had a fleeting moment of insanity, of living beyond reason; Eddy took on the role of a lover who stepped back in and met her in the storm of a possible AIDS-defining death. Both partners found reason and sanity in their health crisis and anchored each other.

**Rose and Eddy:**

*We believe in each other; we have great emotional and physical communication. We use condoms when we make love, yet Eddy goes every six months to be tested for HIV. Intimacy has changed since the diagnosis but we still have intimacy. When I was sick, I thought I would die, and I thought he would leave me. I'm not dead, it's a part of life, living with HIV.*

The inevitability of an AIDS-defining illness came with the AIDS epidemic of the 1970s and 1980s. Rose recognized this foreshadowing of loss, which has always been part of the dominant discourse of HIV. Rose and Eddy so eloquently found a way to walk right next to death, while taking turns understanding how to walk beyond it. Love-making

took on meaning, and condoms were used to protect against the spread of the virus. These intimate details of lovers' delight highlight the sacred right of people to be lovers regardless of their HIV status, and despite the potential risk of spreading the virus to the uninfected partner.

Loutfy et al. (2012) described how HIV-related stigma is associated with deleterious mental, psychological and emotional health outcomes that reduce the quality of life for those who live with HIV. They also described how disclosure of one's HIV-positive serostatus to friends, family and supports can lead to marginalization, isolation, social exclusion which ultimately puts them at risk for psychological and emotional duress. Disclosure had the opposite effect on Rose and Eddy; with disclosure, their love grew, their passion flourished, and they committed to a life together. This blending of bodies, which was not held hostage by the plight of the virus, provided the opportunity for sexual bonding, and the couple could follow the standard medical protocols of condom use for harm reduction. Interestingly, this harm reduction strategy is identical to that used to prevent pregnancy, and everyone hopes, of course, that the condom does not break.

### **Contribution # 3 - Another Lover's Generative Dialogue**

The third couple consisted of one partner who identified as gay and the other who was transgender. Their relationship merged diversity and intimacy, and simultaneously navigated gender fluidity and HIV adversity. It provides a relational story that bridges commitment, the intersection of sexual orientation, race, and HIV. The couple shared their story with the same depth of transparency as the others. Their names have been changed for the sake of confidentiality. Confidentiality for this couple was required due to family members not knowing their HIV status, professional associations acting as oppressors around the issue of HIV and gay-trans relationships, and finally, a sense that the world was not safe enough to reveal the love that binds this diverse couple as they live with HIV.

Loutfy et al. (2012) discussed how, "since the beginning of the epidemic, HIV and AIDS have been associated with "deviant sexuality" (e.g., homosexuality, sex work), reinforcing the notion of the disease as punishment" (p. 7). The idea of punishment brings up a fear for this couple that life would not be safe enough to disclose their relationship and HIV status. In the worst-case scenarios, disclosure can lead to discrimination, or to being fired, rejected by family, beat up, or in some countries killed. As Wade (1997) highlights, the precious act of defense that can come in the form of a refusal to perform the display constitutes an affront that gives no reliable information about the subordinate's true intentions or beliefs. The choice to identify by a different name is an act of resistance against the dominant oppression that exists around identity and HIV status.

#### **James and Carlos:**

*We consider ourselves to be married as we have been in a 30-year relationship. My partner is transgendered; I am not attracted to him as a woman. I try not to bring home stress so that I do not impact negatively my partner who is HIV-positive. I feel responsible for his well-being. I do not want to lose him.*

James and Carlos were deeply committed to each other, and their relationship merged with HIV. James thought through his daily actions as he pondered how his stress

impacted his partner's physical and mental health. They shared the experience of living with the risk and protective factors that can change the health status of someone diagnosed with HIV. In their shared experience of being a diverse couple, living with HIV did not scare them. Their thinking about loss merged with the uncertain outcome that accompanies a low CD4 count – an indication that the HIV virus is stronger than the opposing antibodies and immune system. For Carlos and James, good fortune had been with them, as Carlos's immune system continued to be strong, creating a high CD4 count and a low HIV viral load.

**Carlos:**

*"I have been a transgendered person since I was 14 years old."*

Carlos pondered his process of transition between two socially and biologically defined genders. Carlos knew himself within two gender experiences, but now lived within one body, now with HIV. How does one who is transitioning their gender sit with the experience of HIV, and how does one reconcile being with their HIV-negative partner? Does the line between the challenge of transitioning gender merge with the complexity of HIV, and then somehow further merge with the homosexual partnership? There is the potential for multiple intersections of oppression, due to difference, within this one relational experience. For Carlos and James, their identity as a couple living with HIV, and its intersection with multiple layers of oppression, pushed the boundary on a contemporary lived experience far beyond the social construction of a same-sex or gay relationship.

**James and Carlos:**

*We met at the Devonian Gardens the first year Carlos came to Canada. We developed a friendship, then we became lovers and the sex was great. As a couple we are sympatico; we share and we connect. We share our world, and whether or not we share our worlds all the time, we have orbited together and we have a peripheral state with each other.*

For James and Carlos, there is importance in endorsing each other's sexual desires. This is a core component in their relationship that goes beyond the definition of who they need to be versus who they want to be. James and Carlos, as life partners, found ways to break out of gender and sexual captivity, while allowing each other to transcend their own mental limitations around sexual expression and experience. They identified how each partner would grow into something more and someone different – beyond the limits of socially defined definitions of self, sexual expression and the other. This couple moved through their lives with great transparency as they decided that they were going to live beyond what they had inherited from the greater good of their family, their community and society. They exercised a state of "being with" rather than "being of", and always maintained their connection through their committed relationship. James and Carlos orbited around each other and merged with each other, all while connected to HIV.

**James and Carlos:**

*Partner of HIV transgendered person says, "I thought of myself as a straight, gay man." We need to find an accepting community with no drama. We are not your stereotypical gay couple. We talk the talk; we do not walk the walk of a typical gay couple. He let me, my gay partner, be the person that I needed to be.*

The paradox of being a couple for James and Carlos was letting "me" become



“we”. As a sero-discordant couple, they became “we” together and possibly forever, amidst HIV. For James and Carlos, the gentle acceptance of a partner who would stand with, but not need to define the journey of the soul of their partner, was hard to find but not impossible. A spiritual resistance arose as they travelled beyond socially structured boundaries and transcended predefined heterosexual relationship dogma. James and Carlos discussed how it is naïve to assume that life follows a linear path towards being a gay couple, and that they are an evolved couple who have experienced and will experience many different moments in their lifeline together. They were able to imagine, in real terms, their future as one.

**Carlos:**

*If I did not take the HIV pills, then my partner would be worried. As a person living with HIV, my HIV is managed and I am now having to deal with the pain. I am more cautious and my personality has changed. I am more cautious, anxious and my memory has changed.*

Carlos pondered how to manage his health condition, which took away the best of who he was. He also found a way to manage the many health issues that are co-morbidities of HIV. He talked about how there comes a season of mastery, in which couples realize that they have come to an understanding of the many portals of their experience around living with the HIV virus, the virus’s life cycle, and the virus’s impact on the experience of their lives together. The goal of healthy living was a mystery that could only be solved by the couple; the importance of supporting each other through the difficult issues of health amidst living with HIV was clear. The pills that Carlos referred to defined the virus’s wellbeing; to go without these pills brought fear to both the taker and the other (James, the observer). James and Carlos were dependent on the daily ritual of taking pills in order to render the virus undetectable. The HART medication now defines the couple’s story – whether or not they have a good day, whether or not the virus is suppressed.

**James and Carlos:**

*In keeping this relationship healthy, we need to decrease our isolation while having good communication and at times accept our separateness. We do have our separate times, and then time with friends. In our own relationship, we have more than sexual experiences of each other. We believe that our relationship experience is more holistic and includes the sexual, emotional, mental, and spiritual components of who we are.*

James and Carlos pondered how they could find clusters of people with whom they could dialogue and share their story. How could they find a group of people who were willing to share and listen to their experiences of living with HIV? The day-to-day dynamics that define the couple story can be hard to bring to another group of people when there is a lack of trust and uncertainty about whether others will relate. James and Carlos discussed the significant limitations that accompany their reality as a couple living with HIV - a dynamic only they could know. There was little room for their story to mingle into another’s space, and also significant fear of stigma that arose from the uncertainty about whether or not others would be able to hold their story.

**James and Carlos:**

*When I am out with my bisexual friends, I feel excited and joyful. I feel my HIV-negative partner feels sorry for me. He says, ‘no I love you. I worry that he will be*

*taken by AIDS’.*

James and Carlos identified the importance of connection and separation from others and oneself, and the tendency to project personal suffering onto others. They also pointed out that sometimes couples find a corner of connection within the realm of living with HIV. This couple also described how there is lustful joy in their union that somehow continues to shape their couple experience. They described a dance between the lust that they experience as a couple and underlying feelings of fear and shame. This couple has managed to transcend the societal oppression that often imposes itself onto the story of how many couples should feel, think and behave. James and Carlos continually assert their power by being authentic, by being genuine with each other, and by defining a story that is theirs, not ours.

### **Externalized Conversations: New Perspectives**

The couples in the gatherings and one-on-one interviews brought forth an intimate fluency that allowed them to share their couple language and their identity, which came from building relationships that co-exist with HIV but are not solely defined by it. The same couples built a collective dialogue that wove around their couple experience. This dialogue encompassed fear and courage, desire and denial, loving and being loved, gratification and expression, vulnerability and strength, and a social deconstruction of their identity.

The intersectionality of social location, lived experience, sexual orientation and preference, race, and a multitude of other experiences merge together to create a deeper version of the lived experience with HIV. Based on the data collected here, it appears that a couple changes when confronted with HIV due to social stigma, oppression, and the social construction of what defines a meaningful relationship in the context of HIV. Feelings of expression and rejection merge with and submerge each other; there is a battle between the experience that society prescribes and the newly constructed experience that the couple chooses outside of the confines oppression. Coping strategies and surviving episodes of AIDS defined the landscapes of the stores that the couples brought forward. Resistance in the form of making choices outside of stigmatized and oppressive expectations helped to redefine the meaning of living with HIV; this can be considered a form of action-based critical consciousness.

### **SURVIVING TO THRIVING: COUPLES LIVING WITH PASSION**

Reflecting on the conversations and stories that the sero-discordant couples shared brings a deeper understanding to the interdependent basis of meaning that co-exists within the lived experience of HIV. When couples turn the corner of illness and move into thriving, they laugh and share their stories with pride. There is a sense of being creative, of moving beyond those moments where there is only emotional carnage. What brings so much opportunity to living well as a couple? The couples’ dialogues, which we call data, shared a significant theme called “passion” that was not overshadowed by the HIV virus, or its worst opportunistic version – an AIDS defining illness. The tensions discussed in the dialogues represented a lived experience that situated itself into historical

social constructs – the AIDS epidemic still permeates the social narrative of living with HIV.

The couples made a true leap into expression and expansion through their gatherings and one-on-one conversations. As they chose to tell their stories, they leapt into the unknown and defined themselves as sero-discordant couples. They developed a new theme – an HIV-infused story that undid, redefined and integrated the passion that brought them together and the tension and uncertainty of time and health related to their HIV status. This relational awareness brought forward its own energy. The realization of a unified experience with HIV that transcended stigma allowed the couples to shift from fear to empowerment.

The couples identified how they met and that this seductive energy brought them together into a world of living and loving. This world somehow merged their connection through the chaos of HIV and reduced the structural oppression of social stigma. These couples were able to overcome some of the burden of oppression that accompanies HIV, and in doing so take back their power. They defined their meaning of being gay, transgendered, and heterosexual, old, young, and of various racial origins through the intersectionality of their lived experience in-action. The couples organized themselves in a way that allowed them to rise above the societal oppression that prevails when groups are marginalized and silenced through isolation and HIV-infused stigma. In today's modern world, HIV no longer means certain death. Sero-discordant couples can now bring ideas to the table about how to live well with HIV.

### **The Calling that Was Answered**

As the action-oriented phase of the research continued with ongoing gatherings, by the late summer/early fall of 2012, the group grew into a community of sero-discordant couples who wanted an ongoing meeting place that was safe enough to allow the group to be opened up to other couples. There was a sense of urgency that if an appropriate space was not found, the success of the gatherings would not continue. At this time, I found a new spot in the community for ongoing gatherings within the Calgary Cares Community Centre [later called HIC Community Living]. This was like a gift of support from the larger HIV community. The space provided a gathering place that was equipped with a kitchen, parking space, and space for ongoing support of future development. The space gave the group of couples a safe and comfortable home outside of a medical facility and within a safe community.

As new couples came into the group and were embraced, their awkwardness and emotional rawness were accepted and seen as normal, just as when a new diagnosis comes into a couple's life. Couples told many stories that navigated many themes: betrayal, uncertainty, fear, anger, disgust, shame, need, hatred, powerlessness, and power. Tensions and differences were played significant roles in the stories as the intersectionality of experiences merged. Listening with respect became key to the group moving forward in their discussions.

The core group was incredibly patient and knowing of the moments of despair that were expressed by the newcomers, and all expressions of sero-status were embraced. There was no judgment from the group members of the fragility that comes with newly diagnosed sero-status. People openly struggled with the story of what had happened (or

had not happened) and how they had tried to manage the impact of their lived experience with HIV. The group members did not press for details about infection, an experience that is common among sero-couples in a public health or medical setting.

As new sero-discordant couples joined and merged with existing couples in the gatherings, I observed as the co-researcher a new hybrid community evolved with each new member sharing experiences and conversations that mattered to them. Gergen (2012) referred to cultural hybridization—a secondary creativity or an intermixing of assumptions and practices—that comes from relational dynamics that exist together. The core experience of this group was that of HIV and sero-status, while the fluidity of the group was in the experiences embedded in the varied lived stories of each couple. In the multi-dimensional self, when the new merges with the old, the old accepts the new (or vice versa). The old and new then then merge to build collective self-expression through relational experiences. This is needed to allow each couple to find a space within the larger conversation; conversely, co-creating a relational community with others who live with HIV enables the whole to collectively become multidimensional selves (versus one-dimensional selves who are isolated by HIV-induced stigma).

### **What Matters When Your World is Negotiated with HIV?**

Compliments and encouragement continued to compound the community experience of the gatherings. No one person was above another, and no expressions were deemed wrong. All words mattered in moments of discussion because they weaved into the collective narratives of the lived experience of HIV. During the monthly gatherings, many tears were shed and at times smiles faded as memories were shared around tales of betrayal. Individuals shared stories of how medical professionals had positively impacted their HIV experience. Viral load and medication stories were shared, and many couples were interested in the information that the new couples had to share about, for example, when to start medications, and why. The old told travel stories about their experiences as the United States lifted the travel ban that had previously prevented those with positive HIV status from entering the country.

Sex, sexy and sexual – each of these terms became common topics of discussion within the group. There is still significant fear about transmitting the virus to the negative partner, and safe sex practices came up often in the group's conversations. Some couples indicated that sometimes they slipped and forgot to use a condom; the tenderness and passion of sexual expression was very much part of their journey together as sero-status couples. Couples acknowledged these slips for what they were – a sign that they were human, with needs for sexual expression, passion and love. Relief was also expressed in these discussions that a lover had not been infected with the virus. There seemed to be a collective understanding that the fear of transmission to a negative partner was always there. Others logically dialogued through a discourse that built room for a slip, allowing it to be accepted if ever those human moments got the best of a couple's intimate encounter.

Discussions around sexual practice and “keeping safe” co-existed in the group. Sexual practices were discussed as being medically directed around the need to prevent infection of the sero-status partner. Using condoms was discussed as part of sexual hygiene, specific to prevention. Risk, always pertinent to the couples' reality, was also

discussed. The participants conversed about the risk of transmission from one person to another. The couples collectively agreed that risk is ultimately defined through medical discourse (e.g., about sexual positions, consequences of a lack of sexual protection). Their dialogues suggested that positive prevention, as promoted by the gay community, encourages persons living with HIV to live a life with high-quality, fulfilling relationships. This shift from a risk reduction strategy to a positive prevention discourse empowered the couples to achieve a good life through making choices to enhance the quality of their relationship with a sero-status partner. This choice was a form of resistance – a deviance that overcame social stigma.

According to the article “A Primer on Positive Prevention,” positive prevention strategies are designed for people living with HIV to:

- (1) “empower people living with HIV to take control of their sexual health as a way of preventing the transmission of HIV and other sexually transmitted infections (STIs);
- (2) promote full, satisfying and healthy emotional and sexual relationships;
- (3) promote the sexual and reproductive rights of everyone, regardless of HIV status; and
- (3) combat stigma and discrimination, to ensure equal access to services that can help improve the health and well-being of people living with HIV” (Knowles, 2010).

Some of these guidelines fit within the group members’ understanding of what they needed. Some of the group members defined a need to protect others from them; like the choice to prevent pregnancy, they wanted to love fully, while taking steps to prevent the proliferation of health challenges. The generative component of their monthly dialogues allowed multi-perspectives and multi-experiences to emerge within one community of lived experience, the common denominator being living with HIV as a sero-discordant couple.

### **Will There be a Cure?**

Multiple times in the group, members collectively pondered the possibility of a cure for HIV. Among group members, there was the sense that a preventative vaccine would be created before a cure. Discussions about HIV prevention became a common topic of dialogue in the gatherings. The social construction of a cure seemed to mean achieving HIV-free status by eradicating the virus through medication. This dialogue situated itself within the larger AIDS discussion in which the sentiment was that, currently, we are not an AIDS-free society.

In the late spring of 2013, a gathering took place at a local pub that was referred to us by one of the members. It was an opportunity to get together and have some food. The location was not ideal; conversations were lost because of too much noise in the pub. Everyone agreed that the food was a great idea, which started the process of bringing food to share as a part of the gatherings. Eventually, the group decided to walk over to the park and talk while sitting on some park benches. This environment and a beautiful evening brought forth open and thoughtful conversations.

As the gatherings continued, long-term survivors provided support to recently diagnosed couples. It was interesting to watch as the couples engaged and developed their

own support model. Those with the longer-lived experience provided validation, information, and support to others in the group. This support eventually became a part of their process of identifying what they wanted in a peer-support model. The 2013 spring meetings became key to the group identifying their needs as a collective. Some of the group members requested a peer support model for their gatherings, while others felt like this was not the most effective way to move forward.

Throughout the experience with the couples, it became evident that many people would benefit from a peer support model consisting of group gatherings. The couple experience is something that requires everyone to negotiate a common ground and create a united voice. Young (2006) argued that action in mobilization tends to change, generate, or evaluate practices and policies. This is what the group was informally doing as the gatherings morphed into a peer-centric model of support. The gathering couples brought much diversity and adversity as they began the sharing and growth process that gave meaning to their needs. The couples found a way to be together, to enjoy each other, and to relate; they also acknowledged the moments when their developmental stage as a couple did not coincide with that of others due to their proximity to their diagnosis, their sexual preference or experience, their age, their class, or other diversity issues. Regardless, the idea of being a couple, of being two together in the couple experience of living with HIV, did bring insight into the needs of the participating couples.

As HIV treatment has advanced, couples living with HIV have evolved and matured in their couple process. HIV does not mean death; living is an ally and the couples must reconcile HIV with its meaning on their lived experience. In this context, it was vital to talk about living well, and to avoid being stuck in loss, fear, shame, or hate. “Living well” became the new norm for the gatherings. Couples wanted to talk about living well and found an agenda that allowed them to understand the importance of finding meaning in living as a couple first, and as a couple with HIV second.

### **Medical Care: The Ultimate Answer to Living Well?**

The Southern Alberta Clinic transformed from a place where people were cared for as they died to a place where they were supported to live well; through medical care that integrated social workers, dietitians, psychiatrists and pharmacists to assist with longer-term chronic disease management. Throughout the gatherings, the Clinic was frequently referred to as a place that was key to the well-being of the sero-discordant couples. For those with an HIV diagnosis, the clinic provided a safety net. The couples dialogue around the Clinic and its staff was full of sentiment as the medical professionals there helped them to thrive. The couples expressed a sense of fear, but not avoidance, around the topic of their diagnosis and situations in which their health was at risk due to a dangerously high viral load. Participants noted how it was a doctor’s quick action that allowed them to live; they acknowledged that their caregiver’s actions allowed them to survive when survival seemed unfathomable. The exchange of names of doctors, nurses, pharmacists, and social workers became a part of the dialogue. There was a sense of wanting to share in the humanity of those who had helped.

Even the HIV-negative partner in the sero-discordant couples expressed esteem for medical staff who often showed concern for the well-being of the partner as well as their patient. These professionals from the Clinic were like lifelines in their narratives of

the initial diagnosis, the ongoing care, and the diagnosis of additional STI's or other ailments. The power of helping professionals was a significant part of the conversation that allowed the sero-discordant couples make sense of their lived experience.

### **Not Being There: A Tremendous Opportunity**

To support the on-going peer support model, I became a facilitator. I made sure that rooms were booked for meetings and that people had pertinent information, and I allowed the group to define my role in their gatherings. In November 2013, I was not able to attend a gathering because of childcare issues. In spite of my absence, the couples gathered without me, talking and sharing food and enjoying their conversations. As a group of like-minded individuals with a common experience, the couples were able to gather together even without my presence. They were successful and it honored the value of the members being able to provide the leadership and depth needed to support a community. This self-led meeting was a turning point, as they began the process of finding a way provide their own structure and to trust their own expertise.

### **They Celebrate as per the Season**

Soon it was the holiday season and it was time to celebrate together. A community research project such as PAR passes through many seasons. The holiday season gave rise to an opportunity to gather and be together. The sharing of gifts, food, and memories were important for the members as they discussed what they do to celebrate the holiday season. There were many similarities in their experiences, and they noted the differences that arose from their diverse cultures, religious beliefs, and personal experiences.

As the holiday discussion blended with personal stories, it became evident that the group had expanded its initiative to include talk about CD4 counts, and to celebrate the strength of their CD4 counts. The group merged dialectical expression of the most pertinent health issues with celebration discussions, all of which was done with ease and consideration of the multiple experiences and needs of the collective group. "As people talk they are negotiating each other into personal relational interactions that are historically and culturally embedded" (McNamee, 2010, p. 360). This group of couples negotiated with each other the diverse emotional needs that came with the discussion of CD4 counts, expressing how well their immune systems functioned; they celebrated knowing that they were now healthy and strong. Stories of CD4 counts were very common at the gatherings. It was evident that CD4 strength was a defining feature of who the couples were: the well or the unwell. Given the history surrounding this community in relation to the AIDS epidemic of the 1970s and 1980s, this common conversation seemed to infiltrate the group discussions even during holiday celebrations.

The couples explored how medical models prevail in their inner dialogues about life and death; CD4 counts, whether high or low, became a prevalent marker of the status of their lives. To seek treatment in the form of medication, or to be told that medication is necessary, can be oppressive and disempowering if a couple is not emotionally ready to embark on such a regimen. It can be difficult for couples to discuss their feelings around

this issue with others who do not share the same experience. Mixed emotions can arise when couples feel like they do not have a choice about whether or not to embark on a rigorous treatment course. The couples gave each other small gifts, which brought big meaning when exchanged with those who shared the experience of living with HIV. The group discussed the shared meaning of the group as being a gift in itself, in which couples were able to find nuggets of commonality and difference.

### **As the Gatherings Continue, They Become the New Normal**

As 2014 began and the gatherings continued to evolve, my role as co-researcher was shifting into a more consultative role, the idea to continue to develop an ongoing peer support model became very important. Many of the couples felt a need to continue to gather and be part of a community. They felt that the gatherings allowed them to connect and brought to them a sense that everything would be okay. The group's interest in helping others to transition from the initial diagnosis to living with some sort of peace was real. The group was supportive of each and everyone's story despite the diversity that existed within the group. The group decided to explore the possibility of meeting once every four to six weeks. The group looked to me, as their co-researcher and coordinator, for guidance as to how to set up the ongoing peer-support gatherings. The responsibility of creating the process was no longer mine, but I was formally invited by the group members to assist with the development of the peer support model.

### **New Knowledge Becomes a Template for Others to Understand**

As time progressed, it became clear that knowledge had now turned into a framework of information from which other agencies, professionals, and clients could benefit. The larger HIV community began to accept that this information was significant and was important to build on. HIV Community Link saw the value in provided funding for the development of the peer support model and took formal responsibility for its further development, in cooperation with the existing community of sero-discordant couples.

The group members were informed of the process, and were included in reviewing the documents that "we" as co-researchers had written and that highlighted the themes the couples had developed around their needs that would be presented and eventually become the written version of their new knowledge. The group was excited that their knowledge would make a difference in the world. They understood the importance of sharing their new knowledge, which came from the action research in which they had participated. The braveness of the group was evident in their commitment to having their collective lived experiences shared – in this dissertation, and with other agencies and funders. They also recognized that additional funding would provide them with money, space, food, supplies and stipends for their hard work.

There is a profound responsibility that comes with sharing the stories of others; one must carefully choose the words that best represent another's experience. This task can be daunting. However, the group itself reviewed the written words of their own narratives, and ensured that the words that were used accurately reflected their stories and their overall experience. A great deal of time was dedicated to writing, reflecting, and



rewriting before any documents were submitted or presented on behalf of this PAR project. Group members read and talked through the themes within this dissertation, an undertaking that all group members felt was a positive experience. It is important to note that such reflective writing with various group members, especially those who had been with the group since its inception, was critical in order to generate a final document that accurately reflected the sentiments of the group and its process.

## **CHAPTER FIVE: PEER SUPPORT & CAPACITY BUILDING**

“Empowerment found through science in-action.” (field notes, P. Miller, 25 April 2012)

### **LIVED EXPERIENCE EXPERTISE: PEER SUPPORT**

“Peer support is based on the primary idea that people who have faced and endured life difficulties can offer hope, support, encouragement and mentorship to those who have experienced something similar” (Kemp & Henderson, 2012, p. 337). The peer support model has a place within the social constructionist paradigm for active community support that allows people to define what they need and actively create a generative space that gives support to what they deem to be important. A peer support model means that leadership comes from within and that each participant is as important as the next.

There are many peer support frameworks that can guide or model a peer support group. Weingarten (2012) wrote about groups in Brazil that are modeled on the American approach, with two facilitators, one of whom is called the Guardian. The author discussed that the Guardian’s role is to assist with group facilitation by keeping track of time, registering those who wish to speak, being responsible for safeguarding order and respect, and supporting those group members who may be experiencing a difficult time (Weingarten, 2012). This concept of the Guardian paralleled the structure of our own group, in which I was the Guardian (or initiating researcher) together with the primary peer support facilitators. We were the keepers of the space, and provided emotional safety and process to the group, allowing it to be inclusive of others.

Hoey, Sutherland, Williams, and White (2011) described that “social support has been identified as an important contributor to general well-being, that it can buffer the impact of stressful life experiences, including those related to physical illness” (p. 87). The social support that was provided in our own peer support model provided a significant buffer to the community of sero-discordant couples as they experienced significant stress from their HIV diagnosis – stress that was reduced when participants were given the opportunity to talk and be less isolated in their stories. It was within discourse that power was found; social support reduced feelings of isolation and allowed words to be shared informally with those who cared.

### **Renewal, Evolving, and Differentiation: Into The New**

During 2014, the group of sero-discordant couples evolved to include couples in which both members were HIV-positive; the goal was to bring together people with similar interests who could provide support to each other. The new couples bridged discussions with the existing couples, providing another level of cross-pollination – new hybrid with a common experience: living with an HIV diagnosis as a couple and its impact on the couple experience.

#### ***Themes of Participant Dialogues of 2014:***

- *The implications of not disclosing HIV status when having sex with potential partners;*
- *Hep C transmission and prevention;*
- *Stigma and isolation;*
- *Relationships issues in general;*
- *What to do if in crisis (e.g., call the Distress Center);*
- *New members and concerns about confidentiality; and.*

- *Gay pride meet-up.*

If every newly diagnosed couple were to have access to couples support and a couple-friendly community, this could help them find their way towards a new, healthy version of themselves. Ideally, they would be able to negotiate new boundaries and ways to be healthy as a couple living with HIV, and would be able to avoid feelings of doom around living with the burden of the virus and the social stigma that accompanies it.

Couples living with HIV need a safe space where their stories can be shared, friendships can be formed, and casual understandings can be developed that bring people together. The hybridity of the original sero-discordant couple gatherings was expanded to include new experiences that could now shape how the group accepted each other's differences. The action dimension of the original group did not reflect that of couples who were both HIV-positive. The advantage of this PAR project was that group members had taken the time needed to evolve through various stages of meaning and action, while moving into action with meaning.

The group wondered whether its expansion to include both sero-discordant couples and dual HIV-positive couples might act as a catalyst for change. The openness of the original members, and their willingness to be both emotionally and mentally available to others living with the HIV, speaks to the humanity that can exist within a peer support community. The idea of allowing all couples who live with HIV to be included in the larger peer-support model was deemed important and quickly became the gatherings' new normal during 2014. MacDonald (2012) argued that the acting cycle of PAR requires that all community members' voices be heard and that the development of goals must be collectively agreed upon. This community action component was congruent with the key principles around the action phase of PAR, with agreed upon goals that would enhance the overall community experience.

The hybridity that was developed within this peer support group can serve as a model for other communities with chronic disease or other shared medical conditions. The peer support working model is currently being considered for other STBBI (Sexually Transmitted Blood-borne Infections) conditions in which marginalized communities would benefit from action and support. It is important that people continue to benefit from and support each other by creating dialogues that generate a comfortable space for others to join in conversation; this is especially true for marginalized communities such as couples living with HIV. The peer support model provides an opportunity for people to transform the science of action into safety, acceptance and support. This action provides a new beginning for couples living with HIV; it brings an evolving humanity and allows the vulnerable to avoid power relations of domination that marginalize them into isolation and silence.

### **Conversations that Merge with Professionals**

Carrying on conversations with people who are a part of the health care community invites medical professionals to become familiar with and promote the peer support model. This is a generative process that enhances people's well-being and decreases isolation. As the peer support model began to take shape, posters and invitations for discussion were offered across the larger health region. The goal was to draw attention to the value of peer support for people living with HIV. This public

advertising further reduced the HIV-infused stigma because it publicly declared that support was available for this validated group of people living with HIV.

The merging of a peer support community model with the larger medical model of care took shape over a period of time. The peer support model of care did have a viable outcome and, as of December 2015, was funded by ViiV Healthcare through the Positive Action Canada Innovation Program. This funding allowed meetings to occur once a month, providing consistent peer support for couples living with HIV. This legitimacy was important for the community and they took their new funded status as a sign that they were a legitimate, powerful and self-sustaining group.

As a co-researcher, I participated in the gatherings as a group member, not as an expert on others' experiences. In serving others, we seek to give and receive for the benefit of the whole. This is a symbiotic process that denounces hierarchy and moves itself into a "power with" stance with those whom the researcher hopes to serve and to grow in service with. Serving the community is a social work value that is historically embedded in many facets of practice. It has its roots in community activism and beyond, and is engaged with all communities. As they hope to empower or co-empower, social workers engage with people to find their strengths and build a stronger base for self-determination. In the context of self-determination, a client system is given a chance to build their own inner strengths and foster resilience. My role in this PAR research project evolved with the project itself, as it moved from being a gathering of sero-discordant couples to an action project of peer support.

The gatherings that we initiated for the group are ongoing as of the Fall of 2017. I have continued to develop relationship opportunities to enable this group to continue. Given the success of the group, I am faced with this question: If I have been encouraging sero-discordant couples to gather for their own best interest, do I continue to gather with them? A community researcher who engages PAR methodology is never really done unless the community decides they are done. One hopes that a community of people will continue to grow and pollinate its own system of ongoing support, beyond the involvement of the researcher. With PAR, there is never a clear-cut ending; while the initiating researcher has a finishing date or academic responsibility to complete, the group members continue to live their reality long after the research is done.

### **THE FUTURE: HAVE ARTISTS AND CREATIVE PEOPLE DONE THIS BEFORE?**

On top of Machu Picchu during the summers of 2014 and 2016, I felt my heart beating as I sat quietly with my thoughts and heart thinking about my dissertation and its meaning. It was time to finish writing. I felt that this written knowledge would be a gift given back to the community and beyond. After all, a PhD dissertation is a tremendous piece of information that is published to inform others seeking to understand new knowledge. However, I was uncertain about whether I had done enough. How did the Aztec people transcend ordinary thinking and develop a society that could establish itself upon a mountain or within a forest, in coexistence with more venomous species than one could imagine in the first world countries of today? This led me to think about how human civilization remains intact in the midst of stigma and isolation. I grappled with many questions regarding the sanity of a humanity that would seek to destroy, through

HIV-infused stigma, its own people, even though his virus can easily be managed with today's medicines.

The gatherings represented a significant undertaking that started with an idea and after six years produced a body of work that was sufficient for a PhD dissertation. Despite this, the meetings would not end with a similar formal closure. The gatherings developed their own identity, separate from the original research question. The next phase of this project is open-ended; metaphorically, it seems analogous to a kaleidoscope. If turned in one direction it could become a mirage of personal experience that leads the couples and myself in one direction; a different turn of the kaleidoscope could manifest a different experience and action that could disrupt the current gatherings and send the couples on a new course.

### **Some New Guidelines to Support a Sustainable HIV Community**

The initial plan for the peer support group was to include sero-discordant couples, or anyone interested in being in a relationship with someone who lives with HIV. This mandate then evolved to include couples in which both partners were HIV-positive. Establishing a consistent gathering date became a goal, as this created a formal identity for the group. The group was advertised and validated as providing a process that was supportive of its community members.

New couples were always welcome, and the group created criteria around who would be included/excluded. The criteria were as follows:

- Group members would consist of a sero-discordant couple/companion, or of people who had identified that they were interested in a sero-discordant relationship;
- Participants would have no known history of interpersonal violence within the relationship;
- Participants must be able to commit to the guidelines of confidentiality;
- Participants must agree to commit to the guideline of being respectful in the group and outside of the group with someone else's confidential story;
- Participants must commit to have fun and be willing to seek an understanding of how to live well with HIV;
- Participants must be adults;
- Participants must be willing to support others living with HIV;
- Participants must commit to attending the gatherings.

Over the three years that the peer-support group has been meeting, the guidelines have been reviewed every six months and there has been critical discussion about how there is a need for ongoing training and manual updates within the program. There has also been peer engagement mediated by HIV Community Link and their assigned staff. There is now tremendous community support and ongoing funding that pays a stipend to the peer support volunteers to recognize the value of their expertise. This gives monetary value to the expertise that comes with living with HIV, and recognizes that a shared story of someone living with HIV is indispensable.

### **Ongoing Evaluation of What is in the Best Interest of the Group?**

Throughout 2015 and 2016, I and the peer support facilitators were asked many questions about the peer support program. Many of these questions arose as the peer support model expanded into the larger community, with clinical support and program management provided by HIV Community Link in Calgary. The following are the questions that were commonly asked:

- Do the criteria for who is in the group and who is not have to change?
- Who gets to make that decision?
- What do the group members want?
- Does the location of the group need to change?
- What does the group need for safety as it changes and evolves?
- What do the peer-support volunteers need to remain healthy as they support others?
- Do we keep notes or other articles of information from the peer support discussions that occur in the gatherings?
- Do we keep a record of our hours?
- When can someone be asked to leave the group due to inappropriate behaviour?
- What happens if someone asks another group member out on a date?
- What can group members not talk about? Or is that even an appropriate question?
- What happens if someone is intoxicated when they attend a gathering?
- Do couples argue in the group? What happens if a couple is experiencing interpersonal violence?
- What happens if the peer support volunteer feels threatened?
- How do we transfer knowledge to others who are interested?

The group decided that all couples living with HIV were eligible to participate in the peer support program, although the general inclusion criteria were streamlined to a LGBTTTQ2 format due to the attrition of the heterosexual members and the inclusion of a larger number of people from the gay and trans community. No other new criteria were introduced. This group decision was formalized by the members after they discussed with each other what they needed as they shared a vision of further reaching out to couples living with HIV. The decision to expand or contract their inclusion criteria was not taken lightly; there was an awareness that considerable trust must come with inviting new people into the group. Managing the group process and keeping members safe became a primary responsibility of the peer support facilitator.

### **THE CORE THEMES OF THE GATHERINGS**

Over the three years that the peer support group has been running, themes were documented into field notes that can now be shared. The hope is that these notes will give direction to others interested in following a peer support model to the benefit of a group of people who have similar needs as the HIV community described here. A peer support framework can be used to build data and important relational understandings when a

group is trying to develop itself for the benefit for their greater good. The themes that emerged from the group sessions were fluid and relevant to the group's process of understanding their own needs. Some of these themes were the impact of social stigma, trust, sexual practices, who to tell/who not to tell, acceptance of diagnosis, and acceptance within the peer support model.

### **A. Social Stigma**

Social stigma was consistently identified as a concern. As noted by a gay male participant, "stigma keeps us locked inside our homes, inside our minds as it's not safe to share the story of the lived experience," and that "stigma hurts, it does not provide us with the friendship or support needed to live well or live beyond isolation with each other or on our own" (field notes, June 20, 2015). Stigma was a barrier to living well and contributed to significant isolation, stress, mental health problems, and other health concerns such as addiction.

Rintamaki, Davis, Skripkauskas, Bennette, and Wolf (2006) revealed how social stigma prevented HIV patients from disclosing their status and seeking ongoing HIV care. They also identified that the same patients who struggled with social stigma were less compliant with taking their medication. I wondered if the social stigma of HIV could be preventing couples from coming forward in the gatherings. Social stigma's covert and overt nature can prevent couples from feeling comfortable, and make them less likely to come forward to build a community of support where they can openly discuss their lives and the relationships they have to each other and HIV. The peer support model discussed here, however, took steps to mitigate this risk factor.

### **B. Trust**

Trust permeated the gatherings as people tried to figure out who could be trusted with their story. One gay male participant said: "how can we trust that no one will tell our story? [...] If someone finds out at work that I am HIV positive, I might not have my job, I cannot afford not to have a job" (field notes, June 20, 2015). No one wants their life to be exposed to others, especially when the audience might take the parts that fit for their own dialogical benefit and use them to harm someone or cause them to lose their job. HIV does not freely travel within cultural dialogues without the social stigma that those who live with it are different (or worse, that they are deviant or destructive to the well-being of others). This dialogical nuance, which is specific to HIV and stigma, leaves people cornered into a seemingly powerless place of forced exposure of their status, or silence as they consider whether others can be trusted.

### **C. Sexual Practices**

How do couples have sexual practices that are healthy when there is pressure to focus on harm reduction and prevention versus freedom and passion – the latter of which can bring adults together when nothing else matters. One participant, a gay male, stated that "sexual practices change or sometimes not when passion takes over and nothing else matters. [...] How to have sexual freedom, when there is so much pressure on having sex with precaution and a sense of knowing that you could infect another" (field notes, June 20, 2015). There was a lot of discussion in the group meetings about sexual practices; outside of the medical community's influence, there was a sense that practicing safe sex should not take precedence over pleasure. Considerable effort was dedicated to making viral loads undetectable, but even so, there was the sentiment that passion may be more important than condom use if it interferes with pleasure. Couples wondered whether it



was it safer to talk through the risk of not using a condom in a peer support group setting versus in their doctor's office. Who was to judge whether a moment of passion was more important than an undetectable viral load and a condom? Clearly, the feeling among group participants was that one's opinion about this issue was dependent on their perspective.

#### **D. Who to Tell or Not to Tell?**

There was constant discussion about who should be informed about a positive HIV diagnosis. From family to lovers, who needed to know and who did not? Why tell someone or why not? The participants did not provide consistent rationale for their chosen disclosures. They did, however, express a need to figure out to whom they could safely disclose their status. Beyond a rather normal discussion of why it mattered (or not), there was a willingness to hear the stories of why this issue mattered to members of the group. The peer-support volunteers discussed how "they shared with very few, not even family" (field notes, June 20, 2015). The group members did have very real concerns that people might find out and not approve, or that their relationships might change. For some, the risk of telling was too much or too risky, with the risks outweighing a desire to be fully accepted as they are, only now living with HIV.

#### **E. Acceptance of Diagnosis**

One of the members explained that diagnosis was a traumatic time in their life, when they felt great fear and as though their life might:

*I was diagnosed with AIDS five years ago. [...] The trauma of those early days gave way to the knowledge that I was not alone, and that there was help. [...] My partner supported me throughout the process and that was a blessing. [...] Now, five years on, I feel stronger, more focused and healthier than I think I've ever been.* (field notes, June 20, 2015)

Diagnosis was noted as a cathartic moment for many of the participants who were HIV-positive. The diagnosis became the epicenter of their existence and the start of a life that was now defined by medical appointments, a sense of not knowing, deep fear around what would happen, as well as much uncertainty about the future.

#### **F. Acceptance within Peer Support**

A friend of the Plus Calgary Support Group talked about the acceptance they found in the group:

*I attribute this to the support group that I've been involved with these past few years. [...] I have learned from the other members of the group and, I hope, that they have learned from me. [...] Support groups normalize the fear that an individual has when they learn of a difficult diagnosis. I am so happy that there is a variety of support today, but it was not so when I first was diagnosed 28 years ago. Then, I had to fend for myself and felt largely alone. They said, "Prepare to let go and wrap up my affairs." Are you kidding me? Boy, were they wrong. Over time, I learned significantly about the science and also learned of my own strengths and weaknesses. Discovering this new support group is an affirmation that I am not alone, just as normal, feisty, deserving and can offer my wisdom to those who need it. I learn, too, it is all good!* (field notes, June 20, 2015)

The sense that it takes a village to support those who live with HIV is correct. There was a significant understanding that community would be important to this group of people living with HIV. They needed each other to create an empowering space that

would allow them to live with the outcome of their diagnosis. Within the group, the isolation that they had experienced lifted, and the community of people that developed enabled participants to feel less judged and more empowered amidst a societal framework embedded with stigma and isolation.

### **SOCIAL CONSTRUCTION OF STIGMA: OPPRESSION ON FIRE**

UN Secretary-General Ban Ki-moon has stated that “one of our biggest hurdles for our global response to AIDS is psychological” (2008, para. 5). Social stigma was a significant theme that embedded itself into the dialogues of all participants and also infiltrates the infrastructure of society. Why is there so much social stigma against HIV when it is only a virus? For some reason, the socially constructed nature of the stigma around HIV is sufficiently strong that it can ruin lives and foster discrimination against its victims. Social stigma against those who live with HIV is society’s way of enforcing oppression against those who it deems are bad, by those who think of themselves as good. This oppression has caused much suffering and destruction to community-building among sero-discordant couples. The impact of stigma was apparent in all gatherings as the couples externalized the stronghold that it had on their lived experience.

The peer support group provided space for the uninterrupted deconstruction of stigma. People diagnosed with HIV do not get the same opportunity as those who are diagnosed with cancer to deconstruct their experience because they often do not feel able to share their status with those who might provide support. There is a sense of needing to be silent so that shame and other significant emotions do not take over the emotional climate of a relationship. Many couples talk about not being able to discuss their status with parents at the playground, with family members at Christmas celebrations, and with other couples when they are out for supper. Some even identify that going back to their home country and disclosing their status is not an option because they fear retaliation and death. Social stigma fuels discrimination and hatred around HIV, giving those who are infected with the virus fewer options, less safety, and less certainty about their future.

In the 1970s and 1980s, those living with HIV experienced true hostility; people were afraid of the virus because of its comorbidity of AIDS. AIDS scared people because it was pervasive and uncontrolled. The inability to treat HIV in the early days of the virus gave birth to the social stigma that has since found its way into the lives of many people. This historical platform still undermines the well-being of those affected by HIV.

The social-emotional hysteria around HIV and AIDS is quieter these days, but society still holds animosity that manifests in a passive-aggressive way. HIV’s prevalent social stigma, although not a criminal act in itself, has the power to control people in the same way that any deviant behavior does. Stigma sits in the minds of people, it is brought forth in the words that people use, and it can exist within the many dialogues that people create when they are excluding or forming discourse around people’s stories. Do people die from social stigma? No, but they are held emotionally hostage by not being able to discuss their status openly. They are afraid to talk with loved ones, with community members, with people in positions of power, and with peers at social gatherings.

Our relationships give our lives meaning. If we cannot form meaningful relationships with others, we tend to experience emotional stress. Emotional stress can put severe limits on our well-being; it keeps us from being able to discuss what we need,

who we are, and what we might become. Life offers many opportunities to co-create a new reality, but this endeavour requires that people work together to gain insight into what they can do to benefit others.

Aging and dialogue are part of human development. However, when a community is silenced because of social stigma, the community cannot develop the resources that it needs to be sustainable. Generative dialogue must be inclusive of its members, and must also consider what its members need. If members of a community are silenced, the true needs of the community will not be discussed and cannot be acted upon. This movement to silence, which maintains invisibility, forms the core of marginalization. People who are marginalized become submerged under the dominant discourse that somehow defines their illness as being bad, as being something that can cause others harm.

### Changing the Language

At various times in 2014 and 2015, we realized that fewer than the expected number of couples were attending gatherings. Many of the couples felt that the introduction of new couples threatened the integrity of the group as a collective, safe community. We engaged a separate relational dialogic process that inquired into the reason for the resistance to new members. This inquiry prompted a change in the language that was used to discuss the peer support process, framing it as protective rather than risky. Bury (1991) identified that chronic illness can permanently affect the trajectory of people's lives, and found that even an encounter with illness can bring a resistance in people's lives to professionals who can help them. A biographical disruption at the onset of the illness can change the story of a person's life. Peer support provided an alternative means of support to people living with HIV, and in doing so permanently shaped their lived story.

We used reflexivity, a circular process of questioning and reflection around language, its meaning, and its power relations (including the dominance and submission that exist in language dynamics) that invoke feelings of insecurity for people who have experienced marginalization. From this reflection came the idea to use less formal language when inviting people to participate in the gatherings that emphasized the desire to build a community based on companionship between people living with HIV. The intent was to bring a sense that the relational dynamics of the couple did not need to fit the box of a defined couple relationship; instead, couples or companions simply needed to be prepared to talk about their relational dynamics in the context of living with HIV. This reformatting of the group's purpose allowed for a focus on personal agency rather than illness. The language of the invitation to the group was changed so that it was more respectful and, hopefully, more inclusive:

*Monthly Peer Support Gathering for Couples & Companions Living with HIV*

*If you are in a partnership, are companions and/or a couple living with HIV, you are welcome to participate in the monthly peer support couples' gatherings, at a community space.*

*This is a safe, confidential, nonjudgmental group for people living with HIV and their partners or companions. If only one person in the relationship wants to participate, they are welcome to come on their own.*

*The group space is an opportunity for people living with HIV to talk about*

*their couple and/or companion experience in a supportive environment. The group is accepting of diversity and the inclusiveness of all gender experiences are welcomed. Trained peer support couples that are living with HIV facilitate the group.*

### **Language, Power and Medical Power: Community-Based Language**

As we engaged more meetings, we explored the possibility of expanding the gatherings into a community-based action project. We hoped to transform the gathering format from monthly meetings into a community movement that would invite couples into an action process that would allow them to come together and participate in a variety of community-based activities (e.g., attending movies, volunteering for other causes, attending public meetings). These ideas for further action were part of an ongoing process that aimed to meet the needs of all participating members and would hopefully allow everyone to be acknowledged for their experience.

The peer-support facilitators and I took a lead role in this transformational process; we would propose an idea to the group that was less medical, more community-oriented, and more relevant to the group members and their lived experience. We knew that we would have to be adventurous but that this would create a cradle for the community (and allow the group to move away from a medical model of support). Our efforts during this time, the summer of 2014, created a sense of freedom within the group that opened up new dialogues and new ways of interacting. The gatherings that took place fostered a relational structure that brought in people and created community.

Community, as defined by the peer support volunteers, was that gathering of people to feel co-empowered together, to live authentically beyond survival mode, to live in wellness, to live seeking Maslow's self-actualization, and to continue in consciousness with a community that would allow for complete acceptance. Illness, community and a redefining of both, merged to create a pathway to living well with others around HIV and the couple experience.

Within a welcoming and accepting community, the meaning of illness to the couples, as well as their relationship with HIV, changed. Bury (2001) discussed "how there are three distinct narratives that encase the experiences that surround chronic illness: contingent, moral, and core narratives" (p. 263). The contingent narrative for this population seemed to be socially defined; it reflected changes between the person and the illness. The moral narrative was used to socially define the relationship between the couple, the illness, and the act that led to their HIV-positive diagnosis. The core narrative reflected the interactions between the HIV-positive person and their surrounding culture, and how this interaction tended to lead and autograph their story for better or worse.

### **New Language: New Meaning**

In the winter of 2015, we reinvented the invitation poster again. We tempered our language to be more inclusive of individuals who might wish to become part of a couple or play the role of companion. This change in language was our formal way of inviting people to consider, to connect, and to relate to the existing community of people who were also seeking to relate as couples and companions living with HIV. The poster

## Couples Living With HIV: GATHERINGS, DIALOGUE AND COMMUNITY ACTION

combined inclusive language with concepts of what a relationship might look like for gay and transgendered people; we intended to evoke a sense of belonging while transcending the rigid concept of a valid relationship. The poster read as follows:

### PLUS FRIENDS CALGARY

#### MONTHLY PEER SUPPORT GATHERINGS FOR GAY/TRANSGENDERED COUPLES & COMPANIONS LIVING WITH HIV

If you are single or in a partnership, are companions and/or a couple living with HIV, we invite you to join us for a monthly get together.

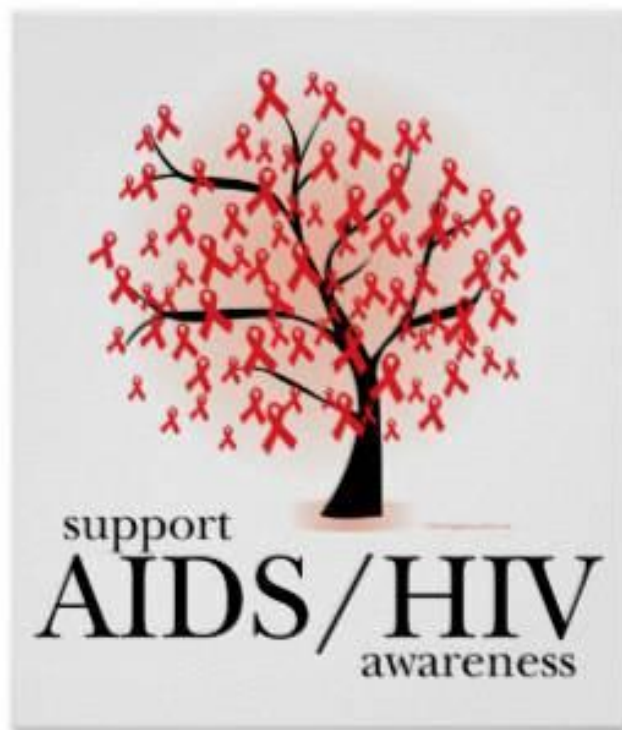
This is a safe, confidential, nonjudgmental group for people living with HIV and their partners, or companions. If only one person in the relationship wants to participate, they are welcome to attend.

The aim of the group is to offer support and companionship in a social setting. We seek to build a community through gatherings, movie nights, dinner and other outings. It is a great way to expand your social circle and meet new friends.

Trained peer support couples that are living with HIV facilitate the group.

Location: The meetings are held at a location in the city center.

Contact: Peer Support Volunteers



### **On-Line Support**

One of the peer support facilitators became very attached to the ultimate outcome of giving back and deepening community support. During 2015, he added a component of support that was on-line. He provided support to others through on-line ads and their accompanying websites. These on-line platforms hosted a variety of conversations that created generative dialogues that fostered relationship-building. Through this medium, the peer support worker mediated multiple supportive dialogues that identified key issues and concerns for numerous people living with HIV. All of the concerns that were expressed were divided into themes and reviewed monthly by HIVcl and the peer facilitators, while being communicated and documented as formal requests for additional funding for training as the peer support model grew into a formal working model. The on-line support consisted of ongoing texts and e-mails that allowed the peer support worker to support others who also lived with the HIV experience (but were not able to become group members).

### **Themes of Relevant Questions?**

Below is a list of the main questions (divided by theme) that arose from the on-line support platforms through conversations between the peer support facilitator and various community members:

1. Support: What does the group offer for support? How is support offered?
2. Confidentiality: Is this group confidential?
3. Inclusivity: Can anyone that is interested come to this group?
4. Sexual relationship opportunities: Does this group offer opportunity for sexual hook-ups? Are members seeking opportunities for sexual experiences where there is shared opportunity for good sex?
5. Social isolation: How can we meet people for companionship and dating? What types of relationships are there and how do we talk about open relationships, or can we?
6. Medications: What types of medications are there and who can provide that medication? How do we take a medication break? Who needs to make this decision? How can we do so in a healthy way?
7. Professional support: Who are the people that can provide professional support and do they really understand what it means to live with HIV? How can I find support beyond professionals at the HIV clinic?
8. Mental Health: Do people that live with HIV need other support such as mental health support? What about addictions - who can provide addictions support to people living with HIV?

### **On-line Peer Support Model: Modern Technology, Immediate Access**

The on-line peer-support program was led by the peer support facilitator, who navigated the layers of on-line peer support through connecting with people both anonymously and relationally on-line. Choosing which on-line sites to use to engage other couples became an important part of his journey, which I consulted with him on. The peer support facilitator and I talked about various sites that could be used, such as



squirt, bareback, and POS, all of which are gay dating sites. The activity on these sites brought a lot of discussion as it became apparent that some of the interested clients wanted to access the group for alternative purposes, including sexual experiences (i.e., “hook ups”). While there is nothing inherently wrong with a request of sexual activity (with other couples or one person only), such requests clearly did not meet the criteria of the group’s mandate (which was to create a gathering space where people could meet to be together and talk through their experience of living with HIV in a safe environment).

Some of the other themes that surfaced from e-mails to peer-support facilitators centered on location, confidentiality, discussion topics, gender, age dynamics, costs, accessibility, openness to new people, sexual experiences, and health issues. Fortunately, one of the peer support volunteers was also volunteering in another program for a related health issue and was able to assist in responding to many of the dynamics that arose from the dialogue created by these e-mails. Every three to four weeks, I and the facilitator met to sort through ideas and develop a framework of guidelines that would allow for a consensual commitment to keeping the gatherings free from invasive inquiry or pervasive power dynamics that would detract from the collective and collaborative dialogue.

As we moved forward, we decided that safety was paramount. Therefore, we decided to be more explicit in the on-line ads that the on-line forum was not meant to be used as a platform to initiate sex-focussed relationships. The peer support volunteer placed some revised ads on-line and was immediately contacted via e-mail by various men and couples who were seeking support. Some of the gay men, however, still indicated that they were not just seeking support, but also sexual opportunities.

My primary peer support facilitator and I engaged in multiple discussions about how to engage clear and concise boundaries. We grappled with how to maintain the criteria for participation that had been laid out. We decided that people wishing to participate in the group would need to provide the name of their doctor because this would help to verify that the group members were, in fact, living with HIV. There were extensive discussions and some struggle about how to be inclusive and non-judgmental, while at the same time keeping our group members safe. Group members were able to connect for emotional supportive purposes, and were able to decide how involved they would become in the personal problems of others, within the guidelines established by the group to help its members stay emotionally safe.

Peer support volunteering is, by its very nature, a volunteer position. Therefore, it brings with it a sense of openness that is not rigidly defined by a position or by funding requirements that might jeopardize its organic nature. The role of the peer support volunteer was defined by the volunteers themselves (with support from me), and reflected the community’s relational dynamics; the role of the volunteers was not expert-client driven, but instead took on a grassroots-up mandate. The social constructionist relational dynamics allowed for there to be significant adaptation around the needs of the people. The relational dynamics were congruent with many of the needs of the original community, which was founded on respect, safety, and a need for ongoing support.

The issue of safety was embedded in a plethora of discussions between myself and the primary peer support volunteers. My professional and academic mind was always assessing the many layers of safety and confidentiality that needed to co-exist within the relational dynamics of the group, and my volunteer was good at engaging me in discussions that broadened my own thinking about the lived experience of HIV and drew

me away from my professional agenda. I was constantly challenged to consider how safety plays out in relationships that are based in peer rather than professional support. There is so much relational engagement in the peer support model that has to be deconstructed so that the relational dynamic is provided through peer support rather than a professional service.

### **Community Development: Moving Outside of the Anarchy of the AIDS Epidemic**

Community development for living well was a process in which people were given a chance to merge their ideas and energies into a framework of life and living that developed a collective of like-minded people (who were able to offer perspective about what living healthy with HIV looks like). I was interested in understanding how couples continue to merge together, in both long term relationships and short term relationships, outside of the context of death and dying? These types of community projects are important for creating a fulfilling emotional landscape for life and living with HIV.

The moral narrative around HIV seems to prevent the narrative of thriving and living well with HIV from entering into the socially constructed world. HIV creates a web of experience that goes beyond medical intervention and forms the foundation for understanding HIV beyond its ability to invoke feelings of loss and crisis. Couples now must live with a system of loving beyond social stigma and medical appointments. Bury (2001) identified how, in temporal sequence, illness unfolds through onset, diagnosis, and treatment. A sense of dealing with the body or “body issues” permeates the discourse around illness and its relationship to a person’s life. The sociological idea of “adaptive responses” to chronic illness, as discussed by Bury (1991), allows people living with illness to place responses in an active position around wellness, and allows them to find a meaning-focussed rather than an illness-focused discourse. “Much of the knowledge that has been created around chronic illness has focused on medicine rather than on the exploration of how people respond, adapt to, and thrive in relation to illness and its impact on their current life” (Bury, 1991, p. 451). In this context, thriving became an important issue for the group to discuss, reflect on, and develop.

As noted by Bury (1991), an interpretative sociological perspective gives meaning to people’s actions; in this context, they act as agents of their illness and move away from being products of the illness itself. This proactive and productive sociological lens creates room for knowledge building in couples living with HIV. Couples who act as their own agents gain protection and mitigate the risks that come with HIV, such as isolation, social stigma, discrimination, and the oppression that arises from power and domination. All of these factors create a social anarchy against people living with HIV, and those who are affected by HIV must then learn to overcome these challenges as they navigate their way through life.

The community-based response initiated by the couples was critical to sustain, over the long term, an environment in which their voices could be put forward. Gergen (1985) described this type of discourse as a relational artifact that defines human experience. Every person will companion on some level, at some time, and HIV does not need to deter those who seek to companion and live well. The continued isolation that binds people to the definitions that are socially constructed on their behalf relegates people to a constant state of being significantly overwhelmed with the uncertainty of how



to live well. The isolation for couples living with HIV arises from not being able to fully come out and engage in conversations within the larger social community, which may not recognize that a couple living with HIV is not solely defined by HIV. The experience of a couple encompasses many moments and many experiences of relating to each other, relating the world, and relating to the virus. Living with HIV is a relational artifact that defies, redefines, embraces, rejects, transforms and evolves the limitations that come with being alive in a world full of oppressive compulsions.

### **THEORY AND RIGHTS: AN UNUSUAL MIX**

Peer support is an interesting relational dynamic that can be framed within postmodern feminist theory in order to diffuse the inherent power dynamics that arise when people are seeking to promote a professional relationship rather than provide a supportive relationship. The latter is about allowing the story to define the process, whereas the former is about the definition of the relationship based on the service, the need, the outcome, or something very definitive. Many discussions took place over the course of several months that ensured that the relationships were safe and healthy for the peer-support volunteers and for the people who might engage those supportive relationships. Questions that were considered were as follows:

1. What types of topics might be more acceptable to engage?
2. How can participants contact you?
3. How many contacts will occur before an in-person meeting might be set up?
4. Where would the initial meetings be held?
5. What safety information needs to be provided to someone so that they are not alone in with someone that they do not know?
6. What can you trust and what can you not?
7. What does it mean to stay within the parameters of the peer support relationship?
8. Is it okay to stop the supportive relationship and why?
9. Are there any topics that relate to living with HIV that we can't talk about?
10. What could I do if a person or couple tried to connect with me?
11. How do you take care of yourself emotionally when you are in people's stories and emotional lives?
12. How do you manage confidentiality in the community?

As the peer support community evolves, it takes on the energy of being its own entity and is defined by what it needs. To promote longevity, the community must take charge of the way it shapes its own structure around its needs. Currently, I do not play a consistent role in this evolution. I am primarily involved in knowledge transfer activities such as keynote presentations on the research process, supporting other disenfranchised groups such as Indigenous persons living with HIV to develop their own peer support programs and consultation with provincial health authorities on peer support best practice with marginalized populations in general. The core peer support group is federally funded under public health funding and is being further developed by the HIV community and the non-profit organization (HIVcl) that supported its inception during the early phases of my research. Currently, more groups are being developed and shaped that feature other underrepresented groups of people who live with HIV, such as Indigenous persons, people of African heritage, and younger and older people.

### **Blending and Merging: Fluidity and Boundaries**

There were questions about what might happen when group facilitators provide peer support for the blending of heterosexual and homosexual couples into a peer support process. The larger HIV community was concerned that the blending of heterosexual and homosexual couples into the same group would not work because the needs of heterosexual and homosexual couples were so different. I wondered, however, if this perceived difference and resistance to merge the two couple groups arose from some form of internalized oppression due to the stigma associated with HIV. Inherently, all of the couples were living with HIV, and all experiences mattered. I discussed with the community of couples if there was a way to create enough inclusiveness through safe dialogues to allow the HIV community, with all its diversity, to gather together to support each other to live well with HIV. This topic was discussed among peer support volunteers and in the larger community. There was immediate feedback from the gay community after the on-line ads were placed that mixing such a group of couples would not be beneficial as there would be too much diversity amidst the social location of sexual preference, sexual experience, and sexual couple identity. It was decided by the group that the peer support community would stay as a gay/transgendered support group only.

One of the peer support participants named Ken shared his experience of the peer support group in the form of a letter. This letter was presented at the Gay Men's Health Conference. (personal communication, October 9, 2017)

*I have been HIV positive since 1984. I have seen it all. I was diagnosed in 1988, the year of the Calgary Winter Olympics. I have seen it and lived it through the early days of the health crisis, with no treatment, to experimentation drug therapy, stigma, to cocktail therapies in the later 90's. It was terrifying to see others pass away like the cruel plague that it is. I was told by professionals in the early days to "get my life in order and prepare for the worst..." It never happened. Partly because I didn't believe it, nor did my close friend. We soldiered on, without help of dedicated community services, because there was none.*

*Fast forward to today, where there is so much more hope! What is different now is Peer Group navigation support. Not so much that I need it, but because I can contribute my own life to serve as an example. I applaud him (the peer support facilitator, whose name remains confidential in order to protect his identity) for contacting me 3 years ago and I believe in what he has accomplished and what he is trying to do. No one understands better what we are going through than someone who has gone through it. Above all, it fosters a friendship where it likely wouldn't have occurred under clinical circumstance. It is not just "technical", it is also about learning through the experiences of others. It can also be just as simple as just holding someone's hand in a crisis and saying "I understand".*

*I sincerely hope that others follow in his steps and forges a continued service that is assured to always be there, rather than "hoped for".*

*My greatest thanks!*

*Ken*

## **CHAPTER SIX: BREAKING UP IS HARD**

“Breaking up is hard to do, ending co-researcher relationships is not really a reality, finding ways to now celebrate is easier, knowledge translation is a responsibility and a honor.” (field notes, P. Miller, November 5, 2017)

### **WHEN WORDS ARE WRITTEN: A NEW IDEAL IS BORN**

An ending is real in people's minds, but who decides when something is finished? From a social constructionist perspective, an ending occurs when all parties involved decide that something is done. This research has no predetermined end, and will continue beyond this dissertation because relationships have been fostered outside of its boundaries. Knowledge was created together, and more knowledge will be shared because of this written work. Because all relationships that were formed through this research are palpable and have developed meaning of their own, the end of this dissertation does not mark the end of these relationships. The participants in this research have transformed into a significant community of people that has brought new knowledge to the larger HIV community and beyond. For their work, I will be forever be grateful.

### **Letting Go: Or Letting Be?**

As the initiator of this research, I must now let it go and let it be. From now on, the community that has developed will make their own decisions, will identify their own needs, and will fulfill those needs through the internal expertise that comes with living with HIV. For academic researchers using a "top-down" approach, this type of ending might be unprofessional or unethical. However, the community that was developed through this PAR project has the right to decide how their work will evolve.

How does one sign off as a community researcher? I have confronted this question many times at conferences and meetings when I have been asked when my dissertation will be published. I have learned that community-based research is a journey, not a destination; it is the process that matters, not the final outcome. As a trained professional in both social work and psychology, it is hard not to actively lead or develop. However, the PAR process set boundaries around my role versus the role of the community. The question of ownership evolved as the research project changed in scope and responsibility.

Moving aside or allowing someone else to take charge and navigate the outcome, which is very process driven, becomes part of the learning process for a community-based researcher. I have been developing a readiness for closure for a long time, although I have yet to reflect on what closure entails. Do I wrap up this process as I would a semester of teaching? Do I suggest closure as I would to a client who seems to have finished working through their counselling issues? Does closing have merit and does it give validity to the process that occurs for the people living with HIV? Does this journey just continue, and if so, who will monitor it? Currently, the peer support group is in its third year of funding. What will happen if the funding does not get renewed? Who will be responsible for keeping it going?

I can now provide perspective and insight into how to support persons living with HIV to live well. Many of the procedures that are needed to successfully run a peer support program have been established, and knowledge transfer is happening provincially, nationally and internationally. This new knowledge can inform the development of participatory action research in other marginalized communities. The working model described here, which is malleable to the needs of any community, can be used as a template upon which other programs can be built. Now, as I get called into

international discussions about HIV and social stigma, I reflect with gratitude on my ability to represent the stories and perspectives of the HIV community that I have supported. I am grateful to those courageous people who shared their stories of living with HIV.

### **Transferring the Learning from Research to Professional Practice**

How does this ongoing research support my current work? Whether in my teaching or within my direct therapeutic practice, I bring the wisdom of walking with couples who have been navigating their life's journey around chronic disease, specifically HIV. Most couples or companions will find themselves working through some sort of illness, health change, or chronic disease that brings with it a new normal. This new normal is often resisted by couples who feel vulnerable, lost and isolated. I have found that working with any couple who is experiencing chronic disease and/or a chronic mental health issue or addiction can be supported by the knowledge that I have gained through learning about how couples experience HIV.

Many couples find it difficult to adapt when faced with a major life change such as that brought on by diagnosis with a chronic illness. This research shows that generative dialogue can be used to place the experience of living with HIV outside of a couple and/or companion, and into a community conversation. This supports the unfolding of the experience of living with HIV and can help those who are part of the dialogue to live well within the confines of their chronic illness. Safe, inclusive conversation can be used as a form of intervention that can overcome feelings of HIV-induced isolation and stigma.

Living well has become a new narrative for people living with HIV. Social constructionist thinking informs the relational interactions that come from merging the old and the new; moreover, future interactions have the potential to shape future dialogues about living well with HIV. A social constructionist relational perspective gives grace to an already significant history of people and their lived experience with HIV and AIDS. If one could peer into the future, one might see a complete radicalization of the experience of HIV that incorporates both prevention and cure. Currently, peer support and other community capacity building processes can be used to empower people. Empowerment allows those affected by HIV to overcome the dominant social discourse that marginalizes their ability to live freely with their diagnosis.

Social constructionist relational dialogue allows for the many relational dynamics that exist in the community of those living with HIV to control how their future will be experienced. There will always be a relational dialogue with HIV. Even if the virus is eradicated, many people have had their stories written by AIDS and death. Too many children have lost parents in Africa, too many lovers have lost their loved one, and too many service providers have felt the pain of their patients.

This relational dynamic will be instrumental in providing a community of support to those who live with the virus. This support will create a brighter future for those who live with HIV – a future in which there is ongoing research, in which medications are able to minimize the impact of living with HIV, and in which people are able to live well. Relationships will continue to develop and new minds will merge with old ones, creating new ideas and knowledge. As technology advances, knowledge transfer will occur more rapidly, leading to faster shifts in our understanding of what it means to live with HIV.

Relational existence is the future for HIV. It is within a relationship that HIV emerges into a person's life, whether this relationship is with another person or with an experience. In some cases, HIV emerges through a relationship that does not have a human face, such as when an intravenous drug user contracts the virus through drug use, or when someone becomes infected through a blood transfusion. These layered relational dynamics can be infused with a sense of peace, or they might evoke feelings of hostility; the sentiments that surface will be dependent on the relational dynamics of all parties involved.

### **Normalizing Life with HIV**

The path to finding "normal" after a chronic illness diagnosis requires that a person look beyond their medical diagnosis and the social definition of what "normal" is. Eriksson and Svedland (2006) discussed how women whose partners were diagnosed with a chronic illness sought support in order to maintain a meaningful partnership with their spouses. The researchers found three themes among these women: feelings of limitation, the struggle of everyday life, and a striving for normalization. Self-actualization within the framework of a couple dyad and illness brings much constraint and struggle in the quest to achieve "normal" and to move beyond suffering. As noted by the authors, some of the needs of the partner of the person living with the diagnosis often go unaddressed as they navigate through the daily experience of illness without adequate support. Often, the person who does not directly live with the chronic illness does not receive the same support as their partner.

A person living with a chronic illness such as HIV finds meaning through the many professionals and experiences that come with the virus. Their partner finds meaning around the bedside, and possibly through a community of support that may or may not be separate from that of their partner. There is significant understanding within the couple experience that each person must find their own meaning. In the context of HIV, the person who lives with the HIV-positive partner must seek relational support outside of the medical system, which tends to focus on supporting the person living with HIV. Because the HIV-negative partner is often not recognized as being affected by the virus, their needs often go unnoticed.

### **The Gift of Perseverance Brought Forth a Community of Support**

The peer support gatherings were developed through the gift of perseverance, hope, and multiple meaningful conversations that brought the peer support facilitators into relationships with people living with HIV who did not want to be alone. The experience of being lonely can be the by-product of HIV and social stigma. The peer support gathering invitation harnessed the ability to build an economy of caring and knowing that would soften social stigma and isolation, and hopefully create an opportunity for significant caring, knowledge building, and sharing.

Now the couples gather with their own sense of knowing that they are fluid and free to define where they meet and how they meet. This less formal structure has brought the group together in many locations, including the staff room of a member's business. As an outsider, I no longer take on an active role as a collaborative knowledge builder;

instead, I continue to support the peer support facilitator in engaging with the process and staying connected to the group itself. It has become apparent that there is a significant group of gay couples who seek to understand how to live, over the long term, with HIV. The support that exists within the group has come into its own, and the participants now recognize that their understanding of their lives must constantly evolve.

### **Social Outings: Lets Help Each Other Live Well**

In the spring of 2014, the Taste for Life event happened in Calgary. This was an opportunity to foster HIV awareness by having some food at restaurants that support the cause. Many dollars were raised during this event, which provided an opportunity to celebrate with good food, companionship, and a sense of knowing that people are consciously aligning with each other, a cause, and a community. I did initiate an evening out with the group so that I could celebrate the cause and meet some of the HIV community peer support group members; they seemed equally as interested in meeting me. Although I had created the initial peer support group, it was ultimately the new group that created a tremendous opportunity for me to academically understand the importance of PAR research within a community action template.

We negotiated a date and time to meet, and a group of seven members came out to be together. This was an exciting time for me. I donated the cost of the meal and invited the group members to give to the cause as well. It seemed important to contribute to a cause that was close to the heart of the peer support community. Because we could not talk openly about our cause in the restaurant unless everyone decided that it was okay, I carefully considered the language that we would use on this outing. Although I had initiated the event, I remained a bystander during the evening's conversation. It was important that the momentum of the discussion be driven by the collective group; I avoided taking on the role of "expert", which threatened to tap in to an internalized oppressed consciousness that comes with systemic oppression.

As a bystander during this outing, I had to be vulnerable as I engaged with the group and acknowledged that HIV sat relationally with all of us. In the end, the evening went well – the food and wine were good and everyone got along. I experienced companionship with a group of gay men, some with their partners and some not, all who lived with HIV. These men had a history together that engaged every corner of their lives, and they found multiple ways to share, unfold through language, touch, and be together. Throughout the evening, the individuals in the group transformed into a collective group with its own identity that was forged through shared conversations. We laughed and ate, and we shared our thoughts on travel and life beyond the small room in the restaurant. It was easy evening with lots of intelligent moments of thoughtful discussion.

### **Voices from Within the Peer-Support Community**

Participants from the gatherings provided a voice to their experiences of being part of the HIV peer support group (i.e., Plus Friends of Calgary). They have not been named but they still speak through the words that have been woven into stories that give meaning to each of them. Some participants contributed personal dialogue while others used brief statements. Regardless of the nature of their contribution, each participant



committed to sharing some of their experience for the benefit others and for the purpose of knowledge development. The group members identified key topics that they felt exemplified their individual and collective experience.

- Inspiration
- Creativity
- Alternative thinking
- Education
- Support
- Acceptance
- Sense of belonging
- Support
- Encouragement
- Positive peer modeling
- Companionship

These topics show the power that relational dialogues can have in providing the infrastructure needed to support a group of people to find strength, courage, and bravery, allowing them to overcome isolation and stigma while living well with HIV.

### **Possibilities and Future Shaping**

There is a new chapter coming that brings possibilities for multiple support groups for those who are underrepresented and live with HIV. Access to information and support is important – it can save a life or stave off the emotional hardship that accompanies an HIV diagnosis. There have been a lot ideas percolating about possible next steps for this research in action project, and my future involvement is an open question.

Six years later, voices have been captured, relational dynamics have been established, and other voices and relational dynamics have disappeared but have not been forgotten. The original understanding of the needs of HIV couples and companions has changed. The couples restructured their language so that gay and transgendered couples and companions could join heterosexual couples in the peer-support community. The group collectively established regular monthly gatherings, social outings, and individual conversations that did not directly include me. I did, however, continue indirectly to understand the needs of HIV-affected couples and companions who identify as gay.

I have received e-mails from a heterosexual couple and a lesbian person asking for insight into the relational representation of the peer support group. This has led me to ponder whether the group should be restructured to allow for a new relational dynamic that brings more diversity (and potential adversity). With thoughts about restructuring come questions about who should be involved in the decision-making process, and whether issues about inclusion are simply limitations of this type of research. The time it takes to have meaningful conversations around inclusion and exclusion of its members may be a fundamental limitation that comes out of creating a community from people who have been marginalized by HIV's social stigma.

The social stigma around HIV is still tangled in ideals that have been radicalized through the media and other forms of social communication. The notion that the limitations of participatory action research prevent a community from developing into



what it needs to be is also a socially constructed belief. This idea of limitations, however, is overcome when a community is allowed to define what it is they need.

There are ideas about reflective groups that could enhance the current peer-support model. Peer navigation, which describes peer-mediated one-on-one support, was one avenue that the group considered. HIV Community Links has also considered developing subgroups that would be specific to younger gay men, African couples, Aboriginal couples, and HIV-positive women. The original concept of peer support, and its successful journey, has opened the door to many other supportive options for those living with HIV.

### **Progressive Narratives That Go Beyond Medical Charts**

I have come to understand through this research that living changes who we are. Personal growth is shaped by the relationships that we develop over time with people, experiences, viruses, and our understanding of life. I am not the same person that I was when I wrote the research proposal for this project. Life changes us, people impact us, experiences shape us, and this change is out of our control. Are the words that I close with now the same as those that I would have chosen in the past? It is clear to me that my passion for this research has not changed. From the beginning, my passion was to begin something that could provide meaning to others, and in doing so serve the greater good of humanity.

Although the calling that a researcher has into a community of people to bring forth new knowledge does not change, the researcher does change in response to the relational experiences that they have while undertaking their work. Moreover, the calling, once ignited, make its way into the world and brings change to both the researcher and the participants. Relational dialogue becomes new knowledge and becomes symbolic of a story that brings new meaning to a world that socially regulates meaning for all of us.

When faced with a harsh new reality, some people may gravitate towards movements that embrace and encompass the re-examining and re-fashioning of their personal and couple narratives. Robinson (1990) called this a “progressive narrative” (in contrast to a “regressive narrative”), in which people move towards their own values and goals; alternatively, people who have regressive goals move away from self or a “stable narrative” that situates itself within status goals. As Robinson (1990) further discussed, stable narratives are typically embedded within biomedical goals and are sustained by the research-driven elements of biomedical needs. The positive construction of progressive narratives allows, instead, for communities to develop their goals based on their own personal needs. Radcliffe, Lowton, and Morgan (2013) discussed how marital and or couple relationships can mediate the experience of chronic illness and disability, and the impact that they have on identity. They proposed that narratives that are co-constructed have the potential to be positively impacted by the couple relationship.

As I have come to understand this portal to self-discovery around illness and its impact on people’s lives, it has become obvious that, although a diagnosis can mark the beginning of the exploration of self, this journey has no ending. Each couple succinctly narrates their story through their day-to-day existence and through the way they self-organize around their diagnosis, medical appointments, procedures, intimacy, lack of intimacy, social discourse in community, and dialectical interactions in the home. A new

narrative history is created from each moment that arises around their new truth of living with HIV as a medically defined chronic illness.

When a couple decides to stultify the medicalized narrative of HIV being a chronic illness that wholly defines their existence, they take control of their experience and how they co-exist with HIV. The medicalization of HIV detracts from the couple experience and marginalizes the human experience and importance of couple longevity; instead, it focusses the couple's experience on all facets of their medical care – the virus, appointments, and CD4 counts. The HIV/AIDS narrative is then defined by the medical journey.

Social rejection of those who live with HIV, as well as social stigma, are part of the social experience that co-exists with HIV/AIDS. These experiences are layered with the historical aspects of the AIDS epidemic, which impregnate themselves into narratives. These narratives can then be sustained, or deconstructed then reconstructed if this is permitted. The norms and morals of society direct and dictate the thinking around the relational social construction and social discourse of HIV/AIDS. In turn, this provides critical thinking frameworks that feed dialogic patterns of conversation that loop back and forth into the social story for couples as they live with HIV.

### **Social Narratives Can Defy History**

The social narrative is prone to being dogmatic based on historical narratives around good/bad and healthy/unhealthy. Social narratives determine how people respond, react, and act in their lives with HIV, which is a permanent guest within their couple experience. Social isolation does not provide the social structure needed to bring out the internalized oppression that exists within the HIV complex, social discourse, and social response that has developed since the inception of HIV into society, which was initially marred with misunderstanding about what it was and who might be responsible for it. Couples who find themselves isolated are more at risk of internalizing the good/bad continuum around HIV, and its medicalization and criminalization. Through a living well approach, couples in the peer support group have progressively found ways to externalize their oppression narrative through making meaning out of their existence as a couple affected by HIV.

Making meaning can come, as noted by many participants in the initial gatherings, through volunteering efforts that support others to share their experiences. One can also find meaning through choosing to live more fully after one's diagnosis. Transcending and transforming become key elements in relational dialogues that coexist within the bedroom and within the mediocrity of the daily lived experience that comes with HIV. Compounding dualities were experienced as couples sorted through the prescribed understandings of HIV and its complexities. Dualities were minimized as couples created their lives together within their own diversity and reached beyond the prescribed cultural understandings of living with HIV. Sometimes couples in otherwise healthy relationships found themselves forced apart by the constraints of HIV; these relationships could not contain the social discord that resulted from an HIV diagnosis.

The social morals and norms that come with an HIV diagnosis are often internalized due to the dominant discourse and the vulnerability that surrounds a diagnosis of HIV. The social structure that is enacted by a new diagnosis brings an

individual into care, and “couples” begin the process of attending to the meaning of the HIV virus in their world. The dominant discourse continues to dish out a new normal that is loaded with social morals that define right and wrong, good and bad, infected and not infected; all of this when a couple is at their most vulnerable.

A succinct formatting of the medical procedures that need to be engaged follow a prescribed process that allows the virus to take its place in the portfolio of a chronic disease. Adherence to treatment becomes the new normal for those who live with an HIV diagnosis. Although individuals can choose to operate within their own unique process within this highly rigid existence, this straying from the status quo is almost always met with resistance from those who manage the medical discourse. Relational dynamics that reflect all aspects of the lived experience with HIV – historical, medical, and social – form the narratives that shape the impact of the virus on a person’s life.

Closure does not happen in a relational world. Because each person is impacted by the relationship(s) that are developed through PAR methodology, there is no simple closure. Co-creation of on-going support, written words, gathered thoughts, and many conversations bring people together so that they can forge a new direction for couples’ support. Dialectical tensions between the medical community and supportive resources need to be acknowledged so that no one agenda dominates the spectrum of services that are developed to support couples living long term with HIV. It is inevitable that couples will find ways to live beyond HIV and the medical discourse that has dominated the AIDS epidemic.

Changes in the world arise from community building, and through the impact of relationships and the building of trust. We are the world, we are the knowledge, we are the relationships; what we choose not to be is a defiance of social stigma, the HIV virus, and its partners of power and control. When people step out of suffering and into living well, they move up Maslow’s hierarchy of needs and exit survival; they then define wellness, they defy oppression, and they choose self-actualization. Stress does not define the brain, but surviving an experience does define the collective movement in its urgency to escape the oppression that continues to permeate humanity as people seek equality in the midst of HIV.

Being real, being relational, developing a community, hearing truth, choosing to be with another, to be with HIV, to live without fear, to be a part of something that is bigger than fear, to be a giver and a receiver of experience that brings hope, to dialogue and birth idea that are bigger, better, braver, and beyond what is prescribed for this group of courageous people. Humanity is awaiting the healing; it is awaiting a movement that brings experience together. Humanity invites a relational pattern that co-exists beyond the mind, and beyond the experience of separateness. This relational pattern is the doorway to exterminating the stigma. Johnson (1987) noted that people are born into communal narratives and live their lives through the nuance of discourse that powerfully shapes human being’s existence. Conversations and relationships that foster these conversations have the power to keep people empowered in order that they bring forth a healthier way of being together. The epigenetics of communal transformation come through the doorway of relational dynamics. Relational dynamics are beyond the control of the narratives that have defined people to be a certain way. The interplay of genetics and relational being brings forth something that is more significant, more powerful, and beyond the social construction of “some” for “others.”

### **The Movement from Within: The People Speak**

Peer support models bring people with a lived experience into the matrix of relational dynamics that support the larger community beyond professional intervention. The growth of the community becomes more real because it is subject to less moderation by professional forces that shape the interaction as helping the “other” and not being one of the “other.” A peer support model has the missing ingredient that many professionals cannot create or buy: the lived experience. The lived experience is the “epigenetics” or “epi” ingredient that supports the building of a substantial protective factor, a relational dynamic, within a peer support model that lays its roots in the dynamic of relationships and conversations among people.

Historically speaking, those who treat, manage, support, educate, research and somehow commit to the well-being of those who live with and live through HIV all relate to, reshape, and reintegrate the current understanding of the epigenetics of HIV. Although the lived experiences around HIV are not isolated, social isolation does interfere with the opportunity for people to live within a more communal experience.

A peer support model can transcend the limiting ideals and social parameters that constrict the lived experience of HIV for couples. A peer support model bolsters those who have lived, will live, and are just learning to live with HIV. The couples’ experience is unique and fluid; the peer support framework invites people to open their communities and provide support that integrates a couple’s experience into the continuum of services available to people living with HIV.

In writing these closing thoughts, I have opened and closed chapters of my own experience. Some chapters feel more complete than others. It is words that will take my experience of this research and the lives of those affected by HIV to some other place. It is a lack of knowing that creates fear, yet the other side of fear is courage, growth, and a better world. A better world includes, protects, and provides justice; it ensures that all people live in harmony and are at peace amidst war and conflict. HIV is a virus that has acted as a catalyst to bring out the worst and best of people, and it highlights the potential for good and bad within humanity.

It is remarkable that a virus with such capacity to infect and destroy via AIDS can also evoke hope, comradery, research, medical advances, resiliency, community and caring. AIDS does not define a person if the person does not allow it to, but first they must overcome a stigma that fosters fear and hatred. Those of us who stand beyond hatred find hope and a way to better humanity. In this way, the HIV virus can be used to bring together, to redefine, to create, to dismantle, and to redefine how life will be and how life can be for those who follow us on HIV’s journey.

### **People, Power and Empowerment of Our Own**

As people, we carry knowledge, and we have the power to redefine the world, its destiny, and its meaning. It is people who (re)define what is good and bad, and who is good and bad: who gets care, who does not, who matters, who does not...the toxicity of oppression, the toxicity of marginalization, the toxicity of hatred, the toxicity of people who lose their humanity, those moments when human worth does not matter, when

human worth goes out the window so that greed and other less humane ways begin to define our worth.

As the research suggests, humanity does not exist in those moments when we find ourselves being defined by hatred; in these moments, only a shadow of our humanity exists. We do not have to ask ourselves how we are going to redefine ourselves; instead, we must ask ourselves when we will redefine ourselves. The latter represents a place of power where we can make things happen, while the former represents a place of powerlessness, where things happen to us.

Through my research I moved with couples through their own process of understanding and re-understanding their experience with HIV, a journey that was a co-created, co-constructed, and reconstructed reality. A couple's process of living with HIV brings much creation within every element of their identity and being. The journey was a significant process for the couples that allowed them to explore the meaning that comes with living with HIV.

As sero-discordant or positive couples living well with HIV, the journey towards defining a meaningful relationship is a significant one. In every moment of the lived journey with HIV, couples get to define, even in micro-moments, their experience. Unfortunately, many couples do so in isolation and, in some ways, become marginalized from the world. Defining the couples' experience of HIV comes with a significant understanding of the delicate balance that comes as couples merge, separate and blend with social norms and morale that define and oppress their existence with HIV.

Most couples will live with a chronic disease or chronic health ailment. So, why is it that HIV is so socially maligned, and considered a disease outside of the normal? Oppression results from following definitions of normal too strictly, and from prescribing to the idea that that "normal" is power and "power" defines normal. It is important to take a stand and to strategically find a way to make our way together so the journey with HIV is not undertaken in isolation.

### **Knowledge Building that is Theirs, Not Mine**

Throughout my research I have pursued knowledge and have sought to engage more responsibility; trying to be an agent of social change, within this action oriented research project. This knowledge building has been done in honor of those who have lived and those who have died. It has occurred at a time when the world has gone somewhat crazy with violence and destruction, but also at a time when the world has become more consciously alive with knowing that everything does matter. Knowledge building in a community of people brings a significant responsibility; this knowledge is not owned and it is not fully representative of all. It has the power to inform and to bring new understandings that will benefit generations to come.

As I worked through the discourse, I navigated the many layers that come from negotiating how to best represent the participants' work. This process was not straightforward because the participants also needed to ensure that the many levels of language that would be used (in my words or their quotes) reflected the inner workings of their narrative. In contrast to traditional quantitative writing, which takes an expert stance, this research acknowledges that the participants know what best reflects their experience.

## **FUTURE POSSIBILITIES**

Future possibilities are taking shape as I write this dissertation in 2016/2017. New ideas are forming between group members who see opportunities to develop workshops that incorporate new knowledge and opportunities for adjustment for people who are newly diagnosed with HIV. National platforms to inform others of the peer support process are building within relational networks, and the power of media platforms is being exploited to make isolation a thing of the past. These endeavours will use peer support volunteers to develop relational weavings that integrate the multiple experiences of those living with HIV with those who are adjusting, resisting, and trying to mold a new experience into their life.

Currently we are trying to establish a framework and timeline for the introduction of relational development endeavours that are aimed at advancing new ideas. There are so many intelligent gay and transgendered people in the community of people living with HIV. Intellectual experience has the capacity to challenge oppression when it can be harnessed to bring new ideas into action. The format of future gatherings will be one that allows everyone to put forth ideas that provide insight into the diversity of experience of people who live with HIV. There is no limit to possibility, there is only limitations in our thinking.

The HIV community is a catalyst community, which means they have weathered the AIDS storm and survived for over 30 years. The HIV gay and transgendered community is shape shifting the landscape of their cultural DNA. If we all live with HIV, then we – all people, including gay, transgendered, lesbian, pansexual, and cultural sexual permeations that have yet to be created – will be more advanced, more evolved, more human, and potentially more full of love and compassion.

## **Final Thoughts, Final Emotions, Enduring Relational Dynamics**

Who am I to write such an important document that brings forth new knowledge about this marginalized group of people? I ponder this question every time that I sit down to write more words, read more words, and rewrite more words. It is difficult to figure out the best way to say something that is only temporarily mine, and that stems from a relational dynamic that allowed me to come closer to the story of another's lived experience. When I waver, I remember that I was given an opportunity and I took it. I found my way into people's lives because I decided that they mattered and that they needed to be heard and supported.

I think about accepting the task, a rather large one, to develop a participatory action research project within a community with the aim of developing new knowledge and possibly leading to change. I think about the principles of postmodern feminist theory and know that a conscious researcher can assist in bringing forward another marginalized group's words without overshadowing/dominating their voice. The key is to find ways to empower the participants and to make sure that all voices are heard. It seemed that so much of my education, practice, and the lived experience of being the "other" (whether a woman, growing up poor, or just knowing that I did not have the same power as others to create dominant discourse) allowed me to connect with this community and to be allowed to co-write their stories with them.

Lastly, within the larger philosophical understanding of the social constructionist paradigm, all relationships matter and no new knowledge is created without relationships. Social constructionist philosophical understandings have guided me in many ways: to live fully in my own humanity and to see the human right of relationship with authentic self, beyond the writers of the dominant discourse that might seek to define you for their benefit. These understandings have become a powerful intellectual medium for my academic understandings and my writing – about the HIV community and beyond. Throughout this research I have written, thought, and related, and I have been discouraged a few times along the way. Despite these setbacks, I have persevered and hopefully have created a dissertation that contributes to the betterment of those people who live with HIV.

## EPILOGUE

The Navajo Indians of North America say that life is like one of their beautiful woven rugs seen from below: lots of diverse colored hanging threads and a pattern that is somewhat obscured within the weaves that hold it. When seen from above, the wholeness, richness and beauty of the collective design emerges with vibrant colors, rich texture and varied movement. Using a participatory action research methodology has the potential benefit of being an action-oriented process that allows for praxis-in-action to be a mutual inquiry of significance. This methodology encourages a vibrant and unique pattern of narrative reciprocity between the designated researcher and the co-researchers (also known as the community members), leading to a collaborative outcome that benefits the whole.

This action-oriented research methodology invited sero-discordant couples into a community of people living with the confounding and compounding reality of HIV. The “in-action” component of this research was paramount – it provided the framework for a social-relational engagement process, supported by social constructionism, that allowed all couple participants to express their lived experience of HIV. Through a post-modern feminist theoretical lens, each couple was invited to bring their authentic voice and understanding of the lived experience of HIV into a collaborative, in-action dialogic process. A beautiful pattern of engagement emerged that was no longer obscured by the overarching, systemic veil of stigma and oppression.

The uniqueness of the social constructionist paradigm allowed for the development of new knowledge (socially constructed by the couples) as they identified their diverse needs. The couples discussed how they were impacted both positively and negatively by the HIV virus, the lived experience of HIV-infused stigma and the relational dynamics that they co-existed within. The in-action component of the PAR methodology and the theoretical lens of post-modern feminist theory allowed for critical reflection (within a dialogic format) that wove diverse ideas with intense emotions such as loss, betrayal, shame, anger, joy and hope within a relational construction of inquiry. Ultimately, this series of gatherings would allow for a collaborative research agenda that enabled disenfranchised voices to be heard and encompassed action-oriented principles of establishing community development processes that came from the co-researchers.

### **Collaborative Dialogues: Empowerment-In-Action**

The strength of this inquiry is that it supported capacity-building from within the community of participants. Initial dialogues were developed using post-modern feminist theory as all voices were invited to be heard but participants could choose to be silent. Some participants gathered only once to be heard and then decided to disengage from the process; there was no enduring expectation for participation beyond the initial dialogues. For others, the gatherings evoked a sense of commitment, specific to the initiation of generative dialogues for the collective engagement in a collaborative agenda they had created. As participants felt heard, they evolved through sharing intimate details of their lived experiences that were not an inherent expectation of the initial gatherings. The strength of sharing stories, understanding diverse views shaped by age, culture, sexual orientation, ability, class and many other unique personhood characteristics, allowed for new knowledge to develop through meaningful relationships.

Inherent in an action-oriented inquiry are the limitations associated with exposure that comes with engaging a community process that requires that participants declare their HIV-positive status. Limitations can also arise from difficulties that come with finding one's voice amidst feelings of marginalization, due to social and structural oppression. Limitations can also be the time required to create processes that will address all of the known barriers and then face new obstacles that a researcher might not even understand due to not being HIV positive. Time as a limitation can relate to how time is used as a resource that requires commitment to a process that might not have an official end date. Lastly, limitations might be identified as being barriers faced when trying to gather diverse populations who have other commitments and health issues. The latter embedded within fears surrounding professional appointments (and being judged) that is beyond the control of the co-researcher, when navigating a long-term longitudinal research study such as PAR.

The possibility of transferring a capacity-building research processes to other disenfranchised or less visible populations is exponential. These research processes embody a generative element that abides with international human rights and is congruent with the sentiment that every human has the right to be heard and valued (i.e., they have a right to equality). Incalculable benefits can be realized by the whole of society when marginalized people gather in an action-oriented format to generate narratives based on their diverse experiences. This is especially true when these experiences are valued and are used to understand the unique needs of those involved, and to build capacity around these needs. The social ascension of the excluded through an action-oriented process should be a required mandate of all academic institutions that ascribe to developing social capital.

The current commitment I have as an action-oriented researcher is to transfer this new knowledge to our First Nations people of Canada (specifically the Blood Tribe) in Alberta, Canada. There is a need for Indigenous-focused capacity building and peer-support for those living with HIV and Hep C, while also facing concurring disorders like opiate and alcohol addictions, merged with the impact of intergenerational trauma. This new knowledge is being acknowledged as a working framework for empowering other groups of individuals that have been disenfranchised through racism and systemic oppression. The uniqueness of action-oriented processes are that they enable communities



of marginalized people to find transformative dialogues. This transformative process encourages First Nations people to celebrate their cultural practices of traditional prayer and the honoring of elder relationships, as a way of addressing the systemic racism that tried to suppress their Indigenous identity. The focus of the relational-gatherings is allowing the First Nations people involved in this action-oriented project to dismantle the impact of colonization and reconstruct with relational engagement a culturally sensitive, Indigenous-focused capacity building model. The facilitation of this collaborative action-oriented project is being done in a respectful manner with Indigenous elders, Indigenous community members and health leaders interested in the process of implementation of the recommendations from the Truth and Reconciliation Commission.

### **Future Directions: Educate People and Give Out PrEP**

The HIV community is a catalyst community, which means they have weathered the AIDS storm, survived for over 30 years, and now are being influenced by new medications such as pre-exposure prophylaxis (or PrEP). The HIV virus in the last 20 years has been suppressed by the introduction of protease inhibitors, in combination with reverse transcriptase inhibitors (Highly Active Antiretroviral Therapy, or HAART). Although there is no cure for the HIV virus, the risk of contracting HIV for those engaging in different sex practices can now be suppressed by PrEP. The HIV gay and transgendered community is shape-shifting the landscape of their cultural DNA. It is inviting the larger world to construct new ideas and to be open to the possibility that members of this community can use PrEP to reduce the risk of HIV transmission. The current lack of federal and provincial funding for PrEP, and a lack of accessibility to this medication, is a barrier for those wanting to have sex differently within the gay and transgendered community.

If PrEP was readily available – for free or at a minimal cost – this might promote the social acceptance of certain sexual practices for the gay and transgendered community. Why not promote sexual freedom for this group of people? Did we not do the same for the heterosexual community when birth control was made available to all women who wished to prevent pregnancy? By denying cost-effective PrEP medication to the gay and transgendered community, we are perpetuating their oppression. Is it not obvious that we are limiting their sexual expression by limiting the availability of PrEP? What is the future for this unique group of people living with HIV? Will there be equity around who is provided which medications and for what purposes? Is this not an issue of sexual inequity?

Family planning is considered one of the most important action points to empower women around the world. PrEP might be the next most important medication to empower the homosexual/transsexual community to have safe sex while the HIV virus is still active. If we all live with HIV, then we – all people, including gay, transgendered, lesbian, pansexual, and cultural sexual permeations that have yet to be created – will be more advanced, more evolved, more human, and potentially more full of love and compassion. We will experience fewer limitations, and more acceptance of love being love and sex being sex. We will become evolved beings who have created the opportunity to be sexually free – with medication (birth control or PrEP) as required by the physiology that drives our desires.

Victor Frankl, the psychiatrist who survived a Nazi death camp and went on to write *Man's Search for Meaning*, described how to live a meaningful life in which human potential can be fulfilled. He wrote that somewhere between stimulus and response is a space that allows us the power to choose our emotional response. In that space lies our chance to engage our growth and choose freedom. We, as diverse people, need to choose to be free of our hierarchical tendencies to dominate and suppress others within our human species based on the difference in worth that we ascribe to those who have different sexual preferences.

### **The Search for Meaning: An Author's Journey**

The meaning of the research participants' stories challenged my own social experience as a heterosexual, HIV-negative female who had never had an intimate relationship with an HIV-positive person. This lack of lived experience meant that I was less knowledgeable and less experienced in the lived experience of being HIV-positive or loving someone who is HIV positive. As a co-researcher in the gatherings and in the larger research project, this lack of knowing how it would feel to experience the diagnosis of HIV was an inherent limitation that challenged my understanding the lived experience of my co-researchers. This lack of lived experience disenfranchised my social experience, a good parity to go through in order to know the "othered" experience. Being a co-researcher allowed me to sit with, seek to understand, and become more informed as I heard the story of the shared experience around HIV. The stories of living with HIV had so many hidden secrets – for example, around the moment in which an HIV-positive person chooses to disclose their status. An undetectable HIV load may mean acceptance because one can avoid disclosing their HIV status, compared to the rejection one might experience by having to tell that they are HIV-positive.

### **Coping With Writing: Understanding HIV Mythology**

Given the opportunity, a unique journey can reveal itself and new levels of meaning can emerge from the outside and from within. These experiences can provide the power to transform our experiences and change our lives. Coping as the writer of this research was not that straightforward. I changed as I walked with this community of people that struggled to find solace in a world in which they would once have been criminally charged or sequestered in order to prevent the spread of HIV. My writing acknowledges that this resilient group of people has the right to love those they love, whether their viral load is detectable or not. For me coping, at times, meant hiding in order to deconstruct the meaning of accepting those who are HIV-positive. Many times, I stepped into conversations with community members who were not ready to accept that sex is sex. Being HIV-positive does not mean that something is wrong with someone, despite the stigma that exists around the virus, which surpasses that for most other viruses that affect the human race.

### **Legacies Learned: The Value of Showing Up**

Legacies are built on the inherent human experience of showing up and being willing to commit to something that matters to someone other than yourself. Woody Allen once said that 80 percent of success is simply showing up. What other peer researchers-practitioners can learn from this research project is that showing up is integral to capacity-building within community-based research practices. The co-researchers (community members) need to get to know you (the academic researcher) and need to see that you're willing to show up. Co-researchers (community members) want to know if you can stand with them, if you have loved, and if you have suffered; they want to know if you are human beyond the research that you seek to develop with them. As I continue to meet with participants in a less formal practice, I now witness their relationships outside of the research and in a more human way; we share the experience of being people, with no writing about their lives and no formal boundaries that make each of us into the "other".

### **The Hero's Journey: Relational Commitment**

In Joseph Campbell's *The Hero with a Thousand Faces*, he explored the idea – first developed by Carl Jung – that all humans share a certain universal experience around relationships that merge out of our human right to love, to be loved, and to create loving relationships. If this research can impart any universal principle for others who want to be action-oriented researchers, it is to find a relational framework that allows you to be more human, more present, more courageous, and less driven by expert-oriented research practices, leaving you open to inherit a diverse world that is waiting to be understood.

The only thing that matters is the relational dynamic that you commit to – it has a nostalgic element and can contribute to the betterment of humanity. It contains a relational energy and belongs to the many people who came before; it is historically Indigenous in nature. Each generation enters into a hero's journey, either with or without the conscious guidance of those who came before. These universal action-oriented research principles are written on behalf of all those who have found themselves invisible or excluded, and have sought their basic human right to be known and respected. Beyond the bindings of what is socially constructed for those disenfranchised by others, there awaits a universal desire to be understood, within the uniqueness of each person as they emerge, unbound, as an important part of humanity.

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## APPENDICES

### APPENDIX A: LETTER OF INVITATION

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**Title of Study: Sero-Discordant Couples – Seeking Relational Dialogues**

**Principal Investigator: Patricia Miller**

**Supervisor: John Gill, Director of the Southern Alberta Clinic**

I, Patricia Miller, of the Southern Alberta Clinic, invite you to participate in a gathering for the research project entitled “Sero-Discordant Couples: Seeking relational dialogues. The purpose of this research project is to bring together ten couples of sero-status that would be interested in discussing a potential research opportunity for sero-discordant couples.

The expected duration of the gathering for the couples would be two hours.

This research should benefit sero-discordant couples by helping them to develop a community of support that would in turn allow them to dialogue about their couples experience of living with HIV.

I will be calling you to follow-up this letter, with a formal invitation to participate in the potential research.

If you have any difficulties with, or wish to voice concern about, any aspect of your participation in this gathering, you may contact the Conjoint Health Research Ethics Board Chair (Dr. Glenys Godlovitch) at 403-210-9757.

If you have any questions, please feel free to contact me.

Thank-you

Study Title: Sero-discordant couples: Seeking relational dialogues  
PI: Patricia Miller MA Counseling Psychology (candidate), RSW, MSW, PhD (student).  
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**APPENDIX B: TELEPHONE SCRIPT FOR GATHERING OF SERO-  
DISCORDANT COUPLES**

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**“Hi (potential participant’s name), my name is (insert name) and I am a Doctoral student. I am contacting you because you are a patient at the Southern Alberta Clinic and are currently in a sero-discordant couple relationship. A sero-discordant relationship is when one person is HIV-positive and the other person is HIV-negative. The reason that I am calling is that I am interested in gathering sero-discordant couples to discuss issues that are most important to them. I would also like the participants to consider a potential research project to support sero-discordant couples on these same important issues. I am wondering if you would be interested in hearing more about these gatherings?”**

**(If no) “Thank-you for your time. Good-bye.”**

**(If yes) Continue**

**“Participation in this gathering involves yourself and your partner coming to an open meeting at the Sheldon Chumir Center on (date/time/room location). This is a gathering with no agenda but to welcome the couples and openly discuss, the issues that are most relevant to sero-discordant couples. If you choose to come with your partner, both of you will get a chance to talk with other sero-discordant couples about issues that relate to your experience of living with HIV. If the group decides that they want to pursue an action research process, then there will also be a discussion regarding what that will be. The meeting will take approximately 2 hours and there will be at most 5 sero-discordant couples in total and myself. I would like to assure you that this gathering has received approval from the office of the Conjoint Health Research Ethics Review Board of Alberta Health Services and the University of Calgary.**

**The final decision about participation is yours and your partner’s.**

**I am gathering sero-discordant couples at this time but if only one of the partners can come it would be okay that she/he come for the gathering on her/his own.”**

**(if no) “Thank-you for your time. Good-bye.”**

**(if yes) “Thank-you. I appreciate your interest in our sero-discordant couples gathering!**

**Let me give you some important information about the gathering. Have you got a pen and paper?**

**The gathering dates are (2x dates, choose the one that works) (location/time)  
On the date of the gathering, please come to the third floor at the Sheldon Chumir  
building. Parking is on the first floor of the underground parking lot.**

**I will give you a reminder call two days before the meeting to make sure you are still  
able to make it. If you have any questions about the meeting that you might want to  
discuss with me prior to the gatherings, you can call me at 403-801-3642.**

**I look forward to seeing you on (day/time of gathering). Thank you very much for  
helping me with this gathering of sero-discordant couples.”**

## **APPENDIX C: PARTICIPANT CONSENT FORM**

### ***Sero-discordant couples: Seeking relational dialogues.***

Initial gathering of sero-discordant couples by Patricia Miller, MA Counseling Psychology (candidate), MSW, RSW, doctoral (student) (403) 955-6311, e-mail: [patricia.miller@albertahealthservices.ca](mailto:patricia.miller@albertahealthservices.ca)

I invite you to take part in a sero-discordant couples gathering being conducted by Patricia Miller. Your participation in this gathering is voluntary and you may withdraw from the gathering at any time. The gathering is described below. This description tells you the benefits, risks, inconvenience, or discomfort that you might experience. Participating in the gathering might not benefit you, but we might learn things that will benefit others. You should discuss any questions you have about this gathering with Patricia Miller, who can be contacted at (403-955-6311).

#### **Purpose of the gathering:**

To gather together sero-discordant couples in Calgary, Alberta in a participatory action research process as a way of developing relational dialogues.

To co-create, a co-action process within a participatory action research methodology that allows sero-discordant couples to be co-empowered.

#### **Who can participate in the gathering:**

You may participate in the gathering if you are a sero- discordant couple living with HIV.

#### **Who will be conducting the research:**

The principal leader for this gathering is Patricia Miller, MA Counseling Psychology (candidate), MSW, RSW, doctoral student.

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## Couples Living With HIV: GATHERINGS, DIALOGUE AND COMMUNITY ACTION

What you will be asked to do:

Once participants have expressed a willingness to be involved in the gatherings, they will then meet with the principal leader at the Sheldon Chumier Clinic. At this gathering the consent form will be read over with the principal leader and the participants. If you are interested in participating in the gathering, you can sign the form at that time.

Once you have attended the gathering, then you can choose to be a part of a collectively decided upon formal research project. The estimated total time commitment for the gathering is approximately two hours.

Potential risks and benefits:

By choosing to participate in this gathering, you might experience certain risks and benefits. I have identified some of the risks and benefits that I think could occur.

Risks:

In discussing components of your couple's story, you might feel a sense of being overwhelmed or uneasy. I will leave my phone number with you, and I will be available to answer questions. As well, I will leave you the number for the Distress Center 24-hour help line.

With regards to confidentiality, all participants within the gatherings will be asked to commit to keeping information heard in the group confidential. We cannot guarantee that no one will share parts of your story outside of the gatherings. The options that you have are to share only what you feel comfortable with knowing that someone else in the group will hear or might tell others. The principal leader will commit to informing everyone who participates in the gathering of the importance of keeping confidentiality outside of the group. **If you do not feel comfortable about participating in a gathering due to concerns around disclosure, I will be willing to meet with you one-to-one at a scheduled time that works for the couple. I will also arrange for an interpreter as needed.**

Benefits:

You will have an opportunity to discuss your concerns as a sero-discordant couple with other couples that attend the gathering. Potentially, a research project may arise to further understand and act on some of the concerns the sero-discordant gathering identifies.

Study Title: Sero-discordant couples: Seeking relational dialogues

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## Couples Living With HIV: GATHERINGS, DIALOGUE AND COMMUNITY ACTION

### Compensation:

We will provide a parking pass or bus tickets.

### Confidentiality:

We cannot guarantee absolute confidentiality, due to the group format. You will be asked not to talk to anyone outside of the group about the members who participated in the gathering.

There are professional limits on confidentiality. If you reveal to me, the principal leader that you have intent to harm or have harmed yourself or another, I am bound by my professional ethics to notify the appropriate authority. If this was to happen, I would inform you of my obligation and support you to contact the authority with my assistance.

### Questions:

Participants will be able to contact the principal leader, Patricia Miller, by telephone at (403)-955-6311. The principal leader will inform you of any new information that might impact your decision to participate in the gathering.

### Problems or Concerns:

If you have any questions concerning your rights as a possible participant in this research, please contact Glenys Godlovitch, The Director Office of Medical Bioethics, University of Calgary, at 403-220-7990.

Study Title: Sero-discordant couples: Seeking relational dialogues

PI: Patricia Miller RSW, MSW, MA Counseling Psychology (candidate), Doctoral student.

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*Sero-discordant couples: The prevalence of clinical issues*

I have read the explanation about this gathering. I have been given the opportunity to discuss it, and my questions have been answered to my satisfaction. I hereby consent to take part in this gathering. However, I realize that my participation is voluntary and that I am free to withdraw from the gathering at any time.

I have read this consent form and agree to participate in this gathering. I will receive a copy of this form once it has been signed by both the participant and researcher.

Participant's Name (please print): \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Signature of Researcher: \_\_\_\_\_

Date: \_\_\_\_\_

Study Title: Sero-discordant Couples: Seeking relational dialogues

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