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## Navigating Life with HIV: The Lived Experiences of Youth Living with HIV

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A thesis submitted in partial fulfillment of the requirements for the degree in Doctor of Philosophy

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NAVIGATING LIFE WITH HIV:  
THE LIVED EXPERIENCES OF YOUTH LIVING WITH HIV

(Dissertation format: Monograph)

by

Tamara Marjorie May Landry

Graduate Program in  
Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Doctor of Philosophy

The School of Graduate and Postdoctoral Studies  
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## Abstract

Youth and young adults living with HIV, between the ages of 15 and 29 represent one-quarter of the new infection rates in Canada, but little is known about the safer sex practices, HIV disclosure processes and coping mechanisms used by this important but often neglected group to manage the every day realities of living with HIV. The primary objectives of this study were to gather qualitative data about the lived experiences of Canadian youth who are living with HIV and enhance our understanding of their experiences of becoming HIV-positive, navigating issues related to safer sex and HIV disclosure, and managing life as someone living with HIV.

This research employed a phenomenological approach to data collection and analysis to understand the lived experiences of participants. This study utilized qualitative methods for data collection and analysis. Eighteen youth living with HIV (14 males, 3 females and 1 transgender female) between the ages of 22 and 29 were recruited for this study through AIDS Service Organizations in Ontario and British Columbia. Each participant engaged in an in-depth individual interview.

The findings from this study highlight four global themes that were representative of the lived experience of what it means to live with HIV for the youth in this study. *Becoming HIV-Positive* includes the participants' perspectives regarding being diagnosed with HIV and the impact of finding out they are HIV-positive, which included isolation, depression and thoughts about suicide. *Navigating HIV* focuses on how the participants' lives have changed since they found out they have HIV, including coming to terms with being HIV-positive, learning to negotiate dating and other relationships, and determining responsibility for condom use. *HIV Disclosure Management* features the participants' experiences regarding

the management of disclosing or not disclosing their HIV status within various relationships. *Finding New Meaning in Life After HIV Diagnosis* focused on how the participants have found or made new meaning in their lives since becoming HIV-positive, including transforming their lives, creating positive changes and future hopes. The findings from this study contribute new knowledge and provide us with a detailed understanding of the lives of youth living with HIV, beginning from when they found out their HIV status through to the many challenges associated with being HIV-positive, and the strategies they use to manage living with HIV.

#### Keywords

HIV-Positive; HIV; Youth; Young Adult; Disclosure; Safer Sex; Phenomenology; Lived Experience; HIV Management; Living With HIV

## Dedication

*This dissertation is dedicated to the most important people in my life,  
Gary, Graceyn and Larkyn.*

*To my amazing husband Gary,*

*You have never stopped believing in me. Your constant encouragement, support and unconditional love have always shown me that there was light at the end of what seemed to be a never-ending tunnel. Without your love and our family, I would not be the person I am today.*

*To our beautiful daughters Graceyn and Larkyn,*

*Even though it was difficult for you to understand how many pages and chapters mommy had to write, you were always right there with me doing your “homework” too; reading your favorite books, writing your own stories or drawing me one-of-a-kind works of art. The sweet smiles on your faces, the giggles in your voices and the unlimited hugs were always the best parts of my day.*

## Acknowledgments

I am very grateful to so many people for their support throughout this process:

- ❖ First and foremost, I would like to express my deepest appreciation to the youth living with HIV who shared their experiences with me for this study. Thank you for trusting me with your stories.
- ❖ I would like to thank my advisory committee for their constant support and guidance through the many obstacles that I faced during this research process.
- ❖ Dr. Bill Fisher for his invaluable leadership, incredible support and extensive knowledge. Even when you were 3000 miles away, you always made time for me. You are the reason I was able to do this research study and I will be forever grateful.
- ❖ Dr. Treena Orchard for her amazing insight, dedication and constant support. You pushed me to think and write beyond what I thought I was capable of and I will always be thankful for your encouragement
- ❖ Dr. Jan Polgar for your constant and unwavering support right from the start of my doctoral studies. Thank you for your important feedback on my chapters during the writing process. I will forever be indebted to you for your kindness, objectivity and understanding.
- ❖ Dr. Lilian Magalhaes for your valuable insight into the development of this research study and your incredible knowledge in qualitative research methods. You always had time to talk with me and provided amazing support to me throughout this process.
- ❖ I would like to thank Gary Thompson, Francisco Ibanez-Carrasco, Todd Coleman, Shamara Baidoobonso, Meredith Fraser, Brian Lester, Carolyn Fitzgerald and Jennifer Ireland for reviewing various pieces of this dissertation. I very much appreciate the time you took to provide me with your perspectives.
- ❖ My deepest gratitude goes to the AIDS Committee of Toronto and Positive Youth Outreach, Regional HIV/AIDS Connection, YouthCo, and AIDS Durham. Thank you for collaborating with me on this research project and providing valuable insight and support.

- ❖ Thank you to the Youth Advisory Committee members who collaborated with me for this research. You are an amazing group of people I will never forget. Your guidance, knowledge and experiences touched my heart and helped to shape this research and ensure it was tailored to the needs and concerns of youth living with HIV.
- ❖ Dr. Francisco Ibanez-Carrasco for being a wonderful and supportive mentor and friend. I am so fortunate to have met you.
- ❖ To Todd Coleman and Shamara Baidoobonso for not only being colleagues and allies during our doctoral studies, but for being great friends I will always treasure.
- ❖ Nancy Inchley and Cathy Collins who were always there to answer all of my questions about everything related to completing a PhD. You always had a smile on your face and a warm welcoming environment for me.
- ❖ Thank you to Sarah Flicker for allowing me to utilize questions from the Toronto Teen Study for this research study.
- ❖ Thank you to Western University, Ontario HIV Treatment Network, Universities Without Walls and the Social Research Centre in HIV Prevention for the generous financial support of my doctoral research.
- ❖ To my parents, Bruce and Joy and my mother-in-law, Vera for your constant encouragement, love and support, it means more than I could ever express.
- ❖ To my husband, Gary and our daughters, Graceyn and Larkyn for their unconditional love, understanding and support throughout my doctoral studies and beyond. I love you more than words could ever say.

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## **List of Abbreviations**

|             |  |
|-------------|--|
| ACT         | AIDS Committee of Toronto              |
| AIDS Durham | AIDS Committee of Durham               |
| AIDS        | Acquired Immune Deficiency Syndrome    |
| ASO         | AIDS Service Organization              |
| ART         | Antiretroviral Therapy                 |
| BC          | British Columbia                       |
| CBO         | Community Based Organization           |
| CBPR        | Community Based Participatory Research |
| GHB         | Gamma hydroxybutrate                   |
| HAART       | Highly Active Antiretroviral Therapy   |
| HCV         | Hepatitis C                            |
| HIV         | Human Immunodeficiency Virus           |
| IDU         | Injection Drug Use                     |
| ON          | Ontario                                |
| PEP         | Post-Exposure Prophylaxis              |
| PHAC        | Public Health Agency of Canada         |
| PYO         | Positive Youth Outreach                |
| REB         | Research Ethics Board                  |
| RHAC        | Regional HIV/AIDS Connection           |
| STI         | Sexually Transmitted Infection         |
| WHO         | World Health Organization              |
| YAC         | Youth Advisory Committee               |

# CHAPTER ONE

## 1 Introduction

### 1.1 Introduction to this study

Now in the third decade of the epidemic, Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDS) continues to affect numerous people worldwide. Until the advent of Highly Active Antiretroviral Therapy (HAART), people living with HIV and AIDS were dying in increasing numbers; which is still the case in many developing countries where HAART is not affordable. In the Western world in particular, access to HAART is more systematically supported and has helped to transform HIV and AIDS from a fatal disease into one that is more chronic and manageable over the life course. However, young people living with HIV were not prepared for what they would encounter in the future because they were not expected to live. Living with HIV as a youth or young adult complicates the normal developmental tasks and behaviors of adolescence, such as becoming independent of parents, forming peer groups, engaging in sexual relationships and establishing their own identities.

Youth living with HIV may encounter a number of different factors that are more challenging, such as negotiating safer sex behavior, criminalization of HIV non-disclosure, HIV medical treatment and HIV stigma (Battles & Weiner, 2002). Previous research with youth living with HIV has shown that they are vulnerable and may often experience disproportionate rates of sexual and physical abuse, homelessness, financial difficulties, addictions, social isolation and stigma (Flicker, Skinner, Read, Veinot, McClelland, Saulnier & Goldberg, 2005). Despite the numerous challenges that youth living with HIV face, little

research has been done in Canada to address their needs and concerns.

This dissertation explores the lived experiences of living with HIV from the perspectives of young people living with the virus in Ontario and British Columbia. Specifically, it explores how they navigate issues related to safer sex, HIV disclosure and in the management of HIV. For the purposes of this study, “youth” are defined as people between the ages of 15 and 29, which corresponds to the official definitions of youth by agencies like the Public Health Agency of Canada (PHAC) and the World Health Organization (WHO). Furthermore, since all of the youth were being recruited through AIDS Service Organizations (ASOs) who provide service to youth between the ages of 15 and 29, it made sense to use parameters already employed by ASOs who serve this age group. This chapter provides a brief overview of the current epidemic worldwide, in Canada and specifically in British Columbia and Ontario. Then, a discussion of the experiences of youth living with HIV with the normal developmental tasks of adolescence and what this means for them. Next, the current gaps in the literature on youth living with HIV in Canada and how this research addresses some of those gaps will be discussed. This will be followed by the research objectives and finally, the organization of the dissertation will be reviewed.

## 1.2 Background

The year 2011 marked the thirtieth anniversary of what we now know as HIV and AIDS. HIV infection targets and weakens the immune system leaving the infected person susceptible to opportunistic infections and certain types of cancer (PHAC, 2008). HIV infection, if left untreated, progresses to AIDS, which is defined by extreme compromise of the immune system, opportunistic infection, and can include meningitis, encephalitis,



dementia, peripheral neuropathy, pneumonia, Candida (fungus infection of the esophagus, trachea, bronchi or lungs), cytomegalovirus infection (herpes), cryptococcal meningitis, cervical cancer, wasting (weight loss), lymphoma (Lyon & D'Angelo, 2006) and eventual death as the individual succumbs to these opportunistic conditions. Progression from HIV to AIDS can take anywhere from two to fifteen years (PHAC, 2008). In the past thirty years of the epidemic we have witnessed many changes and medical advances, such as the development of HAART to combat and slow HIV infection and replication (Canadian AIDS Treatment Information Exchange (CATIE), no date). Successful treatment can reduce the viral load in the body of a person living with HIV. The viral load is the level of HIV in the blood of someone who is HIV-positive. An undetectable viral load does not necessarily mean there is no HIV virus in the blood; it means that the amount in the bodily fluids is beneath the level that tests can detect (CATIE, 2013). An undetectable viral load can greatly reduce the risk of HIV transmission (CATIE, 2014). With the advent of HAART, HIV infection has been transformed into an illness that is no longer an immediate death sentence (Lyon & D'Angelo, 2006).

It is important to grasp the magnitude of the HIV/AIDS epidemic, not only on a worldwide scale, but also on a more focused scale in Canada and specifically the two provinces in which this study took place, BC and ON, which provides the rationale for the focus of this research. The HIV/AIDS epidemic has increased dramatically since the early 1980's, resulting in an estimated 34 million (a range of 31, 600, 000-35, 200, 000) people living with HIV worldwide by the end of December 2010 (UNAIDS, 2011). In 2009, 41% of those infected with HIV were between the ages of 15-24. Worldwide, it was estimated that there were 5 million (range of 4.3-5.9 million) young people between the ages of 15-24 living with HIV in 2009 (UNAIDS, 2011). In 2010 alone, there were 2.7 million (range of 2,

400, 000-2, 900, 000) new HIV infections (UNAIDS, 2011). Globally, it is estimated that 2,500 young people are infected with HIV every day (UNAIDS, 2011).

Compared to the global HIV epidemic, the Canadian epidemic is considerably smaller, though still significant. There have been a total of 22,702 AIDS cases reported to Public Health Agency of Canada since reporting commenced in 1985 and this has been decreasing progressively since 1993 (an 82.6% decrease) with the advent of HAART (PHAC, 2013). In the early part of the HIV epidemic, youth between the ages of 15 and 29 years of age accounted for 39.5% of positive HIV tests in Canada; this number decreased to 21-23% between 1998-2008 (PHAC, 2010a). However, the number of HIV-positive tests in youth between the ages of 15 and 29 increased slightly to 24% in 2009 and remain the group with most new HIV infections in Canada. There were 71,300 people diagnosed with HIV by the end of 2011; of these, 17,980 are not aware that they are living with HIV (PHAC, 2012). The HIV incidence rate, or the number of new HIV infections annually, was estimated at 3,175 for 2011 (with a range of 2,250-4,100), which is very similar or slightly lower than the incidence rate for 2008. In 2012, the HIV incidence rate was 2,062, which is a 7.8% decrease from 2011 (PHAC, 2012). Of the 71, 300 HIV diagnoses in Canada up to 2012, youth aged 15-29 accounted for 26% (19,197) (CATIE, 2012). Youth and young adults between the ages of 15 and 29 represented one-quarter of new positive HIV tests in Canada in 2012 (CATIE, 2014).

When we look at the HIV infection rate in BC and compare it to the national HIV infection rate, we can see that BC accounted for 16% of the total number of Canadian infections by the end of 2011. Between 1985-2009 there were 13,686 positive HIV tests in BC, 11% of which were young people between the ages of 15 and 29 (British Columbia Centre for Disease Control (BCCDC), 2009). As of 2010, there were over 300 youth living

with HIV, 25 years of age and under, in BC (BCCDC, 2010). By the end of December, 2011, there were 11,700 infections (with a range of 9,400-14,000), in BC, which is an increase from 2008 (BCCDC, 2011). In 2011, there were 380 new infections in BC, 15% of these new infections were young people aged 15-29 (BCCDC, 2011). In 2012, there were 238 HIV diagnoses, and while this is a decrease from the previous year, 58 of these were among young people aged 15-29- representing 25% of all new diagnoses in 2012 (BCCDC, 2012).

The HIV infection rate in ON is significantly larger than BC and accounted for 44% (highest amount of HIV-positive tests in Canada) of the total Canadian infection rate by the end of 2011 (PHAC, 2010b). Between 1985-2010 there were 31,596 people diagnosed with HIV in Ontario; 7874 (25 %) of whom were young people aged 15-29 and 142 of whom were born with HIV (Remis & Liu, 2013). In 2011 alone, there were 946 new HIV diagnoses in Ontario, 247 of which are youth between the ages of 15-29 (Remis & Liu, 2013); which represents just over one-quarter (26.1%) of the HIV infections in Ontario for 2011. As of 2011, there were approximately 5,947 (4,463 males and 1,484 females) youth between 15-29 years of age, living with HIV in Ontario (Remis & Liu, 2013). The data on HIV-positive youth in Canada between the ages of 15 and 29 represent approximately 25% of all new HIV infections in the current epidemic (PHAC, 2010a).

### 1.3 Youth and the HIV epidemic

HIV among youth and young adults is an increasing concern because the new infection rates are highest in this population. HIV infection is challenging for this population because they are in the midst of learning to develop or redefine their identity and navigate existing or new

relationships at the same time they are carrying the weight of living with a complicated, stigmatized illness (Hosek, Harper & Robinson, 2002). The advent of HAART increased the number of young people living longer with HIV (Kapetanovic, Christensen, Karim, Lin, Mack, Operskalski, et al., 2009). However, living longer with HIV brought about other challenges and the decisions that youth living with HIV would need to make regarding sexual activity, relationships and HIV disclosure to other people (Levine, Aaron & Foster, 2006). During adolescence there are various changes that adolescents and youth go through which play an important role in their behavior and can significantly change their development and health in positive and negative directions (Huebner, 2009). Even though these youth may be engaging in defining sets of experiences (i.e., substance use and sexual exploration) that are common during adolescence and young adulthood, they might do so in ways that may not always be good for them or might produce situations they are ill-equipped to handle (i.e., compared to adults) given their stage of learning and maturity level.

The specific tasks or sets of experiences in adolescence, include identity formation, autonomy or independence, and intimacy and relationship formations (Huebner, 2009). Establishing one's identity is known as one of the most important tasks of adolescence (Erikson, 1968; Kroger, 2006) in which an adolescent should develop a sense of who they are or their individual or personal identity (Hosek et al., 2002). Establishing one's autonomy or independence refers to being able to become an independent person within relationships and to make their own decisions and follow through with those decisions (Huebner, 2009). Establishing intimacy and relationships with peers is a critical piece in adolescence that sets the stage for future relationships. These first intimate relationships are generally with their friends and then romantic partners where they learn to have open, honest, caring and trusting relationships (Huebner, 2009). It is within these relationships that adolescents and youth

learn to maintain and terminate relationships, practice social skills, become intimate (Huebner, 2009) and learn how to cope with the various stresses of life and relationships.

Living with a chronic illness, especially one that is also highly stigmatized, can make the normal developmental tasks more difficult for youth because of the impact it can have on their ability to create their own experiences and make their own decisions. Youth with chronic illnesses are different than youth without a chronic illness for many reasons, including an additional layer of identity development and the question for them becomes whether or not they define themselves “as their illness” or someone “with an illness” (Huebner, 2009). Autonomy may also be challenging for some youth with chronic illnesses, depending on the type of illness they are living with and the amount of responsibility they are given (Huebner, 2009). In addition, intimacy for youth with chronic illnesses may be tough because they feel different from their peers (Huebner, 2009) and their illness sets them apart from those who do not have a chronic illness. When adolescents are confronted with relationships, they face dilemmas about the choices they should make and their decisions to engage in these behaviors are further complicated by their chronic illness status because of fear, rejection and discrimination. In addition, youth living with HIV need to negotiate medication adherence, stigma, HIV disclosure, and the prevention of HIV transmission (Battles & Wiener, 2002; Levine et al., 2006). Youth living with HIV face the same challenges regarding the normal developmental tasks of adolescence that their HIV-negative peers or youth with other chronic illnesses face, however, these tasks are more complicated and consequential for youth living with HIV by virtue of their HIV status (Battles & Wiener, 2002; Fielden, Sheckter, Chapman, Alimenti, Forbes, Sheps, Cadell, & Frankish, 2006).

## 1.4 What This Current Study Contributes

This study addresses some of the gaps in the current research on youth living with HIV in Canada. This research can provide an understanding of the impact that living with HIV has had on the lives of these youth and how they have learned to manage living with what is now considered to be a chronic illness. The findings from this research have the potential to provide evidence for educators, healthcare providers, ASOs, and youth living with HIV regarding the resilience they have in the management of HIV and the other challenges they face. These findings can also provide a deeper understanding of the safer sex practices, including condom negotiation and responsibility, and the concerns that youth living with HIV – an important but often neglected, group - are now faced with regarding the new legal judgments and HIV-disclosure management. Understanding the safer sex practices and HIV disclosure management of youth living with HIV will help us to then develop safer sex negotiation and HIV disclosure skills and guidelines to assist youth in making safe and healthy decisions regarding sexual behaviors and HIV disclosure management. These issues are significant for the promotion and maintenance of the health and wellbeing of HIV-positive and HIV-negative individuals and for understanding issues associated with the prevention of transmission. These findings are also important to share to honor and respect the diversity of the participants' life experiences.

## 1.5 Research Objectives

The main objectives of this research are as follows: 1) to gather qualitative data about the lived experiences of a diverse group of Canadian youth living with HIV, infected at birth or during adolescence or young adulthood; and 2) to enhance our understanding of their

experiences of becoming HIV-positive, navigating issues related to safer sex and HIV disclosure, and managing life as someone living with HIV. The following research questions comprise the focus of this study for youth living with HIV:

- 1) What are the contextually-based experiences of living with HIV for youth or young adults?
- 2) How do youth and young adults living with HIV navigate sexual practices, relationships and HIV disclosure?;
- 3) What strategies do youth and young adults living with HIV use to manage the impact of living with HIV on their social, relational, and emotional lives?

## 1.6 Organization Of The Dissertation

This dissertation has seven chapters, including this introductory chapter. Chapter Two presents a review of the literature on what is known about youth living with HIV, including a focus on sexual behavior, stigma, HIV disclosure, the criminalization of HIV non-disclosure and the lived experience of managing life with HIV. Highlights of the limited studies on youth living with HIV in Canada will follow, and then the potential impact of this research will be discussed.

Chapter Three describes the methods used in this study, including the epistemological and ontological lens of this research, the phenomenological approach, a youth advisory committee community-based approach, data collection and analysis methods, ethical considerations and qualitative rigor.

Chapter Four provides a social profile of the eighteen research participants, which provides the reader a more intimate understanding of the youth in this research. Their social profiles are presented in this chapter by province (BC and ON) and then gender.

Chapter Five provides a presentation of part one of the findings, which includes the results that relate to the global themes of *Becoming HIV-positive* and *Navigating HIV*. *Becoming HIV-positive* includes the participants' perspectives regarding being diagnosed with HIV and the impact of finding out they are HIV-positive, which included isolation, depression and thoughts about committing suicide. *Navigating HIV* provides a discussion of how the participants' lives have changed since they found out they have HIV, including coming to terms with being HIV-positive, learning to negotiate dating and other relationships, and determining responsibility for condom use.

Chapter Six presents part two of the findings of this research with discussion of the final two global themes of *HIV Disclosure Management* and *Finding New Meaning in Life After HIV Diagnosis*. The *HIV Disclosure Management* theme features a discussion of the participants' experiences regarding the management of disclosing or not disclosing their HIV status within various relationships. In the *Finding New Meaning in Life After HIV Diagnosis* theme, the participants' discuss how they have found or made meaning in their lives since becoming HIV-positive, including transforming their lives, creating positive changes and future hopes. Presenting the global themes in this order provides the reader with an understanding of the trajectory of their lived experience from becoming HIV-positive and coming to terms with it, to navigating dating and safer sex practices, and their on-going struggles related to HIV disclosure, to finding new meaning in their lives.

Chapter Seven features a discussion of the key research findings and how they relate to, inform, or contest the current literature related to youth living with HIV in Canada. Limitations of this study will then be discussed, followed by the recommendations from this study. This chapter will conclude with the implications for future research and their importance for understanding the lived experiences of youth living with HIV in Canada.



## CHAPTER TWO

### 2 Review of the Literature on Youth Living with HIV

#### 2.1 Introduction

This chapter provides an overview of the relevant social science and health-related literature on youth living with HIV, primarily in relation to the issues of sexual behavior, stigma, HIV disclosure, the criminalization of HIV non-disclosure, and the lived experience of managing life with HIV. While the literature on adults living with HIV are generally relevant to some of the experiences of youth living with HIV, the focus of this literature review will be on youth living with HIV since many of the youth in this study were reflecting on experiences during their younger, adolescent years and the data were interpreted with that frame of reference. While references are made to global literature, the dominant focus of this review is on studies conducted in the North American context, and Canadian where possible (there are comparatively fewer studies in Canada than the U.S.). Most of the existing literature focuses on HIV-positive youth who were infected perinatally, and to a lesser extent on those who were infected during adolescence or young adulthood. Where pertinent in this review, I will distinguish between these two groups of youth. This chapter will conclude with the gaps in the current literature and the relevance of this study.

#### 2.2 Sexual Behavior

Dating, sexual exploration, and negotiating relationships are complicated for any young person, but in all likelihood even more challenging for youth living with HIV (Bush-Parker, 2000). Engaging in sexual activity since becoming HIV-positive requires youth to consider

the implications of HIV transmission to their partner, which involves abstaining or delaying sexual activity, negotiating condom use to prevent transmission, or evaluating the risks of not engaging in safer sex practices. The literature reveals that youth living with HIV may avoid or delay sexual activity because of their fear of transmitting HIV. Marhefka and colleagues (2011) found that HIV was viewed as a “weapon” that could cause other people harm if the youth did not engage in protected sexual activity to prevent transmission (Marhefka et al., 2011). This is in contrast to the findings of a Canadian study by Fernet and colleagues (2007), who found that many youth discussed being afraid of engaging in sexual activity after being diagnosed with HIV and felt a sense of responsibility in protecting other people because they did not want to transmit it to anyone else.

For youth living with HIV who do engage in sexual activity, there is a relationship noted in the literature between condom use and responsibility, which was also related to HIV disclosure. According to Leonard and colleagues (2010), youth believed that having sex without a condom was acceptable if they had disclosed their HIV status to their partner. In complementary findings, Rice, Batterham, and Rotheram-Borus (2006) found that disclosing one’s HIV status changed the dynamic of responsibility to their partners; youth felt that HIV disclosure shifted the responsibility for condom use to their partner. Another study revealed different connections between disclosure and condom use where some youth felt that HIV disclosure was not necessary if they were practicing safer sex through condom use (Leonard et al., 2010). This is similar to the findings of the Canadian study by Fernet and colleagues (2011) who found that youth felt that disclosure was not needed if they were using condoms to practice safer sex. However, in the earlier Canadian study by Fernet and colleagues (2007), the youth talked about their sense of responsibility in protecting other people, but feared negotiating condom use with a partner because of disclosure and rejection. Fielden

and colleagues (2006) found similar results in their Canadian study where youth were afraid to disclose their HIV status to a girlfriend or boyfriend because of fear of rejection.

Of interest to note in the literature regarding sexual behavior is the tendency of youth living with HIV to transition from practicing safer sex to taking more risks as time passes after diagnosis. For example, Koenig and colleagues (2010) looked at the prevalence and predictors of transmission-related behaviors with youth living with HIV and found that approximately half of the participants had taken risks in subsequent relationships and engaged in unprotected sex after becoming HIV-positive. Furthermore, Marhefka and colleagues (2011) also found that girls living with HIV took more risks with regards to sexual behavior in order to fit in with their HIV-negative peers. In the Canadian qualitative study by Fernet et al. (2011), it was found that all the sexually active youth used a condom at least once since they found out their HIV status. However, similar to findings from Koenig et al. (2010) and Marhefka et al. (2011), Fernet et al. (2011) found that over half of the youth who used condoms during their first sexual relationship, after diagnosis, engaged in unprotected sex in later relationships. In addition, the youth in this study viewed condoms as a barrier to intimacy and a reminder that they were living with HIV. Their findings illustrate a change in risk perception, with youth living with HIV taking more chances with regards to unprotected sex, especially when their viral load was undetectable and their partners did not become infected after practicing unprotected sex in the past (Fernet et al., 2011).

### 2.3 Stigma

Goffman (1963), who provided the seminal work on stigma, defined stigma as "an attribute that is deeply discrediting" (p. 13), and asserted that stigma is a relationship where "an attribute that stigmatizes one type of possessor can confirm the usualness of another" (p. 13).

In Goffman's (1963) view, stigma arises when normative expectations regarding a person's identity, most commonly located in one's appearance, are not conformed to. This discrepancy causes those who are not stigmatized ("normals") to view those with non-conformist identities as being not fully human, thus marking them with a "spoiled" social identity. Key outcomes of this stigmatization process include the isolation of those stigmatized from society and feelings of deep shame, which is often the result of internalized stigma among those afflicted. HIV/AIDS-related stigma refers to "all unfavorable attitudes, beliefs, behaviors, and policies directed at persons perceived to be infected with HIV, whether or not they actually are infected and regardless of whether or not they manifest symptoms of AIDS" (Herek, 1990, p.7). Even though HIV-related stigma has declined since the early 1980's, it is still a considerable issue (Herek, Capitano, & Widaman, 2003) that has far-reaching implications for people living with HIV and AIDS.

Stigma has also been conceptualized further into the categories of felt or enacted stigma. Felt stigma is internalized and refers to one's subjective feelings and awareness of discrimination, including being rejected, and a change in one's social identity, which can have an impact on coping abilities, access to social support, and psychological well-being (Swendeman, Rotheram-Borus, Comulada, Weiss, & Ramos, 2006). Felt stigma leads people to alter their behaviors or engage in protective behaviors to avoid experiencing further stigma, such as not adhering to medications, not disclosing their HIV status and not seeking support (Herek, Chopp, & Strohl, 2007). Enacted stigma, on the other hand, refers to the overt acts of other people towards individuals who are perceived as different, such as not shaking hands with someone who is living with HIV (Scambler, 2004). Ayres and colleagues (2006) found that felt stigma was described by subjective feelings of embarrassment that was linked with social discrimination and fear of disclosure to other

people and enacted stigma occurred when the youth felt that their rights were denied, such as access to health care. Similarly, Swendeman and colleagues (2006) found that youth living with HIV experienced enacted stigma (job loss, denial of medical treatment, abuse) and felt stigma (social rejection and shame), with almost all participants (147 participants in the study) reporting felt stigma and over one-quarter reporting enacted stigma experiences.

HIV/AIDS stigma has historically been associated with groups of people and modes of transmission (e.g., men having sex with men, intravenous drug users, sex workers and promiscuity) that were believed to be negatively viewed by society (Diaz & Ayala, 2001; Parker & Aggleton, 2003; Swendeman et al., 2006). Stigma has long been a cause of stress because of its unequal effect on sexual minorities in particular (Herek & Garnets, 2007) and its contribution to sexual stigma. “Sexual stigma,” is defined as “stigma based on sexual orientation...society’s negative regard for any non-heterosexual behavior, identity, relationship, or community (Herek, 2004; Herek, Chopp, & Strohl, 2007). For sexual minorities, awareness of stigma is chronic and contributes to an ongoing need to monitor situations where stigma could arise (Herek, Chopp, & Strohl, 2007). Youth living with HIV who are sexual minorities experience multiple layers of stigma because of the early link between HIV and sexual orientation.

HIV stigma has been noted in the literature to have numerous negative social, psychological and physical effects on youth living with HIV. HIV stigma affects whether one will seek social support (Lam, Naar-King, & Wright, 2007) or isolate themselves from other people. In a Canadian study by Flicker and colleagues (2005) youth living with HIV felt lonely, stigmatized, sad and depressed and these feelings negatively influenced their ability to access social support. Furthermore, in a study by Hosek and colleagues (2008) they found that youth would self-isolate and dissociate themselves from their friends soon after

diagnosis in order to avoid rejection due to HIV stigma. Similarly, Rao and colleagues (2007) found that youth would isolate themselves and hide their HIV status from their peers or family members because of stigmatizing comments about people living with HIV or because they experienced discrimination whereby they were asked to use separate eating utensils.

## 2.4 HIV Disclosure

Whether to disclose one's HIV status is a difficult decision that is often negotiated in an ongoing way during people's lives, and dependent upon various issues like social context, safety, and emotional/mental health (Eustace & Ilagan, 2010; Thoth et al., 2013). HIV disclosure is a complex and multifaceted process, which requires a person living with HIV to consider a number of social and contextual factors (Eustace & Ilagan, 2010). Disclosing one's HIV status is a unique consideration for each person and each situation and can be filled with uncertainty about the consequences and confidentiality of disclosure (Lyon & D'Angelo, 2006). HIV disclosure is not a one-time event; it is a process that requires one to develop knowledge and skills to effectively communicate, and to read the context of the situation to ensure disclosure is safe. Disclosing one's HIV status is about the communication skills required to tell another person about a potential life-threatening, transmissible, stigmatized illness (Wiener, Mellins, Marhefka, & Battles, 2007). HIV disclosure is also the act of telling another person or persons about one's HIV status, with or without the consent of the person living with HIV (Ontario Advisory Committee on HIV/AIDS (OACHA), 2003).

HIV disclosure is not a single entity; it requires an understanding of the dichotomy between disclosure and non-disclosure. HIV disclosure and HIV non-disclosure are

considered to be two distinct issues, however, both are similar in that they consist of processual and situational events. Nevertheless, a division exists in the effect that disclosing or not disclosing may have on the person living with HIV. Issues related to disclosure are complex and may not always be helpful to the person disclosing that he or she is living with HIV (Thoth et al., 2013). People living with HIV do not disclose their HIV status because they fear negative reactions, privacy violation, stigma, and potential criminalization related to HIV/AIDS (Swendeman et al., 2006). At the same time, *not* disclosing information to other people can have a negative effect on one's emotional and psychological well-being and their health functioning (Pennebaker, 1997), and has even resulted in violence and criminal prosecution for some people living with HIV (Canadian HIV/AIDS Legal Network [CHLN], 2012b). However, disclosure of one's HIV status has often been framed as a valuable process for creating intimacy and open-ness, decreasing isolation and increasing emotional and social support (Thoth et al., 2013), which is associated with improved health status and fewer negative mental health symptoms (Abramowitz, Koenig, Chandwani, Orban, Stein, Lagrange, & Barnes, 2009; Lam et al., 2007; Wiener & Battles, 2006).

When deciding to disclose their HIV status to other people, studies have shown that youth take a number of situational and relationship factors into consideration. Batterham and colleagues (2005) noted that youth who had been recently diagnosed were less likely to disclose their HIV status than those who have been living with HIV for longer. A qualitative study by Michaud and colleagues (2009) found that adolescents were less likely to disclose their HIV status if their parent was also living with HIV, in an effort to protect their family. In a similar qualitative study by Hogwood, Campbell, and Butler (2013) it was found that the relationship between the youth and the person they are disclosing to was critical in making the decision to disclose. For example, youth considered the length and/or quality of their

relationship with the person, as well as whether they could trust that person (Hogwood et al., 2013). In addition, youth felt that building peer relationships were more important at their stage of life than risking rejection by disclosing their HIV status to their peers. Building relationships was also a way to test the 'disclosure waters' to see how people would react (Hogwood et al., 2013).

The decision to disclose one's HIV status can be filled with tremendous fear and there were several barriers noted in the literature for youth living with HIV related to confidentiality, rejection, and serostatus of their partner. Leonard and colleagues (2010) found that not being able to control who other people told after they disclosed was a barrier to disclosing one's HIV status. This type of management is what Goffman (1963) terms "information control" because the person is constantly trying to monitor the information, "...to display or not to display; to tell or not to tell; to let on or not to let on; to lie or not to lie; and in each case, to whom, how, when and where." (p. 42).

Disclosing to a sexual or romantic partner or potential partner is shown in the literature to be a particularly challenging situation (Michaud et al., 2009) because youth living with HIV feared being rejected (Foster et al., 2007). Michaud and colleagues (2009) found that youth were afraid to disclose their HIV status because of previous painful experiences that resulted in rejection. There are also notable differences in the literature between disclosure decisions to main and casual partners, with disclosure to casual partners occurring less often than disclosure to main partners (D'Angelo et al., 2001; O'Brien et al., 2003). In addition, HIV disclosure was increased two-fold for youth living with HIV who knew their partner was also living with HIV (D'Angelo et al., 2001), whereas youth who had an HIV-negative partner were less likely to disclose their HIV status (Batterham et al., 2005).



The literature demonstrates that youth who chose to disclose, reported a number of positive social and health outcomes compared to those who did not yet disclose (i.e., at the time of the study). For example, D'Angelo and colleagues (2001) and Lyon and D'Angelo (2006) have found that youth who disclosed their HIV status to their family and friends reported improved mental health and emotional status and an enhanced sense of social support resources. Wiener and Battles (2006) found that disclosure of HIV status to family and friends facilitated future disclosure and increased confidence with this challenging aspect of life, including in situations with sexual partners. Along with increased social confidence and enhanced relationships, disclosure has been connected with improved adherence to HIV medications (Mellins, Brackis-Cott, Dolezal, & Abrams, 2004) and a higher CD4 count (Sherman, Bonanno, Wiener, & Battles, 2000).

## 2.5 The Criminalization of HIV Non-Disclosure

The stresses associated with HIV disclosure have been exacerbated by the Supreme Court of Canada's October 2012 decision that persons with HIV must disclose their status prior to situations where sexual contact poses a "realistic possibility" of HIV transmission (CHLN, 2012). The criminalization of HIV non-disclosure has emerged as an issue that presents significant *barriers* to HIV disclosure for people living with HIV/AIDS. People living with HIV or AIDS can and have been charged for not disclosing their status to a sexual partner. Three HIV non-disclosure criminal law cases (*R. v. Cuerrier*, 1998, *R. v. Mabior*, 2012 and *R. v. D. C.*, 2012) ultimately led to the Supreme Court of Canada decisions in 2012. In *R. v. Cuerrier* (1998) a man was charged with two counts of aggravated sexual assault because he engaged in unprotected sexual activity with his partners without disclosing that he knew he

was living with HIV (Canadian HIV/AIDS Legal Network (CHLN), 2012). Cuerrier was acquitted by the trial judge because the crown prosecution did not prove an assault happened because the complainants (Cuerrier's partners) consented to sexual intercourse (CHLN, 2012). As a result of the Cuerrier case, the Supreme Court of Canada had to decide if the criminal law of assault could be applied to cases of HIV non-disclosure (CHLN, 2012). In the Supreme Court decision in *R. v. Cuerrier*, it was decided that people living with HIV have a legal responsibility to disclose their HIV status prior to sexual activity that poses a "significant risk" of serious bodily harm (i.e., HIV transmission; CHLN, 2012). According to the Supreme Court, a person living with HIV could be convicted of aggravated assault for HIV non-disclosure when consent for sexual activity was achieved fraudulently (i.e., without disclosure; CHLN, 2012).

In *R. v. Mabior* (2012) a man was charged with nine counts of aggravated sexual assault because he did not disclose his HIV status to his partners, none of whom were infected (CHLN, 2012). Mabior was convicted on six counts of aggravated sexual assault, which were reduced to two counts after appeal (CHLN, 2012). In *R. v. D. C.* a woman engaged in sexual intercourse once with her partner without disclosing her HIV status; her partner did not contract HIV (CHLN, 2012). After that first sexual encounter, D. C. disclosed her HIV status to her partner and they continued their relationship (CHLN, 2012). After D. C. and her partner broke up her partner went to the police and told them she had not disclosed her HIV status prior to their first sexual intercourse (CHLN, 2012). D. C. was arrested, charged with sexual assault and aggravated assault and convicted at trial because there was no condom used during the first time they engaged in sexual intercourse (CHLN, 2012). Her conviction was set-aside on appeal because she had a low viral load making the likelihood of transmitting infection quite improbable. The Supreme of Canada set aside her

original conviction because it was based on conjecture (CHLN, 2012).

The Supreme Court of Canada's decision regarding HIV disclosure means that people living with HIV, regardless of their viral load (i.e., low, undetectable, high), are legally obligated to disclose their status prior to having vaginal or anal sex without a condom (CHLN, 2012). People living with HIV are not legally obligated to disclose their HIV status if they have a low or undetectable viral load and use a condom during vaginal intercourse (CHLN, 2012), however, the legislation is not clear for anal sex. According to the Supreme Court ruling, the criminal charge for HIV non-disclosure is aggravated sexual assault or grievous bodily harm (CHLN, 2012). Charges of aggravated sexual assault can carry a maximum penalty of life in prison and registration as a sex offender (CHLN, 2012). A conviction for HIV non-disclosure does not require the actual transmission of the virus but only a significant risk of serious bodily harm (i.e., HIV transmission) (CHLN, 2012).

There is little evidence that the new criminal law on HIV non-disclosure is effective at HIV prevention (CHLN, 2012). These recent legislative rulings can make some HIV-positive people feel persecuted, and be, prosecuted if they do not disclose their status. The criminalization of HIV may actually push people away from HIV testing, counseling and support, and partner notification (CHLN, 2012) because of their fear of rejection and legal repercussions. The Supreme Court decisions are literally a step backwards from the previous court decisions (CHLN, 2012). Prior to October 5<sup>th</sup>, 2012, the law stated that a person who knows they are living with HIV only has a duty to disclose their HIV-positive status if they are engaging in sex that poses a "significant risk" of "serious bodily harm" (CHLN, 2012). The 1998 Cuerrier decision was not overt enough regarding what comprises "significant risk" of HIV transmission (CHLN, 2012) and led to much confusion. In 2012, instead of clarifying the law on HIV non-disclosure, the Supreme Court decision exacerbated these

issues, which resulted in ambiguity, injustice and an increase in the stigma and discrimination faced by people living with HIV (CHLN, 2012).

## 2.6 Lived Experience of Managing Life with HIV

At present, there is still no cure for HIV; however, with the advances in medical treatment and the availability of HAART, HIV is now considered to be a “manageable chronic illness” (McGrath et al., 2014). What this means in terms of living with and managing HIV/AIDS is controversial in the literature and focuses on “the biomedical norming of HIV/AIDS...[with] little to say about the life stages and processes for those who are HIV-positive” (Philbin, 2014, p. 290). While HIV/AIDS has been acknowledged as a chronic illness since the advent of HAART and does fit with quite a few of the chronic illness criteria, such as, an unknown path of the illness, prescribed treatment, and identity alteration, there are three specific challenges that prevent HIV from being a manageable illness like other chronic conditions (Swendeman, Ingram, & Rotheram-Borus, 2009). The three challenges that impede the self-management of HIV are the “lack of direct self-monitoring of physical status, stigma and disclosure, and criminalization of HIV exposure” (Swendeman et al., 2009, p. 1324). The first challenge refers to the inability to self-monitor the physical status of HIV progression such as CD4 count and viral load (Swendeman et al., 2009). Other chronic illnesses, such as diabetes, have self-monitoring tools available that allow the level of glucose in one’s blood to be monitored frequently and managed immediately with insulin if necessary, whereas HIV does not have tools that will assist with the physiological self-monitoring of HIV (Swendeman et al., 2009).

The second challenge that may prevent HIV from being a manageable chronic illness relates to the stigma associated with HIV and the necessary steps one may be required to take

to manage disclosure (Swendeman et al., 2009). There are a number of chronic illnesses or health conditions that carry a certain level of stigma, such as diabetes, lung cancer, colon cancer, obesity, leprosy, and epilepsy, which vary depending on whether one is believed to be responsible for their illness, the contagious nature of the illness, and whether the illness will result in visible changes to their physical body (Siegel & Lekas, 2002; Swendeman et al., 2009). The idea that a person living with HIV can live a manageable, normal life as HIV-positive assumes that they have the ability to control stigma, which is not always the case, especially in relation to HIV (McGrath et al., 2014). Living with HIV is stigmatizing for youth because they are more concerned than others with how they are perceived by others, their body image, peer pressure and being rejected by their peers (Lyon & D'Angelo, 2006). Young people living with HIV are forced to deal with other people's fears and lack of knowledge and at the same time they are trying to deal with their health and building relationships. These factors are also at play when it comes to managing HIV disclosure or non-disclosure since people living with HIV/AIDS fear that they will be rejected and discriminated against if they disclose their status to others (Lyon & D'Angelo, 2006). Disclosing one's HIV status carries more negative effects than the disclosure of other illnesses (Lee & Rotheram-Borus, 2002; Lee, Rotheram-Borus, & O'Hara, 1999), such as Diabetes, Cancer, and other sexually transmitted infections.

The third challenge that impedes HIV from being a manageable chronic illness is the criminalization of HIV exposure (Swendeman et al., 2009). There are now laws in many countries that criminalize people living with HIV who put other people at risk of HIV through unprotected sex, even if the other person does not become infected (Canadian HIV/AIDS Legal Network, 2014; Swendeman et al., 2009). No criminalization laws exist for other chronic illnesses that are not sexually transmittable, however, public health law and

criminal assault law could be applied in any case of knowingly exposing someone to a disease, which makes it more challenging for people living with HIV to effectively manage their illness because of fears related to HIV disclosure. Fear of criminalization can also decrease HIV disclosure (Dodds, Bourne, & Weait, 2009; Mykhalovskiy, Betteridge, & McLay, 2010) and hamper HIV prevention (Swendeman et al., 2009). These three challenges make it very difficult for someone living with HIV to consider HIV a chronic illness that is manageable on a daily basis (Swendeman et al., 2009).

Despite the challenges that people living with HIV/AIDS face, many are very resilient and learn to manage their illness in various ways that make sense to them. A number of studies with adults living with HIV have focused on the lived experience of being HIV-positive and the ways in which they manage their physical, psychological and social health since being diagnosed. Mosack and colleagues (2005) in their study with drug users living with HIV found that the participants saw HIV as a “wake up call” or a second chance to take responsibility for their health and care by stopping self-harming behaviors. These included abstaining from drug and alcohol use, adhering to the medication regimens, and eating regularly and more nutritiously, which helped them to feel physically stronger and improved their health more than they were before they diagnosed with HIV. Similarly, Emlet and colleagues (2010) in their study with adults living with HIV found that self-acceptance, optimism and a positive outlook on living with HIV were important insights for their participants to overcome the negative effects and complexities of HIV and remain hopeful about their well-being. Furthermore, some participants saw their HIV diagnosis as a time to reconnect with family or friends and repair relationships, which ultimately contributed to support with managing the challenges of living with HIV (Emlet et al., 2010). In addition, Ezzy (2000) found that an HIV diagnosis not only provided opportunities for

some of their participants to complete school, have careers and a family, it also gave them the chance to support other people living with HIV.

Resiliency and managing the realities of living with HIV have not been well studied from the perspective of youth living with HIV. However, a few studies have noted ways that youth living with HIV are learning to manage their illness, such as planning more for the future, attending support groups and providing peer support (Di Risio et al., 2011; Lightfoot & Healy, 2001). Lightfoot and Healy (2001) found that some youth who thought death was imminent when they were first diagnosed are now planning for the future because of the availability of life-extending HIV medications, and attending school and developing careers. Di Risio and colleagues (2011), in their Canadian study found that support groups gave their participants a sense of relief and optimism knowing that there were other youth like them that they could relate to. Di Risio et al. also found that participants who educated other people about HIV/AIDS felt that this diminished the weight of managing their own illness. What is missing from the literature is an in-depth understanding of the ways that youth living with HIV learn to manage living with HIV and navigating the many challenges that they face.

## 2.7 Gaps in the Current Literature

The literature on youth living with HIV is limited and the research concerning this group in Canada is even more inadequate. There are very few in-depth qualitative studies that honor the lived experiences of youth living with HIV. Much of the literature about youth living with HIV is with regard to sexual behavior, HIV-related stigma and HIV disclosure and has been conducted in the United States. Canada is also a very unique situation for people living with HIV because of the criminalization of HIV non-disclosure laws, which is not applicable to people living in the United States. The focus on youth living with HIV is critical because

as these youth become sexually active, criminalization will be a focus in their lives and they may not be as equipped as adults to handle the challenges that come with living with HIV and navigating life. Furthermore, the research tends to focus more on youth with perinatal transmission than youth living with HIV who were infected during adolescence or young adulthood. Studies outside of Canada reveal that we still need to understand a number of issues regarding the sexual behaviors of youth living with HIV. For example, we need to understand why youth living with HIV choose to delay sexual activity after being diagnosed with HIV (Bauermeister, Elkington, Robbins, Kang, & Mellins, 2012), which would help to identify factors such as the timing of the delay in order to help develop supportive resources to assist youth. It is also important to understand the sexual knowledge and behavior of youth living with HIV so we are able to tailor reproductive health education and secondary prevention programs (Ezeanolue, Wodi, Patel, Dieudonne, & Oleske, 2006). This information would assist HIV-positive youth in their decision-making with regards to sexual health and provide health care providers with an understanding of how to integrate support and advice to youth living with HIV (Koenig, Pals, Chandwani, Hodge, Abramowitz, Barnes, & D'Angelo, 2010)).

We also need to understand numerous issues related to HIV disclosure management for youth living with HIV, including their decisions to disclose or not disclose. For example, understanding the role of disclosure in promoting or inhibiting safer sex would enable the development of safer sex negotiation skills that could assist youth living with HIV to increase their safer sex practices and condom use. In addition, it is important to understand the disclosure differences, if any, between youth who have perinatally acquired HIV and those who were infected during adolescence or young adulthood (Thoth et al., 2013). Preliminary research (e.g., Michaud et al., 2009; Thoth et al., 2013; Thurston, Bogart, Fields, Hu, Skeer,



Closson et al., 2014) with youth who were born with HIV and youth who were infected in later life tell us that they have different experiences of being HIV-positive, including length of time living with HIV, engagement in sexual activity and dealing with dual disclosure of finding out one's HIV status and telling other people. Understanding these differences would facilitate the development of specific resources that are tailored to the needs and stages of each group of HIV-positive youth.

Another important gap in the literature relates to understanding the effects of HIV disclosure over time (Thoth et al., 2013). Knowing how disclosure affects HIV-positive youth at different stages in their life would help us understand how to support youth during these times—throughout their lives as well as the different stages of 'youth' or young adulthood. Existing studies have discussed some of the positive and negatives aspects of disclosure, however, it is critical to understand the specific barriers and facilitators to HIV disclosure (Hogwood et al., 2012) in order to help support youth living with HIV with disclosure management and assist them with developing communication skills (Gillard & Roark, 2013; Thoth et al., 2013; Wiener & Battles, 2006).

Canadian research with youth living with HIV and issues related to safer sex practices and HIV disclosure is limited to focusing on sexuality, HIV prevention and risk management, romantic relationships and reasons for HIV disclosure or non-disclosure with youth who acquired HIV through perinatal transmission (e.g., Fernet et al., 2007; Fernet et al., 2011; Fielden et al., 2006; Michaud et al., 2009). Few Canadian studies have focused on issues related to the impact of finding out one has HIV, negotiating safer sex practices, HIV disclosure concerns and managing their lives living with a chronic illness. While there have been studies on sexuality and sexual health with youth who acquired HIV through perinatal transmission, to my knowledge there are currently no published Canadian studies that focus

specifically on the safer sex practices and HIV disclosure practices and concerns of youth who were infected during adolescence or young adulthood or both groups of youth living with HIV.

There are still a number of gaps in the Canadian context regarding youth living with HIV and safer sex practices and HIV disclosure. According to Fernet et al. (2011), more research is needed to understand the development of intimacy and the impact of rejection on the mental and sexual health of youth living with HIV, as well as research that specifically focuses on romantic relationships. These data are important because they will provide us with insight into how youth living with HIV navigate these relationships and face the challenges of disclosure. It is also important to gain insight into these issues within different modes of infection for comparison so we can understand how to address potential differences between youth who were born with HIV and youth who were infected during adolescence or young adulthood. In addition, it is imperative to have more research specifically on the resiliency and coping strategies of youth living with HIV. This study provides some insight into how youth living with HIV are managing living with HIV, however more research is needed to provide us with an in-depth understanding of their resiliency and coping strategies.

Research and supportive policies or guidelines around how and when to disclose to partners (Fielden et al., 2011), especially in light of the potential criminalization of HIV non-disclosure (Fernet et al., 2011), are needed to understand when and where young people living with HIV can feel safe disclosing their HIV status. Healthcare providers and people in the social and familial networks of youth living with HIV also need guidelines to assist young people with creating safe spaces that allow them to talk openly about HIV, stigma and other experiences and to disclose if and when the time is right. In addition, what is absent from the research on HIV disclosure are studies with youth infected during adolescence or

young adulthood and knowledge about the support and resources that youth living with HIV need to safely disclose their HIV status within various relationships outside of partners, including family members, friends, employees.

## 2.8 Relevance of this study

This research addresses some of the gaps in the current research on youth living with HIV in Canada and can provide an understanding of the impact that becoming HIV-positive has had on the lives of these youth and how they have learned to manage living with what is now considered to be a chronic illness. The findings from this research also have the potential to provide evidence for educators, healthcare providers, ASOs, and youth living with HIV, which can be shared to honor and respect the diversity of the participants' life experiences, the resilience they have in the management of HIV and the other challenges they face. These findings can provide a deeper understanding of the safer sex practices, including condom negotiation and responsibility, and the concerns that youth living with HIV – an important but often neglected, group – are now faced with given the new precedence on the criminalization of HIV non-disclosure. Understanding the safer sex practices and HIV disclosure management of youth living with HIV will help us to then develop safer sex negotiation and HIV disclosure skills and guidelines to assist youth in making safe and healthy decisions regarding sexual behaviors and HIV disclosure. These issues are significant for the promotion and maintenance of the health and wellbeing of people living with HIV or AIDS and HIV-negative individuals and for understanding issues associated with the prevention of transmission. Given this study's emphasis on the lived experience of

youth living with HIV, this research provides unique and rich insights into their lives on their own terms.

## 2.9 Conclusion

This chapter provided an overview of the current literature on youth living with HIV with regards to sexual behavior, HIV stigma, HIV disclosure, the potential criminalization of HIV non-disclosure and the lived experience of managing a chronic illness. The literature tells us that youth living with HIV are challenged with many issues related to the complications that arise from the realities of being HIV-positive, including negotiating dating, relationships and safer sex practices. Youth living with HIV fear transmitting HIV and either avoid or delay sexual activity or negotiate condom use. Condom use was also linked to HIV disclosure in the literature, with youth living with HIV feeling that sex without a condom was acceptable if they had disclosed their status, which then shifted the responsibility to their partner. In addition, the literature also shows that youth felt disclosure was not necessary if they practiced safer sex or they feared disclosure would result in rejection. Sexual risk taking was also noted in the literature among youth who engaged in unprotected sex after finding out their HIV status. Some youth engaged in unprotected sex as they became more experienced after diagnosis and their perception of risk changed, while other youth took sexual risks so they could fit in with their HIV-negative peers.

Stigma has been a constant issue and concern for people living with HIV or AIDS since the beginning of the epidemic. Stigma was noted in the literature to impact youth living with HIV socially, psychologically, and physically (Lam et al., 2007; Rao et al., 2007; Swendeman et al., 2006). HIV-related stigma affects one's access to social support and

coping abilities and also impacts the mental health of youth living with HIV through isolation and feelings of discrimination (Lam et al., 2007; Rao et al., 2007).

HIV disclosure is noted in the literature as one of the most complex processes that people living with HIV have been challenged with and has been exacerbated by the Supreme Court of Canada's decision in 2012. Youth living with HIV consider the relationship length and quality before they disclose to someone (Hogwood et al., 2013). However, disclosure to peers was less likely until they had built a trusting relationship with them. Studies with youth living with HIV have shown that disclosure is less likely to occur when a parent is also HIV-positive. Numerous barriers to disclosure were noted in the literature including fear of rejection, lack of confidentiality, and the serostatus of their partner. Positive outcomes of HIV disclosure were also noted in the literature, which included improved mental and emotional health, increased access to support, greater confidence and coping abilities and improved health.

There are many challenges that come with being youth and living with HIV and the literature shows that managing HIV is about much more than living with a chronic illness. For youth, managing HIV can prove to be more demanding because not only are they dealing with adolescent development issues, they are trying to manage challenges such as medication adherence, stigma, and HIV disclosure. Despite the challenges, people living with HIV are finding ways to manage their illness and move on with their lives. Managing HIV has not been well documented in youth, however, literature focused on adults with HIV infection show that being diagnosed with HIV is, for some people, a reason to stop self-harming behaviors, take care of their health and enhance their positive outlook on life and forge opportunities for education and relationships. Some of these are similar in a few studies with youth living with HIV that show youth are planning their lives out more now than before

they became HIV-positive, getting and providing peer support, getting an education and planning careers.

As previously mentioned, there is very little research on youth living with HIV and even less from the Canadian context. The existing research tells us that we still need to understand more issues related to sexual behavior and HIV disclosure, especially with an understanding of the differences between youth who were born with HIV and those who were infected during adolescence or young adulthood. We also need to understand these issues within the context of various relationships in order to develop tailored resources and support services for youth living with HIV. This study will help to provide an in-depth understanding of the trajectory of becoming HIV-positive for the youth in this study, which includes learning to manage their illness and the challenges that come with living with HIV.

## CHAPTER THREE

### 3 Methodology

#### 3.1 Introduction

This chapter describes the research methods employed in the current study. It begins with describing this study's underlying research paradigm and methodological approach, including the epistemological and ontological lens, a discussion of the rationale for choosing a qualitative research approach and the particular frameworks of descriptive and interpretive phenomenology. This will be followed by a description of the study design, including the research setting, sampling and recruitment, data collection, data management, and data analysis. The chapter concludes with a discussion of qualitative measures of trustworthiness for ensuring rigour in research and ethical issues.

#### 3.2 Research Paradigm

A research paradigm is a set of basic beliefs that represent the researchers worldview (Denzin & Lincoln, 2005). Embedded with a research paradigm, or guiding philosophy, is the ontological (what is the form and nature of reality) and epistemological (what can be known and how it can be known) lens (Guba & Lincoln, 1994; Nagy Hesse-Biber & Leavy, 2004). The research paradigm that was chosen for this study was guided by the objectives and research questions, which sought to explore the lived experience of what it means to be a youth living with HIV. The interpretivist paradigm adopts relativist ontology, subjectivist epistemology, and a hermeneutic, dialectical methodology (Denzin & Lincoln, 2005; Guba & Lincoln, 1982; Guba, 1990). Interpretivist methods focus on obtaining insight and understanding of the behavior from the participants' perspective and employ qualitative

methods for data collection such as interviews, questionnaires and focus groups (Scotland, 2012) to obtain a rich, detailed description of their experiences. Analyses of the research data are from the researchers interpretations of the information, therefore it is critical that the researcher make explicit their assumptions and understandings at the beginning of the study (Scotland, 2012). Qualitative data collection and analysis methods will be discussed in the sections below. Table 3.1 provides an overview of the research paradigm, methodology and process.

The interpretivist paradigm became the guiding philosophy of my study because of its focus on uncovering the “insider perspective” in order to understand reality from the perspective of the participants. The interpretivist approach focuses on the meanings that people attach to their experiences and how they interpret, make sense and attach meaning to them (White, 1999). I felt the interpretivist paradigm was very complementary to the phenomenological approach employed in this study, which sought to understand the lived experiences of the phenomena under study. Interpretivism seeks to understand the researched phenomena from the point of views of the people involved, as it is lived and individually socially constructed. Therefore, the goal of interpretive research is to understand multifaceted realities through the eyes of the participants (Guba & Lincoln, 1982; Cohen et al., 2007). The manner in which the participants give meaning to the phenomenon of what it means to live with HIV can be different as a result of their socio-cultural experiences. For example, the way youth living with HIV perceived and experienced becoming HIV-positive could be different, even though they are living with the same chronic illness. It is important that the researcher is able to interpret the different meanings that each participant attributes to their experiences.



|  |   |
|--|---|
| PARADIGMATIC ASSUMPTIONS   |   |
| Ontological and epistemological paradigm   | Interpretivist paradigm   |
| Methodological paradigm  | Hermeneutic phenomenological framework  |
| RESEARCH DESIGN  |   |
| Qualitative, phenomenology using interview data gathering methods  |   |
| SELECTION OF PARTICIPANTS  |   |
| Purposeful sampling  | Selection of 18 youth living with HIV, including youth who acquired HIV at birth and youth who acquired HIV in adolescence or young adulthood |
| DATA COLLECTION  |   |
| In-depth individual interviews, descriptive questionnaires, reflexive journaling, and youth advisory committee   |   |
| DATA ANALYSIS AND INTERPRETATIONS  |   |
| Application of HYPERRESEARCH to manage the data for coding and thematic analysis. Development of basic, organizing and global themes from the participants' perspectives |   |
| QUALITY CRITERIA   |   |
| Credibility and confirmability   |   |
| ETHICAL CONSIDERATIONS   |   |
| Informed consent, voluntary participation, confidentiality and anonymity of participants through pseudonyms  |   |

Table 3.1. Research paradigm, methodology and process

### 3.2.1 Rationale for a Qualitative Research Approach

Qualitative research is used in many disciplines and encompasses numerous methods, such as case study, individual interviews, focus groups, and participant observation (Denzin &

Lincoln, 2005). This research approach seeks to understand and interpret the meaning of people's experiences and strives to "...seek answers to questions that stress how social experience is created and given meaning" (Denzin & Lincoln, 2005, p. 10). Given its emphasis on generating in-depth insights, it also aims to "allow people to speak in their own voice, rather than conforming to categories and terms imposed on them by others" (Sofaer, 1999, p. 1105). I used multiple methods in this study, including a qualitative community-based research approach, the development of a Youth Advisory Committee (YAC) in-depth individual interviews, and descriptive questionnaires. Triangulating my data collection through the use of these methods was ideal for this study because it enabled me to obtain a deep and more holistic understanding of the experiences of youth living with HIV. Adopting these approaches also allowed me to build partnerships and capacity with AIDS Service Organizations (ASOs), which was key to tailoring the research so that it reflected the unique needs and concerns of youth living with HIV.

### 3.2.2 Phenomenology

A number of methodologies are used in the interpretive approach, including phenomenology, grounded theory, ethnography and case studies (Crotty, 1998; Creswell, 2009). I employed a phenomenological approach in this study because of the emphasis of this particular research paradigm on understanding the lived experience of participants and the phenomena under investigation. Phenomenology is an example of interpretive methodology; therefore it aligns nicely with the interpretivist paradigm that frames this research. Phenomena are defined as the "appearances of things, or things as they appear in our experience, or the ways we experience things, thus the meanings things have in our experience" (Smith, 2013, np).

There are several different traditions within phenomenology, including transcendental phenomenology, existential phenomenology, and hermeneutical phenomenology (Schwandt, 2001). For the purpose of this research study, I adopted the hermeneutical phenomenological approach as defined by Max van Manen (1990; 1997), which includes the descriptive and interpretive methods. I chose van Manen's method for this research because it encompasses both the description and interpretation of lived experience (Cohen & Omery, 1994), which allowed me to better ascertain a deeper understanding of the lived experience of youth living with HIV.

Van Manen identifies six principles that are essential to consider when doing hermeneutical phenomenological research: *turning to a phenomenon of interest; investigating the lived experience; reflecting on the essential themes; writing a description of the phenomenon; maintaining a strong and oriented relation to the phenomenon; and balancing the research context by considering the parts and whole.* The first principle, *turning to a phenomenon of interest* was employed prior to data collection and refers to the various activities the researcher can focus on to acknowledge past experiences and knowledge of the phenomenon, and increase one's understanding of the lived experience of that phenomenon. Three such activities are orientation to the phenomenon, developing the phenomenological question, and explicating assumptions and pre-understandings. In orienting oneself to the phenomenon, I began by identifying a phenomenon that was of interest to me-HIV/AIDS. I found myself thinking back to my journey in the field of HIV/AIDS and where it all started. It was not until I went to university that I began to learn more about HIV and AIDS, after taking an anthropology course called "Plagues and People". What sparked my interest in becoming involved in the field of HIV/AIDS over 15 years ago was, and still is, stigma. Stigma has been fuelled by the HIV/AIDS epidemic for the past 30

years and has had a profound effect on people who experience it and I wanted to understand why. To me, HIV and AIDS should be no different than any other illness, but people living with HIV are treated differently than people who have illnesses such as cancer or diabetes. My quest was to understand why HIV and AIDS are portrayed in such hurtful, stigmatizing ways? Why are people living with HIV tainted to such a provocative extent than other sexually transmitted illnesses or any illness for that matter? My specific focus on youth living with HIV in this study is because they are a very vulnerable population and represent 25% of all new HIV infection rates (CATIE, 2012), however, there is also limited in-depth research on the lived experience of this often neglected population.

To develop the research question for this study I needed to ask what the phenomenon is like or is about from the perspective of those who have experienced it. As van Manen (1997) states, we need to ask, “What is the nature or meaning of the lived experience”? I wondered how youth living with HIV experienced growing up, which can be difficult enough, while trying to deal with being HIV-positive and living with a highly stigmatized illness. I began asking questions like: What is living with HIV like for youth? How do youth living with HIV describe their experiences, thoughts and feelings about what it is like to be HIV-positive?

Identifying assumptions and pre-understandings is imperative in phenomenology to ensure that the descriptions of participants’ lived experiences are not shaped by the preconceptions and assumptions of the investigator (Speigelberg, 1975; van Manen, 2011). This principle came into play when I was recruiting members for the youth advisory committee, at an ASO for youth in Toronto. I explained to those in attendance that what I knew about youth living with HIV was based on the literature and my experiences volunteering in an ASO, which is not the same as really knowing what it feels like to live

with HIV. Given this, I shared with them that to ensure I was conducting a study that truly reflected and took into consideration the lived realities of youth living with HIV, I needed their valuable input. The youth were very receptive to this and appreciated this respectful approach to involving them in the study, and that experience formed the seeds of the YAC for this project.

Van Manen's second principle is *investigating the lived experience*, which is focused on collecting data about the lived experience under examination. As van Manen (1997) tells us,

The point of phenomenological research is to “borrow” other people's experiences and their reflections on their experiences in order to better be able to come to an understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole of human experience...we gather other people's experiences because they allow us to become more experienced ourselves (p. 62).

I applied this principle throughout the project and it was a central consideration in the different kinds of data collection I used in this study. Since this principle is within the set of research activities that were carried out during data collection, a more detailed discussion of how I applied this principle will be discussed in the data collection section of this chapter.

Van Manen's third principle, *reflecting on the essential themes*, involves understanding the phenomenon being explored through the analysis and the development of themes that are representative of the research participants' lived experiences. Themes are facets that occur repeatedly in a text and are the pieces that help a story come together (van Manen, 1990; 1997). To develop the themes that represent the participants' lived experience, van Manen (1997) suggests three modes of data analysis or interpretation: the holistic,

selective, and detailed approaches. In the *holistic approach*, researchers view the text as a whole and try to capture its meanings. In the *selective approach*, researchers highlight or pull out statements or phrases that seem essential to the experience under study. In the *detailed approach*, researchers analyze every sentence or collection of sentences to obtain an understanding of what is being portrayed about the phenomenon. In this study, all three approaches were utilized, and the ways in which they were operationalized will be discussed in the data analysis section of this chapter.

Van Manen's fourth principle, *writing a description of the phenomenon*, refers to the ways in which the lived experiences of the phenomenon are rendered visible in the written text. This is a fundamental part of the research process that occurs throughout the course of the project. I approached the writing of the descriptions of the phenomenon in the various data collection methods by first being attentive to what was being said in the interview and questionnaire data, then writing and re-writing a narrative account with the intention of creating a text that revealed the experiences of the participants. Writing the description of the phenomenon will be discussed in further detail in the data analysis section of this chapter.

Van Manen's fifth principle, *maintaining a strong and oriented relation to the phenomenon*, requires the researcher to commit herself to the research question(s) and the phenomena under exploration. Maintaining this commitment enables the researcher to obtain a text that is "oriented, strong, rich, and deep" (van Manen, 1997, p. 151). I applied this principle through the use of a reflexive journal that included my thoughts, feelings and experiences, which will be discussed below in the data collection section.

Van Manen's final principle, *balancing the research context by considering the parts and whole*, is a circular process where the researcher moves back and forth between the parts of the text and the whole text to obtain a holistic understanding the lived experience being

explored. Van Manen (1990; 1997) states that "...at several points [in the research process] it is necessary to step back and look at the total, at the contextual givens and how each of the parts needs to contribute toward the total" (p. 31-32). I applied this principle during data analysis, which involved assessing in an on-going way the overall (whole) research objectives/questions in relation to the themes (parts) that were emerging in order to develop a rich understanding of the lived experiences of the youth living with HIV who took part in the study. Since this part of the research process took place during data analysis, I will discuss the application of this principle in detail in the section below that directly pertains to the analysis of the findings.

### 3.3 Research Setting

This study was conducted in British Columbia (BC) and Ontario (ON), Canada. These provinces were selected for this research because of the research relationships I had established with ASOs in those provinces. I first contacted the AIDS Committee of Toronto (ACT) for their assistance with recruiting a youth advisory committee for this study. I then contacted additional ASOs, including AIDS Durham (a community outside Toronto) and Regional HIV/AIDS Connection (RHAC) (London) in Ontario to increase the possibility of recruitment. This study originally included only the province of ON, however it was later extended to include the province of BC. With the later addition of BC to this research study, I contacted the only youth-specific agency in Vancouver to discuss the research project and the possibility of including this organization in this study. It was very important for me to establish connections with all of these ASOs because the very nature of my research is community-based so I wanted to ensure I was collaborating with organizations who provided

service and support to youth living with HIV. All of these ASOs provided assistance with the recruitment of research participants, research space to conduct interviews, along with very strong support from staff during the research process.

### 3.4 Sampling and Recruitment

There are numerous perspectives on sampling procedures in qualitative research, including purposive sampling, snowball sampling and criterion-based sampling. The research participants in this study were selected using purposeful sampling, which involves the selection of information-rich cases for in-depth study. Information-rich cases provide us with detailed information about the experiences of particular importance to the research purpose (Patton, 1990). The research participants were purposively sampled by age and were also selected based on meeting the study's particular inclusion criteria. In this study, participants were recruited if they fit the following inclusion criteria: living with HIV; between the age of 15 and 29; fluent in English; and living in ON or BC. For the purposes of this study, "youth" was defined as people between the ages of 15-29, which corresponds to the official definitions of youth by the Public Health Agency of Canada (PHAC) and the World Health Organization (WHO). Another reason for using this age range is because it aligns with the age of the young people served by the participating ASOs. In addition, since youth between 15 and 29 years of age account for 26.5% of all the positive HIV tests in Canada, it was important to focus on this age group (PHAC, 2010).

Sample sizes are usually smaller for qualitative research studies, including those guided by the phenomenological framework (Morse, 2000), than for quantitative studies because the interest lies not in the number of participants but in the depth and meaning of



information provided, not the ability to generalize the results or develop hypotheses.

Sandelowski (1995) suggested that deciding on the sample size in qualitative research is a matter of experience and being able to judge the quality of the data collected alongside the purpose of the study, the type of sampling method used, and the research method employed. In this study, I was able to interview 18 youth living with HIV (14 males, 3 females and 1 trans female). According to Creswell (1998) and Morse (1994), sample size for qualitative, phenomenological studies should be between five and 25 or at least six participants, respectively. The number of participants interviewed in this study did fall within the suggested amount for a phenomenological study, which seeks to understand the lived experience of a phenomenon.

Recruitment for this study was facilitated and supported with the help of four ASOs: AIDS Committee of Durham, ACT, RHAC in London and YouthCO in Vancouver. I made contact with all four AIDS Service Organizations regarding the study and they assisted me with posting the recruitment invitation and informing the members in their organizations who fit the inclusion criteria for the study. Each of these ASOs expressed their enthusiasm for supporting this study because they felt that this research was not only so important for HIV-positive youth, but it could potentially assist ASOs with supporting youth living with HIV. The recruitment invitation is displayed in Appendix B.

### 3.5 Data Collection

This qualitative study involved the use of several different methods, including the development of a youth advisory committee, in-depth individual interviews, descriptive questionnaires, and reflexive journaling.

### 3.5.1 Youth Advisory Committee

Before attempting to recruit participants and conduct the research, I established a youth advisory committee (YAC) made up of three youth living with HIV from the Positive Youth Outreach (PYO) at the AIDS Committee of Toronto (ACT). Youth living with HIV approached me in person after a social event at ACT or emailed me of their interest in being part of this committee. All of the YAC members consented to participating on the advisory committee. The YAC only included youth living with HIV from Ontario because the committee was formed prior to the addition of the province of BC to this study. A central aim of establishing the YAC was to work collaboratively with the youth to develop the research instruments, to ensure they were youth-friendly and relevant to their experiences. All of the research instruments used in this study were developed with the input of the YAC, including the participant recruitment invitation, the letter of information and consent, the interview guide and the questionnaire. Honoraria for interview participants, research dissemination and the creation of workshops and websites to meet the needs of youth living with HIV were additional aspects of the project discussed.

The three YAC members and I met bi-weekly for approximately 6 months, at the AIDS Committee of Toronto. All youth advisory committee meetings were audio recorded with consent from the members so I could review our meetings and my notes at later dates when writing took place. The members were all reimbursed for any travel expenses they incurred to attend our meetings. Lunch was provided for each meeting and each YAC member was provided with a \$25 gift card to Cineplex Movie Theatres as a thank you for his or her time at each meeting.

Developing an advisory committee is a customary aspect of conducting of Community-Based Participatory Research (CBPR), which is designed to engage community members and stakeholders in the research (Israel, Schulz, Parker, Becker, Allen, & Guzman, 2003; Minkler & Wallerstein, 2010). A CBPR approach includes the following principles (Israel et al., 2003):

1. Recognizes community as a unit of identity
2. Builds on strengths and resources within the community
3. Facilitates collaborative partnerships in all phases of the research
4. Integrates knowledge and action for the mutual benefit of all partners
5. Promotes a co-learning and empowering process that attends to social inequalities and different perspectives
6. Involves a cyclical and iterative process, returning to renegotiate planning and strategy throughout the process
7. Disseminates findings and knowledge gained to all partners in an accessible way.

While working and collaborating with the YAC for this study was not a comprehensive CBR approach, I embodied this method to the extent that it was possible in this research process. Further detail regarding the YAC inclusion in this study process will be discussed in the Ethical Considerations and the Protection of Human Subjects section of this chapter.

Collaborating with the YAC provided a wonderful opportunity to connect and build capacity and empower the youth, and it also helped ensure that the study was reflective of their lived experiences. Of the many aspects of the project the YAC helped develop, the reshaping of several key terms often used in HIV research with youth were particularly important. The term “behaviorally infected”—a term used in the current literature to explain people living with HIV/AIDS who were infected through risky behavior. I originally used this term in my research study, however, a few of the YAC members highlighted their discomfort with the term and the associations it made which made them feel like they were at fault for acquiring HIV. After discussing various terms, we agreed upon one that would be used for this study. Instead of youth who were “behaviorally infected”, we are now using the

term “infected during adolescence or young adulthood”. The youth preferred this term, because it did not imply that they were infected with HIV because they had done something wrong.

### 3.5.2 The Interviews

Youth living with HIV who were interested in participating in the study contacted me directly via telephone or email either after they saw a recruitment poster (See Appendix B) or after they were referred by an ASO staff member. My contact information was provided on the recruitment invitation, as well as to the staff at each ASO. We discussed where the interviews would take place, the approximate length of the interview (1-3 hours), the recording of the interviews, and any questions they had. Once I explained the study and each participant signed the letter of consent (See Appendix C), the interview began. Each in-depth interview took place in a private room at an ASO or a location chosen by the participant and consisted of participants answering questions from the interview guide (Appendix E and F) and completing a questionnaire (See Appendix G) (discussed below).

As the interviews were semi-structured, I used an interview guide to help ensure the same questions were asked in each interview (for data consistency), but I also made sure that participants were allowed to take the discussions where they wanted to so they felt appreciated and able to exert control over the nature of their interview experience. Examples of some of the questions the participants were asked included: “How has your experience of living with HIV impacted your life?”; “Who do you turn to when you need help or support with something in your life?”; “What is your experience of practicing safer sex?”; and “What are your experiences with telling other people you have HIV?” Probe questions were also used to elicit more detailed information on areas that were of particular interest to me and

also relevant to the research participants.

### 3.5.3 The Questionnaires

The questionnaires (See Appendix G), which were administered after the interviews, were designed to elicit descriptive information and consisted of two sections: demographics and sexual health, support services and safer sex practices. In the demographic section of the questionnaire, participants were asked questions pertaining to age, sex, ethnicity, religion, medications and mode of HIV infection. In the Sexual Health, Support Services and Safer Sex Practices section of the questionnaire, participants were asked questions relevant to accessing sexual health services, sex and sexual activity, and practicing safer sex. These data provided essential contextual information regarding various aspects of the participants' lives, and will be discussed in the following chapters where I detail the social profiles of the youth who took part in the study and the two findings chapters. Although a survey approach is not customarily included in a qualitative, phenomenological study, a survey was included for two reasons: 1) the ability to obtain detailed information from each participant without extending the length of the interview too long; and 2) enabling privacy for answering certain questions. The original purpose of the questionnaire was to obtain more detailed background information and information regarding accessing sexual health services and support without increasing the length of the interview. After meeting with the YAC, we discussed certain questions that were originally part of the interview guide that may not be answered by the participants face-to-face. As a result, the original questionnaire, which included questions regarding demographic information and sexual health and support services, was extended to

include questions from the interview guide that the participants may be more comfortable answering in a privately and confidentially, instead of answering them face-to-face.

### 3.5.4 Reflexive Journaling

Throughout the research process I kept a reflective journal that contained my thoughts, feelings, observations, reflections and interpretations about the research process in order to maintain a strong and oriented relation to the phenomenon I was exploring in the study. I wrote my notes before and after each meeting with the YAC, before and after each interview and questionnaire I conducted with the research participants, during analysis, as I wrote each chapter, and after each meeting with my advisors and advisory committee. Using this method, in particular before and after the interviews, enabled me to document what I saw (body language), what I heard (emotions), what I did not hear (silences) and what participants chose to discuss with me that was not in the interview guide. Keeping a reflexive journal also provided me with an opportunity to integrate my own thoughts, ideas and perspectives into the data analysis and interpretation process as a way to contextualize the interview data and obtain a deeper understanding of what it means to live with HIV for the youth in this study. For example, I was able to think about and (re) articulate my own understanding of stigma in relation to how youth living with HIV discussed their thoughts about and experiences with stigma. The new and more in-depth understandings of stigma helped me to appreciate their lived experiences, how they actually felt, how stigma prevented them from accessing support or disclosing their HIV status to other people.

### 3.6 Data Management

Every effort was made to manage and ensure confidentiality of the data gathered during the study. All of the interviews were transcribed by third party transcriptionists, who signed a confidentiality agreement prior to transcribing the interviews. Funding obtained from the Social Research Centre in HIV Prevention enabled me to hire transcriptionists to transcribe the interview data and also provided me with more time to review the interviews and analyze the data. All transcripts were reviewed by the researcher for clarity and accuracy to ensure they were complete and without errors. All identifying information was removed from the transcripts. All of the research participants' transcripts and the YAC transcripts were managed in HyperRESEARCH, a qualitative data analysis software program designed to assist with data management and analysis (ResearchWare, 2013). Digital copies of the original transcripts were maintained on a password protected computer, in password protected files. Paper copies of the original transcripts, the consent forms and the questionnaires were maintained in locked filing cabinets.

### 3.7 Data Analysis

Data collection and analysis were done concurrently and once each of the interviews were transcribed by the independent transcriptionists (as noted above), data analysis began with the reading and re-reading of each transcript. Since I conducted all of the interviews and collected all the data myself, I came to the analysis with some prior knowledge of the data. However, to completely immerse myself in the data, I read and re-read each transcript and questionnaire numerous times, and in doing so became intimately familiar with the depth and breadth of the material. Each transcript was then imported into HyperRESEARCH to begin

the thematic coding process. Coding is a process of identifying themes and patterns within data. Thematic analysis is a standard practice in qualitative research and it aligns well with the phenomenological framework adopted in this study, given that the focus is on understanding the subjective lived experience of the participants and privilege the ways in which participants themselves explain the phenomena under investigation.

As mentioned above, van Manen (1997) advocates the use of three approaches to identifying themes in a phenomenological study: the holistic approach, the selective approach and the detailed or line-by-line approach. I used all three approaches for this study in order to obtain an in-depth analysis and interpretation and a deeper understanding of the lived experience of what it means to live with HIV from the youths' perspectives. In the holistic approach we view the text in its entirety to "capture its meanings" (van Manen, 1997, p.92). All of the interviews were read for an overall understanding of the meaning of living with HIV. In the selective approach, we listen to or read the content numerous times and ask, "What statement(s) or phases(s) seem particularly essential or revealing about the phenomenon or experience being described?" (van Manen, 1997, p. 93). As I read and re-read each transcript, I was looking for patterns in the experiences of my participants that informed the research questions that guided this study, namely what does it mean to live with HIV for youth?; and how the youth described their experiences related to HIV and the ways in which it has affected them.

After familiarizing myself with the data, I began to make a list of ideas about what I was reading. For example, I noted that finding out they were HIV-positive was extremely traumatic for these youth, HIV/AIDS is still a very stigmatized illness, and the youth in this study are very resilient in the face of the many challenges HIV brings into their lives. Then I began looking for words or phrases that occurred frequently within and across the transcripts



that were most pertinent to the study objectives of understanding what it means to live with HIV for youth.

In the detailed or line-by-line approach, we look at every sentence or clusters of sentences at the same time as we inquire, “What does this sentence or sentence cluster reveal about the phenomenon or experience being described?” (van Manen, 1997, p. 93). Detailed line-by-line coding began with the reading of each sentence or set of sentences in order to generate a list of codes, which are concepts that are used to provide a name to describe what the participants are saying. A code can be a word, a phrase, a sentence, or a paragraph that describes the phenomenon under study, which is different than a theme given the latter is a broader constellation or category used to demark or capture the more general phenomenon that the codes refer to (Braun & Clarke, 2006). After analyzing all eighteen transcripts, I developed 182 codes. Of the 182 codes, 26 were not included in the final analysis and written in the two results chapters because they were unique to one or two participants. For example, a few of the unique codes included: *camp*, *co-infection* and *parental sexuality*. Only one participant talked about *camp* and how he felt that it was the only place he felt like he could be himself. In addition, only one participant talked about being *co-infected* with Hepatitis C, which she was diagnosed with at the same time she was diagnosed with HIV. Furthermore, one participant talked about *parental sexuality* in relation to how his father was now gay and he felt like he was not able to discuss issues related to sex with him anymore. Even though the unique codes were not included in the two results chapters, the unique information was included in the social profile chapter for each participant.

Data analysis and interpretation focused on categorizing the remaining 156 codes into basic, organizing or global themes. *Basic themes* are the simplest themes that are “derived from the textual data” and contribute to higher order themes (Attride-Stirling, 2001, p.4).

When taken together, the basic themes constitute *organizing themes* (Attride-Stirling, 2001, p.5), which are “middle-order themes that organize the Basic Themes into clusters of similar issues (Attride-Stirling, 2001, p. 5). A group of organizing themes, when taken together, then makes up a *global theme* (Attride-Stirling, 2001), which are the highest order of themes that encapsulate the essential organizational concepts that work to provide a core interpretation or explanation of the text (Attride-Stirling, 2001). A visual representation of global, organizing and basic themes is illustrated as a thematic map in Figure 3.1.

The approach I used to organize my data began with making decisions about the basic, organizing and global themes that emerged across and within the interviews. For example, the codes: *internet/online communication, face-to-face disclosure and having HIV status revealed by others* are all ways the youth used to disclose their HIV status and were categorized under *basic themes* because by themselves they do not provide us with much detail about the texts as a whole and require an organizing theme to help make sense of the data (Attride-Stirling, 2001, p. 5). The *basic themes* were then categorized under the organizing theme *method of HIV disclosure*, which was then categorized under the global theme of *HIV disclosure management* because they were representative of and captured the participants’ experiences of HIV disclosure. A visual representation of these themes is illustrated as a thematic map in Figure 3.2. These themes are not exhaustive of the experience of being HIV-positive, but they allowed for a methodical exploration of what is was like for the youth in this study to navigate the challenges associated with HIV.

After this first round of analysis, the following *organizing themes* emerged: mode of infection; fear; effects of diagnosis; dating and sexual activity after diagnosis; HIV education; employment; whose responsibility it is to use condoms; trust; stigma; criminalization; reasons for HIV non-disclosure; method of HIV disclosure; relationship

outcomes after disclosure; the future; finding meaning in life, acceptance of HIV and positive and negative outcomes of disclosure. These were identified as organizing themes because they were the overarching themes that made sense of basic themes with issues and were also representative, in that they captured what the majority of participants experienced. The following *global themes* emerged after this stage of analysis: becoming HIV-positive; finding out their HIV status; navigating HIV; practicing safer sex; HIV disclosure management; transforming their life; and finding meaning in life after HIV diagnosis. These were identified as global themes because they were consistently talked about by the youth in this study as being their main issues or concerns since becoming HIV-positive.

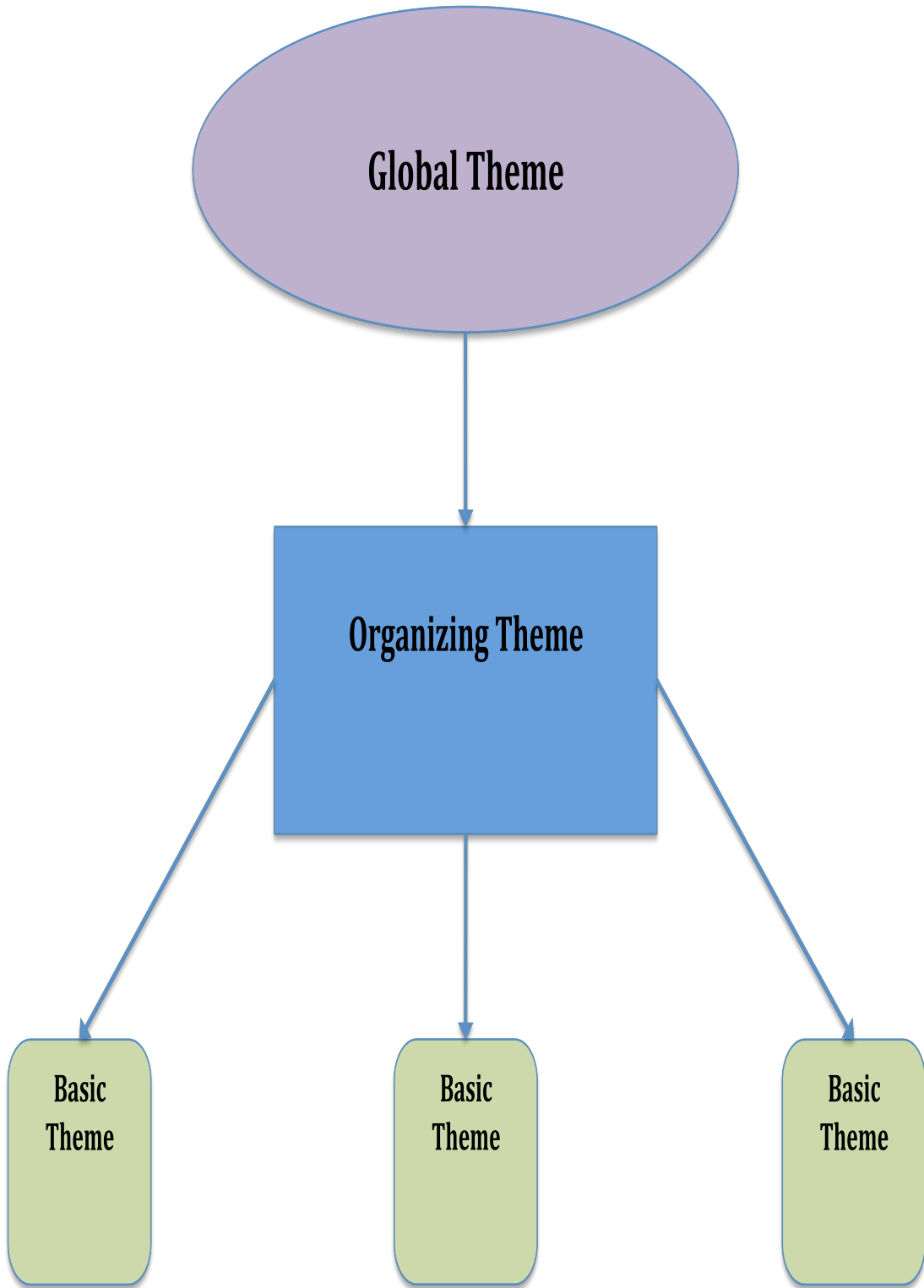


Figure 3.1 Illustration of Basic, Organizing and Global Themes

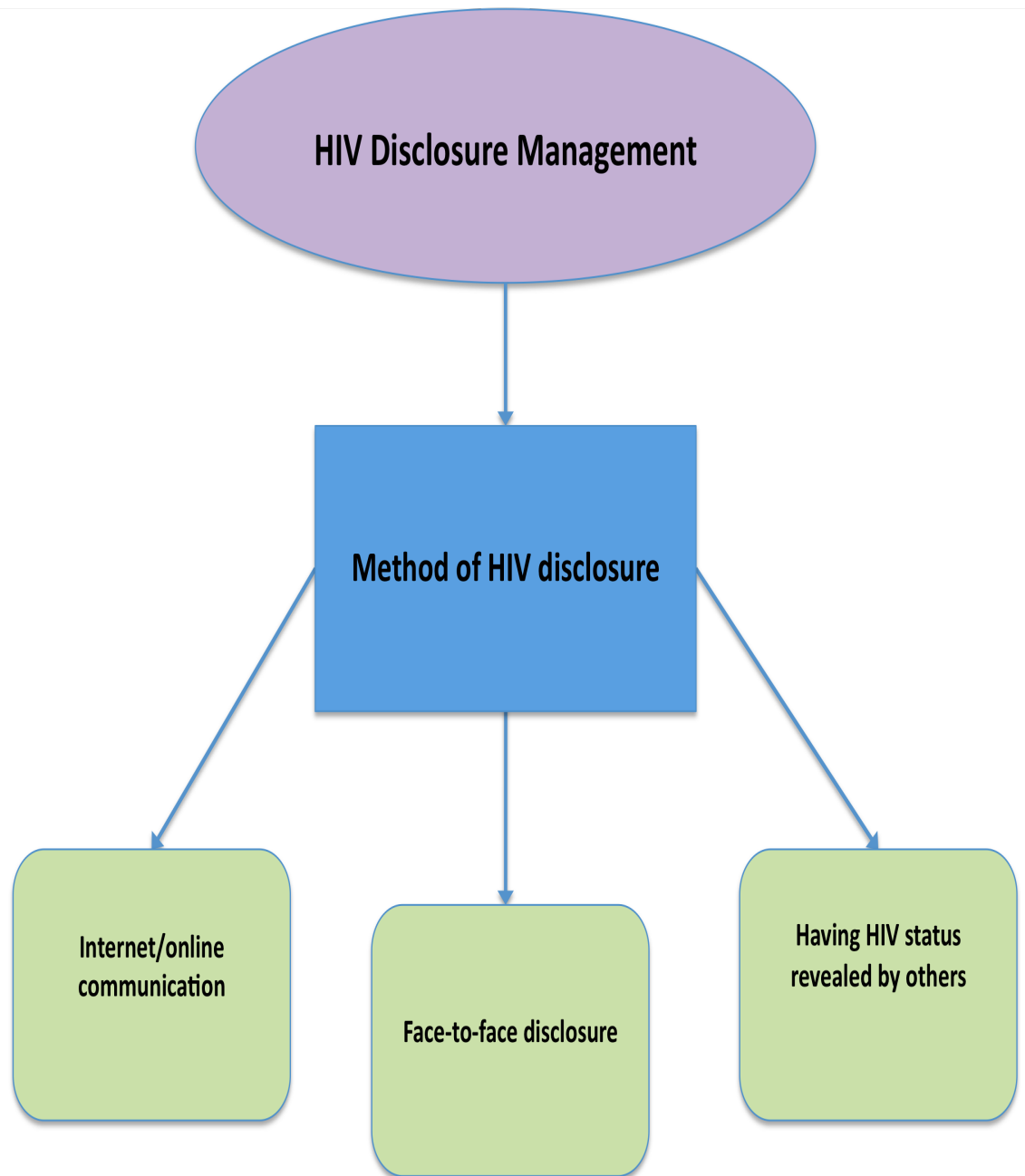


Figure 3.2. Illustration of the Global Theme *HIV Disclosure Management*, one organizing theme *Method of HIV disclosure* with the basic themes

According to van Manen's (1997) research principle *balancing the research context by considering the parts and whole*, the researcher needs to constantly move back and forth between the parts and the whole to obtain the meaning of the lived experience. As I analyzed and interpreted the interview data, I was continually looking at all of the themes (parts) in relation to the overall research objectives/questions (whole) to ensure that I was obtaining the meaning of the lived experience of living with HIV for the youth in this study.

During final analysis, some of the *organizing* and *global* themes were refined because there was not enough data to support them or because they were collapsed into other themes. For example, *acceptance of HIV status* became a basic theme under the new organizing theme *coming to terms with HIV*. The global theme for these was *navigating HIV*. Final analysis resulted in 4 global themes, 10 organizing themes, and 107 basic themes. From these, I extracted the most important themes, those that were representative of the experience of the majority of youth in this study and related to my research questions.

Within and across the interview transcripts, four major themes emerged as representative of the experience of living with HIV for the youth in this study: becoming HIV-positive, navigating HIV, HIV disclosure management, and finding new meaning in life after HIV diagnosis. Each individual theme (part) is a pivotal experience the youth have had to deal with since they found out they are HIV-positive. Taken together (whole), these four themes represent what it means to live with HIV for the youth in this study. The four global themes and a visual representation of the four global themes, eleven organizing themes, and thirty-three basic themes will be presented in chapters five and six. A detailed account of the codes and the final basic, organizing and global themes that were developed during data analysis and interpretation are shown in Appendix A.

As van Manen (1997) states in his fourth research principle *writing a description of the phenomenon*, a good phenomenological text has a way of making us ‘see’ something in a way that enhances our understanding of everyday life experience. After data analysis and interpretation were completed for all eighteen interviews and questionnaires, I began writing and rewriting the “phenomenological text” to provide a deeper understanding of what it means to live with HIV for the youth, from their perspective. The interviews were analyzed and used to develop themes and the questionnaires were analyzed and used as descriptive and background information.

In writing a phenomenological text, we use the participants’ words, spoken or expressed through emotion, to describe their lived experience so that we can unravel the deeper meanings that they hold within their everyday life experience. In writing this text I must be able to tune into language even when it is not spoken and listen for “silences” (van Manen, 1997). As I listened to the participants during the interviews and again in their recordings, I tuned into what they were saying, but also what they did not say. For example, *Xavier* became silent when I asked if he had told his parents about his HIV status. After about a minute of silence, he began to cry, and a few minutes later through the tears he told me that when he disclosed his HIV status to his mother she responded by saying that it didn’t shock her. Xavier’s silence spoke of betrayal and hurt. The weakness in his voice told me that even after three years, his feelings of hurt and betrayal had not disappeared and his relationship with his mother was still very fragile. As I interpreted the participants’ experiences and developed them into themes that were characteristic within and across the interview data, I was able to create what seems to be a profound understanding of the phenomenon of what it means to live with HIV for youth. According to van Manen (1997), a “phenomenological text succeeds when it lets us see that which shines through, that which

tends to hide itself” (p. 130). In writing a description of the phenomenon for this research, I wanted to be able to make visible the experiences of youth living with HIV, as told by them.

### 3.8 Trustworthiness (Quality Criteria)

The following criteria were used in this study to establish trustworthiness: credibility and confirmability (Guba & Lincoln, 1989). Credibility is making sure that the interpretation of the data accurately reveals the lived experience of the research participants (Guba & Lincoln, 1989). The credibility approaches used in this study included prolonged engagement in the field to learn and understand the phenomenon of interest with the YAC members and the ASOs (Guba & Lincoln, 1989). Prolonged engagement was organized through our bi-weekly meetings and email follow-up discussions. Credibility can also be achieved through member checking, which is seen as a technique for improving the accuracy and validity of a participant’s story (Guba & Lincoln, 1989). I was able to contact 9 of the 18 research participants to review their transcript and what was captured in their interview and the analysis of their data for accuracy and to establish validity. I was not able to contact the other 9 participants from this research study due to contact information changes

Confirmability is the level of objectivity and the degree to which the study findings are shaped by the participants and not researcher preconceived notions, motivation, or interest (Lincoln & Guba, 1985). An audit trail and reflexivity were used in this study to establish confirmability. An audit trail is a record of the research process. According to Guba and Lincoln (1989), if the research process or ‘audit trail’ can be followed by other researchers, the research is considered dependable. The audit trail for this study contains a description of the research process from the beginning of the study to writing the findings,



including: reflective journaling, field notes, transcribed meetings with youth advisory committee, interview and questionnaire development data, transcribed interviews, data analysis, and member checking. An audit trail can guide others to follow the development of the research questions and objectives, the methods used in this study, and the data analysis and interpretation of the research. In particular, the data analysis process, including the coding process for developing the themes and subthemes, was described in detail in this chapter and the themes are provided in the appendix of this dissertation.

Reflexivity was also used in this study to establish confirmability and trustworthiness. By keeping a reflexive journal throughout this research study, I was able to record my reflections of the research process, assumptions and interpretations of the data. Working on a regular basis with the YAC and my advisors enabled me to discuss and verify my feelings, assumptions and interpretations of the data to not only understand the youth better, but also the study process and establish content validity.

### 3.9 Ethical Considerations and the Protection of Human Subjects

Ethics approval was sought prior to beginning the data collection for this study. Before each interview I explained the purpose of the study to each participant. All research participants reviewed and signed a letter of consent form prior to their interview (See Appendix D). Our discussions consisted of very sensitive questions and I made sure that each interview was conducted in a safe environment at a local ASO where the research participants had access to a support counselor if necessary or at a location suggested by the participant if they were uncomfortable with the interview at an ASO. The signed consent forms, questionnaires, audio-recordings, transcripts and field notes were kept in a locked file cabinet and on a

password protected computer, and each file was also password protected to maintain confidentiality.

Participation in this research study was voluntary and completely confidential. In order to protect anonymity and help ensure confidentiality, all of the research participants names have been changed to a pseudonym chosen by the research participants if possible or myself if obtaining a pseudonym was not possible. Potential risks of this research included the possibility of some youth living with HIV experiencing emotional upset as they discussed sensitive sexual health matters or HIV disclosure, or other issues. During the interviews, three of the research participants became emotional and began crying as they talked about finding out they were HIV-positive and disclosing their HIV status to family members. Options to address emotionally upsetting issues/experiences included stopping or postponing the discussion, and talking about possible supports for their distress that were available i.e., a support worker, primary care physician or other clinical care team professionals. However, all of the participants wanted to continue the interview. All of the HIV-positive youth were provided with referrals to a support worker at their local ASO should they require debriefing after the interview. Each research participant was given a \$25 gift card plus travel expenses for each interview they participated in.

The protection of human subjects is warranted in research, especially in regards to sensitivity, confidentiality and vulnerable populations. However, challenges I faced with the Research Ethics Board in trying to conduct this research deserve some attention here to ensure that the ethics process is equally applicable to all research. The process of obtaining approval for this study highlighted a number of problematic issues regarding the dominance of quantitative research paradigms and methodologies within ethics review boards, which presents significant difficulties for qualitative researchers doing community-based work with

vulnerable populations. According to Guta, Wilson, Flicker et al. (2010), community-based participatory research

...differs from traditional forms of research through its commitment to social action, relationship building, and collaborative data collection and analysis techniques...these collaborative...approaches often clash with the biomedical model of research on which Research Ethics Board procedures are based (p. 35).

Problematic outcomes of these divergent approaches and the inequitable power distribution between quantitative and qualitative methodologies include delays in the ethics process because of a lack of knowledge and understanding of community-based research methods and the lack of inclusion of guidelines on ethics review forms to assess community-based research projects (Flicker, Travers, Guta, McDonald & Meagher, 2007; Guta et al., 2010).

The length of time it took to obtaining ethics approval for this study impacted this research in two ways: the recruitment of youth participants living with HIV and my ability to have the YAC involved throughout the entire research process. The first challenge I faced in this study with obtaining ethics approval related to recruitment of youth participants living with HIV. This study's original research setting was Toronto, Ontario because of the supportive connection I had with the AIDS Committee of Toronto and Positive Youth Outreach. However, I also became connected to other ASOs in Canada, three from Ontario and one from British Columbia. Accessing other ASOs outside of Toronto provided me with more opportunities for recruitment of research participants. The interviews in Ontario were completed in person, but because of the geographic location, interviewing the participants from Vancouver needed to be by telephone. In order to interview the Vancouver participants by telephone, I needed to have ethics approval. The request to complete the interviews by telephone was submitted to the REB and after waiting many months and providing further

information, I was requested to come to an REB meeting to present to the board why I wanted to complete telephone interviews and my procedures for ensuring safeguarding for recruiting participants. All of this information was submitted in the previous revision request. All of the questions I was asked during the presentation were previously addressed in the revision request. Again, this suggests a lack of qualitative expertise and understand within the research ethics board.

The second challenge I encountered related to the YAC for this research. I submitted a request to the REB in September 2009 asking to recruit a youth advisory committee (YAC) to help guide and inform this research. In my request I asked that the YAC assist with the development of the recruitment invitation, the letter of information/consent, the interview guideline and the questionnaire. The REBs approval of this specific request took approximately four months. Once the YAC and I had completed the study documents noted above, I submitted a second request to the REB asking to continue working with the YAC in research dissemination and workshop development for this study. In yet another lengthy process. I received a negative response to my request that essentially told me I could no longer work with the YAC I had just built a trusting relationship with, if I wanted to have a YAC to assist me further I needed to recruit a new one. As a result, I was not able to incorporate a full CBPR approach in this study. In community-based research, it is essential to build a relationship and trust with the people you work with and sometimes this process can take years. The fact that the REBs response was to recruit a new YAC suggests a lack of knowledge regarding community based research and working with vulnerable populations. It also indicates the lack of qualitative expertise on the REB. A basic understanding of qualitative, community-based research would provide ethics officers with knowledge they

require to make informed decisions regarding ethical review of these kinds of research projects.

Although REBs are established to ensure the rights and welfare of research participants are protected, they create barriers and challenges for those research studies that employ modern methods of qualitative research. In my experience, the REBs process is subjective and ethics officers are not familiar with (or unwilling to accommodate) new and diverse research methods. There remains a divide between quantitative and qualitative research methods and this divide promotes “authoritative knowledge” with one-sided power and an unwillingness to consider other epistemologies. The difficulties I encountered are formidable for all researchers, but present particular difficulties for graduate students who may be on tight timelines and who are relatively inexperienced and unempowered in dealing with the academic ethics bureaucracy. To ensure an equitable process for all researchers, regardless of the kind of research they engage in, the ethical review process needs to incorporate knowledgeable members who have the expertise to understand the research methods. If these challenges are not rectified it may inhibit researchers who focus on community-based research or work with stigmatized populations from conducting much needed research. According to Guta et al. (2010), researchers conducting community-based participatory research projects have experienced and “...expressed concern over being delayed by the ethics review process, and denied opportunities to work with communities in appropriate ways” (p. 41). If universities want to continue being leading research institutions, they need to be willing to breakdown the wall of barriers to REBs and be inclusive of all styles of research because they are inhibiting the development of Canada’s next generation of researchers and preventing important research projects from fruition.

### 3.10 Conclusion

This chapter described the research methods employed in this study, including the qualitative approach, the theoretical framework, the community-based approach, the data collection and analysis methods, ensuring qualitative validity and the process of obtaining ethics approval. This research was framed within van Manen's phenomenological approach to explore the lived experience of youth living with HIV.

Data collection included in-depth individual semi-structured interviews and the completion of a questionnaire with eighteen youth living with HIV who were selected through purposive sampling and voluntarily consented to the study. Anonymity was maintained through the use of pseudonyms for the research participants. The interview data were audio-recorded and transcribed verbatim and analyzed using van Manen's thematic approach to isolating themes. The interview data were analyzed and essential themes were developed using all three of van Manen's approaches to isolating themes, the holistic approach, the selective approach and the detailed approach. These three approaches allowed for an in-depth analysis and interpretation of the interview data. Through data analysis and interpretation, codes were developed and categorized into basic, organizing and global themes. Final analysis resulted in 4 global themes, 10 organizing themes and 107 basic themes, from which the most important themes that were representative of the interview data and research questions were extracted and will be presented in chapters five and six. The validity of this study was assessed through the qualitative measures of credibility and confirmability. In addition, ethical considerations and the protection of human subjects was discussed, ethics approval was received by Western University's REB, and challenges regarding the ethics process was discussed.

## CHAPTER FOUR

### 4 Social Profile of the Eighteen Participants

#### 4.1 Introduction

Prior to presenting findings concerning the lived experiences of the youth in this qualitative study, it is important to situate the findings within each participant's story of how we met, why they wanted to participate in this study and some descriptive information that they provided to me about their lives. While the themes that will be presented in chapters five and six capture the lived experience of what it means to live with HIV for the youth in this study, these profiles provide a more intimate understanding of the participants. Their social profiles are presented here according to place (i.e., the provinces they are from). Some participants went into greater depth about various aspects of their lives and this is reflected in the profiles below, some of which are longer and more detailed than others. All of the participants' names have been changed to pseudonyms.

#### 4.2 Profiles of the British Columbia Participants

##### 4.2.1 Charlotte

Charlotte is a 25-year-old heterosexual Aboriginal woman who lives in British Columbia. I met her through an ASO, where I interviewed her for this research study. She did not go into detail about why she wanted to participate in this research, but she did say that she wanted to be able to help other people who have HIV by sharing her experiences. Charlotte was diagnosed with HIV and Hepatitis C (HCV) at the age of 20 after her lung collapsed and she

went into a coma. She has two children that do not live with her and both are HIV-negative. Charlotte is currently juggling a lot of issues, including addictions and troubling relationships with family members, which is having an impact on her ability to see her children. These are hurtful experiences she is struggling with, while at the same time learning to manage HIV.

#### 4.2.2 Maggie

Maggie is a 27-year-old Aboriginal trans-gender woman (male to female) who lives in British Columbia, which is where I interviewed her for this research study. She wanted to participate in this study because she hopes that research will help get more services created for people living with HIV. Maggie was diagnosed with HIV at the age of 21 and has been living with HIV for six years. Finding out her HIV status had a devastating effect on her and she isolated herself and turned to substance use as a way to cope. Maggie feels that once she was able to start making her own choices to live a healthier life, she became stronger and began to accept her HIV status. She has gone back to school and has also been attending training sessions on positive leadership and has been funded to attend various conferences in the HIV field.

#### 4.2.3 David

David is a 24-year-old self-identified gay man who lives in British Columbia. I met and interviewed him at an ASO. He wanted to participate in this study because he is very interested in providing his experiences and learning about the results of other youths' experience of living with HIV. He also feels that the results will assist him in providing support for other youth living with HIV. David was diagnosed with HIV at the age of 20 and has been living with HIV for four years. He feels that finding out his HIV status has had a



negative impact on him at first because he felt like he had to come to terms with death much younger. However, since finding out he feels as though he is the healthiest he has ever been because he has taken control of his health and is learning to manage life with HIV.

#### 4.2.4 Xavier

Xavier is a 25-year-old self-identified gay man who lives in British Columbia. I met him through an ASO, where I interviewed him for this study. He wanted to be involved in this research because he feels there are very few resources available for youth living with HIV and sharing his experiences might help to increase awareness. Xavier was diagnosed with HIV when he was 20-years-old and has been living with HIV for five years. He battled some very difficult situations in his early teens, including the death of a family member whom he had a close relationship with and leaving home because of a broken relationship a parent. After leaving home in his early teens, Xavier was raped by a man in the park. He also began living on the streets, became addicted to drugs and was beaten and almost sold into the sex trade. Since becoming HIV-positive, Xavier has continued to struggle with addictions, but he feels that finding out his HIV status has really been a blessing in disguise and has given him a greater appreciation for life.

#### 4.2.5 Reid

Reid is a 26-year-old, self-identified gay man who lives in British Columbia, which is where I interviewed him for this study. He wanted to be part of this study because he feels that youth living with HIV are understudied and the findings from this research will be extremely useful for him. Reid was diagnosed with HIV at the age of 25 when he went to the hospital

for a post-exposure plan and tested positive for HIV. At the time I interviewed him, he had only been living with HIV for 1 year and expressed anger about becoming HIV-positive. When he was first diagnosed he ignored it for the first few months and just tried to move on with his life by keeping busy with work. Reid does not like to think or talk about HIV and feels that he has not really come to terms with his HIV status yet.

#### 4.2.6 Link

Link is a 28-year-old self-identified gay man who lives in British Columbia. I met him through an ASO where I interviewed him for this research study. He wanted to be part of this study because he feels that there needs to be a better understanding of youth living with HIV and their needs. Link was diagnosed with HIV at the age of 23 and has been living with HIV for five years. He feels that living with HIV has complicated relationships with friends and partners. However, he also believes testing positive created encouraging changes in his life, such as getting involved in and working in the field of HIV. Link feels that being involved in HIV work enables him to help other people living with HIV because he can share his own experiences. He is currently in a relationship with an HIV-negative partner.

## 4.3 Profiles of the Ontario Participants

### 4.3.1 Bajaa

Bajaa is a 25-year-old heterosexual woman who lives in Ontario. I first met her through an ASO, where I interviewed her for this study. She was very interested in being part of this research because she feels that she is able to share her personal experiences to help educate other women living with HIV by showing them that they can still have children. Bajaa had a very difficult childhood growing up and feels that because her parents struggled with addictions she was forced into sexual activity at an early age and ended up on the streets at a very young age and into prostitution around the age of 12. She spoke with great maturity beyond her 25 years as she discussed what her life was like prior to becoming HIV-positive. Bajaa was diagnosed with HIV at the age of 20 when she was pregnant and has been living with HIV for five years. A few weeks after she found out she was HIV-positive she gave birth by emergency c-section. For the first few years, she ignored her HIV and focused on being a new mom. It was almost two years before Bajaa was ready to start reaching out and learning about HIV. Bajaa has three children now, all of whom are HIV-negative. She is also in a loving relationship with her partner who is HIV-negative.

### 4.3.2 Taryn

Taryn is a 29-year-old heterosexual woman who lives in Ontario. I met her at an ASO in Ontario where I interviewed her. She wanted to participate in this research so she can share her own experiences and hopefully help other youth who are living with HIV with the findings from the study. Taryn was diagnosed with HIV at the age of 17 and felt like it

shattered her world because she was so young and she thought her life was over. She battled depression when she first found out because she thought she would never be able to have children. She feels that becoming HIV-positive was like a blessing and once she was ready to learn more about HIV and accept her status, Taryn was able to move on and begin managing her life living with HIV. She has been living with HIV for twelve years and is in a relationship with an HIV-negative partner, who is also the father of her child.

#### 4.3.3 Mason

Mason is a 22-year-old heterosexual man who lives in Ontario. I met him through an ASO in Ontario where I interviewed him for this research study. He wanted to participate in this study because he thought it would help other youth who are living with HIV. Mason was born with HIV and has been living with HIV for 22 years. He feels like he is the only youth living with HIV in his area. Mason lost a parent and a sibling to AIDS when he was young. Mason is very independent, but he is also shy and very nervous when he talks, especially to women. He spends time volunteering with ASOs and has travelled to help people living with HIV. He talked a lot about the time he spent at camp for kids living with or affected by HIV and felt that it was the closest place to home where he could be himself. Mason wants to go to school and he also wants to find someone to love.

#### 4.3.4 Foxy

Foxy is a 22-year-old, self-identified gay man who lives in Ontario. I met him at an ASO in Ontario where I interviewed him for this study. He wanted to take part in the project because he feels that if there is more research with youth living with HIV there will be less

misconceptions regarding HIV. Foxy was diagnosed with HIV at the age of 20 after he had been raped and has been living with HIV for two years. He battled depression after finding out his HIV status and turned to substance use as a way to cope. When Foxy was ready to come to terms with HIV, he then began learning about HIV. He has always had the love and support of his mother. Foxy has also gone back to school to finish his university education and has become an advocate for other youth regarding sex, sexual health and HIV prevention.

#### 4.3.5 Koby

Koby is a 23-year-old, self-identified gay man who lives in Ontario. I met him through an ASO in Ontario, where I interviewed him for this study. He was interested in taking part in this project because he wanted to be able to help other youth living with HIV by providing his experiences. Koby was diagnosed with HIV at the age of 21 and has been living with HIV for two years. When he was first diagnosed, he struggled with depression and was not able to face his family or friends. Once Koby was able to come out of his depression, he developed an optimistic mindset about being HIV-positive and was able to accept his status.

#### 4.3.6 Noah

Noah is a 24-year-old heterosexual man who lives in Ontario. I met him at an ASO in Ontario where I interviewed him. He wanted to participate in this research because he feels that his experiences could help other youth living with HIV. Noah was born with HIV and has been living with HIV for twenty-four years, but he did not find out his HIV status until he was 16 years old. He feels as though his life was taken away from him and is still trying

to come to terms with finding out his HIV status when he did. He talked a lot about his inexperience with women and feels that his difficulties building relationships are because of his anxiety about his HIV status. Noah has learned to come to terms with HIV and feels that having friends who are also living with HIV has helped him because they are able to understand what he is going through.

#### 4.3.7 Kyle

Kyle is a 25-year-old, self-identified gay man who lives in Ontario. I met him at an ASO in Ontario where I interviewed him for this study. He became involved in HIV-related research not long after he found out he was HIV-positive. Kyle wanted to be part of this study because he feels that it is important to provide his perspective to help researchers understand what youth living with HIV need. When Kyle was diagnosed with HIV at the age of 17 he felt like his whole world came crashing down. Kyle experienced discrimination, isolation and rejection that was so extreme it forced him to quit high school before he graduated. He felt like everything he had been working for was taken away. Kyle experienced many roadblocks after he became HIV-positive, but he was determined to get through it and feels it has made him a better person today.

#### 4.3.8 Gabriel

Gabriel is a 25-year-old self-identified gay man who lives in Ontario. He and his siblings spent most of their lives in and out of foster care. I met Gabriel at an ASO in where I interviewed him for this research study. He was very interested in participating in this research because he felt that his input and experiences could contribute to positive outcomes

or change to help youth living with HIV. Gabriel was diagnosed with HIV at the age of 21 and has been living with HIV for four years. Finding out his HIV status was so devastating for him that he wanted to jump in front of a subway and end his life. Gabriel feels that becoming HIV-positive has put a strain on his relationship with his siblings because he is not able to tell them as he feels he has let them down. It was his drive to live and be there for his family that encouraged him to think about his health more, learn about HIV and be more in control of his life. Gabriel is very shy and lacks confidence when it comes to building social relationships. He feels that living with HIV has impacted his chance to find someone to love because he thinks he can no longer meet just any guy; he must only look to meet men living with HIV.

#### 4.3.9 Donovan

Donovan is a 29-year-old self-identified gay man who lives in Ontario. I met Donovan at an ASO in Ontario where I interviewed him for this study. He wanted to participate in this study because he feels that his experiences could be passed on to help other youth living with HIV. Donovan was diagnosed with HIV at the age of 20 after he was raped and has been living with HIV for nine years. He was afraid to admit to his family that he had HIV because he had already battled stigma when he came out to them as being gay. Finding out his HIV status was so traumatic for him that he almost attempted suicide. It took him a long time to come to terms with HIV, but Donovan feels as though it has made him a stronger person and his life is more focused.

#### 4.3.10 Griffin

Griffin is a 28-year-old self-identified gay man who lives in Ontario. I met him at an ASO in Ontario where I interviewed him for this study. He wanted to participate in this study because he had been part of a few other research studies and is always interested in the outcomes. Griffin was diagnosed with HIV at the age of 25 and has been living with HIV for three years. He feels like he has come to terms with HIV, but he still worries about what will happen to him in the future because he is still learning to manage his HIV. After learning about HIV, he feels like his lifestyle has changed and he is taking better care of himself by eating healthier. Griffin wants to go to school for hospitality or culinary management or nursing. Since he became HIV-positive, Griffin has met a lot of great people through support groups, but he really wants to find someone to love and settle down with.

#### 4.3.11 Robert

Robert is a 28-year-old self-identified gay man who lives in Ontario. I met him at an ASO in Ontario where I interviewed him. He was very interested in participating in this study because he believes that by providing his experiences, he is helping other youth living with HIV. Robert was diagnosed with HIV at the age of 26 and has been living with HIV for two years. The period immediately after diagnosis was very traumatic for him because he thought his life was over and he would never find love because he was living with HIV. Robert feels as though being able to see past his HIV status was the one thing that got him through and jump-started his life again. Robert does not want to be seen as a diseased person; he wants people to see and love him for who he is and not feel that they need to be



protected from him. He still struggles with issues of acceptance and has difficulties separating love from security in his relationships.

#### 4.3.12 Pierce

Pierce is a 29-year-old, self-identified gay man who lives in Ontario. I met him through an ASO in Ontario where I interviewed him. He was interested in being part of this study because he hoped that sharing his experiences would be able to help other youth living with HIV. Pierce had a very difficult childhood growing up because he was physically and sexually abused. Since that time, he has faced numerous mental health issues, including schizophrenia and depression. Pierce was diagnosed with HIV at the age of 21 after getting tested for HIV when he suspected his partner was lying to him about his HIV status. He has been living with HIV for 8 years and has spent many years trying to work through his issues and living with HIV, but knows it is a healing process. Pierce has gone back to university to complete his education.

### 4.4 Conclusion

This chapter presented a description of each of the eighteen participants in this study. Providing a profile of each participant enables the reader to learn a little bit about each person's life. The youth in this study have been living with HIV for between one and twenty-four years and included fourteen men (12 gay men and 2 heterosexual men), three heterosexual women, and one trans-gender woman. Several common themes emerged from the profiles in this chapter, including the role of depression, addictions, sexual violence, relationship with an HIV-negative partner, employment or engagement in the HIV field, and

going back to school. In addition, a number of unique themes also emerged from the profiles that only affected only one or two youth, including perinatal infection, loss of family to HIV/AIDS, growing up in foster care, having children after becoming HIV-positive, co-infection with Hepatitis C, and prior mental health issues. Also noted in this chapter were a number of pre-existing vulnerabilities, including childhood sexual and physical abuse, mental health issues, prostitution at an early age, drug addiction, among some of the youth in this study that may have contributed to their HIV-positive status and early life as someone living with HIV. These profiles contribute to a deeper understanding of the lived experience of each of the youth in this study and provide contextualization for the two findings chapters to be presented next.

## CHAPTER FIVE

### 5 Becoming HIV-Positive and Navigating HIV

#### 5.1 Introduction

The objective of this study is to understand the lived experiences of HIV-positive youth. The four global themes that emerged as most representative of the participants' experiences of living with HIV are: *Becoming HIV-positive*, *Navigating HIV*, *HIV Disclosure Management* and *Finding New Meaning in Life After HIV Diagnosis*. Global themes one and two will be discussed in Chapter Five and global themes three and four will be discussed in Chapter Six. Presenting the global themes in this order offers an understanding of the trajectory of the youth's lived experience from becoming HIV-positive and coming to terms with this to navigating dating and safer sex practices, and youth's on-going struggles related to HIV disclosure, to finding new meaning in their lives.

#### 5.2 GLOBAL THEME 1: BECOMING HIV-POSITIVE

Participants identified two sets of issues related to becoming HIV-positive that impacted them in an especially powerful way, learning of their HIV status and their initial reactions to their HIV status. A visual representation of the themes are shown in Figure 5.1 as a thematic map to illustrate the global, organizing and basic themes.

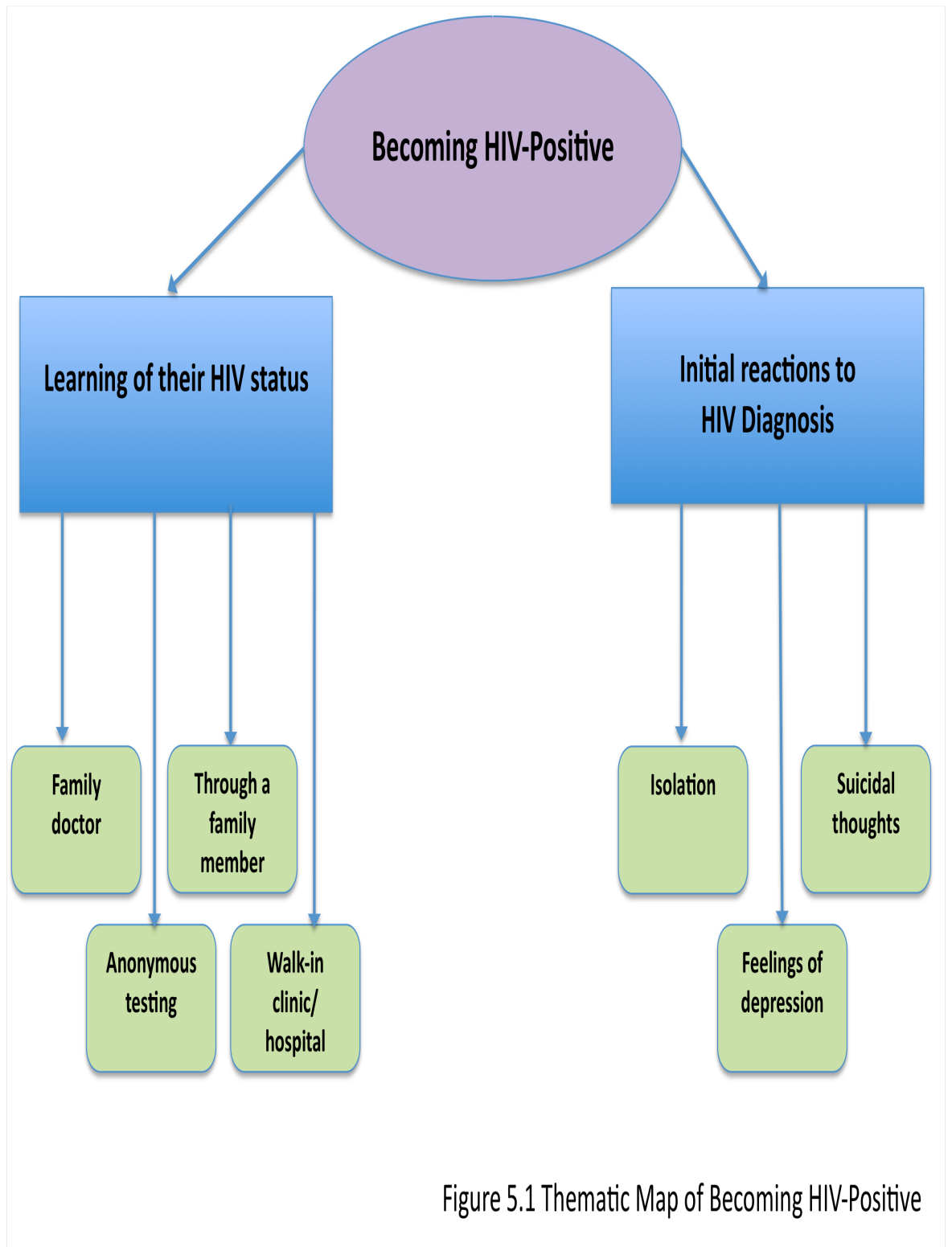


Figure 5.1 Thematic Map of Becoming HIV-Positive

## 5.2.1 Learning of their HIV status

With respect to how the participants learned of their HIV status, this occurred in various ways, including disclosure by a family member, anonymous testing, HIV testing in a clinic/hospital, and random or regularly scheduled blood work at a doctor's office.

### 5.2.1.1 Through a family member

Two male participants, Mason and Noah, were infected perinatally and have been living with HIV for 22 years and 24 years, respectively. These participants had very different experiences of finding out their HIV status, with Mason being told by his parents at a very early age and Noah finding out by accident when he was sixteen years old. Mason has known all his life that he is living with HIV, from the age of 2-3 years. As he explains, finding out his HIV status happened around the same time as he lost a parent and a sibling to HIV/AIDS:

[I was] young, like 2 or 3...it just feels like bright and ingrained in my memory. I don't remember figuring it out I just remember knowing. I was really young so probably my parents told me. I lost my [parent]...when I was probably around 3 or 2. So that's probably why I said 2. And my [sibling] [died] when I was [young]. Those were difficult times.

Noah did not find out he was living with HIV until he was 16 years old and he found out by accident at school. As he explains, he felt deceived:

I was 16 when I found out and I found out 'cause something bad happened. They [principal and teachers] tricked my mom and they told her my nose was bleeding but it wasn't...so I [learned] from a phone call from my mom...It's still astonishing to me

that there was no justice in my eyes because as soon as I heard those three words... I didn't deserve to find out about my HIV in such a hostile place...I mean the whole thing changed my life.

#### 5.2.1.2 Walk-in clinic or hospital

Xavier, Gabriel, Donovan, Pierce, Charlotte, and Reid found out their HIV status when they went to a walk-in clinic or the hospital for either a regular check-up or because of another health issue. When Xavier went to a walk-in clinic to get a sore on his leg examined he had blood tests done, which revealed that he had HIV:

I had a staph infection that circulated through my body for two and a half years...I never got better and I didn't know why. I went out to visit my mom and I had gotten a sore on my left leg so I went to a walk-in clinic and I guess working protocol when you walk into a walk-in clinic with a staph infection or abscesses they do blood work. And in this blood work is when they had found out that I was HIV-positive. I had done blood work three and a half months earlier and I never got the results back and [the hospital] tried to tell me that I had never gotten the blood work done there. I had a witness who sat there right with me and watched them take all the vials of blood and so I think I would have found out three months earlier than I did.

Gabriel also found out he was living with HIV when he went to a walk-in clinic, to get checked because he felt a burning sensation when he urinated, and like Xavier he did not know he was being tested for HIV. He explains that getting a phone call from the clinic, and seeing the doctor about his test results was a terrifying experience:

[It was] just random blood work that I did. I didn't even really know I was being tested for HIV. Apparently, I would have had to sign a consent, but I don't remember

signing a consent. I just went into a walk-in clinic, not a sexual health clinic, not a youth clinic, just a walk-in clinic because at the time...when I peed it was burning a bit, so I thought I would go to get tested for STIs. And everything came back negative, except I kept getting these calls from the clinic, saying please come in, and then I was really terrified. So, I did go in and a doctor walked in the room staring at the ground and said that everything came back negative except the worst one...HIV...he just stared at the ground and I started kind of having a panic attack, and he just said I could stay in there for a few minutes before I left. They gave me a number for the sexual health info line and that was it...that was one of the scariest events.

Donovan found out he was living with HIV when he went to get tested for HIV and STIs after he was raped. However, after he was tested the first time, he could not face finding out the results so he avoided it and moved back home, but ultimately decided to get another HIV test a few months later:

About two weeks later [after I was raped], three weeks later, it just seemed like time was going by very fast. I went to the... Youth Centre...and I got an HIV test done there and it was basically a couple weeks after that I was so scared to get my results back. I was very, very, very, very scared because I just thought to myself, “Oh my God, my dad’s going to be right [about me getting HIV]. My dad’s going to be right” and I didn’t want him to be right at all...I thought to myself I can’t go for my results”. So at the moment, I kind of waited until my next pay cheque and I got my bus ticket back home. Going back home, it was about a couple months after that, I thought to myself, “Ok, I need to get tested”. And I basically went and I got tested and I came up positive.

Pierce decided to get tested for HIV at a clinic because he felt his partner was not telling the truth about his HIV status. As he explains:

I actually went for an HIV test because I suspected my partner was lying to me about his status, which he was. So, right before I got the test back, my partner told me he was HIV positive and so I figured that I may have very well become positive, as well. And, when I went in to get the HIV test, it turns out that I had, in fact, seroconverted.

Charlotte found out that she had HIV and Hepatitis C when she went to the hospital for a collapsed lung and a coma, during which time she had bloodwork done. As she explains:

I was in my kitchen and my right lung collapsed on me then I was in the hospital...I was in a coma for two days and when I came out I had like 10...15 doctors in my room and they were like all explaining to me that I had HIV and had Hep-C.

Reid found out his status when he went to the hospital to obtain post-exposure prophylaxis (PEP), because he thought he might have been exposed to HIV after having sex without a condom. As he explains: "I'd actually gone to the hospital looking to get a post-exposure plan. I got tested there and found out that I was already positive".

### 5.2.1.3 Anonymous testing

Kyle went for HIV tests through a mobile testing van because he thought his partner was lying to him about his HIV status. Getting tested for HIV and obtaining the results was very difficult for him because he was told his test needed to be repeated in three to six months. As he explains, Kyle was very shocked at the way his test results were revealed to him because he said the person acted like testing positive was a death sentence:



It's really hard. I knew there was a possibility because an ex [boyfriend] had lied to me about his status in the past. The first test came back negative... Well, they say you have to go three to six months later... I did a repeat test, three months later in an anonymous testing van. It shocked me how they present the page to you because, I've heard the story from so many people that it has a yellow highlight through the page, which automatically means you're positive. So before they even have a chance to say something to you, you know there's a yellow highlight through the page, and they said to me, "Are you OK?" And I said I'm fine. I kind of knew it was coming. She said, "Are you going to kill yourself or jump off a bridge?" And I said no I'm perfectly fine. And she said, "So, do you need any help or whatever?" And I said, no, I'm good; I'm going to take the results and go. What I was even more surprised about is the tone they ask you that question, it's like, they automatically think you're going to die, or go jump off a bridge, like it's still 1984.

#### 5.2.1.4 At their doctor's office

Bajaa, Foxy, Taryn, Koby, Griffin, Robert, Maggie, Link, and David all found out their HIV status through their family doctors when they received blood test results for regular check-ups. Bajaa found out her HIV status when she was pregnant and subsequently gave birth to her first child later through emergency surgery. As she explains:

I was 20 years old. I was diagnosed [when I was] pregnant. I had my [baby]...by emergency C-section. I became a mommy at the same time I found out I was HIV positive.

Foxy went for STI testing every six months and found out his HIV status through his family doctor over the telephone. As he explains, the immediate support that he received from his doctor helped him to accept the news and move forward to his next steps:

You're not supposed to, but I found out over the phone. My family doctor called me...He said, "Are you alone now?" "I'm with my fiancé." He said, "Good, he should hear this, too. Well...". And then he just told me. And he said, "Next step, we'll just move forward, don't worry about it. I already got a new doctor for you, but I'm still going to be here for you as your doctor, as well." He was actually more comforting because he was calm rather than, well, "I have some bad news." It was just, "Oh, well, the test results came back and you're HIV positive." And then he just kept on talking, so that way it wouldn't give me a second to be, like, \*gasp\*. It just made me think of, Oh, ok, next step, rather than, \*gasp\*.

Koby found out he was living with HIV when he had a physical exam and blood work. As he explained, he always got tested regularly to ensure that if he tested positive for an STI he could take care of it right away, but he did not anticipate HIV:

I just went in for my routine physical and when I go in for my yearly physical I would get blood work done. That was just precautionary, 'cause, well, if I had something, I wanted to know. I wasn't one of those people that kind of put it off. Like not knowing, I'd rather know, get it looked at, everything like that. Mind you, I wasn't exactly expecting HIV, but, that's kind of where we ended up.

Taryn found out through an unlikely source—her boyfriend's wife—that he might be living with HIV and decided to go to her family doctor to get an HIV test. As she explains:

I found out through my boyfriend's wife...she phoned me and said she was hearing around that he was HIV-positive and that she thinks that I should go get tested. So

that's what I did...He didn't tell me anything. He came to my face because he was mad at me because I did talk to his wife. He's just like, 'Yeah, I killed you. I took your life from you and I'm just like, 'What are you talking about?' because I had no idea. He's like, 'Don't worry, you'll find out'...[I got tested] and found out through my family doctor.

Griffin found out his HIV status when he had his annual physical examination and as he explains, he received immediate support from his family doctor:

[It was] just an annual check-up. There was just a regular test, with the doctor that I had at that time. I got a phone call to come in. She [my doctor] told me face-to-face. She basically sat me down and said, 'There's no easy way to say this...' As soon as she said that, I knew what it was. And then I broke down after that. She was very supportive. The first thing she did was hook me up with an HIV specialist.

## 5.2.2 Initial reactions to their HIV status

A considerable piece of my interviews with the participants focused on how they reacted to the news of their HIV status because finding out was a transformative event. Youth in this study talked about how they went through a period of mental and emotional adjustment after their diagnosis, including isolation, depression and thoughts about committing suicide.

### 5.2.2.1 Isolation

Youth in this study talked about how they struggled with isolation after they found out their HIV status. Isolation was discussed in relation to feeling isolated by other people because they thought no one would associate with them now or would treat them differently or

isolated themselves after finding out they have HIV because they did not know how to deal with the news. Robert felt cut off from everyone because he thought no one would want him as a friend or in an intimate relationship as a partner because of his HIV status. He stated: “My initial response was that no one would ever touch me again and that I would be totally isolated from society socially and sexually”.

Xavier felt like becoming HIV-positive exacerbated the addictions issues he was already struggling with; he felt very alone and did not understand how to deal with being HIV-positive. He explained his experience of isolation by using a metaphor of being locked in a cage:

When I first tested positive, the only way I could describe it to somebody is like I was put in a cage, it was like something I never knew I had was taken away from me. I’ve been... I was addicted to drugs before I found out and I’m still addicted to drugs so... my immune system and my body isn’t at what I think a 25 year old young man’s body’s at, it’s a lot more run down...I don’t have energy, I don’t recuperate as fast as everybody else I’ve noticed. Things take longer to heal.

Maggie’s way of dealing with her diagnosis was to isolate herself and try to cope through substance use. As she explains:

A lot of negative stuff has happened to me. I was feeling isolated for a while and in that isolation I turned to alcohol and heavy drug use and I was avoiding finding any support for myself. This was in the first year of finding out that I was HIV-positive and during this time I just thought to myself that I didn’t care about my body. I didn’t care about my life. I just wanted everything to end. I did not see any good coming out of being HIV-positive and it really hurt and I was scared. I isolated myself and I didn’t tell anyone the truth. I was always making it sound like

my life was great towards people when it was not. I stopped trusting people for a while because I didn't know what I could tell them without them looking into my life and finding out that I'm HIV-positive...In the first few years, I truly felt like I was never going to find someone who would love me, someone that I could love back because I was HIV-positive.

#### 5.2.2.2 Feelings of depression

Youth in this study talked about feeling depressed upon learning of their HIV status, and many turned to substance use as a way to self-medicate and cope with this traumatic turn of events in their lives. As Foxy explained: "I went through a point of depression where I was drinking and smoking weed all the time and then I partied a lot, going out living life". When Taryn found out she was living with HIV she thought her life was over and she would never find someone to love or have children with. Finding out her HIV status caused her to struggle with depression, as she explains:

When I first found out I was pretty depressed. I thought I was never going to have children. I thought I was never going to get married. I thought I was never going to do anything you know. I thought I was going to die. So, that was like a struggle.

Koby battled depression when he found out he was living with HIV because he was not ready to face the world. As he illustrates:

I find I've kind of introverted a lot. I'm slowly starting to open up again and let people in. For the first while, anyway, I didn't really want to see anybody or talk to anybody, and went into a depression. Not necessarily the most severe, but all the

time anyway. I just kind of took myself away from the world, didn't do very much, and stayed in my room as much as possible.

Noah, who was born with HIV, found out about his status when he was 16 and it was very distressing for him. He discussed feeling like his childhood had been taken away from him and that he struggled with depression as a result. As he explains:

It [finding out] caused all mental stress for me. I'm suffering with depression right now and because of what happened and I shouldn't be going through this because I, I didn't deserve it...I never grew up as a kid. My adult days began when I was 16 because I was forced to grow up too fast and I didn't know how to deal with the stress.

### 5.2.2.3 Suicidal thoughts

Participants in this study talked about how they contemplated suicide when they found out they were living with HIV, and one participant attempted suicide upon learning of this news; a particularly distressing finding. Some youth contemplated or attempted suicide because they could not cope with their feelings of self-blame related to becoming infected, and because this kind of dramatic life change was too overwhelming to think about learning to live with. Donovan told me that he attempted suicide because he blamed himself for getting HIV, which he framed as being connected with the fact that he was partying with people he did not know and not leaving a the party when a friend of his did. As he explains:

I ended up going to an after-hours house party...I ended up drinking from a water bottle which had GHB [*gamma hydroxybutyrate*, a date rape drug] in it...I started feeling a little weird after and then I was at some strange guy's

apartment...then I woke up on the side of the street the next morning on the bench and belt buckle's undone...I kind of got up, my pants were falling down...when I got home I realized that I had been raped. I had dry blood on the back of my legs... It was a bad experience for me and it was something that I kind of wish never happened that way, I wish I had have known the people that I was partying with...I should've left with my friend and I didn't...When I first found out I stabbed myself 17 times and I ended up on top of a bridge and the cops had to drag me off the bridge and they brought me to the hospital to see a shrink...I blamed myself for a lot of years...but it's not something I blame myself for anymore.

Gabriel thought about committing suicide when he found out he was living with HIV because he was terrified and did not know what else to do. As he explains: "I felt like, outside of myself. It was so surreal, and I felt like jumping in front of a subway, I felt like I just didn't know what to do at that point. It was quite scary". For Charlotte, finding out she was living with HIV exacerbated her existing struggles with addictions and sent her spiraling down a path that seemed to lead, at least in her mind, to suicide as an option for dealing with this traumatic new reality. As she explains:

When I first found out I didn't know very much about it and because I was addicted I went deeper into addiction. I was doing stuff that I wouldn't normally do like putting myself in really, really bad [situations]...I just went on a suicidal rampage.

### 5.3 GLOBAL THEME 2: NAVIGATING HIV

The youth in this study discussed how their lives changed since finding out their positive HIV status. More specifically, they spoke about trying to manage the complex process of

navigating HIV in relation to the following issues: coming to terms with having HIV, learning to negotiate dating and other relationships, and determining responsibility for condom use. Coming to terms with their HIV status meant learning about HIV and understanding the implications of the illness, but it also involved thinking about their acceptance - and their family members', friends' and partners' - acceptance of their HIV status. The youth also talked about how dating and relationships were complicated by their HIV status because of two main issues: they felt the need to avoid sexual activity and they had to negotiate condom use with their partner(s). A visual representation of the theme *Navigating HIV* is shown in Figure 5.2 as a thematic map to illustrate the global, organizing and basic themes.

### 5.3.1 Coming to terms with HIV

A theme that came up consistently among the youth when they talked about learning to navigate life with HIV was coming to terms with their status. This meant learning about and understanding the illness, accepting their HIV status, and accessing peer support from other people living with HIV. Family members, friends and potential partners were also important sources of support for these young people as they moved through the complicated terrain of life with HIV.

#### 5.3.1.1 Understanding the illness

Youth in this study knew very little or nothing about HIV prior to testing positive, and after their diagnosis they expressed a desire and need to learn more about what HIV is and how to live with it. The youth discussed learning how to manage living with HIV after



seroconversion by learning about the infection. Examples of how they learned about HIV included, finding out what medications they needed to take, understanding how to eat healthier, and getting their blood tested regularly. They began reading books and searching the Internet for information about HIV and also accessed resources through their physicians. Learning about HIV provided Griffin with a new perspective that transitioned him from being unaware to changing his outlook and learning about how to manage his life. As he explained:

I'm more educated. I know I was one of those people that, when I was negative, I would not have given somebody the time of day if they had told me they had HIV. But I knew nothing about it, so I guess it opened me up a lot. And it changed my lifestyle, I eat healthier now, I look after myself better. There are a lot of positives from it and I've met some really great people through the support groups.

For Gabriel, learning about HIV provided him with the knowledge he needed to understand the illness and become more at ease with his health, instead of the constant worries he used to have. As he explains, he feels like his life is more manageable now:

[Becoming HIV-positive] made me think about my health a lot more, so I tried to eat more healthy and go to the gym and focus on my health. I did so much research about HIV, and the medications and complications and everything. Like people always comment, doctors and naturopaths and all, like, people I see, are so amazed by, like, how knowledgeable I am on it. So it made me want to learn. But I think now I'm starting to feel a lot better and more in control. Especially after starting meds a year ago. Less scared for my life, and you know, not worrying so much every three months, like, what's the numbers gonna be, what the results of the blood test. 'Cause that always scared me, you never knew what your blood work

would come out to be. So now, you know, going every three months and seeing “undetectable” and CD4 slowly rising, it helps to make you feel a little more reassured.

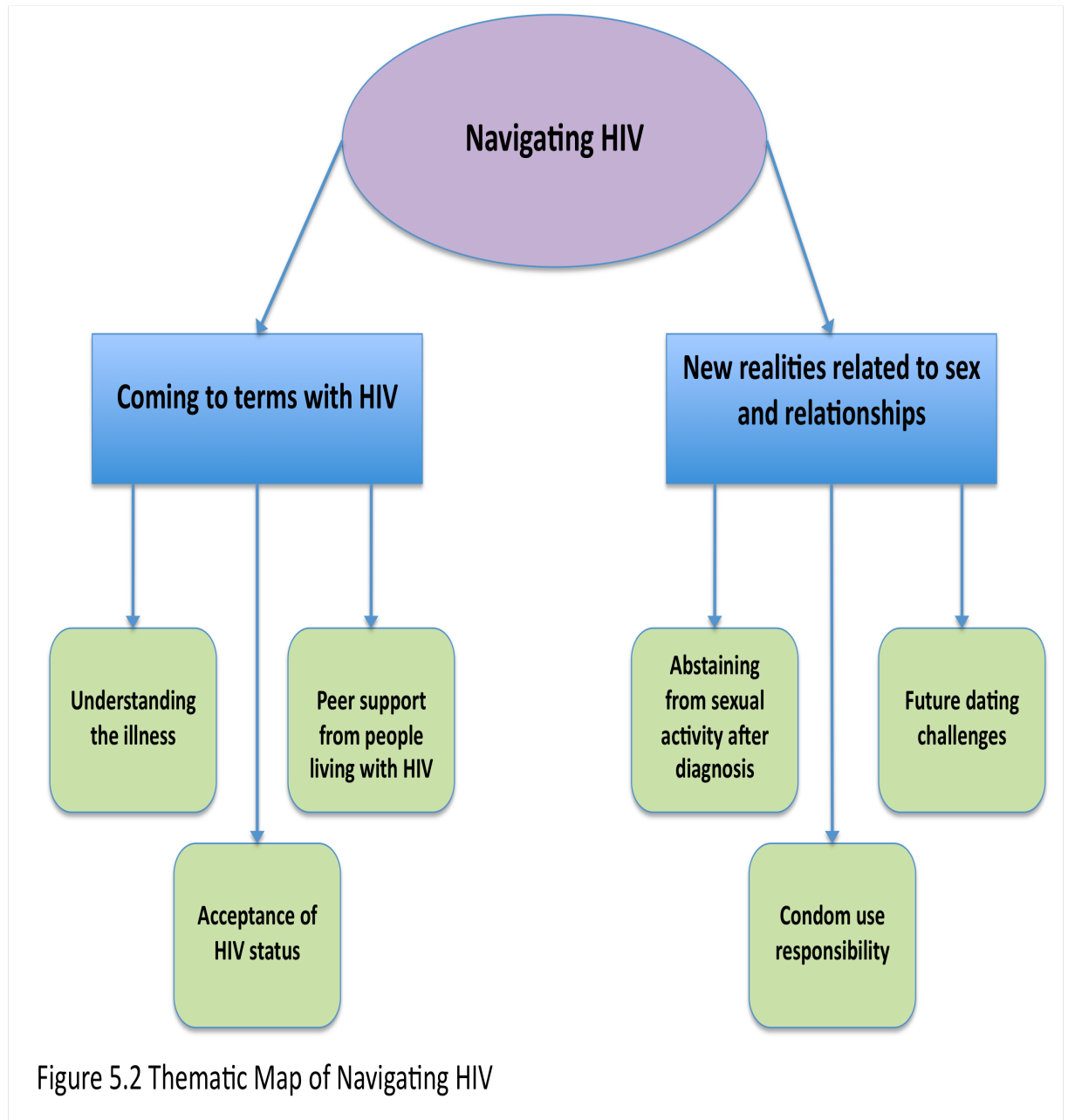


Figure 5.2 Thematic Map of Navigating HIV

### 5.3.1.2 Acceptance of HIV status

The youth in this study discussed various processes that helped them learn how to accept their HIV status, which involved taking control of their lives, surrounding themselves with people who were accepting, and having the support of their families. Bajaa's optimistic outlook on living with HIV encouraged her to take control of who she is and not let her life be defined by her HIV status. As she explains:

I'm very open with it [my HIV status], I'm not ashamed. Well, I can't say that I'm not ashamed, but it's not something that I hide. One of those things, if you don't like it, whatever, leave kind of thing, you know? I am who I am, it doesn't define me...It's part of who I am. I felt the need to be open. The percentage of people are quite supportive and look at me as an inspiration.

For Koby, accepting his HIV status did not come easily; it was a process that took time. As he explains, it was his attitude that changed everything:

I still have good and bad days, but slowly and surely, the good days are outnumbering the bad ones...I guess it's a mindset. I started to really accept it...For the most part, like if you had asked me...a year ago...I would have said no, but, over time, I've, I guess, come to accept it, and realized it's going to be a part of my life no matter what.

Xavier knows that being able to accept his HIV status will always be a struggle, but he is working through it. He explains: "I have days where, you know, I've accepted my own part in being HIV-positive, but at the same time, it's...I think going to be a battle all of the rest of my life. Right?" For Kyle, being HIV-positive meant learning to come to terms with being

different, but also making sure he surrounded himself with people who accepted him. As he explains:

I realize, over time, making new friends, it was, it got better over time because I had to come to terms that I am different from other people and people have to learn to kind of, accept you, so it was kind of like I had to pick the right group of people who were tolerating of me.

Donovan's family slowly learned to accept his HIV status once they began to learn about what it means to live with HIV, which for him was a powerful way they showed their support:

At first...they [family] were all very, "Oh well, don't touch this" or "Don't drink out of this" and "Don't leave half eaten sandwiches in the fridge" and stuff like that. But, within a couple of months, they became very aware of HIV, they read up on it, they've done their research and they're like, "Well, gee, it's not as, having cancer is worse than HIV now". It's not like they went to doctors and stuff and started asking questions. It's that they got the books and started reading and finding out for themselves and because they were more worried for me. They were thinking I was going to die within a year or two. Within a couple of months or maybe four months, all of them read up on books and everything and read how I could live for 40, 50, 70 years and all this medication and stuff and they started educating *me* on the whole HIV thing.

Kyle talked about how he encouraged his family to learn more about living with HIV by providing them with a book and acting as a resource whenever they had questions about HIV. As he explains:

It was over the years, learning things for me and educating more. It was funny, one year I came back for Christmas and I gave everyone in my family a book...it talks about now you're HIV, and basically everything you need to know about HIV viral loads, CD4, how to be safe, how to keep your body active and living well...One of my other family members decided to be a nurse, so now her and I are kind of like the center of educating the family...Whenever there is a breakthrough of something, like a vaccine or a new treatment, they have questions.

### 5.3.1.3 Peer support from people living with HIV

Youth in this study talked about how beneficial it was to have other people who are living with HIV to talk to who are empathetic and shared their feelings and experiences. Having peer support helped the youth to gain a better understanding of HIV and what it is like to live with it from people who understood and could share their experiences to help them through challenging times. For Griffin, knowing he had people to talk to and friends that have been in his shoes helped him get through the initial period of diagnosis. He explains:

Just knowing there's other people out there in the same boat and they, they always seem to be able to direct me to the resources I need...The support groups...because most of my friends are HIV-positive so they, understand already, what it, we all go through. It took a lot of support, a lot of coming to the groups and just surrounding myself with people that were in similar situations, I guess, helped a lot. And just have a good friend support, I guess.

Kyle described having friends who are also living with HIV as a kind of blessing, because they are able to empathize with him and also offer needed support that other people in his life are unable to provide. As he explains:

Most of my friends I have made over the years, from, being positive, that I've met at various ASOs or conferences, who I remain close to. And you hang on to them with your dear life because you recognize they share the same fear, the same pain, and understanding that you can turn to them pretty much about anything. And they won't judge you, and they, they always have a word of support.

Xavier finds it easier to open up to and talk with other people who are living with HIV because he feels like they are the only ones who helped him grasp what it means to live with HIV. He explains:

It helps that there's, like some of the support workers that I deal with, they've been in my shoes. Right? So like and I know that they have been and I know where they came from so I kind of...I'm more willing, I'm more comfortable with being open with them, because I know that they've already been there, you know? And that they are not, they are not just...they do understand where I'm coming from because they have been in my shoes before.

### 5.3.2 New realities related to sex and relationships

Becoming HIV-positive shaped many new realities related to sex and relationships for the youth in this study. The three main issues that the participants discussed in relation to this theme were abstaining from or avoiding sexual activity after diagnosis, future dating challenges, and condom use responsibility.

### 5.3.2.1 Abstaining from sexual activity after diagnosis

Participants in this study reported that after they learned of their HIV status they abstained from sexual activity and faced numerous challenges navigating their new sexual lives, particularly in the early days of their diagnosis. Some youth were not comfortable with engaging in sexual activity because they did not have enough information about the risks of HIV and feared transmitting HIV to their partner. Others avoided sexual activity because they did not want to coerce their partner to have sex until their partner was ready. Gabriel talked about abstaining from sexual activity after he was first diagnosed until he met someone, which encouraged him to learn more about HIV and ultimately resulted in the return of his desire for intimacy. As he explained:

I think I did [abstain] for at least the first year after being diagnosed, then I met a partner, and I think that changed, and then, you know, also doing all the research that I did do, and I started to feel a little more okay, and some of the interest in sex and stuff like that came back. But, it makes it difficult in terms of meeting people.

Xavier discussed avoiding sexual activity because he feared transmitting HIV to someone else, including other people living with HIV. As he explained:

A lot of the time yes [I would abstain]. Even with other people that are positive, I get really---I don't know maybe it's my own, my own fear of passing it on to someone. I just don't want to take a chance of bacteria with another person's bacteria and that can cause bacterial infections.

Pierce and his partner, who is HIV-negative, avoid certain sexual activities that might put his partner at higher risk of HIV transmission. As he explains:

I actually go through that a lot with my partner that I have now because you know, we have certain fears. So there are certain sexual activities that I'm afraid to do, like having unprotected anal sex. You know, it's something that feels better physically, but it's something that really scares me and so we avoid doing that. I even have some apprehension about having protected anal sex because there's the fear that the condom could break.

Even though Koby still wanted to engage in sexual activity after his diagnosis, he abstained for a year because he needed to wait until his HIV-negative partner was ready. As he explains:

It was more difficult for him. He wasn't all gung-ho for condoms and I think that was partly why it took so long for us to have sex, to start having sex again. He clearly had to get his head wrapped around it. It's not hard for me because I'm not the one wearing the condom. It wasn't so much me. Like, I was still raring to go, but it was the fact that my boyfriend, he had to get his head wrapped around it and kind of accept it, I guess. Like, there was probably a time well we only recently started having sex again, maybe in the last five months or so. So we went close to, if not, just over a year without having full sexual intercourse...I wasn't going to pressure because that's not me. Just because I want to get off doesn't mean I should put my boyfriend in a more uncomfortable position until he's ready. I finally waited for that, and after a while it just happened again.



### 5.3.2.2 Future dating challenges

Becoming HIV-positive has made dating and building relationships more challenging for the youth in this study, which impacted who they could date, intensified their existing dating challenges and changed the dynamics of sexual activity. Youth in this study felt that they could only date people living with HIV because it was easier than dealing with some of the challenges related to HIV, such as rejection and disclosure. Youth felt that they lacked confidence in their ability to meet people because of their HIV status, which they identified as key barrier to dating. For some youth, meeting potential partners could no longer be spontaneous and would always require negotiating safer sex or disclosure.

Koby feels that if his current relationship were to end, he would only date other people living with HIV in order to avoid rejection. He explains:

I don't want to put myself through all the heartache and emotional stuff of liking this person and then telling them, and then just getting pretty much thrown out. If my boyfriend and me were to break up I've already come to the conclusion that I would more than likely only date other positive people. Simply for the fact that I don't want to put myself through all the heartache and emotional stuff of liking the person and then telling them and then just getting pretty much thrown out. There's lots of HIV-positive dating websites, so I would probably stick to that rather than going out meeting people and hoping that they're accepting of it.

Gabriel also discussed feeling limited about his choices with dating because of the challenges associated with HIV and transmission and wants to find someone who is also living with HIV. As he explains:

I think it's made trying to find the kind of ideal relationship that I've always hoped for very difficult. So, I don't even try to meet people. I only try to search on HIV-positive websites or meet people that way...I think it makes me worry about transmitting HIV. It makes me worry about my long-term health and wellbeing. But it also makes me want to find a partner that I can be comfortable with, that's living with the same virus that I am.

Mason has always been very shy and nervous and lacks confidence in his ability to meet girls, and in many ways living with HIV has exacerbated his difficulties with dating:

It comes with its complications of course. It's a complicated issue growing up with AIDS and HIV...When I was younger I mean the sex wasn't like, I'd say it got worse in grade nine, when I went to high school for the first time 'cause that's when sex is first like relevant. Before then I had no problem having girlfriends and stuff in grade school. But yeah, once sex has come into the picture, I was no longer a player...The most difficult part is finding a girlfriend...it makes me nervous...I turn myself down before I ask anyone out knowing my HIV status...I wish it didn't because just thinking about asking out a girl or thinking about it makes me nervous. I wish it didn't make me so nervous.

Gabriel has always found dating difficult because of his lack of confidence and, like Mason, feels that living with HIV has made dating much more complicated:

I think it's made it a lot more difficult. It's kind of like three years now, but before I was diagnosed I found it very hard to go out in the community or meet other guys or go on dates. I found it very, very difficult and I rarely did it, so since be diagnosed, I found that it further isolated me.

Xavier, who talked about how meeting people and engaging in sex was electrifying and impulsive before HIV, feels that sex has become something very different and less exciting now that he has HIV. He explains:

I remember when I first started having sex it was a feeling of excitement and the rush of like meeting somebody and going home and doing the wild—it was like a whole different feeling to it then there is now...I never even thought twice about it, about the sexual freedom and the openness about it until I had been sat down and told that I was HIV-positive. I could no longer you know, go out to a bar or go out to a function with somebody, meet somebody and go home and have sex with them and have spontaneous fun, you know, crazy moment...It's no longer...you can't be fun and spontaneous about it. I can't have that anymore, it's gone, it's never an option in my life anymore...You have to be serious and sit the person down and tell them, "Listen, this is what I have" and right then and there that takes the fun and spontaneous-ness out of it.

### 5.3.2.3 Condom use responsibility

Condom use and sexual activity were consistently brought up by the youth in this study in relation to individual and partner responsibility. Participants framed condom use during sexual activity as something that is their individual responsibility because they want to prevent the transmission of HIV. Xavier spoke in great detail about feeling a sense of responsibility for his partners or potential partners, which is why he is adamant about using condoms during sexual activity. As he explains:

It is my job and my responsibility to make sure that nobody else gets infected by me....Whether I like it, whether it makes me sad whether it makes me happy

whether it makes me feel good or bad it's beside the point. It's not even a choice with me, that's the way it has to be because that's my responsibility. My responsibility for me and my responsibility to the rest of the world, to make sure that everybody's aware and it doesn't get transferred you know. I don't know if I would be able to live with myself. Because it's like, I wouldn't wish it on my worst enemy.

Kyle also feels a need to practice safer sex to prevent disease transmission, which he explained as being central to helping to ensure his partners do not have to go through the same kind of traumatic experiences he has had related to living with HIV. He explains:

I think back every day that what would happen if I infect another person and did exactly what my partner did to me. That person would go through the same hell I went through. It's kind of like taking a life away from someone, that they won't be able to have. I'd rather be safe...so that they don't get it.

Charlotte feels that practicing safer sex is imperative because she does not want the responsibility of infecting someone with HIV on her conscience. As she explains:

It's very important. I find that it is extremely important for a person with HIV to practice safe sex. With me personally, even that one time or if you didn't use condoms, I feel that if I was ever to pass on HIV on to another person and feel like I'm responsible for that, I don't know, I would feel like a murderer.

Koby believes that sex should be protected all the time and if it is not, people should not have sex because the pleasure of sex without a condom is not worth the risk. As he explains:

For me it's more of a straightforward answer: Wrap it up. Whatever gets your rocks off, I guess, would be a good way, but just make sure you're safe about it.

Use a condom. If you don't have one, then don't have sex. If you want to fool around, go for it. But, don't assume the pull out method or anything like that works because it doesn't. I would definitely say use a condom if you have a chance to. If you don't have a chance to, don't have sex. It can wait, it's not that important. If you honestly feel that it's that important, then you should be carrying a condom on you at all times for the "what if?"

Youth in this study told me that practicing safer sex through the use of condoms during sex is left to their partner's discretion after they have disclosed their HIV status. The participants framed partner responsibility in relation to two main issues: communicating the risks of HIV transmission associated with sexual activity and weighing the risks through mutually decision-making. For Taryn, it is important to discuss the risks of HIV transmission with her partners so they can make an informed decision: "It's their choice. I given them their choice because I never had a choice and that's what I love about me, I guess, because I give people choices".

Bajaa and partner have both learned about the risks of HIV transmission and after weighing the risks and benefits of not using condoms, they have chosen not to use condoms. As she explains:

Now that my partner is educated, he has made the decision that he's willing to take the risk. And, being a person living with HIV, I don't want to infect anybody, I mean, that's what I think a person with HIV's worst nightmare is infecting someone...He wants to make the choice to have unprotected sex, so. It's important even though, I guess I'm a kind of hypocrite, saying that when I'm having unprotected sex, obviously. But at the same time, my partner has weighed the risks versus the benefits and he makes that choice.

Robert also talked about the possibility of not using condoms with his partner through communication of his viral load and weighing the risks. As he explains:

In my most recent long-term relationship, based on my numbers and based on his risk factors, he also felt like if we wanted to not use protection that was okay with him. And that was like a huge, like, it boosted my confidence immeasurably. Where I was like, 'oh my god, I'm a normal person. There is nothing that separates me from anybody else'.

For Link, practicing safer sex is about the mutual communication and decisions that happen between him and his partner before engaging in sexual activity about the risks of HIV transmission. He explains:

I think that practicing safer sex is simply about discussing the risks of the sex that you're about to have with your partner or partners before you have it. So, whatever agreement you come to with your partner is an acceptable level of risk for both of you through honest discussion. That's what I like to think of as safer sex. It's very difficult to practice safer sex. It's easy to put on my condom. I mean it's not about the act of putting on a condom, it's the knowing when to discuss it, negotiating it.

## 5.4 Conclusion

This chapter explored how the participants in this study discussed the impact of becoming HIV-positive had on them and their capacity to understand and navigate through what it means to live with HIV. Finding out their HIV status was distressing for the youth on a number of levels; which for some depended on when and how they found out. Youth in this study experienced isolation after finding out their HIV status because they did not know how to deal with being positive or felt that no one would understand or accept them. Youth also

battled depression after finding out and coped by self-medicating or substance use. Youth in this study contemplated or attempted suicide because they either blamed themselves or did not have the coping skills to manage being positive. These findings are important and speak to the needed support and services that should be in place for youth living with HIV immediately after HIV diagnosis.

Becoming HIV-positive changed the lives of the youth in this study because it now required them to come to terms with living with a highly stigmatized illness, negotiate dating and sexual activity, relationships and condom use. What makes these issues different for youth is that the participants talked about sexual activity as not just practicing safer sex, it was about how they saw it as protecting other people from getting HIV from them. Coming to terms with HIV meant learning about HIV and understanding how to take care of themselves, but it also meant seeking support from other people and this support came from peers who had been in their shoes. A critical part of living with HIV for these youth was the process of accepting their HIV status, not only by themselves, but their family, friends and partners. Acceptance of their HIV status was a coping mechanism for the youth, but it was also viewed as a form of support from other people that normalized living with HIV.

Fear of HIV transmission was a key finding and resulted in youth abstaining from sexual activity because they feared transmitting HIV or because their partner was not ready. Sexual activity and dating were now viewed as issues that required negotiation and were no longer spontaneous and some youth felt that their only option was a relationship with someone who is also living with HIV to avoid rejection.

Condom use responsibility was a significant finding in this study that was raised by all of the youth. An interesting dichotomy among the findings was the notion of individual responsibility versus partner responsibility for condom use. Individual responsibility was

structured around preventing transmission and ensuring that their partners did not become infected like they did. While partner responsibility for condom use and safer sex practices was framed by the youth in relation to disclosure of HIV status and communication regarding the risks. In the next chapter the findings from global themes three and four, *HIV Disclosure Management* and *Finding Meaning in Life After HIV Diagnosis*, will be presented. Table 5.1 encompasses all of the themes that are presented in Chapters Five and Six, including the 4 global themes, the 10 organizing themes and 30 basic themes.

| <b>GLOBAL THEME</b>                                    | <b>Organizing Theme</b>  | <b>Basic Theme</b>   |
|--|--|--|
| <b>BECOMING HIV-POSITIVE</b>                           | <i>Learning of their HIV Status</i>  | -Through a family member<br>-Anonymous testing<br>-Walk-in clinic/Hospital<br>-Family doctor   |
|  | <i>Initial reactions to HIV diagnosis</i>  | -Isolation<br>-Feelings of depression<br>-Suicidal thoughts  |
| <b>NAVIGATING HIV</b>                                  | <i>Coming to terms with HIV</i>  | -Understanding the illness<br>-Peer support from people living with HIV<br>-Acceptance of HIV status                                       |
|  | <i>New realities related to sex and relationships</i>                                | -Abstaining from sexual activity after diagnosis<br>-Future dating challenges<br>-Condom use responsibility                                |
| <b>HIV DISCLOSURE MANAGEMENT</b>                       | <i>Barriers to HIV disclosure</i>  | -Fear of physical harm and rejection<br>-Stigma<br>-Criminalization<br>-Desire for disclosure-related skills, guidelines or support        |
|  | <i>Method of HIV disclosure</i>  | -Internet/Online communication disclosure<br>-Face-to-face disclosure<br>-Having HIV status revealed by others                             |
|  | <i>Managing disclosure in the context of socio-sexual and familial relationships</i> | -Managing Relationships with friends<br>-Managing Relationships with family<br>-Managing Relationships with partners, & potential partners |
| <b>FINDING NEW MEANING IN LIFE AFTER HIV DIAGNOSIS</b> | <i>Transforming their life</i>   | -A new beginning<br>-Value of HIV in their life  |
|  | <i>Creating positive changes</i>   | -Going back to school<br>-Helping others learn<br>-Providing HIV peer support  |
|  | <i>Hope for the future</i>   | -Finding a cure for HIV<br>-Love and family  |

Table 5.1 Complete Global, Organizing, and Basic Themes from Analysis



## CHAPTER SIX

### 6 HIV Disclosure Management and Finding New Meaning in Life After HIV Diagnosis

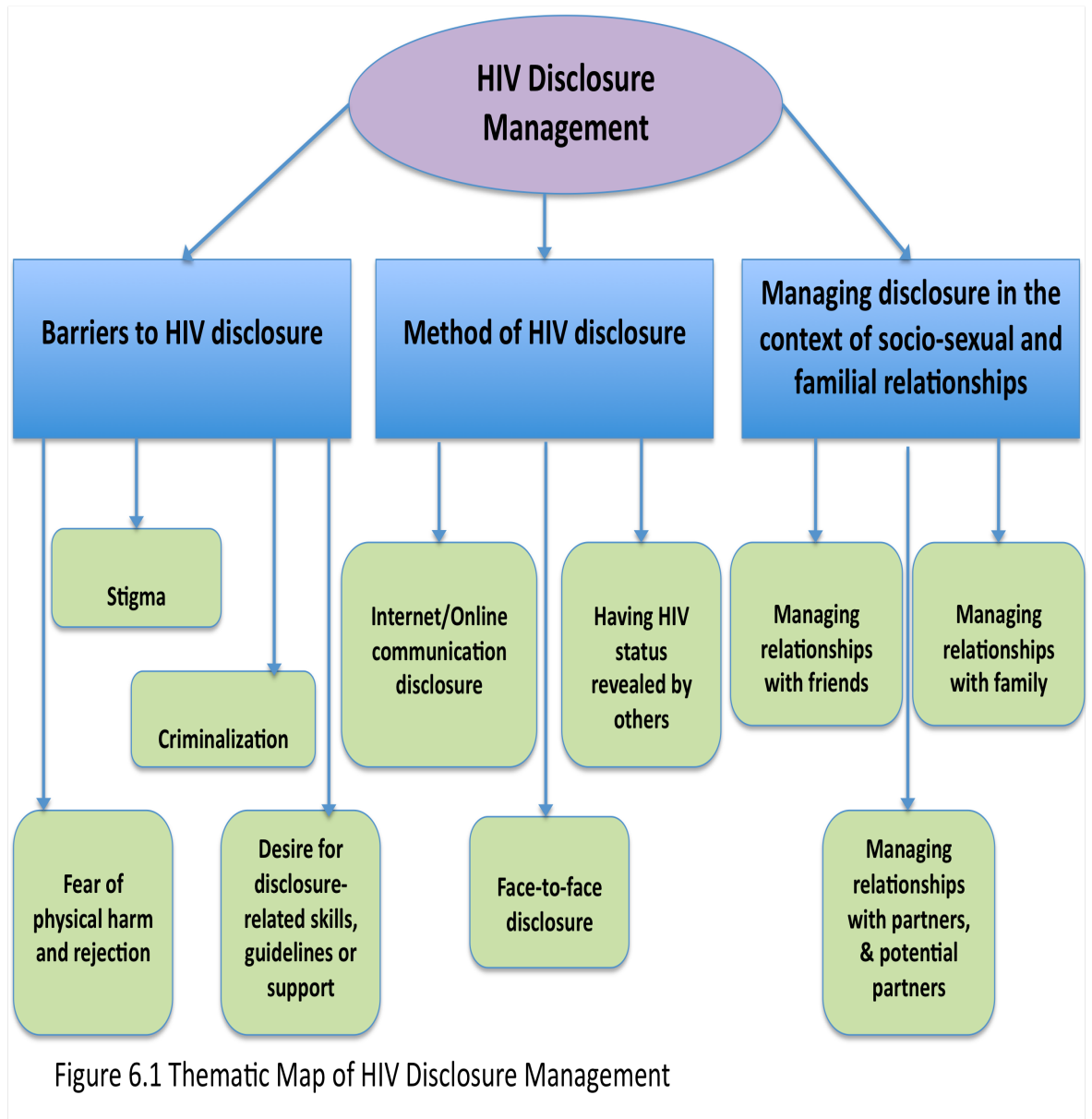
#### 6.1 Introduction

This chapter features data that illuminate and explore youth's experiences regarding HIV disclosure and finding new meaning in life after their HIV diagnosis. The youth in this research raised three key issues in relation to HIV disclosure management to contextualize this facet of their lives: barriers to HIV disclosure, the method of HIV disclosure, and managing disclosure in the context of socio-sexual and familial relationships. With respect to the theme finding meaning in life after HIV diagnosis, the discussion focuses on how they have transformed and created positive changes in their lives, along with the ways in which they seek and are cultivating hope for the future.

#### 6.2 GLOBAL THEME 3: HIV DISCLOSURE MANAGEMENT

HIV disclosure management emerged as the primary theme in this study, which makes sense considering the profoundly transformative impact that the youths' HIV status has on their lives in terms of who they are and how they live in the world. Participants' experiences with disclosure are significantly impacted by various barriers, such as how they learned about disclosure itself as well as the conditions that make not disclosing their status a preferred and/or safer option. Some youth focused their discussion on experiences related to disclosing

for the first time, whereas others talked in more depth about their ongoing management with the special situation(s) related to HIV disclosure. A visual representation of the global, organizing and basic themes that relate to HIV Disclosure Management are shown in Figure 6.1.



## 6.2.1 Barriers to HIV disclosure

The youth in this study cited numerous barriers to disclosing their HIV status, including the threat of physical harm, the fear of being physically harmed, and rejection. Participants also talked about the multi-faceted effects of stigma related to HIV, including their fears of being judged and – in some cases – criminalized, if they disclosed their status. The lack of disclosure-related guidelines or strategies and information was also raised by the youth, who felt that having such specialized resources would be a tremendous asset in helping them to understand how, to whom and when to disclose.

### 6.2.1.1 Fear of physical harm and rejection

Youth in this study talked about how they had been threatened or felt fearful of being physically harmed when they disclosed their HIV status to another person. Furthermore, participants refrained from disclosing their HIV status because they feared that someone they loved would be physically harmed. Pierce had his life threatened when he disclosed his HIV status to a partner for the first time and now adopts a careful approach to disclosure that involves taking consideration of his emotional and physical safety. As he explains:

First, I consider physical safety. Will this person tell other people that could potentially assault me, physically? Will I physically be in danger by telling this person? Like that person that threatened to kill me that one time. Secondly, will I be hurt emotionally or will this person reject me? Will I face stigma because of it? Then I consider if this said person could tell other people and if that could have negative ramifications. It's definitely a process that I have to go through.

Taryn too is scared of disclosing her HIV status because she fears that someone may physically harm her and/or her daughter. As she explains: “The fear factor of telling somebody it’s just, it might hurt me in a way. You know? Like physically hurt me or physically hurt my [child] or something you know? So, that would be my fear”.

Youth in this study also talked about their fear of being rejected as an important consideration related to HIV disclosure. For example, Gabriel feels that by becoming HIV-positive he has let his family down, so he avoids disclosing his status to them because he does not want to lose them. As he explains:

I think after first being diagnosed I felt like I couldn’t look at my...siblings in the face again...I felt like I would be another let down for them...they’ve looked up to me for so long... I felt like I had let down my family. I’ve heard lots of people have lost friends and family members when they’ve disclosed. I haven’t put myself into situations like that, so I don’t know that experience...I hope I’m not that naïve, I really think no one knows.

#### 6.2.1.2 Stigma

The youth in this study talked about stigma as being associated with HIV as a barrier to disclosing their HIV status to other people because they feared negative reactions or the loss of relationships. The participants referred to various instances where they felt that HIV stigma had or would prevent them from disclosing their HIV status. Gabriel talked about stigma in relation to disclosure, in the context of his workplace and being rejected by friends, but he also shared his fears of rejection by people in the gay community.

[I'm] too scared of their reaction. My one co-worker, said at one point, early on after I had been diagnosed, something about how she wouldn't be able to be friends, she didn't think she'd be able to be friends with one of her friends if they told her that they were HIV positive. When I hear those types of things...it scares me...so I don't tell people...There is a lot of stigma and discrimination within the gay community itself, about and around HIV. There's a lot of hateful things and people won't even want to talk to you—if they know you're HIV positive.

David is also afraid to disclose his HIV status because he does not know how others will react to finding out he is living with HIV. As he explains: “There's the element of the unknown due to stigma. You don't really know what someone's reaction might be 100%”.

Kyle struggles with knowing who he can trust to disclose his HIV status to and fears that because of the stigma attached to HIV, if he discloses to the wrong person they may use this confidential information against him, which could result in a loss of relationships:

It's hard to tell people because you want to trust people so much that they're not gonna be vindictive about you and spread hate towards you or talk bad about you to other people in the community, but unfortunately, there are a lot of people that have hate and stigma and they use it against people. There's still so much stigmatization that even if you tell someone you're positive, they won't be friends with you. It's hard.

Taryn will not disclose herself as living with HIV because of the respect she has for her partner. As she explains, she will disclose herself as having another illness to avoid being stigmatized and to protect her partner:

I've had to deny it a lot of times too. My boyfriend really worries about being judged and stuff like that. I respect his wishes. But it's like, some people in his

family he thinks that they might disown him. Sometimes I tell them I have cancer, just to see their reaction because cancer's like a little serious.

### 6.2.1.3 Criminalization

One of the main reasons the youth did not disclose their HIV status to other people, especially sexual partners, were the legal implications associated with HIV non-disclosure and related issues. The youth in this study are confused about what the law requires them to do, when they need to disclose and whom they need to tell. The stresses associated with HIV disclosure and non-disclosure have been exacerbated by the Supreme Court of Canada's decision (previously discussed in-depth in Chapter 2). The fear of legal repercussions from partners they may have previously put at risk, including being reported to the police, even if they did not engage in sexual activity, prevented one-third of the youth from disclosing their HIV status. Link finds disclosure to partners where risk is involved or has been in the past very challenging because of how HIV criminalization is portrayed in the media, the legal implications of HIV non-disclosure and the fear that he will be physically harmed. As he illustrates here;

I think that revealing health status to sexual partners is a particularly sensitive area of disclosure and that in my personal experience I've had no problem discussing issues of disclosure with my partner, or my family or my friends, or people around me, because it's not controversial for the most part to disclose to someone whom you haven't put at risk or you're not about to put at risk. But when talking about issues of disclosure to sexual partners, the issue becomes very controversial and very sensitive. There are people that I can't disclose to because I fear that I have put them at risk and

I fear that they might respond to that risk by taking legal action or violence or aggression and so I can't go there, I can't disclose to them...I think, in my experience it's been really scary to disclose information about my experiences with disclosure and sexual...like in sexual situations...because the issue of criminalization has always been sensationalized in the media and you hear a lot about people being charged and there's all these rumors about people being charged with murder and manslaughter. I hear a lot of fear and I know that there's a lot of fear about disclosing exactly what kind of situation people have put themselves in or have gotten themselves into.

Noah also does not want to disclose his HIV status because he is afraid he will be reported, even if he and his partner have not engaged in sexual intercourse:

I'm scared to tell women basically because of what they'll do or what they'll say that I did or something, like we had sex or something like that. I'm scared of what the repercussions are going to be from me not telling because it's the law.

#### 6.2.1.4 Desire for disclosure-related skills, guidelines and support

Youth in this study talked about challenges regarding disclosure that were related to not knowing how to undertake, approach, or prepare for sharing their HIV status with people, in person and in on-line contexts. Related to this was an expressed desire among many participants for resources, support services that focus exclusively on disclosure, and specific guidelines that could help them learn how to disclose and manage this complex process. For instance, Gabriel wants to learn skills that will assist him with how to disclose his status online because this method offers more anonymity and safety:

I think one of the best things I need for me would be good ways to do it electronically. I think it would be the best way to help me because it would be hard to hit the “Enter” or the “Send” but I could just push myself and I’d hit it, and then I’d be okay, it’s done. And then, you know, wait for a response.

Pierce feels that disclosure is a process that is learned and skills that are acquired over time and he feels that because he did not have the skills to disclose his HIV status to his partner when he needed them. As he illustrates:

When I was first diagnosed, I didn’t have that skill and it wasn’t taught to me. The guy that infected me lied to me about his status, so that’s not healthy disclosure. I believe that human beings are social creatures and I later found out that there were other guys that I had been with that had not disclosed. It was extremely, extremely difficult for me. I was abused sexually, emotionally, mentally and physically. I didn’t have the tools or the capabilities to disclose my status. Unfortunately, it landed me in some trouble...I’ve since learned how to disclose. I’ve learned that disclosure is a skill, it’s something that I’ve gotten really good at.

Griffin feels that having workshops that could teach him how to disclose his HIV status in person and would provide him with the skills to disclose when he is ready. As he said:

A workshop on how to facilitate a face-to-face conversation with someone who might not understand it...most likely it would be certain people. I don’t feel that everybody needs to know. Like, not every friend would need to know, necessarily. They will find out eventually, but I believe it’s a need-to-know basis.

Link identified a confidential support service that focuses exclusively on disclosure as something that would be of particular value or use for him and other gay men living with



HIV, who often struggle with finding a safe place to discuss issues and experiences around HIV disclosure:

I think a “disclosure only” support service could be really handy. Some way of confidentially disclosing information about what you’ve done and getting information on what the implications of that might be, how to avoid that in the future, this is something that I know myself and that I hear from a lot of other young positive gay guys is an issue coming up a lot for them. It is not being able to talk about the reality of their sexual experiences and the complications that HIV has created. If there was a counseling service that was specific to the needs of HIV positive gay men...not in a community-based organization...but a health based service that provided counseling to HIV positive gay men that I felt I could approach and talk about issues of disclosure without judgment I would have done so.

Robert feels that specific guidelines—regarding the legal context around and ramifications of HIV disclosure are needed so that those living with the virus can better understand and deal with that aspect of disclosure. As he explains:

It would be nice if there were guidelines legally. You know that kind of little thing that talks about disclosure and how it relates to the rest of the world. Also, the significant risk stuff is really challenging you know? It doesn’t tell us anything because that’s just so subjective. But I just want to know by law...it would be comforting. Just in the same way that if I was a lady and I wanted to take my top off, I would want to know that it’s ok to take my shirt off, because right now you can’t do that on the street, but you would know that it’s actually legal for you to do that and

then you would have like one more thing that you can support yourself with in case people freak out.

## 6.2.2 Method of HIV disclosure

The youth in this study appeared to be divided with respect to their preferred methods of disclosing their HIV status. Three disclosure methods were discussed among the youth, including Internet/Online communication disclosure, face-to-face disclosure and having HIV status revealed by others. Some youth in this study preferred to disclose their HIV status through online communication and others preferred in person disclosure. However, some youth also talked about and experienced another method of disclosure: having their HIV status revealed by other people without their consent, which was not a preferred method.

### 6.2.2.1 Internet/online communication disclosure

Disclosing on the Internet or via online communication provided privacy, confidentiality and the avoidance of in-person rejection for the youth who preferred to disclose through this method. Others disclosed online because they felt that it provided them with written proof of disclosure for their legal protection should their partner deny they knew of their HIV status.

For Kyle, disclosing on the Internet is less complicated than disclosing in person because he does not have to see the person's reaction while he is disclosing or face them in person if he is rejected. As he explains: "I find it easier to disclose more on the Internet because you're not having to deal with that person in front of you". Robert also prefers to disclose his status online because he feels that it takes the stress off of sharing information, but it also helps him to avoid rejection in person:

I always feel this interesting dichotomy between sharing. If I want to get to know someone sexually I don't feel pressured so much as I just feel like for me it's the right thing to do, to disclose, fairly up front. I'll chat with somebody online or on "Grindr" [a social networking site geared towards gay and bisexual men] or something. I will tell them probably in our first conversation. And part of that is a defense mechanism that if they're going to reject me they can reject me right away.

For Gabriel, disclosure will always be challenging because of the unknown, but he feels that the best method for him is communicating online because it provides privacy and confidentiality. As he explains:

I think the easiest for me would be, and that's not how I've done it in the past, is electronic communication, like sending an email and hoping I'll get a response. I think for me it will always be a very difficult thing.

Bajaa wanted to disclose her HIV status over the Internet to her partner because it was a way to manage and maintain written proof of disclosure in order to protect herself if her partner were to ever deny that she did not disclose to him. As she explains:

It [Disclosure] was uncomfortable, but I think it not as uncomfortable as it would have been had I been face-to-face. Obviously that's not the way you want to start a first date. It may be bitter sweetness because of the fact that I was able to, control the situation in a sense where if he was uncomfortable, then I wouldn't have to deal with necessarily his facial emotions... For me, telling my current partner online was a safety net because of criminalization of HIV. I wanted to be able to keep a record. By telling him in an instant message, I was able to actually save the message for future. I wanted to be able to protect myself because you hear about horror stories where

people are disclosing and then, later on, their partner said, he said, she said, they didn't disclose.

#### 6.2.2.2 Face-to-face disclosure

Youth who preferred to disclose their HIV status face-to-face indicated that this mode of disclosure enabled them to see people's reactions and answer questions or explain their story (of how they became infected) in person. Koby finds that disclosing in person allows him to assess whether the person he is disclosing to is accepting or not and also provides an opportunity to dispel some of the myths related to HIV. As he explains:

If I can, I'd much rather do it in person. I'm one of those kinds of people. This way I can actually gauge the other person, see their reaction to it, then fully explain anything that they may have either questions on or I can just tell them, like, "Don't worry, it's not the death sentence that it used to be, I can still live, like I'm 80, whatever. If anything I'm more likely to because I'm forced to live a healthier lifestyle than you." So, definitely in person as much as I can.

Taryn feels that when she discloses to a partner or potential partner it should happen in person so she is able to explain her story. However, because of the stigma attached to HIV and its association with certain kinds of sexual behaviors, when she discloses she uses a fictional story to avoid judgment:

Like if I go out on a date, I wait three dates, just to get to know the person a little bit better. But if I like the person a lot, then it's the first date. Then I'm just like, 'Yeah, by the way, you know, I'm HIV positive'. Or, I typically don't tell them my story that it was like random and I was a big time hoe. But I say that I was

raped when I was like 17 and the guy was HIV positive and stuff like that. I go into a different story. So, that's how I tell them. I know it's not cool, but I'd rather not tell the whole story. A lot of people think that people with HIV deserve it because they were promiscuous and I was like 'No, that's not the case. So, it's like I don't think anybody deserves it. Nobody. Not even on my worst enemy I would wish it.

### 6.2.2.3 HIV status revealed by other people

Youth in this study discussed how they had their HIV status disclosed for them, and a few talked about how they had their status almost disclosed, by other people without their permission. Disclosure by other people meant that the youth were unable to choose who found out and when, which often resulted in a loss of trust in those who disclosed their status as well as the dissolution of various relationships. Gabriel talked about a very distressing incident whereby a health care provider almost disclosed his HIV status without his consent. He had not yet disclosed to his friend who was with him, and was very panic-stricken when his confidentiality was almost breached. As Gabriel explained:

Recently I was hospitalized for pericarditis...I was with my friend...and this pericardium came at three in the morning, I thought I was dying, I couldn't breathe and had this excruciating pain all in my chest. I got to the hospital...they did an ECG...then all of a sudden they're rushing me down into emerg, bypassed all the people in the waiting room...They're [doctors and nurses] asking me questions and you know it was hard. I didn't answer, I didn't mention HIV for like 5 or 10 minutes and then I said, 'well, there's something else'. Then I was like, 'can you go wait in

the lobby?’ to my friend. My...friend...that knows I’m gay and he came out to me, but doesn’t know my HIV status. Then I said, ‘There was something I didn’t tell you because I don’t know if that could affect it or maybe that was what caused it or the medications’. They’re like, ‘are you on any medications’. And I’m like, ‘well yes.’ But that was really hard for me, just disclosing that to people I don’t normally see. And the question from both the doctor when she came and the nurse was, ‘how did you get it?’ Why did they ask me how did I get it...Then he [my friend]was coming again, and I was, they were getting me to take my antiretroviral medication, so they closed the curtains. But I mean when he showed up again and then the doctor was there, to me, I had to be, like, I had to tell the nurse that, when they’re bringing up the conversation about specifically HIV that it’s confidential, they can’t be doing that if my friend is right there.

Bajaa was unable to control who and when her HIV status was disclosed multiple times and she was faced with her partner’s sister and her own father revealing her status without her consent. As she explains:

We went through a period, my newest partner and I, where his [sibling] had realized that I was HIV positive and...was calling other family members, and, it caused quite a stir up in his side of the family...my [parent] also [told] everybody in my family. I didn’t really get to choose in my family who I wanted to tell.

For Kyle having his HIV status disclosed without his consent by his friend at school made him question whom he could trust and what he needs to consider before disclosing to other people. As he explains:

Apparently, a friend of mine that stopped talking to me decided to broadcast it. It’s kind of like that was, that one, of being outed out of the closet. I felt that I had no

protection because the school said there's not much we can do about it, it's not like he's not speaking the truth. That put a shock to me 'cause that automatically said, OK, well, who can you trust and who can you tell? And, from that point forward, I realized you had to be more and more careful who you told, whom you shared it with because people would want to talk about you and be vindictive.

Pierce was also unable to choose who he disclosed his HIV status to, but for different reasons that had to do with a media story about the special context of his infection-related situation. As he explains, he had no choice: "My name was in the [media], I really didn't have much option in keeping it quiet. Like my entire extended family all found out that way."

### 6.2.3 Managing disclosure in the context of socio-sexual and familial relationships

The youth in this study talked at great lengths about their experiences with disclosing their HIV to their family, friends, and partners or potential partners. While disclosure was difficult within all relationships, disclosing to a partner or potential partner was the greatest challenge for these youth because they feared rejection and legal implications. HIV disclosure for the youth in this study had both negative and positive effects on their relationships with their family, friends, and partners and potential partners; some youth lost relationships, while others found that they were strengthened.

### 6.2.3.1 Managing relationships with friends

HIV disclosure to friends resulted in both positive and negative outcomes, ranging from the loss of friends to complete support from friends. Finding out he was living with HIV was an emotional rollercoaster for Kyle and resulted in him losing most of his friends. As he explains,

Back when I first found out I was positive, it was like hitting a brick wall, I lost a lot of friends because they felt that I had betrayed their trust. I lost a lot of friends in the youth group that I went to. I basically got made fun of at school. I got told that I was a slut, a whore. I was a disease and there was nothing good about me anymore and it was God's way of punishing me. They felt that I was dirty. It was hard because I lost the most important people in my life.

Pierce also lost many friendships and these negative reactions have increased his fear of HIV disclosure:

I had this one friend...after I told her about my HIV status, she freaked out and we're not friends anymore. So, I have lost friends because of it. Unfortunately, I have had bad reactions. And that just kind of reinforces the fear of disclosing when you have someone react negatively toward you, it makes it even harder to, um, to disclose in the future and that even has, you know, repercussions.

Link's disclosure of his HIV status to his friends did not always involve rejection, but it still changed these relationships:

I've had a few friends who didn't quite get it, although there wasn't any rejection, or anyone leaving me right from the beginning, but um...you know from differences in opinion have come up over time regarding certain issues relating to my having HIV and so, it has I think over time changed my relationships with some of my friends.



Some youth had very positive, supportive reactions from friends when they disclosed, which set the stage for more positive experiences with disclosure in the future. Receiving a positive reaction the first time Robert disclosed his HIV status encouraged him to disclose to other friends, even though their reactions were not as supportive. As he explains:

The very first person that I told that I was concerned that it might be true was my friend...her response was just to like hold onto me all night. That was like an amazing reaction. I told another couple of friends and actually ironically a couple of people that I told are no longer my friends. I don't think it was as a result of that [HIV], but I definitely felt like there was additional stress added to our relationship because I was going through such a rough time.

Disclosing his HIV status for the first time was very scary for Gabriel, but when he did the friend to whom he disclosed was very supportive:

...Basically, I couldn't tell her...we had to drink...so we just cried and she just asked, could it be wrong, could the blood work be false. She's very much, like, an in-charge type person, she was saying, you know, everything's going to be fine. So, that was good.

Koby's friends have always been supportive so he had no fears of disclosing his HIV status to them. As he explains:

I've told maybe about five or six friends. Most of them it was right after finding out, or within a month or so of finding out. Just because I knew no matter what my friends are going to be there for me. I made sure to keep good people around me, in my life. So, I knew they wouldn't be judgmental or anything like that.

When Maggie disclosed her HIV status to her friends she was not judged by them, but was accepted unconditionally. As she explains:

I had a lot of people who really cared for me. I was fortunate that the people around me understood where I was coming from. So they respected, you know, where I was at in my life and they took the time just to take it for what it was.

### 6.2.3.2 Managing relationships with family members

Reactions from the young people's family members after learning of their HIV status ranged from very negative and hurtful to positive and supportive. Some youth talked about how reactions from their family were negative and resulted in the loss of relationships. Pierce's family did not react well to finding out that he is HIV-positive and he no longer has a relationship with them: "My, mom told me that I wasn't allowed in the house anymore. That was like 3 years ago, I'm still not allowed out there".

For Xavier, disclosing his HIV status to his mother resulted in an insensitive reaction from her that hurt him more than when he was diagnosed with HIV. As he explains:

I phoned my Mom and I said I think you might want to sit down and her comment to me was, "No, I don't want to sit down, just tell me what you have to tell me". And I said, um... "Well, I'm HIV positive". And her response to that was, "Well, that doesn't shock me"...it...it hurt...it hurt more than even being told I was positive. (Very emotional and crying again) Because it was like...like I don't know my Dad right? And I have a step-dad and we never got along so and my grandma died when I was 11 so it's like my Mom was supposed to be my solid ground right? And she basically, in other words said, well "I look at you as a piece of shit". So that, you know...just shocks you. You know, and it was like, like well, you obviously think

really highly of me? Don't you? Like you kind of were expecting this? Like... I don't know, maybe that wasn't the right way to say it? But it hurt... it hurt a lot.

However, other youth talked about how HIV disclosure resulted in bringing the youth and their parent(s) closer together. Charlotte always had a distant relationship with her mother, however, when she disclosed her HIV status to her it strengthened their relationship. She explains:

I shared with my mom a little while after I was still on my addiction. It brought me and my mom a bit closer, like me and my mom were never close right when I was growing up. I told her that I had HIV, it seemed like we're closer now.

Bajaa's parents were both supportive of her when she disclosed her HIV status to them, but as she explains, they support in very different ways:

I've had really good experiences with relationships but it is scary to tell someone. They're [parents] supportive. My mother doesn't really talk about it too much. Well, neither of my parents talk about it too much. But they are aware of my status and they're supportive, and my dad makes a bit of an effort to come to the different AIDS walks and that kind of thing, but not so much my mom. I think my mom thinks it's something I should just keep private and people shouldn't know.

Even though Koby's parents were very supportive when he disclosed his HIV status to them, he second-guessed himself because he was not sure he was ready to disclose when he did:

I'm lucky in that aspect. My family is very supportive. Good or bad, they're going to be there by your side, kind of thing. For the first little while after, I kind of had, the feeling like I shouldn't have told them. But, I'm glad that I did, just for the sake of having them there for me. 'Cause there was no question in my mind

whether or not they would have been. I knew they would have been no matter what. But, again, in that stage [depression], when I was in that stage, that's when I was kind of wishing that I hadn't of told them.

When Robert disclosed his HIV status to his parents, they were very supportive of him but also upset that he withheld this information and dealt with it by himself for a long time. As he explains:

It was hard for my parents. They were very sad that I didn't tell them right away because they knew that I went through a really rough time and they didn't know why. I'm a good actor, so I did okay. I think now that they know kind of what's going on or what was going on in my head, they have a better, an appreciation for what that kind of struggle was like.

Two participants (Kyle and Donovan) drew parallels between their HIV disclosure with coming out to their parents as gay, both of which were traumatic events in their relationships with family members (and other people). Kyle's mother was supportive of him when he disclosed his sexual orientation to her, and he thought or hoped she would also be supportive of him when he disclosed his HIV status; which she has been:

I've always been her number one boy and it doesn't matter what I've done. It could be bad, it could be good, it could be up and down, she says to me despite whatever happens, I overcome whatever the obstacles are...It's like we have a mutual bond. It's like her having another daughter, but not a daughter. It's interesting because I can only imagine what it was like coming out to my mother, she knew everything about what gay was because she had a gay friend back in the day. I think her main concern was the fact that gay was the big trend in HIV. So she would always be fearful that I would get HIV. She was supportive about me being gay, but she was

deathly ill worried that something could happen to me. I guess coming out to her had given her enough time, enough understanding and education, to prepare herself for the worst. When I did tell her, I guess she'd had enough education about HIV at that point.

Kyle and Donovan shared their unique experiences around disclosing their HIV status to their fathers; which took place after disclosing to their respective mothers first. They both linked this experience with coming out a second time because their fathers told them that they would get HIV when they disclosed their sexuality. Although Donovan was afraid to disclose his HIV status to his father because of his negative experience of coming out to him, his disclosure eventually brought them closer.

When I turned 15, I kind of came out to my parents and basically they took it really hard at first. And I said, 'Then why is it a big deal that I'm gay? I'm homosexual. It's who I am and it's not going to change. It's not going to change for you guys, it's not going to change for anybody else. If it ever changes, it's going to change for myself'...[My dad] always did say the first year or two that, 'Oh, you're going to get HIV, you're going to get AIDS, you're going to die, that's why I don't want, want you to be gay. I want you to be like your brothers'. Within the next four to five years I ended up getting HIV and my dad really took it hard again...but it more or less brought us closer. He wasn't mad at the fact that I had HIV.

Kyle also experienced difficulties disclosing his HIV status to his father because of how his father treated him when he disclosed his sexuality, but his father eventually accepted it and became supportive. He illustrates:

Particularly, my father. It was very hard for him to deal with me being gay, in the first place. And then it was even harder for him to deal with the fact that I was positive, when he found out. One day he said to me, “I told you that’s the disease that fags get when you came out to me”. It was kind of like coming out was one thing of a betrayal, but getting it [HIV] was even worse. It took a while for him to come around...

### 6.2.3.3 Managing relationships with partners and potential partners

Youth in this study talked about how disclosure of their HIV status to a potential or current partner resulted in the further development of or continuation of the relationship. When Bajaa told her current partner about her HIV status, he was very receptive and she felt accepted by him because he stayed in the relationship and demonstrated his care and love for her:

It kind of just was black and white...as soon as I told him, he started asking questions and wanting to know what did I mean and that kind of thing. He took the initiative to start finding information and I pointed him to good resources as well, and he went from there... So, that was my first step in disclosing with him and then once we got more into a relationship he was coming to different, events through my local AIDS resource. Eventually, he actually partook in public speaker’s training through my local AIDS Committee.

Mason has always been afraid to disclose his HIV status because he fears being rejected. However, when he did disclose his HIV status to a girl who was still interested in him, it made all the difference in him feeling accepted:

She was really persistent on dating me and I wasn't the keenest on dating her so she really forced me and it was my first time pulling the card out and saying, 'I have HIV, you don't want to date me' and she still wanted to date me. So, that kind of sparked a little bit of interest in me because I'd been afraid of telling anyone my whole life and being rejected my whole life. So having someone accept me.

Charlotte struggled with disclosing her HIV status to her partner, however, when she did he was very accepting of her status. As she explains:

I had a partner...it was really hard for me to disclose to him right and I just started crying and he asked me "what's wrong" and I said "I have to tell you something" and he goes "You can tell me anything" and I'm like "No...it's really hard for me to tell you" and he kind of got a stare right, he goes "What do you have Hep C?" and I said "Yeah I do...there's something else I need to tell you" and he goes "What you've got HIV?" I said "Yes" and the next thing he asked if I was able to have children and I said yeah I am but you know we have to do it differently. But it was hard for me to tell him.

Koby was in a relationship when he found out he was living with HIV and was concerned about rejection from his partner, who is HIV negative and a relatively new partner at the time. Even though they had to work through some issues, the support he received from his partner solidified their relationship:

Well there was a lot of crying. You could say that. More-so disbelief. Although we had only been going out for a couple of months, it was one of those, within the first week, we felt like we had known each other for years and years. I more or less, I was more worried that he was going to leave and just bugger off and

everything, but that wasn't the case at all. He was right there with me. He was actually more worried about everything than I was because he's had friends that are HIV positive. His biggest thing was I guess were with all the emotional changes and everything that they went through. He didn't want that. He was scared for that to happen with me. It apparently didn't happen as bad. I'm assuming because of two reasons. One, the support that I've had and, two, I was kind of ignorant to it. What I mean by that is, I just knew about HIV. I didn't know in-depth anything about it. I guess it really didn't affect me as much as it affected some of the people that he knew that actually were informed on it.

Unfortunately, not all of the reactions from partners or potential partners were positive or supportive and youth in this study experienced threats and/or rejection following disclosure that resulted in a loss of the relationship. Robert did not disclose his HIV status to his partner before engaging in unprotected sexual activity, which resulted in his life being threatened, but he faced the risk of being "outed". As he explains, he thought his partner would understand the risks of HIV transmission because of he was knowledgeable about HIV:

I told someone after we fooled around and we had unprotected oral sex. Everybody does. I feel very confident it's not risky and he was someone that was recommended to me by a friend that knew and he was doing...HIV research. Part of the reason why I didn't disclose right away was because I felt— like he would be cool with it and he wasn't and he threatened to kill me and he threatened to call the police and he was going to tell everyone that I knew and he was going to post pictures of me on Facebook and tag me as being positive. That was probably the most negative reaction.



Donovan also disclosed his HIV status prior to engaging in sexual activity with his partner, however, his partner had a negative reaction and rejected him:

Once I had this guy I made out with, kissing a person you don't have to disclose to a person, kissing someone, like making out with them. When it comes to the sexual part of oral sex or anything like that you have to disclose. But making out with someone, I started making out with him and I was thinking in my head "How am I going to tell him"? He wanted to make out and go, start to a go a little further and I sat up and I'm like, "Okay, I have to tell you something first, I have HIV". And he's like, "I just made out with you". And I said, "Well, you can't get it from making out". He's like "Oh, oh, oh my god, oh my god, oh my god". He got up and he just stormed right out of my place and he was still in his boxers and everything and he ran out and down the hall.

### 6.3 GLOBAL THEME 4: FINDING NEW MEANING IN LIFE AFTER HIV DIAGNOSIS

Despite the many complicated and negative outcomes associated with living with HIV the youth in this study also talked about new finding meaning in their lives as a result of becoming positive. Three themes emerged as particularly relevant in their journey to find and make new meaning in their lives, including transforming their lives, creating positive changes, and hope for the future. A visual representation of the global, organizing and basic themes that relate to *Finding New Meaning in Life After HIV Diagnosis* is illustrated in Figure 6.2.

### 6.3.1 Transforming Their Life

The youth in this study talked about how living with HIV resulted in them re-evaluating their lives, which was related to learning how to take care of themselves, valuing their lives, and finding a new appreciation for life.

#### 6.3.1.1 A new beginning

Youth in this study talked about how living with HIV caused them to stop and think about their current lives and find new ways of learning how to take care of themselves. Bajaa struggled with addictions and was involved in the sex trade before she found out she was living with HIV. Giving birth to her baby was a life-changing event that took over and sidelined her HIV. It was not until almost two years later that she was ready to begin taking care of herself and learn about HIV so she could have a future with her child:

It's completely like day and night, I guess. I was in prostitution probably from the time I was 12 or 13 years old. As well as addicted to crack-cocaine, so I'm clean, I very rarely drink, I don't prostitute anymore. I'm living I guess what some would say a normal life, if there is such a thing. But it completely changed my lifestyle and my views on life and just taking care of myself and doing what's best for me in order to have a future. Whereas, I guess, before I had my [baby]and the HIV diagnosis, I probably didn't have much of a future. A lot of people 20 years old, living the lifestyle I was living don't get to where I am today. A lot of people just end up back on the streets losing custody of their children and I knew for me that wasn't an option. Kind of something I like to say, "I have HIV, but HIV doesn't have me".

Charlotte talked about how she had been struggling with addictions before she found out she was living with HIV, but it was not until she got help for her addictions that she began learning about HIV and taking care of herself more than she had prior to becoming positive.

As she explains:

I ended up in drug court and that's when I ended up in a recovery house and where I found out a little more about HIV and it kind of changed my life because I kind of thought about my life more than I have in the past when I didn't have HIV.

Xavier talked about HIV in a unique way, as being like a blessing. He had been battling a drug addiction and believed that living with HIV forced him to learn the negative effects that being addicted to drugs could have on his life. As he explains:

My immune system and my body isn't at what I think a 25 year old young man's body is at...I'm a lot more run down...I don't have energy, I don't have the recuperation period, I don't recuperate as fast as everybody else I've noticed. Things take longer to heal...I hate to say this but it's been kind of a blessing in disguise because when you're addicted to drugs and you're HIV-positive you're playing Russian roulette with knowing everything...I've found that I've gotten a greater appreciation for maybe not necessarily the things you can see or feel in life, but more the sentimental things and appreciation for people who are willing to be around me and the people that take time out of their days to do nice things and stuff like that you know?

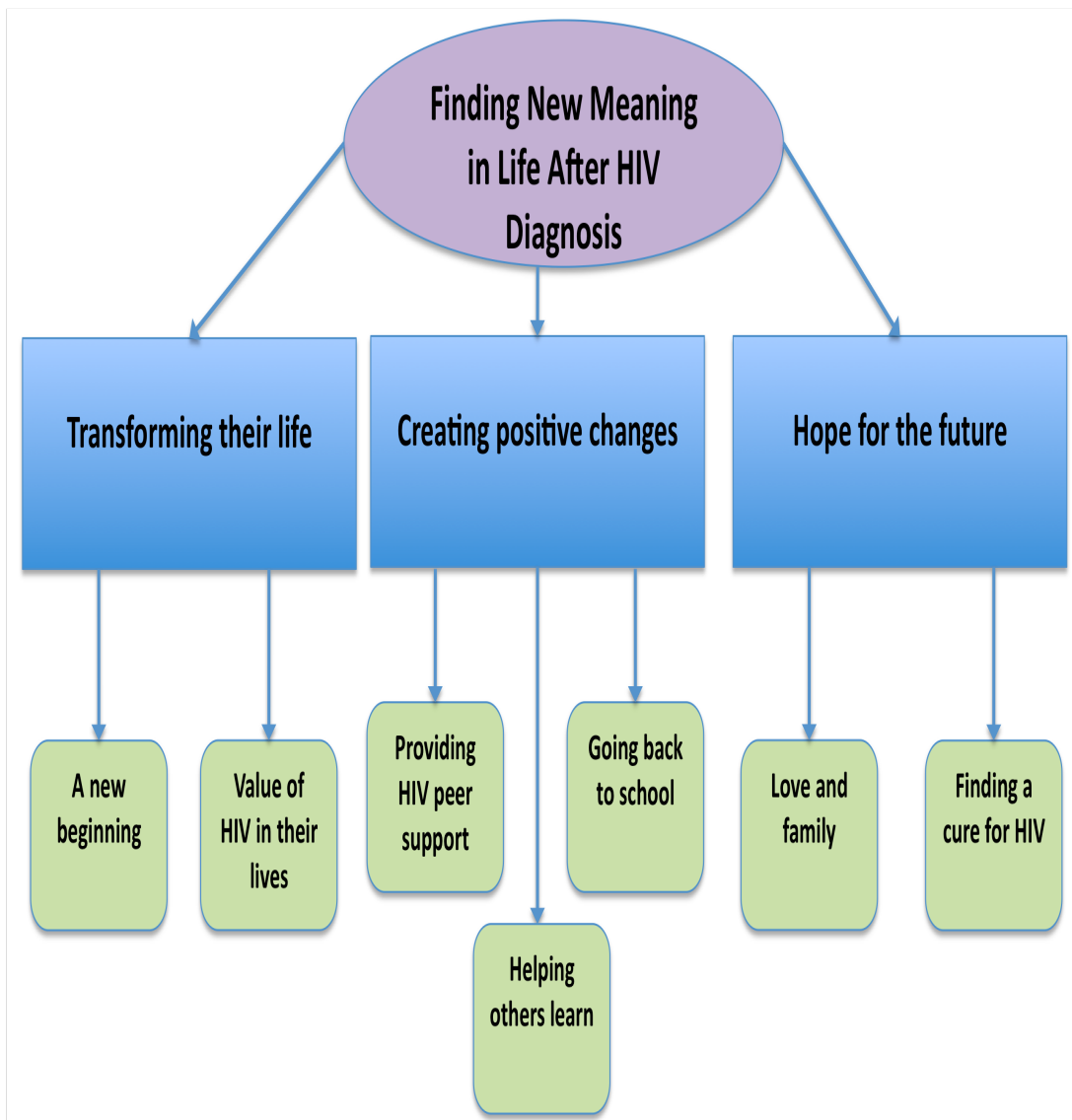


Figure 6.2 Thematic Map of Finding New Meaning in Life After HIV Diagnosis

### 6.3.1.2 Value of HIV in their lives

Youth in this study talked about how living with HIV resulted in them finding value in their lives and a greater appreciation for living life. Donovan sees everything differently now and he feels that living with HIV has given him a new lease on life and made him more determined to focus on the positive changes his life has to offer. As he explains:

If I hadn't gotten HIV, I would not be here sitting in this seat today. I'm living life to the fullest, but I'm living it for myself. I'm not living it for anybody else. I think HIV is the best thing that's ever happened to me. Like now I think that I'm stronger, I'm more focused on my life. I'm not proud that I got HIV, I'm proud that HIV I didn't let it run me, I ran it. I'm not going to let it control me at all. I'm glad that I did end up getting it because it changed my life and it really helped me out in finding my self-respect...I've changed for the better, really...I am happy with my life and I am glad I have HIV today and I am happy that I've gotten it because I wouldn't be where I am today. And that's the thing, you've got to make the best out of it. You have to really take HIV and just grab it and use it the way you want to use it and not to let it use you.

When Robert first tested positive for HIV he felt like his life was over, however, his determination for living and a new found understanding for what his life had to offer him, helped pave the way. As he explains:

Initially I was pretty convinced that I was just going to die and at the end of my life and it was going to limit my possibilities and then I decided that it wasn't going to do that and I've kind of kick started my life as a result. So now I feel so unlimited that it's almost like it's completely the reverse, I feel like I can do anything. It's just amazing.

### 6.3.2 Creating Positive Changes

Youth in this study talked about the positive changes they have made in their lives since they found out their HIV status. For some, these changes involved going back to school and finishing their education. For other youth, it meant being able to help others learn about HIV and share their experiences with other people/friends/peers/youth living with HIV or those at risk. Two youth spoke about how it meant finding new meaning in life through their involvement in peer support at an AIDS Service Organization (ASO). Going back to school, helping others learn about HIV or providing HIV peer support provided the youth with the opportunity fulfill previous goals and to share their experiences to help other people.

#### 6.3.2.1 Going back to school

Youth talked about how living with HIV provided them with the opportunity and/or motivation to create changes for themselves and go back and finish high school or college/university. For Kyle, going back to school was like fulfilling a dream as he was forced to quit school when he found out he was living with HIV. As he explains: “It’s made me better today...[I’m] finishing my high school, with intentions of going to college. It’s been a long eight years. I’ve gone from rock bottom back up, and hopefully it stays that way”.

After finding out she was living with HIV, Maggie decided she wanted to go back to school to increase her opportunities in the future. As she explains, she has set goals to make a better life for herself:

I have gone back to school so that I can make a better future for myself, more secure. I feel a lot healthier now. It is not a constant battle to get everything I

need in my life. I feel like I have everything that I need in my life now...I have goals that I'm working towards and it helps me out. I make healthier choices for myself that would better myself for the future.

Griffin feels that he is now ready to go to school and fulfill his aspirations of a career so he can build a future for himself. As he illustrates,

I have been volunteering...for the last five years. Now I want to go to school in the fall. I want to study three different things actually...two bachelor programs, one's for hospitality operations management, the other is for nursing. Or I want to study culinary management.

Foxy always knew he wanted to go back to school, but he needed to wait for the right time in his life. As he explains:

I'm more motivated now; I'm going to school. I'm going to be looking for work soon enough. I just want to get my regular schedule because I need a field placement for school. Once I get that schedule, then I'm going to get back to working.

Koby wants to make positive changes in his life and have, in his words, the "same thing as everyone else", which includes finishing school and finding employment. As he explains:

I guess the same thing as everybody else sees. Build a life for myself. I'm still not entirely sure what that life is going to consist of, especially job, education-wise, but, I still want the same things as everybody else.

### 6.3.2.2 Helping others learn

Youth in this study talked about being able to share their stories with other people/friends/peers/ youth living with HIV or those at risk to help them learn about HIV and what it is like to be HIV-positive. Some youth talked about sharing their experiences with friends or people who are at risk of HIV infection could have a positive effect, as they could be a source of support. Charlotte feels that being able to share her story with other girls who are struggling with addictions is helping others learn about HIV, but it is also helping her change the image of what people think a person with HIV looks like and that HIV can happen to anyone. As she illustrates;

I go to the...[society] and there were some people that were just talking about addiction and I turn around and said you know addictions screwed up my life. I spoke to one girl and said you know what I was in the exact same spot that you were and now look at me, I'm 25 years old and I have HIV and thought it's never going to happen to me and before you know it I had it right? I look at it as a positive thing to disclose to my friends so they kind of understand what's happening with me. I know a lot of people when they think of a person with HIV you think of a junkie they think of someone that's really looking ill, like really looking sick like they're on their death bed that type right? When I come in and say, you know what, I have HIV and I'm the type of person that doesn't look like a person that has HIV...I feel like I'm changing the face of what people think of when they think of HIV. And I feel really good about it. I've been asked to come and speak of how I got my HIV—to people that are not HIV. I find going up in front of people that are not HIV and telling them my story I find that it makes it easier for me to move on more and accept what I have.



For Bajaa, being able to help her friends and other youth learn about HIV helps her to be optimistic about her HIV status and has created a leadership role in her life:

In the five years that I've been positive, I've been educating myself a lot. Taking part in various public speaking workshops and training and I've been able to educate myself and actually take that education and go out and speak at high schools, and try to help educate other youth. Most people that I've come in contact with are pretty good, receptive and open to learning information. It's actually funny now because I have a few different friends who call me when they've had, like, the condom break or something. They call me to educate themselves because they are scared to turn to other people in the community and that makes me feel good that something good comes out of being positive.

### 6.3.2.3 Providing HIV peer support

Living with HIV opened up the opportunity for Link and Reid to get involved in the HIV/AIDS field, providing peer support and create positive changes in their lives, which they both view as a valuable part of their lives:

I think it has created a lot of changes for me because it set a lot of things in motion. I got involved with HIV work, so now I work in this field and I kind of do this issue as an everyday issue for me now (Link)

I became really involved in the HIV community right away, which is actually been really positive for my life. It hasn't changed my life directly in a lot of ways---like I'm fortunate to be employed and to have a roof over my head that's

safe. I'm in a much better situation than a lot of the youth that have to come to [here] (Reid).

### 6.3.3 Hope For The Future

When I talked to the youth about the future and what they hope to see, they talked about wanting a cure for HIV to be found, more HIV education and prevention, and someone to love. Some youth talked about how a cure for HIV would mean not having to face some of the challenges of living with HIV, such as taking medications, stigma and discrimination. Other youth talked about how a “cure” represents a greater need to increase education about HIV, transmission and safer sex practices in order to reduce the infection rate. Kyle hopes for a cure or a vaccine for HIV because he feels that it would help to increase the acceptance of people living with HIV. As he explains:

I see the cure happening or at least the vaccine or something that will be even simpler than the medication that we take today that will help us live better and people slowly understanding and accepting HIV/AIDS a lot more than they do today. I would like to see health care advance and hopefully we won't be battling this virus anymore the way we do today, I hope for peace with HIV/AIDS one day.

Bajaa also wants to see a cure for HIV, but she hopes for less infections and feels that more education is critical to preventing HIV transmission. As she explains:

I hope to see, more education, less, positive results for people. More education and more prevention. I hope to see the numbers going down. Potentially I hope to see something that will either protect others from being infected or something to cure the disease all in all.

The majority of the youth talked about wanting to find someone to love who accepts them for who they are, get married and/or have a family and children. Mason hopes that he can learn to build confidence in himself so he can find someone to love. As he explains:

I mean there's always the hope for a cure but, other than that I mean, maybe I'll grow out of my jitter stage and actually, maybe I'll find that person again who I tell and just accepts me too, it's a touchy subject.

Koby wants to find the person he can build a relationship with. As he explains: "I want to grow old with somebody, get a house, car, all that kind of stuff. Oh, and married. I guess that would be one, too".

Bajaa wants to be happy and provide a safe environment and childhood for her children because she does not want them to grow up with the same worries she had. As she explains:

I hope for happiness. I'm hoping in the next couple years, we'll be able to purchase our first home. Just living. I had a really rough childhood growing up, my parents were addicts, I was on the streets at a very young age and I just want stops for that. I want my [children] to be in school regularly, I want [them] to not have to worry about a roof over [their] head, and not have to worry that mom's falling asleep on the couch 'cause she's high on heroin. Just a very normal lifestyle, being clean, raising my kids and having a future. Because before I had my first [child], I didn't have a future at all.

## 6.4 Conclusion

This chapter illustrated the youths' experiences with and perspectives on HIV disclosure and non-disclosure, as well as the ways they have learned to manage their life with HIV and find new meaning. Disclosing or not disclosing one's HIV status emerged as the primary theme in this research because the youth felt that everything revolved around disclosure or non-disclosure. The youth in this study had disclosed to at least one person prior to this study and discussed their experiences with the barriers they faced with HIV disclosure, their preferred and non-preferred methods of disclosure and the results of disclosing their HIV status to other people. Disclosure of one's HIV status was fraught with numerous barriers, including the fear of physical harm to themselves or someone they love or being rejected by family members, friends, or a partner. Stigma was also a prominent barrier to disclosure and resulted in non-disclosure of HIV or the disclosure of another illness that did not carry the stigma of HIV.

The criminalization of HIV non-disclosure was paradoxically a key reason for *not* disclosing one's HIV status because of the legal implications in connection with, for example, unsafe sexual contact in the past or feared exploitation of legal options by individuals not put at risk but who have malevolent agendas. Youth also referenced confusion over the law and when, to whom and how they were required to disclose to. A related barrier to HIV disclosure was that youth felt ill-equipped and lacked skills, guidelines, or supports to assist them with disclosing to others; which resulted in a fear of criminalization and non-disclosure.

When the youth did choose to disclose their HIV status, they discussed two preferred methods: Internet or Online disclosure and Face-to-face disclosure. Internet or online

communication was preferred by some youth because they could avoid rejection in person, but it also gave them proof of disclosure for legal protection if needed. Face-to-face disclosure was also preferred by some youth because they wanted to be able to see other people's reactions and provide education if necessary. A disturbing finding in this study was a method of disclosure that was experienced by some youth, which was not preferred – having their HIV status revealed by other people without their consent. Disclosure by other people resulted in a loss of trust and relationships for the youth who experienced this involuntary method of disclosure.

Disclosing one's HIV status within various relationships resulted in both positive and negative experiences. Disclosure to friends for some youth resulted in a loss of relationships because they experienced rejection or a change in their friendship, while others resulted in relationships being supportive and strengthened. Disclosure to family members resulted in the majority of the youth experiencing negative reactions, including the deterioration of already fragile relationships. However, youth did experience positive reactions that ultimately reinforced their existing relationships. An interesting finding in this study is the dual disclosure experience of two youth who linked disclosing their HIV status to disclosing their sexuality to their parent's, particularly their father's. Their experiences of disclosing their sexuality to their father's resulted in being told they would get AIDS, which impacted their disclosure of their HIV status years later. However, their father's reactions when they disclosed their HIV status ultimately resulted in strengthening their relationships.

HIV disclosure to a partner or potential partner was described as the most challenging relationship in which to disclose because of the fear of rejection or physical harm.

Disclosure for youth in this study resulted in positive reactions; for some youth, disclosure was to a new potential partner, for other youth, disclosure was to a current partner. The

encouraging and supportive reactions ultimately provided acceptance to the youth and hope with regards to relationship development. The youth who talked about negative reactions from HIV disclosure to a partner resulted in threats of physical harm, rejection, or the possibility of their HIV status being revealed by that person if they did not maintain their confidentiality.

In spite of the challenges that the youth have faced in navigating HIV and struggling with issues related to dating, sexual activity, relationships and HIV disclosure, the youth talked about learning to manage their HIV and finding new meaning and hope in their lives since they became HIV-positive. These findings indicate that for some youth learning ways to manage living with HIV meant discontinuing self-harming behaviors, such as substance use and sex trade work because they did not want to continue putting their lives at risk anymore; for other youth, it was about learning how to live healthily and take control of their own lives. Creating positive changes was also reflected in the findings with youth taking the opportunity to go back to school and finish the education they once started. It also provided some youth the chance to help other people learn and share their experiences. For two youth, these changes meant becoming involved in peer support with an ASO. The youth in this study also talked about the future and what they hoped to see, including a cure found for HIV so they did not have to deal with so many challenges. Some youth talked about simply wanting what everyone else wants—to find someone to love, get married, and provide a future for their families.

## CHAPTER SEVEN

### 7 Discussion and Conclusion

#### 7.1 Introduction

The purpose of this chapter is to synthesize and discuss the main findings presented in Chapters 5 and 6, the limitations of the study, recommendations, and implication for future research. The objective of this qualitative study was to explore the lived experience of what it means to live with HIV for youth, with a focus on the issues of navigating safer sex practices, HIV disclosure, the criminalization of HIV non-disclosure and finding new meaning in the experience of living with HIV infection. Using a phenomenological approach in-depth, individual interview data were collected from eighteen youth living with HIV, twelve from Ontario and six from British Columbia. The research questions that framed this study were:

- 1) What are the contextually-based experiences of youth or young adults living with HIV?;
- 2) How do youth and young adults living with HIV navigate sexual practices, relationships and HIV disclosure?;
- 3) What strategies do youth and young adults living with HIV use to manage the impact of living with HIV on their social, relational, and emotional lives?

## 7.2 Characteristics of the participants

Eighteen youth living with HIV from ON (12 participants) and BC (6 participants), aged 22-29, participated in this research, with fourteen identifying as males (12 homosexual and 2 heterosexual), three as females (3 heterosexual) and one as a transgender female (1 heterosexual). The youth in this study became HIV-positive through various modes. These included unprotected sexual intercourse; unprotected sexual intercourse where their partner did not disclose their HIV status; non-consensual sexual intercourse; perinatal infection; and injection drug use. The youth have been living with HIV between one year and twenty-four years. Age of HIV infection ranged from at birth to twenty-seven years of age, with over half of the participants becoming HIV-positive between 20-21 years of age. Antiretroviral (ARTs) medication use for the youth in this study varied with over half taking ARTs daily, one-quarter rarely taking them and almost one quarter taking these medications as they felt they needed.

## 7.3 Main findings from this study

The findings from this study shed important light on and contribute to deeper understandings of the lived experiences of youth living with HIV. The key findings from this study regarding the experiences of youth living with HIV were focused within two main areas: finding out one's HIV status and how becoming HIV-positive has changed their lives. The main findings from within each of these areas will be presented below.



### 7.3.1 FINDING OUT ONE'S HIV STATUS

Finding out they were living with HIV was very traumatic for youth in this study and conditions in which they learned of their HIV status significantly impacted how they coped with the diagnosis and life from that point on. Sixteen of the youth were infected during youth and were diagnosed through a healthcare provider in a hospital, a clinic, a doctor's office or an anonymous mobile testing site. Two of the youth were infected perinatally at birth and had their status disclosed to them by a parent at different time periods in their lives, which resulted in completely different experiences. One youth was told when he was approximately 2 to 3 years old, while the other youth was not told of his HIV status until he was 16 years old. The youth who learned he was infected very early in life became accustomed to living with HIV, however, the youth who found out when he was a teenager experienced adverse mental health issues, anger, loss of trust and the loss of relationships. This is consistent with Lester and colleagues (2002) who found that delaying HIV status disclosure among those infected perinatally can have negative effects, including psychological and behavioral problems. The experience of the youth who was not aware of his HIV status until the age of 16 has several implications, not only from the youths' perspective because he battled mental health issues, but also from a public health perspective to aid in the prevention of HIV transmission. The timing of HIV status disclosure to youth who were perinatally infected needs to be carefully considered because of the impact it can have on their psychological and emotional well-being.

The experiences of the youth who were diagnosed by a health care provider are two-fold: some experienced stigma and discrimination from the healthcare provider when they were diagnosed, while others described their diagnosis as a very supportive experience.

Youth in this study talked about negative experiences they had with health care providers when they were diagnosed with HIV. For example, Gabriel talked about how his doctor came in to the room looking at the floor and then told him “all his test results came back negative except for the worst one, HIV”. Some youth talked about how they did have a supportive reaction from their health care provider and it had a better, immediately compassionate experience, setting an encouraging path for them to come to terms with their HIV status. For example, Foxy and Griffin both explained that when their doctors informed them of their HIV status they were very supportive in the way they spoke and provided them with a referral for a specialist and their next steps in care and in living with HIV. The experiences of finding out one is living with HIV suggest that youth need a great deal of support, especially peer support, beginning immediately at the time of diagnosis and this support needs to be without moral judgments, especially from healthcare providers. This finding also speaks to a need for supportive policies and sensitivity training for healthcare providers that could include updated, nonjudgmental information about HIV and AIDS, which can help in assisting youth when they are being diagnosed.

In addition to *how* the youth in this study found out their HIV status, the results illustrated the *impacts* of finding out: isolation, depression or thoughts of suicide. These findings are consistent with Hosek and colleagues (2008), who found that the youth in their study experienced depression, isolation and suicidal ideation prior to the period of HIV acceptance. Some youth in this study talked about how they struggled with isolation after finding out their HIV status. For example, both Xavier and Maggie struggled with addictions prior to learning their HIV status and finding out intensified their battle with addictions because they did not know how to deal with the news and avoided finding support, further forcing them into isolation.

Some youth also talked about how they experienced feelings of depression after their HIV diagnosis and engaged in various self-harming behaviors as a way of coping. For example, Taryn and Koby both battled depression after they found out their HIV status because they felt like their life was over so they turned to substance use to numb the pain. These findings are similar to Brown and Kimball's (2013) study on the experiences of self-harm. All of their participants discussed the role of self-harm in their lives and all attributed past experiences as reasons for the self-harm behavior. Their participants also discussed self-harm as a coping strategy that helped their overpowering feelings and some even talked about how self-harm brings clarity to them when they are dealing with difficult times. A few youth in the current study talked about how they even contemplated or attempted suicide after they were diagnosed because they did not know how to deal with being HIV-positive. For example, Donovan attempted suicide when he first found out he was HIV-positive because he blamed himself and did not know what to do or where to turn. These findings speak to the critical need for supportive counseling policies for HIV-positive youth immediately after diagnosis. These policies could assist youth living with HIV to understanding their diagnosis and coming to terms with the next steps in managing their HIV.

### **7.3.2 HOW BECOMING HIV-POSITIVE HAS CHANGED THEIR LIVES**

The results from this study demonstrated numerous challenges and new realities related to sex and relationships, disclosure management, and learning to live with HIV within the context of life post-diagnosis.

### 7.3.2.1 New realities related to sex and relationships

Three main issues arose regarding the new realities related to sex and relationships post-diagnosis for the youth in this study, including abstaining from or avoiding sexual activity, condom use responsibility and dating relationships. Abstaining from or avoiding sexual activity after diagnosis was a challenge faced by youth because they feared transmitting HIV to someone else or were faced with a partner who was unwilling to engage in sexual activity. Some discussed this challenge in relation to a lack of knowledge regarding HIV and HIV transmission through sexual activity. For example, Gabriel talked about abstaining from sexual activity after he was diagnosed because he did not have a complete understanding of HIV or the transmission risks and did not want to transmit HIV to anyone. These findings are consistent with Marhefka and colleagues (2011) who found that the youth in their study were afraid of transmitting HIV to someone else so they would avoid or delay sexual activity to prevent transmission. Fernet and colleagues (2007) found similar results with many of the youth in their study who talked about being afraid of engaging in sexual activity after finding out their HIV status because they felt a sense of responsibility in protecting other people from transmission. Koby talked about his partner's fear of engaging in sexual activity after he disclosed his HIV status to him and how he felt he needed to respect his partner and wait until he was ready. These findings speak to the need for supportive educational policies designed to increase the awareness and understanding of HIV and the transmission risks for newly diagnosed people. They also speak to the need for specific HIV prevention education and counseling support for sero-discordant couples at different stages in life to increase their knowledge and understanding regarding safer sex practices and HIV transmission risks.

Since finding out they are living with HIV, the youth in this study talked about condom use responsibility with regard to protecting other people, and negotiating responsibility with their partner. Youth talked about condom use in relation to their responsibility because they need to protect other people from HIV transmission. For example, Xavier and Kyle talked about condom use in relation to their own responsibility because they do not want anyone else to become infected. Fernet and colleagues (2007) also found similar findings with the youth in their study who talked about their sense of responsibility in protecting other people from HIV. Furthermore, Charlotte also talked about condom use as her responsibility but related it to the analogy of feeling like a murderer if she did not practice safer sex and infected someone with HIV. These findings are consistent with Marhefka and colleagues (2011) who found that the youth in their study talked about HIV as a weapon that could hurt other people if they did not practice safer sex.

Condom use and partner responsibility was discussed by the youth in relation to communicating the risks and HIV disclosure to their partner(s). Youth in this study framed condom use following disclosure to their partner as being ultimately left up to the discretion of their partner. For example, Robert talked about weighing the possibility of not using condoms based on his viral load and communicating the risks of transmission with his partner. These findings are consistent with Koenig and colleagues (2010) and Fernet and colleagues (2011) who found that about half of their participants had taken risks and engaged in unprotected sexual intercourse in later relationships. Taryn and Bajaa both discussed condom use as their partner's responsibility or choice once they disclose their HIV status. These findings are consistent with Leonard and colleagues (2010) who found that some of the youth in their study felt that having unprotected sex was okay if they disclosed their HIV status to their partner. These findings are also similar to Fielden and colleagues (2006) who

found some of the youth in their study felt that condom use responsibility was shifted to their partner if they disclosed their HIV status.

Youth in this study talked about feeling limited regarding who they could date and engage in a relationship with since they found out they are living with HIV and felt that they could only date other people living with HIV. These youth felt that dating only other people living with HIV would be easier than facing rejection. For example, Koby talked about how dating other guys who were also living with HIV would involve less rejection and he did not want to put himself through the emotional heartache. These findings speak to the need for more awareness about HIV to reduce the stigma associated with living with HIV.

### 7.3.2.2 HIV disclosure management

HIV disclosure management was a key finding that emerged in this study. Disclosure management was very challenging and encompassed many complicated and significant issues and for youth, the experiences they discussed were related to disclosing for the first time, while for others, disclosure was a continual process. Results were categorized in three areas: barriers to HIV disclosure, the criminalization of HIV non-disclosure and managing relationships after HIV disclosure.

#### 7.3.2.2.1 Barriers to HIV disclosure

HIV disclosure was often spoken about as a barrier for the participants, who linked their concerns about disclosing with feelings of fear and stigma. The youth also discussed the lack of skills, guidelines and support for disclosure as a barrier to disclosing their HIV status.

Youth in this study feared being physically harmed or rejected or had experienced the threat

of physical harm when they disclosed their HIV status. For example, Pierce was threatened by his partner after he disclosed his HIV status and carefully considers his emotional and physical safety prior to disclosure. Gabriel was afraid his family would reject him if he disclosed his HIV status, so he chose not to. This is consistent with Michaud and colleagues (2009) and Fernet and colleagues (2007) who found that the youth in their study feared disclosing their status would lead to rejection or discrimination. In addition, Taryn specifically talked about her fear that someone would physically harm her or her daughter if they found out she was HIV-positive. The solution for Taryn to avoid this was to disclose herself as having another illness, not HIV (e.g., cancer). This finding speaks to the fact that stigma still exist today and after thirty years into the epidemic some people living with HIV would rather disclose an illness that does not carry the stigma of HIV.

Facing stigma was another important barrier to HIV disclosure for the youth in this study because they feared how other people in society, especially in their own communities where stigma still exists, would perceive them. The youth talked a great deal about how people living with HIV are still stigmatized, which prevented them from disclosing their HIV status unless they were able to trust the person and knew how they would react. David talked about how stigma is still so present today, particularly in the gay community, and he feared disclosing his HIV status because he is gay and will be stigmatized within his own community. These findings are consistent with Michaud and colleagues (2009) and Leonard and colleagues (2010) who found that the youth in their study did not want to disclose their HIV status because of how negatively society views people living with HIV.

A very interesting and unique finding from the youth in this study related to wanting the necessary skills, supports and guidelines to be able to safely and effectively disclose their HIV status to other people, which included workshops to develop skills, disclosure-only

support services and access to legal guidelines. Youth in this study talked about how a lack of disclosure skills, guidelines and support were barriers to disclosing their HIV status. While some youth talked about wanting to learn skills to be able to disclose their HIV status online, others talked about wanting to attend workshops to learn how to disclose in face-to-face situations. One youth, Link, felt that having a disclosure-only support service within a non-judgmental health based service would provide an avenue for gay men to access these confidential services. Another youth, Robert, wanted legal guidelines that explained the criminal law on HIV non-disclosure and provided support for people living with HIV to understand where they stand. These findings speak to the critical need for HIV disclosure guidelines to assist youth with the ability to learn the process of disclosure, including skills needed to understand when and how to disclose, so they can feel safe and comfortable when they choose to do so. According to Thoth and colleagues (2013), youth want help with HIV status disclosure skills and regardless of the outcome of disclosing, if they do not have the skills disclosure is less likely to happen. Youth living with HIV need to develop skills they can use to increase their capacity to disclose when, where, how and to whom they choose to. Providing communication skills for HIV disclosure can also increase a youth's ability to manage the process of disclosure (Thoth et al., 2013).

#### 7.3.2.2.2 The criminalization of HIV non-disclosure

The criminalization of HIV non-disclosure was revealed by the youth as a primary and paradoxical reason for *not* disclosing their HIV status to other people. The Supreme Court Decision in 2012 created confusion about the law and increased the fear of physical harm and rejection among people living with HIV. Youth in this study talked about their uncertainties regarding the criminal law and when, how and to whom they are required to disclose their



HIV status. Particularly worrisome among the youth was disclosing one's HIV status to a partner or potential partner because they feared negative and/or legal repercussions from previous partners who might use the law against them. For example, Link is afraid to disclose his HIV status to partners that he may have previously put at risk because he fears the legal repercussions as a result of how criminalization has been sensationalized. In addition, youth in this study worried that if they did disclose their HIV status it would be difficult to prove, even if no sexual activity occurred. For example, some youth, like Noah, worried he would face legal implications of HIV non-disclosure even if he had not engaged in sexual activity. There is very little research available on Canadian youth who are living with HIV regarding the criminalization of HIV non-disclosure, however, Fernet and colleagues (2011) noted that the HIV-positive youth in their study worried about criminalization because of the number of people living with HIV who have already faced criminal charges in Canada.

#### 7.3.2.2.3 Managing relationships after HIV disclosure

The youth in this study revealed a great deal about their experiences with managing HIV disclosure and shared stories that involved rejection, support and the unfortunate circumstance of having their HIV status almost disclosed or disclosed by other people. Some youth talked about how rejection was difficult because they lost relationships. For example, Kyle talked a great deal about how he lost all his friends when they found out he was living with HIV, which resulted in future trust issues for him. Xavier talked about how his already fragile relationship with his mother was fractured after he disclosed his HIV status to her. These findings are similar to Michaud et al. (2009) who found that the youth in their study feared disclosure because they were previously rejected. Youth who were supported after

disclosing their HIV status talked about how these supportive reactions made future disclosures less challenging, and for some strengthened their relationships with family members and/or friends. Maggie talked about how she was not judged by her friends when she disclosed her HIV status to them and felt fortunate to have people who cared for and respected her. For Charlotte, disclosing her HIV status to her mother brought them closer together. This is consistent with D'Angelo and colleagues (2001) who found that youth often experience positive reactions and support from parents and close friends.

Disclosure to family and friends, while difficult, was not as concerning to the youth as disclosing to partners or potential partners. This is consistent with Wiener and Battles (2006) who found that disclosure of HIV status was the greatest worry of their adolescent participants. Disclosure to partners or potential partners was particularly concerning for the youth in this study because they were afraid of being rejected or physically harmed. For Robert and Donovan, their fears became reality when they both experienced rejection after disclosing their HIV status to their partner. This is consistent with Fernet and colleagues (2011) who found that some of the youth in their study experienced violence after disclosing their HIV status to their partner. Disclosure of their HIV status to a partner or potential partner was much more challenging than any other relationships for the youth in this study because disclosing within intimate relationships carry numerous risks, including fear of violence, rejection and legal repercussions.

Some youth did talk about how they experienced very positive reactions from their partner when they disclosed their HIV status and maintained their relationship. For Bajaa, Mason and Charlotte disclosure to their partners resulted in very encouraging, supportive reactions. The findings on managing relationships after HIV disclosure speak to a number of considerations for the youth in this study that focus on the type of relationship they have with

the person they are disclosing their HIV status to. When disclosing to a friend or family member, the youth in this study talked about needing to consider their relationships very carefully and whether they trust the person prior to disclosing their HIV status. This is consistent with Hogwood and colleagues (2012) who found that their adolescent participants talked about the importance of considering the relationship and the trust within the relationship with the person before disclosing.

Managing relationships was difficult for the youth in this study when they were faced with having their HIV status almost disclosed by a health care provider or disclosed by other people without their consent. One youth in particular from this study, Gabriel, encountered a stressful situation when he was admitted to the hospital and his HIV status was almost disclosed by health care providers to his friend without his consent. This is also consistent with Hosek and colleagues (2008) who found that the youth in their study were faced with disclosure events in a healthcare facility where the hospital staff revealed their HIV status without their consent. This is particularly troublesome for health care providers because many consider them as a source of confidential support. When health care providers breach confidentiality we run the risk of people living with HIV accessing their services and support less and less, which can ultimately affect their health and well-being. Further, youth in this study talked about how they experienced having their HIV status revealed by other people without their consent. For example, Bajaa talked about how her partner's sister found out that she was living with HIV and told other family members without Bajaa's consent. This finding is consistent with Hosek and colleagues (2008) who found that several of their youth participants had experienced a peer revealing the youth's HIV status to other people without their consent. This is also worrisome for the youth living with HIV and indeed for anyone living with HIV because having their HIV status revealed by others may have the reverse

effect on them where they withhold telling anyone and risk not only access to various types of support systems, but also the further transmission of HIV and the potential for criminal entanglement.

### 7.3.2.3 Finding new meaning in life

Despite the many challenges and negative impacts of finding out their HIV status, living with HIV resulted in a number of unexpected and positive findings related to transformative, positive changes and optimistic goals among youth in this study. More specifically, the youth in this study spoke at great lengths about re-evaluating their lives after finding out their HIV status and finding new meaning through fulfilling goals, helping other people learn, providing peer support in ASOs, and striving for the future to find what everyone else wants; someone to love and a family. Life transformations for the youth in this study resulted in new beginnings that consisted of no longer engaging in self-harming behaviors, learning how to live healthier, and being determined to push past the challenges associated with HIV. For Bajaa, Charlotte and Xavier, becoming HIV-positive gave them the opportunity to re-evaluate their lives, which resulted in positive choices to eat healthier, and for some, taking antiretroviral medications, and for others, avoiding behaviors that might put them at risk. These findings are consistent with Flicker and colleagues (2005) who found that some participants described their HIV diagnosis as an “empowering opportunity” (p. 309), “a new lease on life” (p. 309), and a chance to re-evaluate their lives to make positive changes. Martinez, Lemos, Hosek, and Adolescent Medicine Trials Network (2012) also found that their participants gained a new sense of purpose and a better appreciation for life after the initial period of adjustment following their diagnosis. These findings are also similar to Mosack and colleagues (2005) in their study with adults living with HIV who were

struggling with addictions and viewed becoming HIV-positive as a wake-up call and a second chance at restoring their health and avoiding self-harming behaviors that created even greater threats to their health. Their study also found that the participants had become healthier and grew stronger as a result of living with HIV.

Youth in this study also talked about finding new meaning in life after their diagnosis through fulfilling previous goals they had made, which included going back to school. In this study, Kyle talked about fulfilling his dream of finally going back to school after being forced to quit eight years ago because of the stigma and discrimination he faced after he was diagnosed with HIV. These findings are consistent with Ezzy (2000) who found that adults living with HIV saw their HIV status as an opportunity to return to school, have a career and help support others. These findings are consistent with the Canadian study by Flicker and colleagues (2005) who found that some of their participants saw their diagnosis as a chance to focus on attaining their goals.

Some youth talked about how living with HIV provided them with the opportunity to help others learn about HIV or become involved in peer support with an ASO. Charlotte and Bajaa talked at great lengths about helping other people learn about HIV by sharing their stories and experiences with HIV. Link and Reid talked about becoming involved in the HIV sector through employment with an ASO as support workers. In their Canadian study with people living with HIV who had received peer counseling and peer counselors who had provided counseling to other people living with HIV, Harris and Larsen (2007) found that peer counseling helped newly diagnosed individuals find hope, increase their well-being and desire to survive. Their participants also talked about how peer counseling offered ways to combat the stigma and isolation associated with living with HIV because their peer counselor was able to empathize with them and were credible sources of information who could share

their own experiences. This is also similar to Flicker et al. (2005) whose youth participants described peer support from other people living with HIV as very valuable.

#### 7.4 Limitations of this study

There are several limitations of this study, including recruitment and generalizability. The participants were recruited through ASOs, and while this is an efficient method of recruitment it limits recruitment to the voices youth living with HIV who access their services and support. Since the participants in this study were recruited through these organizations they may have greater knowledge and awareness about HIV than youth living with HIV who do not access the services or support. This method does not allow for recruitment of youth who do not use services and support provided by ASOs and who may be in the earlier less well-adjusted stages of living with HIV that were described by nearly all of the participants in this study.

A further limitation of this study was related to the diversity of the participants recruited. My hope was to be able to recruit equal numbers of youth who acquired HIV through perinatal transmission and youth who acquired HIV during youth or young adulthood, however, I was only able to recruit participants through ASOs, which limited my ability to do so. Attempting to recruit youth who are living with HIV through a healthcare institution also proved challenging due to additional requirements from the healthcare institutional Research Ethics Board. Moreover, additional barriers related to health care providers protecting their patients and not recommending the study to them meant recruitment was limited to ASOs. The ASO partners in this study ultimately referred the perinatally infected youth who were recruited for this study because they accessed services in their organization. As a result, comparisons made between perinatally infected youth and

youth who were infected in adolescence or young adulthood were done with caution due to smaller sample sizes. An additional limitation related to the diversity of recruitment was that I was only able to recruit two females and one trans-gender female for this study. I had hoped to recruit an equal number of males and females for this study, however, because I was limited to recruiting through ASOs, access to a diverse population was limited to the individuals who accessed resources and support at these organizations. An inability to recruit more women for this study could also have resulted from less women accessing services at ASOs because of confidentiality of privacy and a fear of disclosure.

Given that this was a qualitative, phenomenological study, the findings are not meant to be generalizable beyond the group studied and they provide an in-depth illustration of the lived experiences of a group of youth living with HIV from Ontario and British Columbia. The experiences of the youth in this study are unique to the communities they are living in with access to their own healthcare systems and resources. The purpose of a phenomenological study is to generate ideas about the meaning of a set of experiences, not generalizability. Subsequent research with this population could tell us if there are common ideas among youth living with HIV in other areas.

## 7.5 Recommendations

This study provided us with extraordinary insight into the lives of the participants and what it is like to live and manage HIV, from their own perspectives. Despite the medication now available to treat HIV, it still remains a very complicated and challenging illness to manage and should not be thought of simply as any other “chronic illness”, since most chronic illnesses are not infectious or carry the stigma burden that HIV and AIDS do. HIV stigma is still very prevalent in our society and contributes heavily to complications of living with

HIV, including managing HIV disclosure and navigating safer sex practices. The data from this study contribute new knowledge and provide us with a detailed understanding of the lives of youth living with HIV, beginning from when they found out their HIV status through to the many challenges associated with living with HIV, to contemplating their future.

A number of recommendations can be made from the results of this research for healthcare providers, ASOs, researchers, policy makers and youth living with HIV. The first recommendation refers to the development of supportive policies for healthcare providers regarding diagnosing a youth with HIV. This is an essential piece for development since a youth in this study not only experienced negative, inappropriate reactions from their healthcare provider, they were also not provided with immediate support or referrals for their next steps in understanding their diagnosis. Supporting policies and training for health care providers on sensitivity and confidentiality can provide a youth with a welcoming, open and safe environment when they are being diagnosed with HIV.

Finding out one is living with HIV can be traumatic, regardless of age. Youth, specifically, require additional support during initial diagnosis and afterwards since a supportive environment is conducive to setting an optimistic perspective from the outset of the journey of living with HIV. Supportive counseling should also be available in the form of peer counseling from someone who is also living with HIV and has an empathetic understanding of what it means to live with HIV and manage challenges. Providing this type of support could enhance the diagnosis experience of youth by providing a very safe, welcoming environment where they can understand the process and learn to manage some of the challenges.

The third recommendation relates to education policies regarding knowledge and awareness of HIV and other Sexually Transmitted Infections (STIs) that should be



implemented in primary and secondary schools. The youth in this study and many other studies spoke of the misconceptions and a lack of knowledge regarding HIV in society. In addition, stigma education is also critical to eliminating barriers that still exist in regards to HIV and AIDS. Stigma remains prominent, with HIV and AIDS being one of the most highly stigmatized illnesses in the world. Providing more education on HIV and other sexually transmitted infections throughout the primary and secondary school years could help increase the awareness and lessen or eliminate persistent stigma.

The fourth recommendation relates to HIV prevention education for youth living with HIV to prevent the further transmission of HIV or transmission of other STIs to other people living with HIV, given that the HIV infection rate is highest in the 15-29 year old age group. According to Fisher, Kohut, and Fisher (2009), there is very little research on supportive interventions for people living with HIV. Fisher et al. (2009) provide justification for “Prevention for Positives”, which are supportive prevention efforts that are specifically tailored to people living with HIV. A key example of prevention for people living with HIV is the Options Project (Fisher, Fisher, Cornman, Amico, Bryan, & Friedland, 2006), which is an intervention that was developed to be delivered by HIV healthcare providers to individuals living with HIV through the use of the theoretical model, the Information-Motivation-Behavioral Skills Model theoretical model for promoting and understanding risk behavior change and motivational interviewing techniques, during routine care. HIV healthcare providers were trained to assess their patients’ risky and safe sexual and injection drug use behaviors, then evaluated their willingness to change and then obtained strategies from their patients on how they could change their behavior. The final step was to provide a written “prevention prescription” plan of action that was agreed to by the provider and the patient. The results of this intervention showed that “HIV+ patients who received the

intervention reported significant reductions in total unprotected insertive and receptive vaginal and anal intercourse and insertive oral sex over a follow-up interval of up to 18 months” (Fisher et al., 2009, p. 64)

The fifth and final recommendation refers to the development of HIV disclosure guidelines (discussed in the next section on implications for future research) that ASOs, Community-Based Organizations and healthcare providers could use to assist youth living with HIV in their quests to understand the disclosure process and learn the skills on how to safely and comfortably disclose their HIV status when ready. Disclosure remains challenging for anyone living with HIV, but especially for youth, a very vulnerable population. Disclosure is not a one-time event, it is a process that needs to continually be re-assessed as new relationships are formed and emerge. The criminalization of HIV non-disclosure, is an especially salient issue for youth living with HIV since the new Supreme Court ruling in October 2012 resulted in precedent (not laws per se) that amplified potential criminal repercussions compared to the previous practice and precedent. Given new criminal judgments concerning HIV non-disclosure, it is imperative that youth living with HIV understand how, when, and to whom they are required to disclose in order to avoid criminal prosecution. Providing youth living with HIV with anonymous, accessible and affordable social media channels through which to acquire this information would be a first step.

## 7.6 Implications for future research

Given the relative paucity of in-depth qualitative research, this study has illustrated the challenges that youth living with HIV face in learning to manage becoming HIV-positive and navigating through the new realities related to sex and relationships post-diagnosis. The

exploratory, qualitative nature of this study on the lived experience of youth living with HIV suggests a number of prospective areas of future research. The findings from this study point to a need for quantitative research with a larger sample size of youth living with HIV at the time of diagnosis and across the life course to obtain a greater understanding of how youth and/or young adults navigate their HIV diagnosis and the implications of their HIV status throughout the following years. A quantitative study would provide us with the opportunity to explore themes that emerged from this study on a larger scale.

Second, research should compare and contrast the experiences between youth infected during adolescence or young adulthood and youth infected at birth related to engaging in sexual activity, safer sex practices and HIV disclosure. Comparing these two groups of youth remains a limited area of research and has implications for understanding the impact that living with HIV since birth versus being diagnosed during adolescence or young adulthood has on issues related to safer sex practices, HIV disclosure and managing the realities of living with HIV. This would allow us to elucidate and understand any differences between these youth and the mode of infection in order to provide support tailored to the specific needs of each group. While this study did not allow for extensive comparison of the youth who acquired HIV during adolescence or young adulthood and the youth who acquired HIV through perinatal transmission, there were some differences noticed in their experiences that could be expanded upon in future studies.

Third, given the limited research on HIV disclosure with youth in Canada, it is critical to understand the process of disclosure for youth living with HIV and what makes youth choose to disclose or not disclose. Understanding this process would enable us to provide valuable insight into efforts that could help to facilitate voluntary, safe disclosure among youth living with HIV. A related recommendation is the importance of understanding how

disclosure might change for youth living with HIV in subsequent relationships, since this study found that some youth felt that they could only date or would only date other people living with HIV in the future.

In addition, participants in this study also pointed to the need for HIV disclosure skills, guidelines and supportive services, which is also consistent with and noted in previous literature on youth living with HIV (e.g., Fernet et al., 2007; Thoth et al., 2013).

These guidelines can be viewed as a comprehensive source of educational materials, supportive information, and socio-legal resources related to disclosure of HIV status, which would be intended to help inform and support youth living with HIV as they move through the disclosure process. Developing these guidelines could assist youth living with HIV in their understanding of how to safely and comfortably disclose their HIV status to other people.

Furthermore, given the ever-changing landscape regarding the criminalization of HIV non-disclosure, the youth in this study were very fearful, confused and challenged with understanding who, how, and when they were required to disclose their HIV status. In light of this, we need to understand the implications of these changes and whether/how HIV disclosure has changed for youth living with HIV since the precedent with respect to judgments showed how existing laws might be applied. In addition, since the criminalization of HIV non-disclosure is a society-wide issue in Canada, it is critical to focus our efforts in this area for all people living with HIV, not just youth.

Fourth, since the focus of this research was to understand the lived experience of what it means for youth to live with HIV, I used a phenomenological paradigm as the guiding ideological and methodological framework. However, the findings from this study align with many of the guiding principles and ideas inherent in the following theoretical models: the

Theory of Reasoned Action, the Theory of Planned Behavior, the Health Belief Model and the Information-Motivation-Behavioral Skills Model.

Value-expectancy theories assume that people will engage in protective behavior if they expect the benefits to outweigh the barriers or costs of engaging in the behavior. The Theories of Reasoned Action and Planned Behavior focus on one's attitude and intention towards behavior (and in the case of the Theory of Planned Behavior perceived behavioral control as well). These two theories are relevant to themes that emerged from this study, which focused on the constructs of attitude towards behavior, social influences on the behavior and perceived behavioral control over the behavior. In this study, attitude towards behavior can be linked to the youth talking about themes related to abstaining from sexual activity after diagnosis and condom use responsibility. The youth discussed both positive and negative attitudes towards abstaining from sexual activity and condom use responsibility since they became HIV-positive. Social norms can be linked to the themes related to abstaining from sexual activity after diagnosis and condom use responsibility because youth talked about how their partner influenced whether they engaged in sexual activity after diagnosis or used condoms. Social norms can also play a role in the theme coming to terms with HIV because youth talked about how social influences from other people living with HIV helped them to come to terms with being HIV-positive. Perceived behavioral control can be linked to the theme HIV disclosure since youth talked about having their HIV status disclosed for them without their consent by other people, which was beyond their control.

The Health Belief Model was originally developed to identify why people did not engage in preventive screening behaviors and is focused on one's perceptions of threat and expected net gain, which is similar to weighing the benefits and barriers of behavior and their

belief (self efficacy) in their ability to engage in protective behavior. The constructs of perceived threat, expected net gain and self efficacy can be linked to the themes from this study. Perceived threat and expected net gain can be linked to HIV disclosure because the youth talked about how they would weigh their decisions to disclose their HIV status based on their relationship with the person, whether they could trust them or whether they thought they would be rejected. Self efficacy can be associated with HIV disclosure and condom use responsibility since the youth talked about their ability to tell other people their HIV status and negotiate safer sex practices with a partner. Many of these constructs and related themes, of course, overlap with the constructs and themes discussed in relation to the TRA and TPB.

The Information-Motivation-Behavioral Skills Model was originally developed to understand risk behaviors in the early part of the HIV/AIDS epidemic (Fisher & Fisher, 1992). The core constructs thought to influence risk and preventive behavior appear in the title of the model and all can be applicable to themes that emerged in this study. The information construct can be linked to a number of themes, including coming to terms with HIV, abstaining from sexual activity, barriers to HIV disclosure, and accurate or inaccurate understanding of criminalization issues. Youth talked about needing more information after they found out their HIV status to understanding what it meant to be HIV-positive and come to terms with it. Youth also talked about how they abstained from sexual activity after diagnosis because they did not have enough information and understanding regarding HIV and transmission and were afraid of infecting someone. Furthermore, youth talked about how they did not have the information they needed to understand how to disclose their HIV status to other people.

The motivation construct is applicable to the themes of coming to terms with HIV, condom use responsibility, and finding new meaning in life after HIV diagnosis. Youth talked about their motivation to come to terms with their status through peer support from other people living with HIV as well as their own will to accept their status. Youth in this study also referred to their motivation to use condoms in relation to their responsibility not to transmit HIV to anyone else. Finding new meaning in life after HIV diagnosis can also be linked to motivation since the youth talked about being motivated to start over and create positive changes in their lives. The behavioral skills construct relates to the themes of coming to terms with HIV and HIV disclosure. Coming to terms with HIV required the youth to learn new skills to not only understand HIV, but to learn how to be healthier. HIV disclosure is linked with behavioral skills because the youth discussed at great lengths how their *lack* of skills to disclose their HIV status was a barrier to telling other people. One of the major implications of the current research involves the need to develop skills training and guidance concerning disclosure.

As previously mentioned, these theories were intentionally not directly applied to the current data collection and analysis, nor were they the focus of this research, since our core aim was to apprehend the lived experience of youth living with HIV from their unique perspective without the top down intrusion or imposition of theoretical structure. At the same time, however, themes that emerged from this study can be linked to health behavior theories and understood from the perspective of these theories. The finding that these themes are connected to constructs from various health behavior theories points to a need for research that specifically applies theoretical models to understanding how youth living with HIV make decisions regarding their health and navigate through the many challenges associated with HIV, such as their decisions to disclose or not to disclose and their decisions to practice

safer sex. Research in this area would provide us with a deeper understanding of complex behaviors and situations related to living with HIV/AIDS, which can therefore enhance our abilities to develop programs and interventions that are guided by the theoretical constructs to help us make environmental, social and policy changes that will enhance health behavior and the health of everyone (DiClemente, Salazar & Crosby, 2013). The current participant informed approach provides lived experience direction for the application of theory to the challenges that participants have identified.

Fifth, in order to create societal-level changes related to stigma, education and awareness of HIV/AIDS, it is critical that we turn our attention to research that is focused on people who do not live with HIV. These findings tell us that stigma and misconceptions regarding HIV/AIDS are still very prevalent in our society and are the reasons that many people living with HIV fear building relationships, engaging in sexual activity, accessing support and services, or disclosing their HIV status. We need to strive to break down the stigma barrier and create an environment where everyone is treated the same, whether they are living with an illness or not. De-stigmatizing HIV/AIDS and increasing education and awareness could ultimately prevent new HIV infections and reduce health care costs, increase the willingness of people living with HIV to access social support from family, friends and partners and resources and support from health care providers, increase the quality of life of people living with HIV and protect the health of HIV-positive and HIV-negative people.

Finally, the powerful experiences and stories that the youth in this study shared provide us with a glimpse into what it is like for them to live every day with HIV, some of the challenges they have faced, but also some of the strategies they have used to overcome



these, pushing past many obstacles. The youth in this study represent an incredible group of people who have turned an HIV diagnosis once considered a “death sentence” into a new beginning, developing a new sense of purpose in their lives. These findings highlight a need for more research that moves beyond simply listing complexities and negative aspects of living with HIV and focuses more on understanding the positive, optimistic ways that youth living with HIV are living their lives, with an illness that does not always follow a linear path. A deeper understanding of these positive experiences can help us in developing specific supportive services and resources that could assist not only ASOs in providing support to youth living with HIV, but also other youth living with HIV who could benefit from understanding HIV from the perspectives of other youth who have had similar experiences.

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|  |  |   |
|--|--|---|
|  |  | <ul style="list-style-type: none"> <li>• <i>Open about disclosure</i></li> <li>• <i>Parental acceptance of HIV status</i></li> <li>• <i>People's reactions</i></li> <li>• <i>Relationships</i></li> <li>• <i>Relationships changed</i></li> <li>• <i>Support</i></li> </ul> |
|--|--|---|

| <b>Global Themes</b>  | <b>Organizing Themes</b>  | <b>Basic Theme</b>   |
|---|---|--|
| <i><b>Finding New Meaning in Life After HIV Diagnosis</b></i> | <p><b>Transforming their life</b></p> <p><b>Creating positive changes</b></p> <p><b>Hope for the future</b></p> | <ul style="list-style-type: none"> <li>• <i>A new beginning</i></li> <li>• <i>Blessing</i></li> <li>• <i>Choosing to live</i></li> <li>• <i>Disclosure rejection made me stronger</i></li> <li>• <i>Found meaning after diagnosis</i></li> <li>• <i>Greater appreciation for life</i></li> <li>• <i>Plan life out more now</i></li> <li>• <i>Value of HIV in their life</i></li> <li>• <i>Became involved with HIV work</i></li> <li>• <i>Change the face of HIV</i></li> <li>• <i>Educating other people</i></li> <li>• <i>Getting an education</i></li> <li>• <i>Helping others</i></li> <li>• <i>Peer education</i></li> <li>• <i>Sharing my story</i></li> <li>• <i>Cure</i></li> <li>• <i>Family</i></li> <li>• <i>Reduce infections</i></li> <li>• <i>Someone to love</i></li> </ul> |

| <b>Organizing Themes after first analysis:</b>  | <b>Final Organizing Themes:</b>  |
|---|--|
| Mode of HIV infection<br>Fear<br>Effects of diagnosis<br>Dating and sexual activity after diagnosis HIV<br>Education<br>Employment<br>Whose responsibility is it to use condoms<br>Trust<br>Stigma<br>Criminalization<br>Reasons for non-disclosure<br>Method of HIV disclosure<br>Relationship outcomes after disclosure<br>Negotiating sexual relationships<br>The future<br>Finding meaning in life<br>Acceptance of HIV<br>Positive and negative outcomes of disclosure | Finding out their HIV status<br>Initial reactions to HIV diagnosis<br>Coming to terms with HIV<br>New realities related to sex and relationships<br>Barriers to HIV disclosure<br>Method of HIV disclosure<br>Managing disclosure in the context of socio-sexual and familial relationships<br>Transforming their life<br>Creating positive changes<br>Hope for the future |
| <b>Global Themes after first analysis:</b>  | <b>Final Global Themes:</b>  |
| Becoming HIV-positive<br>Finding out their HIV status<br>Navigating HIV<br>Practicing safer sex<br>HIV disclosure management<br>Transforming their life<br>Finding meaning in life after HIV diagnosis  | Becoming HIV-positive<br>Navigating HIV<br>HIV disclosure management<br>Finding new meaning in life after HIV diagnosis  |

| <b>Unique Codes</b>                            |
|--|
| Camp   |
| Co-infected                                    |
| Coming to terms with death younger             |
| Demystifying HIV                               |
| Disclosure to children                         |
| Grew up in foster homes                        |
| Growing up on the street                       |
| Growing up with HIV                            |
| History of abuse                               |
| HIV testing without consent                    |
| Lack of information or referral                |
| Loss of services when turned 21                |
| Naïve  |
| No family support growing up                   |
| Other people think they are experts            |
| Parental death from AIDS                       |
| Parental HIV                                   |
| Parental sexuality                             |
| Policy changes                                 |
| Sibling death from AIDS                        |
| Sibling death from fire                        |
| Stigma from HIV-negative person at conferences |
| Survivor                                       |
| The only youth with HIV                        |
| They haven't been in my shoes                  |
| Travelling complications                       |

**Appendix B**  
**Recruitment Invitation**  
*Knowing When to Tell: Concerns of HIV+ Youth*

Tamara Landry, a PhD Candidate in the Health and Rehabilitation Sciences Program at The University of Western Ontario, is conducting research, under the supervision of Dr. Fisher and Dr. Orchard, to explore youths' sexual health concerns and questions, and concerns and feelings about revealing their health status to others. We also wish to explore youths' feelings about the health services that are available to them and their opinions about health services and support that are needed but not available, in connection with sexual health concerns.

- Who is needed for this Research?** Youth who are HIV positive  
14-29 years of age.
- What will happen during the Research?** You will participate in a confidential individual interview to discuss your concerns and needs about sexual health. It will be private and no one but the researchers will have access to what you have to say.  
You will fill out a brief confidential health and support questionnaire.  
All of your answers will be confidential and anonymous (your name will not appear on any of your responses and no one but the researchers will have access to your answers).
- How long will this take?** Approximately 1-2 hours
- Where will this take place?** At a mutually agreeable location in your area or via telephone.
- Why am I doing this Research?** To understand the needs of HIV positive youth, about their sexual health concerns and about revealing their health status to others.  
  
To determine available and needed support for HIV positive youth about sexual health concerns.

***YOUR DECISION TO PARTICIPATE OR NOT PARTICIPATE WILL HAVE NO EFFECT ON YOUR HEALTH CARE.***

**If you are interested in this research or would like more information:**

Please call Tamara Landry collect at (XXX) XXX-XXXX or email at XXXXXXXXXXXXX

**The University of Western Ontario**  
Health and Rehabilitation Sciences  
Elborn College • London, Ontario • CANADA - N6G 1H1  
PH: 519-850-2453 • F: 519-850-2469 • www.uwo.ca/fhs

**Appendix C**  
**Letter of Information and Consent**  
**Study Title: *Knowing When to Tell: Concerns of HIV+ Youth***

**Co-Investigator:**

Tamara Landry, MA, PhD Candidate  
Health and Rehabilitation Sciences  
University of Western Ontario  
Phone: (XXX) XXX-XXXX  
Email: XXXXXXXXXXXXX

**Principal Investigator:**

Dr. William Fisher, PhD  
Distinguished University Professor  
Department of Psychology and Obstetrics and Gynaecology  
Social Science Centre, The University of Western Ontario  
London, Ontario. N6A 5C2  
Phone: XXX-XXX-XXXX, ext. XXXXX  
Email: XXXXXXXXXXXXX

Dr. Treena Orchard, PhD  
Assistant Professor,  
Faculty of Health Sciences  
The University of Western Ontario  
Phone: XXX-XXX-XXXX ext. XXXXX  
Email: XXXXXXXXXXXXX

You are being invited to take part in a study being conducted by Tamara Landry from the University of Western Ontario, under the supervision of Dr. Fisher. You are eligible to participate in this study if you are HIV+. Tamara is studying youths' sexual health concerns, and the concerns of youth about revealing their health status to others. We are also studying youths' needs for support and services in these areas, among 84-140, 14-29 year old youth with HIV infection (48-80 participants). This research will take place at a mutually agreeable location in your area or via telephone (e.g., the Hospital for Sick Children in Toronto, Positive Youth Outreach at the AIDS Committee of Toronto, Regional HIV/AIDS Connection in London, Positive Women's Network, YouthCo).

Participant Initials \_\_\_\_\_

1 of 3





The purpose of this research is to:

- 1) Obtain the opinions of youth who are HIV+, concerning sexual health and revealing their health status (where appropriate) to others (for example, to a future boyfriend or girlfriend);
- 2) Determine youths' opinions concerning available and needed support services concerning sexual health issues.

**What will I have to do if I choose to take part?** Participate in an individual interview where you will be asked questions about your sexual health concerns and revealing your health status to others, and concerning your needs for services and support in these areas, you will also be asked to fill out a short questionnaire concerning your background and desires for support and services for your health needs. The interview and questionnaire completion should take approximately 1-2 hours to complete.

**Are there any risks or discomforts?**

There are no known risks to participating in this research, although we will be asking questions in potentially sensitive areas relating to your concerns about sexual health and revealing your health status (if applicable). If you experience any discomfort during the interview, we can stop the interview, move to another topic, and you can be referred to a social worker, primary care physician or other clinical care team individual.

**What are the benefits of taking part?**

While there are no direct benefits to you taking part in this research, the proposed research is intended to enhance our ability to create education, support, and prevention programs designed specifically for youth with a chronic health condition and youth without a chronic health condition concerning their sexual health.

**Compensation**

You will be reimbursed for any travelling and parking expenses. You will also be provided with a gift card (e.g., Cineplex, Starbucks, itunes).

**What happens to the information that I tell you?**

The individual interviews will be recorded on an audio recording. What you say on the tape will be typed out. *The only people who will listen to the tapes will be the researcher (Tamara), the person who types out the interviews, and research study investigators.* Workshops will be designed for the purpose of presenting the findings to all research participants. To protect your identity, only

Participant Initials\_\_\_\_\_

2 of 3



numbers will be used to identify transcripts of the tapes. The consent form, tapes, transcripts and questionnaires will be locked in a secure place at the University of Western Ontario in London, Ontario and kept for future research projects by the researchers. These future research projects may include efforts to develop sexual health support and HIV prevention education programs for HIV positive youth. Your name and contact information will be kept confidential and separate from the interview transcripts, tapes and consent forms. You are being asked to provide your full name, address and phone number so that you can be contacted for a possible follow-up study that may be developed in the future. Only Tamara will have access to your contact information. Representatives of the University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research. If the results of the study are published, your name will *not* be used and no information that reveals your identity will be released or published. All of your answers will be confidential (your name will not appear on any of your responses once we have recorded them). These confidential responses will not be seen by anyone other than the study researchers.

**Other Information about this Study:**

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time with no effect on your future care by informing the researcher. If you do drop out of the study, any information that you have provided may still be used in the research findings. You do not have to answer any questions on the form or in the interviews and you do not have to talk about anything in the interviews if you do not want to. You do not waive any legal rights by signing the consent form.

Being in this study or dropping out will not affect your care in a hospital or in the community. **YOUR DECISION TO PARTICIPATE OR NOT PARTICIPATE WILL HAVE NO EFFECT ON YOUR HEALTH CARE.**

This letter is for you to keep.

If you have any questions or require additional information, please telephone collect Tamara Landry at (XXX) XXX-XXXX or her doctoral supervisors, Dr. William Fisher at (XXX) XXX-XXXX ext. XXXXX or Dr. Trenea Orchard at (XXX) XXX-XXXX ext. XXXXX.

If you have any questions about the conduct of this study or your rights as a research participant you may contact the Manager of the Office of Research Ethics, University of Western Ontario at (XXX) XXX-XXXX, or by email at: [ethics@uwo.ca](mailto:ethics@uwo.ca).

Participant Initials \_\_\_\_\_

3 of 3



**Consent Form to Participate in the Research Study**  
***Knowing When to Tell: Concerns of HIV+ Youth***

**Investigator:** Tamara Landry, MA, PhD Candidate

I have read the letter of information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

\_\_\_\_\_  
Printed Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Printed Name of Person Obtaining Consent

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Person Obtaining Consent

Do you agree to provide your name, address and phone number for us to keep for the purpose of contacting you about a follow-up study?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

Do you agree that the researchers can keep your data for future research? Your identity will be kept confidential.

\_\_\_\_\_ Yes

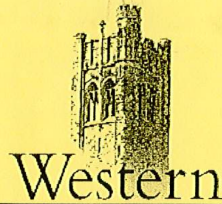
\_\_\_\_\_ No

If you agree that your data can be used in future research, would you like to be contacted prior to the study being conducted?

\_\_\_\_\_ Yes

\_\_\_\_\_ No

# Appendix D Ethics Approval



## Office of Research Ethics

The University of Western Ontario  
Room 4180 Support Services Building, London, ON, Canada N6A 5C1  
Telephone: (519) 661-3036 Fax: (519) 850-2466 Email: ethics@uwo.ca  
Website: www.uwo.ca/research/ethics

### Use of Human Subjects - Ethics Approval Notice

**Principal Investigator:** Dr. W.A. Fisher

**Review Number:** 16302

**Review Level:** Full Board

**Review Date:** July 7, 2009

**Protocol Title:** Sexual Health Concerns of Adolescents With and Without Chronic Health Conditions: A Mixed Methods Approach

**Department and Institution:** Psychology, University of Western Ontario

**Sponsor:**

**Ethics Approval Date:** September 15, 2009

**Expiry Date:** August 31, 2011

**Documents Reviewed and Approved:** UWO Protocol, 3 Letters of information & consent forms (HIV Positive Participant's, Diabetes & No Health Issues), 3 Assents (HIV Positive Participant's, Diabetes & No Health Issues), 3 Recruitment Invitations (HIV Positive Participant's, Diabetes & No Health Issues)

#### Documents Received for Information:

This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research Involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/ICH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this REB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the UWO Updated Approval Request Form.

During the course of the research, no deviations from, or changes to, the protocol or consent form may be initiated without prior written approval from the HSREB except when necessary to eliminate immediate hazards to the subject or when the change(s) involve only logistical or administrative aspects of the study (e.g. change of monitor, telephone number). Expedited review of minor change(s) in ongoing studies will be considered. Subjects must receive a copy of the signed information/consent documentation.

Investigators must promptly also report to the HSREB:

- a) changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) all adverse and unexpected experiences or events that are both serious and unexpected;
- c) new information that may adversely affect the safety of the subjects or the conduct of the study.

If these changes/adverse events require a change to the information/consent documentation, and/or recruitment advertisement, the newly revised information/consent documentation, and/or advertisement, must be submitted to this office for approval.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

  
\_\_\_\_\_

Chair of HSREB: Dr. Joseph Gilbert

#### Ethics Officer to Contact for Further Information

Janice Sutherland

Elizabeth Wambolt

Grace Kelly

Denise Grafton

*This is an official document. Please retain the original in your files.*

cc: ORE File



**Use of Human Participants - Ethics Approval Notice**

**Principal Investigator:** Prof. William Fisher  
**File Number:** 6364  
**Review Level:** Full Board  
**Approved Local Participants:** 40  
**Protocol Title:** Sexual Health Matters: Concerns of HIV+ Youth (REB# 16302)  
**Department & Institution:** Social Science Psychology, Western University  
**Sponsor:**  
**Ethics Approval Date:** May 16, 2012  
**Ethics Expiry Date:** August 31, 2014

**Documents Reviewed & Approved & Documents Received for Information:**

| Document Name                           | Comments   | Version Date |
|---|--|--------------|
| Revised Western University Protocol     | Revised objectives and study population, Revised study methodology, Revised inclusion criteria, revised recruitment process, revised study instruments and revised confidentiality procedures. |              |
| Revised Letter of Information & Consent | HIV Positive Youth   | 2012/04/23   |
| Advertisement                           | Recruitment Invitation- HIV Positive Youth   | 2012/04/23   |
| Revised Study End Date                  | Extended to August 31 2014.  |              |
| Addition of Co-investigator             | Dr. T. Orchard has been added to the study team. J.Polgar, S. Read and A. Bitnum have been Removed from the study team.  |              |
| Other                                   | Interview Guide (Appendix E)   |              |
| Other                                   | Questionnaires (Appendix G)  |              |

This is to notify you that the University of Western Ontario Health Sciences Research Ethics Board (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans and the Health Canada/CH Good Clinical Practice Practices: Consolidated Guidelines; and the applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced study on the approval date noted above. The membership of this HSREB also complies with the membership requirements for REB's as defined in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB's periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request form.

Member of the HSREB that are named as investigators in research studies, or declare a conflict of interest, do not participate in discussions related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

\_\_\_\_\_

Signature

**Ethics Officer to Contact for Further Information**

|                   |             |                 |
|-------------------|-------------|-----------------|
| Janice Sutherland | Grace Kelly | Shantel Walcott |
|-------------------|-------------|-----------------|

*This is an official document. Please retain the original in your files.*

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**Appendix E**  
**Individual Interview Guide for In Person Interviews**

**Study Title: Knowing When To Tell: Concerns of HIV+ Youth**

Introduction: Before we begin talking about the questions, I would like to ask you if you have read the letter of information and consent form? If so, do you understand the letter of information and consent form? Do you have any questions regarding this letter of information and consent form? Do you have any questions regarding the study?

Do you agree to provide written consent, voluntarily, to participate in this study?

Do you also agree to complete the questionnaires I have provided for you?

The questions I will ask are to help me understand the concerns and needs of HIV positive youth about their sexual health and revealing their health status.

If you experience any discomfort during the interview, we can stop the interview, move to another topic, and you can be referred to your support worker, primary care physician or a counselor.

You do not have to answer any questions that you do not feel comfortable answering. **YOUR DECISION TO PARTICIPATE OR NOT PARTICIPATE WILL HAVE NO EFFECT ON YOUR HEALTH CARE.**

Directions:

Ask the following questions of each participant where applicable:

Ice Breaker Questions:

1. Tell me a bit about yourself.
2. What made you decide to participate in this study?

Social Support Questions Adapted from the Social Support Questionnaire Short Form Revised (SSQSR; Sarason et al., 1987):

1. Who can you really count on to listen to you when you need to talk?
2. Can you rely on that person when you need to talk or need help?
3. Are there other people who you can depend on?
4. Who do you feel really appreciates you as a person?
5. Where do you turn to when you need help or support with something in your life (e.g., parents, friends, family doctor, community-based organization, youth groups, internet support)?
6. Who are you unable to turn to when you need to talk?
7. Have you been in a situation where you were unable to talk to someone?

### Revealing Health Status Questions:

1. How old were you when you found out you are HIV+?
2. How did you find out you were HIV+?
3. How has your life changed since you found out you were HIV+?
4. When did your parents or caregiver tell you that you are HIV+ (For HIV+ infected at birth)?
5. How did you and your parent(s)/caregiver first talk about it?
6. Have you told anyone about your HIV status? If so, who?
7. What happened when you told that person you have HIV?
8. Do you feel comfortable telling other people you have HIV?
9. What are some important issues to consider when you are deciding to tell someone you have HIV?
10. Due to your HIV status, do you avoid or abstain from sex or sexual activity?
11. If you do not abstain from sex or sexual activity, do you find it difficult to disclose your HIV status?
12. How do you disclose your HIV status to others?
13. Do you feel comfortable disclosing your HIV status to partners or potential partners?
14. Is it difficult for you to practice safer sex?
15. What else prevents you from telling others you have HIV?
16. Are there some people you don't feel you could reveal your health status to? Why?
17. Who do you feel you could reveal your HIV status to? Why?
18. Have you accessed the services of community based organizations, youth organizations, or health care professionals for support?
19. Have you accessed the services of community based organizations, youth organizations or health care professionals on how to discuss disclosure of your HIV status?
20. What do you think would help you reveal your health status to others? (e.g., resources, guidelines, access to a counselor, etc.)
21. If you had this kind of help, would you be more likely to disclose your HIV status to others?
22. Do you think this kind of help would be the same for revealing your HIV status to everyone or only certain people? If so, why? Why would others be different?
23. Is it easier to disclose your HIV status if you have already told someone?
24. Does it get easier to disclose to people the more experience you have?
25. Does having a support network or support system make it easier for you to disclose to others?

### Sexual Health Questions:

1. Do you find it difficult to talk about sexual health?
2. Who, if anyone, have you talked to about sexual health?
3. Do you feel you can talk to certain people about sexual health?
4. Who are you unable to talk to about sexual health issues?
5. Do you talk to your parents about sexual health? If not, why?
6. What topics on sexual health are relevant in your life (e.g., safer sex, STI's, sexuality)?
7. What are some of the topics that are difficult for you to talk about?
8. What issues are easy for you to talk about?
9. What are your thoughts about safer sex?
10. Are other youth your age sexually active?

11. How are other youth your age talking about sex or are talking about being sexually active?
12. Do you think they practice safe sex? (e.g., using condoms, birth-control pill, etc.) 13. What does it mean to you to practice safer sex?
14. What do you think about teenagers and sexual activity?
15. Are you thinking about becoming sexually active?
16. How does it make you feel when you think about sexual health issues and sexual activity?
17. What might prevent you from thinking about sexual health and sexual activity?



## **Appendix F**

### **Individual Interview Guide for Telephone Interviews**

#### **Study Title: Knowing When To Tell: Concerns of HIV+ Youth**

Introduction: Before we begin talking about the questions, I would like to ask you if you have read the letter of information and consent form? If so, do you understand the letter of information and consent form? Do you have any questions regarding this letter of information and consent form? Do you have any questions regarding the study?

Do you give your verbal consent, voluntarily, to participate in this study? Do you also agree to provide written consent on the letter of information and consent provided to you and return this consent form to me in the mail in the expresspost envelope provided?

Do you also agree to complete the questionnaires I have provided for you and return these to me in the addressed expresspost envelope you have been given?

The questions I will ask are to help me understand the concerns and needs of HIV positive youth about their sexual health and revealing their health status.

If you experience any discomfort during the interview, we can stop the interview, move to another topic, and you can be referred to your support worker, primary care physician or a counselor.

You do not have to answer any questions that you do not feel comfortable answering. **YOUR DECISION TO PARTICIPATE OR NOT PARTICIPATE WILL HAVE NO EFFECT ON YOUR HEALTH CARE**

Directions: Ask the following questions of each participant where applicable:

Ice Breaker Questions:

1. Tell me a bit about yourself.
2. What made you decide to participate in this study?

Social Support Questions Adapted from the Social Support Questionnaire Short Form Revised (SSQSR; Sarason et al., 1987):

1. Who can you really count on to listen to you when you need to talk? 2. Can you rely on that person when you need to talk or need help?
3. Are there other people who you can depend on?
4. Who do you feel really appreciates you as a person?
5. Where do you turn to when you need help or support with something in your life (e.g., parents, friends, family doctor, community-based organization, youth groups, internet support)?
6. Who are you unable to turn to when you need to talk?
7. Have you been in a situation where you were unable to talk to someone?

### Revealing Health Status Questions:

1. How old were you when you found out you are HIV+?
2. How did you find out you were HIV+?
3. How has your life changed since you found out you were HIV+?
4. When did your parents or caregiver tell you that you are HIV+ (For HIV+ infected at birth)?
5. How did you and your parent(s)/caregiver first talk about it?
6. Have you told anyone about your HIV status? If so, who?
7. What happened when you told that person you have HIV?
8. Do you feel comfortable telling other people you have HIV?
9. What are some important issues to consider when you are deciding to tell someone you have HIV?
10. Due to your HIV status, do you avoid or abstain from sex or sexual activity?
11. If you do not abstain from sex or sexual activity, do you find it difficult to disclose your HIV status?
12. How do you disclose your HIV status to others?
13. Do you feel comfortable disclosing your HIV status to partners or potential partners?
14. Is it difficult for you to practice safer sex?
15. What else prevents you from telling others you have HIV?
16. Are there some people you don't feel you could reveal your health status to? Why?
17. Who do you feel you could reveal your HIV status to? Why?
18. Have you accessed the services of community based organizations, youth organizations, or health care professionals for support?
19. Have you accessed the services of community based organizations, youth organizations or health care professionals on how to discuss disclosure of your HIV status?
20. What do you think would help you reveal your health status to others? (e.g., resources, guidelines, access to a counselor, etc.)
21. If you had this kind of help, would you be more likely to disclose your HIV status to others?
22. Do you think this kind of help would be the same for revealing your HIV status to everyone or only certain people? If so, why? Why would others be different?
23. Is it easier to disclose your HIV status if you have already told someone?
24. Does it get easier to disclose to people the more experience you have?
25. Does having a support network or support system make it easier for you to disclose to others?

### Sexual Health Questions:

1. Do you find it difficult to talk about sexual health?
2. Who, if anyone, have you talked to about sexual health?
3. Do you feel you can talk to certain people about sexual health?
4. Who are you unable to talk to about sexual health issues?
5. Do you talk to your parents about sexual health? If not, why?
6. What topics on sexual health are relevant in your life (e.g., safer sex, STI's, sexuality)?
7. What are some of the topics that are difficult for you to talk about?
8. What issues are easy for you to talk about?
9. What are your thoughts about safer sex?
10. Are other youth your age sexually active?

11. How are other youth your age talking about sex or are talking about being sexually active?
12. Do you think they practice safe sex? (e.g., using condoms, birth-control pill, etc.) 13. What does it mean to you to practice safer sex?
14. What do you think about teenagers and sexual activity?
15. Are you thinking about becoming sexually active?
16. How does it make you feel when you think about sexual health issues and sexual activity?
17. What might prevent you from thinking about sexual health and sexual activity?



Appendix G  
Questionnaires

Background Information

1. How old are you?

- |                                    |                                    |                                    |
|------------------------------------|------------------------------------|------------------------------------|
| <input type="radio"/> 14 years old | <input type="radio"/> 15 years old | <input type="radio"/> 16 years old |
| <input type="radio"/> 17 years old | <input type="radio"/> 18 years old | <input type="radio"/> 19 years old |
| <input type="radio"/> 20 years old | <input type="radio"/> 21 years old | <input type="radio"/> 22 years old |
| <input type="radio"/> 23 years old | <input type="radio"/> 24 years old | <input type="radio"/> 25 years old |
| <input type="radio"/> 26 years old | <input type="radio"/> 27 years old | <input type="radio"/> 28 years old |
| <input type="radio"/> 29 years old |                                    |                                    |

2. Are you...?

- |   |                            |                                  |
|---|----------------------------|----------------------------------|
| <input type="radio"/> Female                                      | <input type="radio"/> Male | <input type="radio"/> Trans male |
| <input type="radio"/> Trans female                                |                            |                                  |
| <input type="radio"/> Other: Please specify if comfortable: _____ |                            |                                  |

3. What are the first three digits of your postal code?

\_\_\_\_\_

4. What languages are most often spoken in your home? (Please check all that apply)

- |  |   |                                  |
|--|---|----------------------------------|
| <input type="radio"/> English          | <input type="radio"/> Mandarin                | <input type="radio"/> Cantonese  |
| <input type="radio"/> French           | <input type="radio"/> Tamil                   | <input type="radio"/> Portuguese |
| <input type="radio"/> Spanish          | <input type="radio"/> Italian                 |                                  |
| <input type="radio"/> Greek/Macedonian | <input type="radio"/> Others (please specify) | _____                            |

5. How long have you been living in Canada?

- |  |   |
|--|---|
| <input type="radio"/> All or most of my life | <input type="radio"/> 10 years or more      |
| <input type="radio"/> Between 4 and 9 years  | <input type="radio"/> Between 1 and 3 years |
| <input type="radio"/> Less than 1 year       |   |

6. Are you...? (Please check all that apply)

- |   |  |                               |
|---|--|-------------------------------|
| <input type="radio"/> Aboriginal: Please specify: _____ |  |                               |
| <input type="radio"/> Catholic                          | <input type="radio"/> Agnostic                               | <input type="radio"/> Sikh    |
| <input type="radio"/> Hindu                             | <input type="radio"/> Anglican                               | <input type="radio"/> Jewish  |
| <input type="radio"/> Atheist                           | <input type="radio"/> Lutheran                               | <input type="radio"/> Baptist |
| <input type="radio"/> Muslim                            | <input type="radio"/> B'hai                                  | <input type="radio"/> United  |
| <input type="radio"/> Protestant Christian              | <input type="radio"/> Buddhist                               |                               |
| <input type="radio"/> No religion                       | <input type="radio"/> Religion/Spirituality not listed here. |                               |
|   | Please specify: _____  |                               |

**7. Which of the following best reflect(s) your racial background? (Please check all that apply)**

- Aboriginal: Please Specify: \_\_\_\_\_
- Black-Canadian
- White-Canadian
- Black-Caribbean (e.g. Jamaica, Barbados)
- Asian-East (e.g. China, Japan, Korea)
- Asian-South (e.g. India, Sri Lanka, Pakistan)
- Asian-South East (e.g. Vietnam, Malaysia, Philippines)
- Latin American (e.g. Argentina, Mexico, Nicaragua)
- Middle Eastern (e.g. Egypt, Iran, Israel, Saudi Arabia)
- White-European (e.g. England, Greece, Sweden, Russia)
- Mixed Background. Please Specify: \_\_\_\_\_
- Other. Please Specify: \_\_\_\_\_

**8. Do you have a chronic health condition (e.g., Diabetes, HIV/AIDS, Hepatitis, other STI's, etc.)**

- Yes (Continue with Question 9)
- No (Move to Question 12)
- Not sure

**9. If you are HIV positive, how do you think you became HIV positive (For HIV Positive)?**

- Blood transfusion
- Needle injection
- Oral sex
- Mother-to-child transmission
- Other. Please Specify: \_\_\_\_\_
- Unprotected sexual intercourse
- Non-consensual sexual intercourse
- Knowingly infected

**10. Can other people tell that you have a health condition or disability?**

- I do not have a health condition or disability
- Never
- Sometimes
- Always

**11. How often do you take prescribed medications?**

- I do not have a health condition or disability
- Rarely/never
- Daily
- When I need them

**12. Who do you live with most of the time? (Mark all that apply)**

- Mother
- Stepmother
- Father
- Stepfather
- Foster parent(s)
- Adoptive parents
- On my own
- Other adults related to you
- Other adults not related to you
- Do not live with any adults

**13. How much do you feel that people in your family understand you?**

- Not at all
- Some
- A lot
- I do not communicate with my family

**14. How much do you feel that you and your family have fun together?**

- Not at all
- Some
- A lot
- I do not communicate with my family

**15. Do you ever feel the need to get away from your family? If yes, why? (Mark all that apply)**

- I do not feel the need to get away
- My family does not understand me
- I fear being judged or embarrassed
- I need to find people I can relate to
- Other. Please Specify: \_\_\_\_\_
- My family is judgmental
- The stress is overwhelming
- I have complicated health needs
- Confidentiality issues

**Sexual Health and Support Services**  
**(Some questions adapted from Toronto Teen Survey)**

**1. Have you ever gone to a clinic for any of these things? (Please check all that apply)**

- Information on safer sex
- Test for other sexually transmitted infections (e.g. Syphilis, Chlamydia, Gonorrhea, Genital herpes)
- Pap test (sometimes called a pap smear)
- Birth control information or prescriptions (e.g. getting on the pill)
- Information or instructions on condoms
- Getting free condoms
- Emergency contraceptive pill (sometimes called 'the morning after pill')
- Pregnancy test (not a home pregnancy test)
- Prenatal care
- Information or counselling for sexuality
- Information or counselling for sexual abuse, sexual assault or sexual violence
- Other (please specify)

---

I have not gone for any of these

**2. Have you ever been to any of these places for sexual health services? (Please check all that apply)**

- Family doctor
- University or College health center
- Walk in clinic
- Mobile health services
- Specialist doctor (e.g., Obstetrician, Gynaecologist, Urologist)
- Hospital/emergency room (please specify where)

---

Other place (please specify if comfortable:\_\_\_\_\_

I have never gone to any of these places for sexual health reasons.

Community based organizations (e.g., youth organizations, public health unit, AIDS Service Organizations). Please specify if comfortable:\_\_\_\_\_

**3. Can you tell us anything else about what makes a GOOD sexual health clinic for youth?**

**4. Can you tell us anything else about what makes a BAD sexual health clinic for youth?**

5. Is it important to have a dedicated sexual health clinic or service for youth to access? If so, why?

6. Which of these might stop you from going to a clinic for your sexual health? (Please check all that apply)

- There is nothing stopping me-I already access services
- Fear of being judged or embarrassed
- Services not friendly towards youth
- I'm worried that services aren't confidential (i.e. kept secret)
- My parents'/caregivers' reactions
- Location is far away
- I don't know what services or information I need
- I don't think I need services or information
- Racism
- I don't know where to go to get services
- My religion, culture or ethnicity
- I think I'm too young
- I have complicated health needs.  
If comfortable please specify: \_\_\_\_\_
- Homophobia (Homophobia refers to prejudice against (fear or dislike of) homosexual people and homosexuality).
- Fear of parental notification
- Fear of being lectured by health care professionals
- Fear of legal repercussions/consequences
- Not pro-choice
- Lack of education in healthcare professionals
- Lack of up-to-date information
- Other (please specify): \_\_\_\_\_

7. What are the three most important things we could do to help YOU get the sexual

health info you need? (Please check THREE only)

- Make sexual health resources more public
- Recognize that sexuality and sex is important
- Provide confidential services
- Parent education on healthy sexuality
- Make sure there are enough resources to reach all youth
- Outreach to youth instead of waiting for youth to receive services
- Make sure that staff are sensitive to my religion
- Recognize that youth are sexually active
- Have youth involved in peer sexual health education
- Make sure staff and services are sensitive to my culture or ethnicity
- Make sure staff and services are sensitive to Gay, Lesbian, Bisexual and Transgender people
- Other suggestions (please specify): \_\_\_\_\_



**8. Please check all of the places you have had sexual health classes or workshops.**

- Elementary school (e.g. Kindergarten to Grade 8)
- High school
- Public School
- Religion-Oriented Schools (e.g., Catholic, Muslim)
- Private School
- University or College
- Community Based Organizations
- Youth group (Please specify) \_\_\_\_\_
- Religious group (i.e. church, temple, mosque)
- Other \_\_\_\_\_
- I have never received sexual health classes or workshops

**9. What kinds of things have you learned about? (check all that apply)**

- Information on HIV/AIDS
  - Information on sexually transmitted infections and diseases
  - Information on communicating/talking about sex
  - Information on pregnancy and birth control options
  - Information on healthy relationships
  - Information on sexuality or sexual orientation
  - Information on sexual abuse/assault or sexual violence
  - Information on how to discuss sex and/or sexual orientation with parents or guardians
  - Information on how to discuss sex and/or sexual orientation with healthcare professionals
  - Information on how to discuss sex and sexual health with potential or current partners
  - Information on sexual pleasure
  - Information on abortion
  - Information on where to seek sexual health services or support
  - Other information (please specify)
- 
- I have not received any sexual health information

**10. What would you like to learn more about? (check all that apply)**

- Information on HIV/AIDS
  - Information on sexually transmitted infections and diseases
  - Information on communicating/talking about sex
  - Information on pregnancy and birth control options
  - Information on healthy relationships
  - Information on sexuality or sexual orientation
  - Information on sexual abuse/assault or sexual violence
  - Information on how to discuss sex and/or sexual orientation with parents or guardians
  - Information on how to discuss sex and/or sexual orientation with healthcare professionals
  - Information on how to discuss sex and sexual health with potential or current partners
  - Information on sexual pleasure
  - Information on abortion
  - Information on where to seek sexual health services or support
  - Other information (please specify)
- 
- I have not received any sexual health information

**11. Where do you go when you have a question about sexual health stuff? (Please check three ONLY)**

- Friends
  - Parents/caregivers
  - Siblings or other relatives
  - Social Worker
  - Anonymous phone lines (e.g. Kids Help Phone, LGBTQ phone line, etc)
  - School
  - Media (books, magazines, TV, movies)
  - Internet  
Please specify web site (e.g. Google or sexualityandu.ca): \_\_\_\_\_
  - Doctor or nurse
  - Religious group (i.e. church, temple, mosque)
  - Youth group  
Please specify:
- 
- Community health service or clinic  
Please specify:
- 
- Other place/person  
Please specify:
- 
- I have never received sexual health information

**12. We understand that “having sex” means different things to different people. In your opinion, have you had sex?**

- Yes
- No
- Not sure

**13. Have you ever had any of these sexual experiences? Please check ALL that apply.**

- |   |  |
|---|--|
| <input type="radio"/> Kissing                                 | <input type="radio"/> Dry humping                            |
| <input type="radio"/> Given or received oral sex              | <input type="radio"/> Vaginal intercourse                    |
| <input type="radio"/> Anal intercourse                        | <input type="radio"/> Given or received anal sex             |
| <input type="radio"/> Masturbation                            | <input type="radio"/> Given or received a hand job/fingering |
| <input type="radio"/> Used sex toys with someone else         |  |
| <input type="radio"/> Other. Please specify: _____            |  |
| <input type="radio"/> I have not had any of these experiences |  |

**14. How old were you when you had sexual intercourse for the first time?**

- I have never had sexual intercourse (If you choose this answer, please go to question 25)
- Less than 12 years old
- 12 years old
- 13 years old
- 14 years old
- 15 years old
- 16 years old
- 17 or more years old

**15. How old was the partner with whom you first had sexual intercourse?**

- I have never had sexual intercourse
- Less than 13 years
- 13 years old
- 14 years old
- 15 years old
- 16 years old
- 17 years old
- 18 years old
- 19 years old
- 20 or more years old
- Other: Please specify if comfortable: \_\_\_\_\_

**16. The last time you had sexual intercourse, did you or your partner use a condom?**

- I have never had sexual intercourse
- Yes
- No

**17. In the last THREE months, how often did you or your partner use a condom or other latex barrier?**

- I have not had vaginal or anal sexual intercourse in the last three months
- Always
- Most of the time
- Some of the time
- Rarely
- Never

**18. In the last SIX months, how many often did you or your partner use a condom or other latex barriers?**

- I have not had vaginal or anal sexual intercourse in the last six months
- Always
- Most of the time
- Some of the time
- Rarely
- Never

**19. The last time you had vaginal or anal sexual intercourse, did you or your partner use a condom to prevent a Sexually Transmitted Infection?**

- I have never had sexual intercourse
- Yes
- No

**20. In the last THREE months, how often did you or your partner use a condom or other latex barrier to prevent a Sexually Transmitted Infection?**

- I have not had vaginal or anal sexual intercourse in the last three months
- Always
- Most of the time
- Some of the time
- Rarely
- Never

**21. In the last SIX months, how often did you or your partner use a condom or other latex barriers to prevent a Sexually Transmitted Infection?**

- I have not had vaginal or anal sexual intercourse in the last six months
- Always
- Most of the time
- Some of the time
- Rarely
- Never

**22. If relevant, the last time you had sexual intercourse, what method(s) did you or your partner use to prevent pregnancy? (Mark all that apply)**

- Not relevant or Not applicable
- I have never had sexual intercourse
- No method was used to prevent pregnancy
- Withdrawal (“pulling out”)
- Male Condoms
- Female Condoms
- Birth control pills
- The patch
- Nuvaring (a type of birth control)
- Contraceptive Film
- Dental Dam
- Diaphragm/contraceptive sponge
- IUD/IUS (Intra-Uterine Device)
- Emergency contraception (“morning after pill”)
- Some other method
- Not sure

**23. If relevant, what method(s) did you or your partner use to prevent pregnancy during the past THREE months? (Mark all that apply)**

- Not relevant or Not applicable
- I have not had sex in the last three months
- I have never had sexual intercourse
- No method was used to prevent pregnancy
- Withdrawal (“pulling out”)
- Male Condoms
- Female Condoms
- Birth control pills
- The patch
- Nuvaring
- Contraceptive Film
- Dental Dam
- Diaphragm/contraceptive sponge
- IUD/IUS (Intra-Uterine Device)
- Emergency contraception (“morning after pill”)
- Some other method
- Not sure

**24. If relevant, what method(s) did you or your partner use to prevent pregnancy during the past SIX months? (Mark all that apply)**

- Not relevant or Not applicable
- I have never had sexual intercourse
- I have not had sex in the last six months
- No method was used to prevent pregnancy
- Withdrawal (“pulling out”)
- Male Condoms
- Female Condoms
- Birth control pills
- The patch
- Nuvaring
- Contraceptive Film
- Dental Dam
- Diaphragm/contraceptive sponge
- IUD/IUS (Intra-Uterine Device)
- Emergency contraception (“morning after pill”)
- Some other method
- Not sure

**25. If you have never had sexual intercourse, what are the reasons for this? (Mark all that apply)**

- I have had sexual intercourse
- I don't want to have sexual intercourse
- I'm not ready
- Someone in my family would disapprove
- Some of my friends would disapprove
- Most students in my school don't have sexual intercourse
- My friends don't have sexual intercourse
- Because of my religious or spiritual beliefs
- I don't want to get a sexually transmitted infection
- I don't want to infect someone with a Sexually Transmitted Infection
- To prevent an unplanned pregnancy
- I'm worried about the legal repercussions
- Fear of rejection
- Stigmatization
- No one has asked me to/I haven't had the chance
- I'm waiting until I meet the right person
- I'm waiting until I get married
- Other. Please Specify: \_\_\_\_\_

**26. Is there anything else that you would like to tell us that we haven't talked about already?**

## Curriculum Vitae

**Name:** Tamara Marjorie May Landry-Thompson

**Education:** The University of Western Ontario  
London, Ontario, Canada  
1994-2002 Hons B.A.

University of Windsor  
Windsor, Ontario, Canada  
2002-2004 M.A.

The University of Western Ontario  
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2007-2014 Ph.D.

**Academic Honours, Fellowships, and Awards:** Ontario HIV Treatment Network  
2010-2012

Social Research Centre for HIV Prevention  
2011-2012

Universities Without Walls Fellowship  
2010-2011

Graduate Student Thesis Award  
2010, 2012

Western Graduate Research Scholarship – Health and Rehabilitation Sciences, 2007-2010

**Related Work Experience** Instructor  
The University of Western Ontario  
2009-2014

Graduate Teaching Assistant  
The University of Western Ontario  
2008-2010

**Research Grants** Title: HIV serodiscordant couples in Canada: A mixed-methods study of risk management, health and wellbeing for people living with HIV and their partners.  
Nominated Principal Investigator: Calzavara Liviana.  
Co-Investigators: Allman Dan, Bisallion Laura, Bourne Adam, Burchell Ann, Conway Brian, Daftary Amrita, Gladstone Brenda, Landry Tamara, Loutfy Mona, Masching Renee, Meili Ryan,

Mendelsohn Joshua, Myers Ted, Routy Jean-Pierre, Stewart Kris, Tharao Wangari, Watchorn Jocelyn.

Collaborators: Baril, Jean-Guy, Clement Ken, Doolittle-Romas Monique, Edmiston Laura, Evans Michelle, Howard Terry, Palmer Hazelle, Ryan Shannon, Sanche Stephen, Skinner Stuart, Summers Marcie, Tsoukas Chris, Wong Alexander.

Funder: CIHR, Amount: \$471,733, Duration: 2 years 6 months. (Start date: 2014-10-01; End date: 2017-03-01)

Title: Southwestern Ontario Has HIV/AIDS Research Too!

Co-Principal Investigators: Landry, T., Coleman, T., Baidobonso, S., Pugh, D.

Funder: RBC Community Partner Project Grant: \$670.

**Peer-Reviewed  
Publications**

Landry, T., Luginaah, I., Maticka-Tyndale, E., & Elkins, D. (2007). Orphans in Nyanza, Kenya: Coping with the struggles of everyday life in the context of the HIV/AIDS pandemic. *Journal of HIV/AIDS Prevention in Children and Youth*, 8(1), 75-98.