University of Alberta

Hope and the Potential High-Risk Period Following an HIV-Diagnosis: A Hermeneutical Interpretation

by

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Abstract

Despite advances in medical and psychological HIV treatment, receiving an HIV diagnosis is still often experienced as devastating and emotionally overwhelming. Although the majority of people who receive an HIV diagnosis reduce and eliminate any existing high-risk behaviours that could put themselves or others at risk, some people who receive a diagnosis of HIV maintain and even increase their high-risk behaviours (Diamond & Buskin, 2000; Hook & Cleveland, 1999; Siegal & Meyer, 1999). Finding ways to cope with the news of HIV and make lifestyle changes, such as reducing high-risk behaviours, are important aspects of care. Researchers (e.g., Chammas, 1999; Heinrich, 2003) have reported that hope is an important internal resource for helping individuals living with HIV to experience increased well-being and to survive with HIV; however, little research exists exploring the experience of hope for people receiving an HIV diagnosis, especially among those engaging in high-risk behaviours.

Within this community-based qualitative research project I interviewed 12 people diagnosed with HIV or AIDS in order to explore their experiences of receiving an HIV diagnosis and subsequently continuing or increasing in their high-risk behaviours (i.e., behaviours that could put them at risk, such as becoming suicidal, or behaviours that could place others at risk, such as unsafe sexual practices). The focus of the study was on participants' high-risk behaviours following diagnosis and on experiences of hope and mental health services during this difficult time. Specific high-risk behaviours (e.g., unsafe sexual practices, sharing IV drug equipment) and unhealthy behaviours (e.g., refusal to maintain healthy eating and sleeping patterns) that participants engaged in following diagnosis and also multiple factors that may have been related to their high-risk choices are discussed. Most participants suggested that having hope helped them to deal with the diagnosis of HIV and to reduce their high-risk behaviours. The discussion focuses on implications related to high-risk behaviours, hope theory and practice, and mental health services. Implications for health professionals and hope researchers are reviewed.

Acknowledgements

It is important to recognize that this study could not have been completed without the help, involvement, and assistance of many other people. The present research underscores the importance of community-based research, and I want to deeply thank all of the community members who participated in this study. The numerous community members of the HIV/AIDS community-based agencies involved have been exceptional in supporting and assisting in the present study.

I would like to offer a special thanks to the 13 participants who volunteered their time and energy to meet with me and share their stories. Receiving an HIV diagnosis is a life transforming event with tremendous overwhelming emotion, despair, and uncertainty; with the potential to threaten one's perceptions of a desired future. Having the courage and desire to revisit these memories and experiences during the interviews in this study is a testament to the strong sense of purpose and empowerment felt by the participants and many other survivors of HIV. The participants' stories embody a true sense of the word "courage" and pave the road for hope. Thank you.

I would like to thank the University of Alberta for supporting this study. Notably, I would like to thank Dr. Denise Larsen for offering me her wisdom, encouragement, and hope during the study. I would also like to thank my supervisory committee, Dr. Lynda Phillips and Dr. Julia Ellis for their guidance and support with this project. I would also like to thank my extended supervisory committee, Dr. Noorfarah Merali, Dr. Lorraine Wilgosh, and Dr. George Buck as well as my external examiner, Dr. Wendy Duggleby for their time, wisdom, and energy during this process.

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I would like to thank my family for their tremendous ongoing belief that I am capable of achieving my dreams. Without the assistance and encouragement from my wife, Amy Stackhouse Harris, I would not have completed this project. You have been tremendous in helping me to conceptualize and follow through with my ideas. I would also like to thank my mother, Faye Harris, my father, Edward Harris, and my brother, Nick Harris, as this accomplishment would never have been realized without your love and support. Thank you.

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Chapter One: Introduction

Introducing the Problem

Statement of the Research

Conceptual Framework

For some people who receive an HIV-positive diagnosis, the period immediately preceding and/or following the test can be a very destructive time when the newly diagnosed person may place him/herself or others at risk. Several authors (e.g., Beckett, Burnam, Collins, Kanouse, & Beckman, 2003; Diamond & Buskin, 2000; Erickson, 1993; Hook & Cleveland, 1999; Sarwer & Crawford, 1994; Siegal & Ilan, 1999; Sherr, 1996) have reported that newly diagnosed individuals may experience, or engage in: (a) suicidal ideation and suicidal behaviours, (b) unsafe sexual practices, and/or (c) alcohol or drug abuse. The focus of the present research was on learning about the experiences of people living with HIV who have engaged in high-risk behaviours immediately preceding or following a diagnosis of HIV in relation to hope and mental health services.

Throughout the dissertation document I have used various terms to describe the high-risk period immediately preceding or following an HIV diagnosis. For example, the terms "high-risk behaviours" or "high-risk activities" reflect actual behaviours (e.g., unsafe sexual practices, unsafe IV drug use) that can occur preceding or following the diagnosis. These types of behaviours can also occur independently of the period preceding or following the diagnosis. However, within the present discussion they are referring to the time surrounding the diagnosis, unless otherwise indicated. The term "high-risk period" reflects the actual time period preceding or following the diagnosis. It is important to note that there are no clearly defined boundaries that determine when this high-risk period begins and ends. Thus, within the present study, the high-risk period will be defined as the period of time from when the individual suspects that he or she has HIV to two years following notification. This time period has been chosen for two specific reasons. The first is due to reports by some community-based HIV organizations that individuals recently diagnosed may disappear for three to six months and not receive counselling or medical treatment (S. Patten[1], personal communication, October 2002). This suggests that the high-risk period needs to encompass the initial six months following diagnosis. However, many interview participants reported that their high-risk periods lasted for up to two years. Thus, it seems that two years may be a more appropriate estimate of the high-risk period, at least for participants within the present study.

Presently, there appears to have been an increase in the number of individuals engaging in high-risk behaviours as well as increases in high-risk behaviours of newly diagnosed HIV-positive individuals (S. Patten, personal communication, October 2002). Heckman, Kelly, and Somlai (1998) reported that there need to be interventions to reduce the high-risk behaviours of people already infected with HIV. Pinkerton and Abramson (1996) reported that there are potentially a large number of HIV infections transmitted by recently infected individuals, especially due to the increased levels of viral shedding and infectivity early in the primary infection stage. Heckman et al. noted that some of these individuals are unaware of their HIV-positive status; however, others are aware and are still engaging in high-risk behaviours. It has been noted that these potential high-risk

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[1] Ms. Patten was the HIV/AIDS Community-Based Research Technical Assistant for the Alberta Community Counsel on HIV/AIDS during the time of this study. She helped to facilitate research at the community level and had assisted the author in his conceptualization of the present research project.

behaviour periods typically extend for the months immediately following the HIV diagnosis or suspected diagnosis. It has also been noted that some individuals who have suspected their HIV-positive status or been notified of their status, have disappeared from medical care and avoided HIV counselling and medications. It is suspected that during this absence these clients are at an increased risk for engaging in high-risk behaviours (S. Patten, personal communication, October 2002).

Numerous authors (e.g., Carson, Soeken, Shanty, & Terry, 1990; Hall, 1990; Vogler, 2000; Wong-Wylie, 2003) have identified hope as being an important component of working with people living with HIV/AIDS; however, there are very few studies that have explored the high-risk period immediately preceding and following an HIV-diagnosis, and even fewer that have explored the participant's experiences with hope and counselling. Thus, within the present study, participants' experiences with hope as well as mental health services were of specific interest.

Statement of the Problem

In Canada, it is estimated that there have been approximately 58,000 (48,000 to 68,000) total cases of HIV which represents an increase of roughly 16 percent from 2002 HIV prevalence estimates (Health Canada, 2006). Patrick, Wong, and Jordan (2000) reported that although there has been a recent decline in new HIV infections among adults, this trend appears to be leveling off. Research suggests that HIV infections are no longer decreasing, and in some areas and populations infection rates may actually be increasing (Bureau of HIV/AIDS, STD and TB, 2000; Health Canada). The problem, then, is that along with potential increases in HIV infections and apparent increases in high-risk behaviours preceding and/or following an HIV diagnosis (S. Patten, personal communication, October 2002), there is a lack of research exploring the experiences of individuals who have gone through the high-risk period following an HIV diagnosis in relation to their experiences of hope and mental health services. Additionally, much of the efficacy treatment research that has been conducted on reducing high-risk behaviours has focused on people who have sought out treatment (Weinhardt & Carey, 1999), which would likely not include many of the individuals engaging in high-risk behaviours during the period following a diagnosis of HIV. Taken together, this is problematic as hope and mental health services have been shown to be highly important in effectively dealing with HIV and AIDS (Chammas, 1999; Grinstead & Van Der Straten, 2000; Heinrich, 2003; Milton, 1994).

Purpose of the Study

This study was designed to investigate and understand the potential high-risk period preceding and/or following a diagnosis of HIV in relation to participants' experiences of hope and mental health services during this time period. Rich retrospective accounts from people living with HIV/AIDS who experienced the diagnosis of HIV and who participated in high-risk behaviours during the period of time surrounding the diagnosis were sought in order to increase our understanding of this experience. The ultimate goal was to increase understanding of this time period and improve the ability to intervene with people who are experiencing the high-risk period.

Development of the Research Question

The development of the research question for the present study was a long and informative process. It began during my Master's research with gay men living with HIV/AIDS. Some of these participants talked about the potential high-risk period following an HIV diagnosis, and the importance of studying moderating variables, which could reduce the likelihood and severity of high-risk behaviours during this time period. This topic also surfaced upon talking with community workers at AIDS Calgary Awareness Association and with members of the Alberta Community Council on HIV/AIDS. The issue resonated with me, as I was also interested in the period of time following the HIV diagnosis due to my own experiences working with people who had gone through this period. In Edmonton, I was able to talk with members from HIV Edmonton[2], who took interest in the study and confirmed the importance of the study. The present study was a community-based research project and involved community members in its design and implementation. This was an important aspect of the overall research and in the development of the research question. Community members have personal experiences and connections with the phenomena under study. In this study, community members were able to offer unique insights such as an informed position on high-risk behaviours, from personal experiences in some cases. These insights helped to guide the development of the research question, as well as the overall research project. My work at the University of Alberta Hospital in the HIV and Infectious Diseases Program, and my research and course work in regard to hope, further paved the way for the development of the guiding research question of the present study.

The overarching research question for the present study is "What are the experiences of hope and counselling services for those who have gone through the high-risk period immediately preceding and/or following an HIV diagnosis?". In addressing this research question, I needed to explore the relevant background research for the study.

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[2] HIV Edmonton is an HIV/AIDS community-based organization in Edmonton, Alberta and was a partner in the present research project.

Chapter Two: Literature Review

Understanding the Problem

Human Immunodeficiency Virus (HIV)

HIV in Canada

Canada has seen its share of HIV and AIDS cases with more than 58,000 total cases of HIV (Health Canada, 2006). Although there have been recent declines in new HIV infections among adults, this trend appears to be leveling off (Patrick et al., 2000). Research suggests that HIV infections are no longer decreasing and in some areas and populations HIV rates may actually be on the rise (Bureau of HIV/AIDS, STD and TB, 2000; Health Canada).

Presently, there is no cure or vaccine for HIV or AIDS (Canadian AIDS Treatment Information Exchange, 2003; Weinhardt & Carey, 1999). Furthermore, the long-term efficacy of new drug treatments (e.g., Highly Active Antiretroviral Therapy) is still uncertain, especially with large side effects, strict drug regimes, and virus resistance to medications being noted in some cases (Canadian AIDS Treatment Information Exchange, 2002; Canadian AIDS Treatment Information Exchange, 2003; Shelton, 1997). Importantly, the best way to prevent infection is to avoid high-risk behaviours that would place the uninfected individual in contact with the blood, semen, or vaginal fluid of an infected individual (Holmberg & Curran, 1990). Thus, the high-risk behaviour period needs to be explored in hopes of benefiting (a) those recently diagnosed (e.g., helping them to reduce personally destructive behaviours), (b) those who are presently infected (e.g., helping to reduce the chances of others being exposed through reducing high-risk behaviours), and (c) those who unwittingly may become exposed to HIV by others engaged in high-risk activities.

HIV and the Potential High-Risk Period

As previously mentioned, when some people receive an HIV-positive diagnosis, the initial period prior to, and following, the test can be a destructive time when the newly diagnosed individual may place him/herself or others at risk. Numerous authors (e.g., Diamond & Buskin, 2000; Erickson, 1993; Hook & Cleveland, 1999; Sarwer & Crawford, 1994; Schaffner, 1990; Siegal & Ilan, 1999; Sherr, 1996) have reported that newly diagnosed individuals may experience, or engage in high-risk behaviours such as: (a) suicidal ideation, (b) unsafe sexual practices, and/or (c) alcohol or drug abuse. Research (e.g., Bayer & Fairchild-Carrino, 1993; Beltran, Ostrow, & Joseph, 1993; Centers for Disease Control and Prevention, 1996; Heckman et al., 1998; Ehrhardt et al., 1995; Kalichman, Kelly, & Rompa, 1997; Lemp et al., 1994; Ostrow, McKiran, Klein, & DiFranceisco, 1999; Rhodes, Donoghoe, Hunter, & Stimson, 1993; Robins et al., 1994; Singh et al., 1993) suggests that some individuals (e.g., 20-30 percent) still engage in high-risk behaviours (e.g., unsafe sexual practices, unsafe injection drug practices) even following notification of HIV- positive status and counselling interventions. Some individuals even showed increases in high-risk behaviours following notification of being HIV-positive (Beltran et al.; Ostrow et al.). This suggests that some individuals who are aware of their HIV-positive status and who have received counselling may still engage in high-risk behaviours. Indeed, these numbers may be even higher for those individuals, during the high-risk period, preceding or following diagnoses, who have disappeared and who are receiving no counselling or peer-based support. It is important to note that high-risk behaviours can occur prior to the HIV diagnosis and long after diagnosis; however, the focus of the present study is on high-risk behaviours occurring immediately surrounding the diagnosis of HIV.

There have been numerous explanations provided for the choice to continue with high-risk behaviours. These include: (a) depression, anxiety, and distress (Kelly et al., 1995; Kennedy et al., 1993), (b) lack of coping mechanisms to deal with stress (Robins et al., 1994), (c) substance abuse (Kennedy et al.; Robins et al.), (d) lack of skills to disclose HIV status to partner(s) (Schnell et al., 1992), (e) having sex for economic purposes (Centers for Disease Control and Prevention, 1996), (f) lower levels of HIV symptomatology and greater levels of well-being (Heckman, et al., 1998), and (g) sense of fatalism or loss of control over the illness (Joseph et al., 1990; Ostrow et al., 1993). Heckman et al. suggested that the reduction of high-risk behaviours among HIV-positive individuals needs to include the development of interventions that focus on: (a) encouraging the protection of others, (b) highlighting personal responsibility, and (c) educating these individuals about other pathogens that they may contract through high-risk behaviours.

Sarwer and Crawford (1994) reported a five-stage model of living with HIV/AIDS that is consistent with Kubler-Ross's (1987) model of coping with a terminal illness. Although Kubler-Ross's model has been challenged in terms of the progression toward death, the present model is still considered useful for conceptualization of the potential high-risk period (Silver & Wortman, 1980; Taylor, Kemeny, Bower, Gruenewald, & Reed, 2000). High-risk behaviours that occur during the initial psychosocial stage of learning to live with an HIV infection can, in part, be considered to be the effects of denial (Sarwer & Crawford). Within the denial stage, Earl, Martindale, and Cohn (1991) reported three types of denial responses that were typical of people recently diagnosed with HIV. Of these three denial responses, two (i.e., secondary denial and denial without benefit) resulted in the possibility of high-risk behaviours such as unprotected sexual intercourse (Earl et al.). It is important to note that denial has been reported to be an important coping characteristic in reducing anxiety of the initial diagnosis of HIV, and thus is an important consideration in therapeutic treatment (Earl et al.; Sarwer & Crawford). However, the potential for high-risk behaviours need to be explored, as these are not typically healthy denial characteristics.

Murdaugh (1998) reported that individuals recently diagnosed with HIV are in the disintegrating stage of the illness model. During this stage individuals typically experience shock, feel dazed, and feel as if their lives are coming apart (Murdaugh). Following this stage is the renormalizing stage, where individuals begin to seek services and information from health care providers (Heinrich, 2003; Murdaugh). However, the disintegrating stage and the denial stage represent a key time period where there is potential for high-risk behaviours. This time period is critical, as newly diagnosed individuals need medical and psychological interventions to increase their own health as well as to reduce the likelihood of danger to other people. Standard and Hazler (1995) reported that some of the natural psychological responses to HIV (e.g., denial, anger, anxiety) and corresponding psychological obstacles (e.g., difficulty in discussing safer sex or safer needle sharing with partners) can potentially influence the individual's ability to make responsible choices. Standard and Hazler further reported that counselling can help these individuals navigate through these processes in a more healthy manner. The next section of the chapter focuses on research exploring specific types of high-risk behaviours which can occur following an HIV diagnosis.

Suicidal Ideation

Individuals recently diagnosed with HIV may be at a higher risk for suicide. Pugh and O'Donnell (1993) reported that life-threatening physical illnesses are associated with increased risk of suicide. Indeed, several independent researchers (Bellini & Bruschi, 1996; Cadwell, 1994; Catalan, 1995; Martin, 1989; Shelton, Atkinson, Risser, McCurdy, Useche, & Padgett, 2006; Siegal & Meyer, 1999; Sherr, 1995; Wood, Nairn, Kraft, & Siegel, 1997) found that people living with HIV/AIDS are at an increased risk for suicide and suicidal ideation. However, risk factors generally associated with elevated risk of suicide for people living with HIV/AIDS include conditions that constitute a risk of suicide independently of HIV/AIDS (e.g., past suicide attempts, lack of social support, presence of a lifetime or current clinical depressive disorder, central nervous system and/or organic disruption associated with dementia) (Rabkin & Remien, 1993). People living with HIV/AIDS are at an increased risk for some of these risk factors including lack of social support and also recurring subclinical depression. Hence, it is important to examine the individual's circumstances and characteristics, as it is likely the combination of HIV/AIDS and additional risk factors that will determine whether someone may become suicidal (Bellini & Bruschi; Pugh & O'Donnell; Rabkin & Remien). Numerous authors (e.g., Pierce, 1987; Perry, Jacobsberg, & Fishman, 1990; Sherr; Siegal & Meyer) have reported that following suspicion of HIV status and/or notification of HIV status, individuals have increased probability of suicide and/or suicidal ideation. For example, Sherr reported a bimodal distribution of suicidal acts, with increased rates at or around diagnosis and again during the later stages of the illness. Perry et al. reported that 30 percent of people in their study who sought HIV testing reported suicidal ideas; however, following notification of HIV status, this number did not decrease for those who had been infected, while the number decreased by almost 50 percent for those who were not infected. Halttunen, Henriksson, & Lonnqvist (1991) reported that some individuals being tested for HIV had actually committed suicide due to fears of being HIV-positive, and sadly were subsequently found to be negative. Shelton et al. reported that in a sample of HIV-positive men, 59 percent reported thinking about suicide and 50 percent reported attempting suicide at some point during their lives. Taken together, these studies suggest that suspicion and/or notification of HIV-positive status can potentially lead to increased chances of suicide and suicidal ideation.

Hopelessness has been reported to predict subsequent suicide in people living with depression and people who have made previous suicide attempts (Beck, Kovacs, & Whissman, 1975; Beck, Steer, Kovacs, & Garrison, 1985; Hall, Platt, & Hall, 1999; Kelly, et al., 1998). Some research (e.g., Catalan et al., 1992; Hall et al.; Kelly et al.; Rabkin, Williams, Neugebauer, Remien, & Goetz, 1990) suggests that individuals living with HIV infection have increased levels of hopelessness compared to individuals not living with HIV. Furthermore, Holmes and Pace (2002) noted that individuals retrospectively reported increased hopelessness at or around the time of their diagnosis of HIV. This suggests that individuals' experiences of hope and hopelessness may have a bearing on suicidal ideation and behaviours (see section on Hope, Hopelessness, and HIV/AIDS for a more complete discussion).

Alcohol and Drug Abuse

HIV infections have been, and continue to be, a significant concern among substance users. In 1996, roughly 47 percent, or 1,970, of the estimated 4,200 new HIV infections were among IV drug users (Center for Infectious Disease Prevention and Control, 2003a). In 1999, this number decreased slightly; however, it was still high, at 34 percent, or roughly 1,430 of the 4,190 new HIV infections (Center for Infectious Disease Prevention and Control). These numbers continued to decline until the first half of 2002, at which time there were increases in HIV infections among this group (Center for Infectious Disease Prevention and Control). Health Canada has reported that IV drug use is a significant exposure category, and needs to be considered and explored in preventing the spread of HIV.

Researchers (e.g., Caba, 1994; MacGowan et al., 1997) have reported the potential for increases in alcohol and/or drug abuse around the time of an HIV diagnosis. Caba reported that individuals living with HIV may abuse alcohol and/or drugs as a means to cope with the situation, notably as a potential means to cope with the initial diagnosis of HIV. In their study, MacGowan et al. reported changes in injection drug use and sexual behaviours following HIV testing and counselling. Those individuals who were diagnosed with HIV during the follow-up period reported the greatest increase in number of injections, compared to those who had already been living with HIV for longer periods of time.

Unsafe needle sharing is another potential high-risk behaviour shortly following the HIV diagnosis. Clearly, unsafe needle sharing is a significant mode of HIV transmission, especially among IV drug users (Centers for Disease Control and

Prevention, 1998). Within many Canadian cities there have been reports of high-risk drug equipment sharing behaviours. For example, in Saskatoon 53 percent of IV drug users reported sharing equipment and in Vancouver 27.6 percent of IV drug users reported sharing equipment (Center for Infectious Disease Prevention and Control, 2003b). Substance use and abuse have been reported to be highly linked to unsafe sexual practices (Chesney, Bentley, Morrow, & Mayer, 1998; Furlonge et al., 2000; Leigh & Stall, 1994; Seage et al., 1992), which can also occur during the high-risk period.

Unsafe Sexual Practices

Research has also identified increased unsafe sexual practices as a key concern for some individuals recently diagnosed with HIV. The primary mode of transmission of the HIV virus is through sexual contact (Centers for Disease Control and Prevention, 1998; Health Canada, 2004). The potential HIV high-risk period can include risky sexual practices, which can result in transmission of the HIV virus (Beckett et al., 2003; Ostrow et al., 1999). Numerous studies (e.g., Calsyn, 1992; Cleary et al., 1991; Holmes & Pace, 2002; Kalichman, Kelly, & Rompa, 1997; Otten, Zaidi, Wroten, Witte, & Peterman, 1993) have suggested that despite pre- and post-test counselling, some people engage in risky sexual behaviours following an HIV diagnosis. Higgins et al. (1991) reviewed 66 studies that explored high-risk sexual behaviours after HIV notification and discovered that many HIV-positive individuals maintain these high-risk sexual behaviours. However, it is important to note that voluntary pre- and post-test counselling has been demonstrated to reduce the likelihood of risky or unsafe sexual practices in people living with HIV (Beckett et al.; Cleary et al.; Heckman, Kelly, & Somlai, 1998; Muller & Sarangbin, 1995; Sahlu et al., 1999; Wenger, Linn, Epstein, & Shapiro, 1991). Regardless, attention must be paid to the significant number of individuals who maintain high-risk sexual practices following diagnosis. Consideration needs to be given to those individuals who commenced or continued high-risk sexual behaviours even following pre- and post-test counselling, as many of the studies reviewed had participants who continued these behaviours (e.g., Cleary et al.; Holmes & Pace; Otten et al.; Wenger et al.). Furthermore, Weinhardt and Carey (1999) reported that although their meta-analytic review of pre- and post-test counselling demonstrated that increased safer sex practices occurred (i.e., reduced frequency of unprotected intercourse and increased condom use), there were some significant limitations to these research findings. For example, older participants who sought out counselling services on their own significantly contributed to the overall effect size. Thus, the results of this meta-analytic study may not actually represent the behaviours of individuals who did not seek out counselling services (Weinhardt & Carey). This is an important qualifier for the present study, as it has been reported that many of the individuals who are potentially engaging in the high-risk period do not seek out or attend counselling services (S. Patten, personal communication, October 2002). Additionally, in all of the 27 studies that the researchers reviewed, it seems that participants involved in IV drug use programs did not achieve significant behaviour changes in relation to unsafe sexual intercourse and condom use (Weinhardt & Carey). These findings seem to suggest that although pre- and post-test counselling are effective at reducing high-risk sexual behaviours following an HIV diagnosis for some specific groups (e.g., gay men who seek out services), more research needs to be conducted on intervention and prevention strategies for specific groups such as IV drug users during the high-risk period. This seems especially relevant as research suggests (e.g., Chesney et al., 1998; Furlonge et al., 2000; Leigh & Stall, 1994; Seage et al., 1992) that alcohol and drug use are highly related to high-risk sexual behaviours (e.g., multiple sex partners, reductions in condom use), which increases the probability of HIV transmission. Although it has been noted that little is known about the association between substance use and risky sexual practices among HIV-positive individuals (Beckett et al.), it is important to recognize that the potential for increased high-risk behaviours may exist. Weinhardt and Carey also reported, in their meta-analytic study, that studies that included a longer follow-up period demonstrated larger effect sizes for number of sexual partners (i.e., greater reduction in number of sexual partners was observed). This seems potentially obvious, as the number of sexual partners is likely not as sensitive to change over the short term (Weinhardt & Carey); however, it also could be an indicator of the increased likelihood of unsafe sexual practices during the period of time surrounding the initial HIV diagnosis, which would become reduced as time passed. It is important to explore high-risk sexual behaviours during the high-risk period, especially in relation to groups that have additional vulnerabilities such as IV drug use.

Professional Counselling and Peer Support

Within the present study there is a focus on participants' experiences with counselling services. Counselling services refer to professional one-on-one counselling with a trained counsellor and also peer support programs that include a peer counsellor or mentor that works with the newly diagnosed client. Professional one-on-one counselling is defined as "activities between a therapist and a client which focus on the client's issues and dynamics through means of the therapeutic relationship" (Milton, 1994, p. 13). Peer support counsellors work with clients living with HIV, and utilize their own experiences, and training, to help their clients.

Research and Support for Professional Counselling

Many authors (e.g., Feldman, 1989; Grinstead & Van Der Straten, 2000; Milton, 1994; Sarwer & Crawford, 1994; Schaffner, 1994) have reported that professional counselling is beneficial to people living with HIV/AIDS. Pre- and post- HIV test counselling has been noted to be highly beneficial in helping the individual to adjust to HIV and to reduce the occurrence of certain high-risk behaviours (e.g., risky sexual behaviours), especially among certain groups (e.g., gay men) (Cleary et al., 1991; Higgins et al., 1991; Muller & Sarangbin, 1995; Sahlu et al., 1999; Weinhardt & Carey, 1999). However, there is much research (e.g., Bayer & Fairchild-Carrino, 1993; Beltran et al., 1993; Centers for Disease Control and Prevention, 1996; Ehrhardt et al., 1995; Heckman et al., 1998; Kalichman, Kelly, & Rompa, 1997; Lemp et al., 1994; Ostrow et al., 1999; Rhodes, Donoghoe, Hunter, & Stimson, 1993; Robins et al., 1994; Singh et al., 1993) that suggests some individuals still engage in high-risk behaviours even following notification of HIV-status and counselling interventions. This indicates that high-risk behaviours still exist for some individuals who are aware of their HIV-positive status and who have received counselling, potentially suggesting that the numbers of high-risk behaviours may be even higher for those individuals, during the high-risk period, who have disappeared and are receiving no counselling or peer-based support.

Hoffman (1996) noted that professional counselling is likely one of the most powerful ways to address the psychosocial aspects of HIV. Specifically, counselling with people living with HIV has tended to focus on areas such as: (a) preventing suicide, (b) reducing anxiety and depression, (c) promoting social support and community support, (d) exploring existential concerns, (e) reducing high-risk behaviours (e.g., drugs, alcohol), (f) exploring grief and loss, (g) fostering and exploring family/relationships, and (h) helping individuals' cope with thoughts and fears of stigmatization and death (Frierson & Lippmann, 1988; Goldblum & Moulton, 1986; McKusick, 1988; Muller & Sarangbin, 1995; Weinhardt & Carey, 1999). Belyaeva and Routchkina (1993) as well as Chuang, Devins, and Hunsley (1989) reported that support through professional counselling can lead to increased adjustment for people living with HIV, which can potentially improve the disease prognosis. Professional counselling can be highly useful and beneficial for people living with HIV; however, it needs to be offered and conducted in a respectful and nonjudgmental manner (O'Dell, 1997; Schaffner, 1990).

Pre- and Post-HIV Test Professional Counselling

Weinhardt and Carey (1999) reported that HIV counselling and testing are among the largest and most costly HIV prevention strategies available. Numerous research studies (e.g., Muller & Sarangbin, 1995; Sahlu et al., 1999; Weinhardt & Carey; Wenger et al., 1991) suggest that this approach is highly beneficial at reducing certain high-risk behaviours (e.g., risky sexual practices) especially among certain groups (e.g., gay men). However, much still needs to be discovered on how we can improve these prevention and intervention strategies, as there are still concerns with present day options. For example, these types of strategies seem to be effective for many people who seek out testing and counselling and not as effective for those who do not seek out these services (Sahlu et al.; Weinhardt & Carey). Thus, many individuals who are experiencing forms of denial and/or high-risk behaviours preceding and/or following an HIV diagnosis may not be initially willing to seek out these services. Furthermore, among specific groups with additional vulnerabilities (e.g., IV drug issues) there seem to be fewer prevention and intervention strategies and less research available.

Sahlu et al. (1999) reported that initial counselling can be divided into two important components, consisting of the pre- and post-test counselling. Sahlu et al. noted that pre-test counselling includes activities such as: (a) allowing individuals to express their concerns and emotions regarding their previous risks and behaviours, (b) explaining the actual HIV test and its components, (c) assessing the actual need to conduct the HIV test, and (d) exploring the implications of the test results with the individual. Green (1996) and McCreaner (1996) reported that pre-test counselling includes the following activities: (a) exploring individuals' rationales for HIV-testing, (b) assessing individuals' levels of risk, (c) providing information about HIV and the HIV-test, (d) exploring advantages and disadvantages of being tested, (e) helping individuals plan for behaviour changes, (f) preparing for the potential positive result (e.g., actually planning for the visit to the organization to obtain the results, telling other people about the results), (g) explaining the actual physical test procedure, and (h) building the therapeutic relationship for present and future counselling.

Post-test counselling is the counselling directly related to actually giving the client the test results and dealing with the repercussions (Green, 1996). Sahlu et al. (1999) and Weinhardt and Carey (1999) reported that post-test counselling includes activities such as: (a) discussing HIV prevention measures (e.g., reducing high-risk behaviours) and (b) providing psychological support and referrals. Blechner (1997) and Green noted that post-test counselling includes the following activities: (a) giving the results, (b) encouraging individuals to express their needs (e.g., venting), (c) exploring important client background areas (e.g., primary relationship(s), work, leisure, support networks, health, finances, sexual life), (d) identifying immediate issues to be addressed in the present-day session and developing an action plan, (e) identifying any immediate issues that individuals need to address on their own and working out an action plan, (f) exploring and planning for future counselling sessions, (g) ensuring proper referrals are made, (h) ensuring individuals know how to contact the counsellor in the future, (i) answering any factual questions about HIV/AIDS, and (j) building and maintaining the therapeutic relationship.

High-Risk Behaviour Prevention Programs

During pre- and post-test counselling there should also be a focus on prevention of high-risk behaviour. Prevention programs share several common procedures and mechanisms, and can take place with any population of people living with HIV/AIDS or potentially at risk for contracting the virus. Fisher and Fisher's (1992) information-motivation-behavioural skills (IMB) model is one model utilized as a framework for HIV prevention programs (e.g., Fisher & Fisher, 1992; Fisher et al., 2004); however, this model has yet to be specifically utilized for intervention/prevention programs focused on people experiencing the high-risk period following diagnosis. The IMB model is focused at the individual level (i.e., as opposed to a broader social-cultural level), and assumes that the individual needs to have: (a) accurate and sufficient information regarding healthy behaviours, (b) adequate motivation to make change and adopt a healthy lifestyle, and (c) proper behavioural skill sets of appropriate behaviours in order to engage in healthy behaviours.

Social action theory (Ewart, 1991), another model that can potentially be used in HIV prevention programs, suggests that healthy behaviour choices occur through an interaction between three main areas. The first area is internal affective states and their impact on the self-regulation process (Gore-Felton et al., 2005). Thus, better emotional adjustment to HIV/AIDS and more adaptive coping (i.e., improved internal affective states) will result in improved self regulation (Gore-Felton et al.). Social action theory suggests that the individual will need regulated internal affective states prior to being able to consistently engage in healthy behaviour choices (Ewart; Gore-Felton et al.). The second area of the model is the self regulation capabilities of the patient, or how well the patient can regulate his/her self. The focus here is on skill acquisition and educational attainment. Through skill development (e.g., social skills such as sexual negotiation or sexual assertiveness and technical skills such as condom use) and educational attainment (e.g., learning about HIV transmission routes) self regulation processes can become enhanced (Gore-Felton et al.). The third area consists of contextual factors such as a person's relationship status or economic status (Gore-Felton et al.). Contextual factors impact on health behaviours and thus need to be a focus of intervention. Research exploring broader social-cultural factors in HIV prevention/intervention is an area that has been significantly understudied (Crepaz et al., 2006). Most research has focused on the individual, in the absence of broader contextual factors.

Other models and factors that can be considered in reducing high-risk behaviours include: (a) community-based research (e.g., Health Canada, 2002; Harris, 2006), (b) harm reduction (e.g., Carey et al., 2004), and (c) several constructs within positive psychology (e.g., hope, empowerment) (e.g., Farran, Herth, & Popovich, 1995; Purcell et al., 2004). Notably, aspects of hope theory and hope research have important implications for risk reduction. For example, hope theory and research suggests that experiencing hope can help the individual deal with an HIV diagnosis and experience improved quality of life (e.g., Chammas, 1999; Heinrich, 2003). In addition, some have hypothesized that hope can lead to ethical behaviours/healthy lifestyle choices (e.g., Farran et al.; Harrison, 1993; Wong-Wylie, 1997) and that relationship development is a key component of experiencing hope (e.g., Farran et al.).

Research (e.g., Crepaz et al., 2006) suggests that prevention/intervention programs would be benefited through further research involving community members (i.e., a central tenet of community-based research). Additionally, based on my review, few research studies exist utilizing a harm reduction approach combined with principles of positive psychology (e.g., hope). Harm reduction programs attempt to reduce the harms associated with high-risk behaviours (e.g., IV drug use). Positive psychology attempts to capitalize on human strengths and virtues as opposed to focusing on pathology and illness (Emmons, 2006; Fredrickson, 1998; Seligman, 2003). Some researchers (e.g., Purcell et al., 2004) have utilized empowerment within their prevention models with reported success (e.g., increased pro-social attitudes). Empowerment can be defined as a process of taking more active control of one's life and democratically participating in one's environment (Rappaport, 1981; Zimmerman & Rappaport, 1988). Within the current study, empowerment was often developed through a peer mentoring system, involving people with HIV in the prevention program. Other aspects of positive psychology, addressed in the present research, include motivation, or an internal state that energizes behaviour and provides it with direction (Kleinginna & Kleinginna, 1981) and inspiration, or a product of one's creative thinking or work (Merriam-Webster, 2006). Importantly, some research suggests that several positive psychological principles (e.g., inspiration, empowerment) may be central aspects of the hoping process itself. For example, with hope, people may be empowered and inspired to believe that an improved future is possible and obtainable (Hannah, 2002; Miller, 1991; Snyder et al., 1991).

Research is limited on prevention programs that target people dealing with the high-risk period surrounding the HIV diagnosis. In addition, most intervention/prevention programs (i.e., that have been developed for other groups of people dealing with HIV/AIDS) are behavioural in focus. Thus, they focus on changing the individual's behavioural patterns. Researchers (e.g., Fishbein, 2000) note that changing behaviour needs to be the primary and central focus within these types of programs. However, some researchers (e.g., Carey et al., 2004; Crepaz et al., 2006) suggest that a broader focus needs to be included if change is to be made and sustained. The focus needs to include, not only the individual, but broader social-cultural factors (e.g., environmental considerations such as poverty, employment, as well as social and cultural factors that occur at the macro level such as beliefs surrounding sexuality and homosexuality and governmental attitudes toward drug use). Again, few studies of intervention/prevention programs have included these broader social-contextual factors. Those that have (e.g., Carey et al.) have reported beneficial effects (e.g., reduced risk behaviours); however, none have targeted the specific population targeted in the present study.

Peer Support

Research and Support for Peer Support

Peer support has been noted as being very important in assisting people living with HIV. Numerous researchers (e.g., Bastardo & Kimberlin, 2000; Greene, McVinney, & Adams, 1993; Hays, Turner, & Coates, 1992; Koopman et al., 2000; Leserman, Perkins, & Evans, 1992; Serovich, Brucker, & Kimberly, 2000; Turner, Hays & Coates, 1993; Zich & Temoshok, 1987) have reported physical benefits (e.g., reduction of physical HIV symptoms), psychological benefits (e.g., reduction of depression), and emotional benefits (e.g., reduction of helplessness and increase in having a "fighting spirit") of peer support for people living with HIV.

Coates et al. (1987) reported that individuals living with HIV often experience social isolation; thus, social support is one of the most important resources for infected individuals to obtain. Honey (1988) noted that many people living with HIV are neglected or even abandoned by loved ones, leading to the increased need for peer support. It is also important to note that alienation and isolation can threaten hope (Farran et al. 1995; Miller, 1989). Research suggests (e.g., Baumgartner, 1985; El-Mallakh & El-Mallakh, 1989; Getzel, 1991) that there are multiple benefits of peer support programs such as: (a) exploring fears of death, (b) assisting with revealing sexual identity in the case of homosexual individuals who were living heterosexual lives, (c) exploring emotions (e.g., shame and poor self-image), (d) sharing common experiences, concerns, and solutions, and (e) belonging to a group. Kendall (1994) noted that in her study, participants identified the need for closer relationships and connections with others, indicating that two of the most important needs they experienced were human connectedness and intimacy. Furthermore, participants in Kendall's study reported specific key components of developing human connectedness such as: (a) belonging to a community of caring people, (b) sharing with others, (c) expressing honest and sincere feelings, and (d) supporting (i.e., giving and taking).

Peer Support, Peer Education, and Peer Counselling

Peer support interventions and prevention strategies have been becoming more and more recognized as viable options due to their potential usefulness (Campbell & Mzaidume, 1991; Hughes-d'Aeth, 2002; Molassiotis, 2002; Rhodes, 1994). These intervention and prevention modalities typically include one-on-one connections with a recently diagnosed individual and an individual who has been living with HIV/AIDS for some time for counselling and/or educational purposes. Typically, peer educators and counsellors receive training, where they learn about their roles as peer helpers (G. Gertz[3], personal communication, April 2003). In addition, one of the benefits of this type of approach is the use of their own experiences to help newly diagnosed individuals. Thus, peer helpers have the unique opportunity to learn about the theory and practice of helping, and also utilize their own experiences of living with HIV/AIDS. According to HIV Edmonton and AIDS Calgary Awareness Association, some of the roles of peer educators and counsellors include: (a) providing support to newly diagnosed individuals and individuals who have been living with HIV/AIDS for longer periods of time, (b) providing individuals with referrals to other agencies and services, (c) implementing

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harm reduction strategies, and (d) educating others about HIV and related concerns (D. Jakubec[4], personal communication, April 2004).

Some authors (e.g., Campbell & Mzaidume, 1991; Downing et al., 1999; Hughes-d'Aeth, 2002; Johnson, Stanford, Douglas, Botwinick, & Marino, 1993; Madray & van Hulst, 2000; Molassiotis et al., 2002) have reported that a peer support approach can offer important benefits for people living with HIV/AIDS. Some of these possible benefits have included: (a) the newly diagnosed individual experiencing enhanced trust with the peer helper, (b) the peer helper having credibility and acceptability with the newly diagnosed individual, (c) the peer helper being in a position to identify specific target groups such as more isolated groups, (d) the peer helper and the newly diagnosed individual are in a unique position to share knowledge and/or experience, (e) the creation of informal peer networks between those involved that typically can last beyond the peer counselling/education, (f) the development of empowerment among peer helpers as well as the newly diagnosed individual receiving the services, and (g) the development of increased community awareness of HIV/AIDS (French et al., 2000; Hughes-d'Aeth). Some of the reported disadvantages of peer support have included that it is: (a) challenging to monitor the service and (b) challenging to maintain the service due to a lack of outcome data and available funding (French et al.). Another disadvantage has included the potential for boundary problems in relation to sexual and drug use influences (L. Phillips[5], personal communication, July 2004).

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HOPE

Definitions of Hope

The construct of hope is complex and multidimensional. Eliott (2005) reported that hope has many meanings. She went on to note that "Hope is, or can be, positive, negative, divine, secular, interpersonal, individual, social, ideological, inherent, acquired, objective, subjective, a practice, a possession, an emotion, a cognition, true, false, enduring, transitory, measured, defined, inspired, learnt… and the list goes on" (p. 38). Hope definitions have been evolving for almost a half century beginning with Menninger's (1959) seminal piece on hope as an important academic construct in search of a definition. The discursive and the psychological aspects of hope have been explored by many. Discursively speaking, Godfrey (1987) reported that hope can be understood as a verb, a noun, and an adjective. When hope is used as a verb, there is typically an object or event that is hoped for (e.g., he hopes to drive again someday), although the object or event of hope may not always be clearly expressed (e.g., she hopes in her family). Hope as a noun would be something that is desired (e.g., he has hope for change). Hope as an adjective does not necessarily include a clearly expressed object. It represents hoping in general (e.g., she is hopeful for the future) (Godfrey). What follows is an overview of the key qualities and definitions of the construct hope, which are most germane to the current study. Following this discussion, specific models of hope are explored in some detail.

Hope can be defined as a feeling, a way of thinking, and as a way of behaving or relating (Averill, Catlin, & Chon, 1990). This characterizes the multiple levels of the hope construct. Feeling or affect represents the emotional and even energizing aspects of hope. Thinking or cognition represents the cognitive consideration and creativity that occurs within thought. Behaving or relating represents an active process that involves exploring potential alternatives (Farran et al., 1995). Averill et al. reported that hope can also be a state and a trait. If hope is explored as a state, then its focus is in the present, it can be influenced by external and internal mechanisms, and it will likely change over time (Farran et al.). Hope as a trait is perceived as more of a stable characteristic, and less likely to fluctuate in response to external considerations (Farran et al.).

Stotland (1969) reported that the construct of hope is “an expectation greater than zero of achieving a goal” (p. 2). Stotland also noted that action is largely dependent on level of hope. If the individual is not feeling hopeful, then there is a sense of hopelessness and no action. Building on Stotland’s original work, Snyder (1994) defined hope as “the sum of the mental willpower and waypower that you have for your goals” (p. 5). For Snyder, willpower is the mental energy that is involved in hopeful thinking and waypower is the mental planning that directs hopeful thought. Again, this definition of hope has a focus on goal attainment.

Dufault and Martocchio (1985) defined hope as “a multidimensional, dynamic life force characterized by a confident yet uncertain anticipation of achieving a future good which, to the hoping person, is realistically possible and personally significant. Hope has implications for actions and for interpersonal relatedness. Hoping is not a single act but a complex of many thoughts, feelings and actions that change with time. Hope is multidimensional and process-oriented” (p. 380). Obayuwana et al. (1982) reported that hope is a state of mind that results from the positive outcome of multiple characteristics such as religion, perceived family support, education, and economic aspects. Jevne and Miller (1999) defined hope as “looking forward with both confidence and unsuredness to something good" (p. 10). Edey, Jevne, and Westra (1998) noted the subjectivity of hope, and focused on how clients perceived and defined hope, utilizing these client-focused definitions as their definitions for hope.

It is clear from these hope definitions that hope has different meanings for different people. This is an important consideration in the present study, as participants have also reported different ideas and beliefs that represent hope for them. What follows is a description of the various models of hope that correspond with the above definitions of hope.

Models of Hope

Within the hope literature exist numerous models or conceptualizations of the hope construct. These models demonstrate multiple perspectives on hope and highlight the importance of acknowledging that hope has been experienced somewhat differently for each of the participants in this study. Nekolaichuk (1990) reported that various hope models typically can be conceptualized as uni-dimensional or multidimensional, depending on their characteristics. Although not an exhaustive list, what follows is an overview of several hope models which have helped me to broadly conceptualize the various dimensions and qualities of hope.

Uni-dimensional models of hope. Many of the initial perspectives on hope have focused on an action orientation or an expectation of goal attainment (Keen, 2000; Nekolaichuk, 1990). Several of these perspectives (e.g., French, 1952; Lewin, 1938; Mowrer, 1960; Stotland, 1969) maintained a focus on hope being related to obtaining a goal; however, some did not focus on the actual avenues or means through which these goals would be reached, but focused on perceptions or evaluations of probability of reaching a desired outcome. For example, Stotland's model focuses on the individual using cognitive processes to determine goal-related outcomes. The focus is on levels of hope being determined by perceived probability of obtaining a specific goal. These uni-dimensional perspectives and models on hope, although narrow in comparison to some of the multidimensional models (e.g., Dufault & Martocchio, 1985), launched study and conversation on hope and hope related constructs. Furthermore, these models laid the foundation for additional models, which also continued a dominant focus on cognitive processes. Snyder for example (1994) defined hope as "the sum of the mental willpower and waypower that you have for your goals" (p. 5). For Snyder, willpower is the mental energy that is involved in hopeful thinking and waypower is the mental planning that directs hopeful thought. Snyder (1995) defined hope as "the process of thinking about one's goals, along with the motivation to move toward (agency) and the ways to achieve (pathways) those goals" (p. 355). These definitions demonstrate the dominant cognitive orientation of Snyder's model of hope. Snyder (1994) reported that his model was developed out of the premise that hope needs to be connected with a concrete goal.

Multidimensional models of hope. In many ways, Dufault and Martocchio's (1985) landmark study of hope with elderly cancer patients lead the study of hope in healthcare. From this research they developed a hope model that differentiated two spheres of hope, generalized hope and particularized hope. For Dufault and Martocchio, generalized hope refers to a general outcome (e.g., my life will change into something positive for me), while particularized hope refers to a "particularly valued outcome, good, or state of being, in other words, a hope object" (Dufault & Martocchio, p. 380) (e.g., through counselling I will reduce my depression and be happier). Embedded within the two spheres of hope, Dufault and Martocchio also elucidated six-dimensions of hope, including: (a) affective, (b) cognitive, (c) behavioural, (d) affiliative, (e) temporal, and (f) contextual dimensions. The affective dimension includes sensations, emotions, and the energizing component that are part of the hoping process (e.g., broad emotions that may co-exist with hope). Cognition refers to the cognitive processes (e.g., thinking, remembering) that function in relation to hope (e.g., imagination of possibilities). The behavioural dimension refers to the behaviours and actions of the individual in relation to hope (e.g., following appropriate medication schedules, praying). The affiliative dimension refers to relationships that occur beyond the individual self as they relate to hope (e.g., involvement in peer support programs at an HIV community-based organization). The temporal dimension refers to the individual's experiences of time in regard to hope (e.g., past, present, future perspectives that influence hope). The final dimension, contextual considerations, refers to the individual's interpretation of his/her life context in relation to hope (e.g., physical abilities of the individual and how they impact on the individual's level of hope). According to Dufault and Martocchio, as well as many other hope theorists (e.g., Jevne, 1993), hope can become visible and intentional in the face of some loss. We recognize the need for the presence of hope in the face of existential struggles; we need hope in order to be able to see a good future for the self (Farran et al., 1995; Marcel, 1967; Menninger, 1959).

Farran et al. (1995), through their extensive review of previously existing literature on hope, offer a second model. They conclude that hope is "an essential experience of the human condition. It functions as a way of feeling, a way of thinking, a way of behaving, and a way of relating to oneself and one's world. Hope has the ability to be fluid in its expectations, and in the event that the desired object or outcome does not occur, hope can still be present" (Farran et al., p. 6). Some authors (e.g., Jevne, 1993; Larsen, Edey, & LeMay, 2005) have called this a process of refining hope, noting that when one hope object is unobtainable others may be developed or considered. Farran et al. explored the cross disciplinary research (e.g., psychology, philosophy, sociology) on hope and determined four key components of hope as: an experiential process, a spiritual/transcendent process, a rational process, and a relational process. Hope as an experiential process refers to the need for an individual to experience hopelessness, and have his/her hope challenged, prior to experiencing a deeper level of hope. Hope as a spiritual or transcendent process refers to maintaining faith regardless of unknown outcomes, rising above challenging situations, and perceiving possibilities within life as opposed to maintaining a focus on an absolute reality. The rational process of hope refers to the "reality base or the mind of hope" (p. 9), involving thought processes of hope. Farran et al. developed the acronym GRACT, which identifies the key components of the rationale process (i.e., *goals* for motivation, *resources* to provide energy, *active* movement toward the goals, perception of the individual as having *control*, *time* as something that influences hope and change is possible with time). The relational process of hope contains the interpersonal aspects that influence hope (Farran et al.).

Finally, Miller (1991; 2000) developed a model of hope levels or intensities. The first level of hope is characterized by superficial wishes such as hoping or wishing for no rain. The second level of hope involves hoping for such things as relationships, self-improvements, and self-accomplishments. If this level of hope is absent or challenged, the individual's level of despair may result in experiencing anxiety, which can be alleviated through the development of new goals. The third level of hope is developed through suffering or a state of captivity. Within these types of situations exists despair, and this is where hope can have true meaning (Miller). Although Miller explored this third level with the chronically ill, many hope scholars (e.g., Marcel, 1967; Menninger, 1959) have similarly observed an important relationship between hope and despair. Like Miller's research participants with chronic illness, it is reasonable to consider that facing a terminal illness diagnosis, such as HIV, may also not only result in despair but also offer possibilities for a deep experience of hope. Vaillot (1970) eloquently reflects this possibility writing "there is no hope unless the temptation of despair is possible" (p. 271).

Critical considerations of hope models. The above-presented models represent different conceptualizations of hope. It is important to note that each of these perspectives offers important considerations for how hope has been approached within the present study. All of these models have contributed to my own perceptions of hope and I have utilized these in carrying out the present study. Of paramount importance is the multidimensional nature of the hope construct. Although models that focus on goals and cognition are important and useful, other models that elucidate the multiple aspects of hope (e.g., relational, affective, spiritual) have been of primary focus. Researchers (e.g., Eliott & Olver, 2002) have suggested that hope is complex, containing multiple meanings and varying aspects. To capture something as multifaceted as hope requires an equally comprehensive conceptualization and definition of hope. Thus, in this study, I considered hope to be multifaceted. Accordingly, during the interviews and during data analyses I remained open to multiple perspectives on hope. Many of the hope models presented also focused on the related construct hopelessness. This was also an important consideration within the present study, as hopelessness can be a common experience following an HIV diagnosis. Again, accounts of hopelessness were discussed during interviews. In addition, during analyses I explored accounts of hopelessness in relation to becoming diagnosed with HIV, engaging in high-risk behaviours, hope, and mental health services. What follows is a discussion of the related literature surrounding the construct hopelessness.

Hopelessness and Hope

Farran et al. (1995) reported that hopelessness is not perceived to be as elusive or as mysterious as hope. Hopelessness, similarly to hope, is understood to contain an affective component, a cognitive component, and a behavioural component (Farran et al.), demonstrating the multidimensional nature of hopelessness. For example, affectively, the hopeless individual may experience a sense of feeling trapped and alone. Cognitively, he/she may experience distorted thinking, be unable to believe a plan or solution is possible, and/or be unable to believe that others could help (Farran et al.; Stotland, 1969). Finally, behaviourally, he/she typically experiences an inability to engage in actions (Engel, 1968; Fromm, 1968). Hopelessness has been defined as "an essential experience of the human condition. It functions as a feeling of despair and discouragement; a thought process that expects nothing; and a behavioural process in which the person attempts little or takes inappropriate action" (Farran et al. p. 25). Hopelessness has also been reported to exist as both a state and a trait (Farran et al.). Interestingly, Seligman and Csikszentmihalyi (2000) reported that hopelessness was studied prior to hope due to a dominant focus on psychopathology within science and social science disciplines.

Farran et al. (1995) also noted that hopelessness can have multiple dimensions. This is an important distinction as different people in the present study have reported different levels and situational experiences of hopelessness. For example, hopelessness can arise out of a life situation that has challenged the individual's hope and goals, resulting in hopeless cognitions, feelings, and behaviours. Farran et al. reported that this type of hopelessness will likely be perceived due to a major life change such as dealing with loss/grief or an illness. Dealing with loss and a grief reaction would be expected with a diagnosis of HIV. Farran et al. noted that utilization of internal and external resources would resolve this type of hopelessness over time. This is an interesting consideration, as many people diagnosed with HIV do resolve experiences of hopelessness over time; however, the initial time period preceding and following the diagnosis is critical, and how hope is developed needs to be *carefully* explored. Another type of hopelessness is closer to a personality trait. This has been described as an all encompassing perspective where the individual becomes fixated on a belief that he/she is disempowered and cannot create change. Additionally, the individual believes that life is meaningless (Farran et al.). These individuals have a poor self-concept, believing that they cannot be accepted for who they are as people (LeShan, 1989). A third type of hopelessness is more pathological and is typically associated with psychiatric illnesses such as depression and suicide (Farran et al.; Lynch, 1965; Stotland, 1969). Farran et al. reported that this type of hopelessness is distinct from other "normal" types of hopelessness in that in this third type there is a "giving up" tendency and a longer duration and severity of the hopelessness and corresponding symptoms. It is important to note that following a diagnosis of HIV some individuals do experience depression and also attempt or commit suicide (Bellini & Bruschi, 1996; Cadwell, 1994; Catalan, 1995; Martin, 1989; Pugh & O'Donnell, 1993; Siegal & Meyer, 1999). This suggests that this third type of hopelessness is an important consideration within the present study; however, the pathological or psychiatric assumptions may not be appropriate for this population, as many people diagnosed with HIV are not living with psychiatric issues. Thus, a profound sense of hopelessness may not be a pathological response for someone who is dealing with HIV/AIDS and does not have other symptoms of a major depressive disorder.

Kwon (2000; 2002) hypothesized, based on four research studies exploring relationships between defense mechanisms, hope, depression, and adjustment that a subtype of hopelessness termed "defensive hopelessness" exists. People demonstrating this type of hopelessness expect the worst case scenario to occur in order to facilitate motivation. These individuals utilize the anxiety which goes along with the expectation to fail (Kwon; Reff, Kwon, & Campbell, 2005). Reff et al. (2005) noted that individuals displaying defensive hopelessness in their study were able to avoid becoming dysphoric following bad news (i.e., receiving poor examination results), suggesting that having low hope (i.e., low expectations about future) with mature defense mechanisms (i.e., being able to react constructively to stressors) can lead to the maintenance of emotional well being. These results have important implications for the notion of false hope, which has been defined as hope built on pathological denial (Hafen, Karren, Frandsen, & Smith, 1996). False hope develops out of reality distortion, or immature defense mechanisms (Reff et al.). Reff et al. noted in their study that high hope and defense immaturity (i.e., reality distortion) did not lead to maladaptive results, contradicting the notion of false hope. Participants in their study with low hope and immature defense mechanisms were more likely to experience dysphoria following examination results (Reff et al.). People with high hope levels experienced healthy adjustment to the examination results regardless of defense style (Reff et al.).

It has been reported that hope and hopelessness are highly related yet contain distinctions (Farran et al., 1995; McGee, 1984; Yapko, 1991). Early conceptualizations viewed each on opposite ends of a continuum (McGee; Yapko). According to this understanding the two can potentially be polar opposites. However, Nekolaichuk (1995) noted that hopelessness is not necessarily on a continuum with hope. Nekolaichuk observed that the factors involved in losing hope are not necessarily the opposites involved in the maintenance of hope. Thus, there exists disagreement within the research literature in terms of how the constructs relate to each other. Despite this disagreement, each is an important consideration within the present study and is an important consideration within the context of counselling. It is also possible that the relationship between hope and hopelessness may be uniquely experienced by each individual, which is a key consideration within the present study.

It is also important to note that anxiety symptoms can be experienced by the individual living with HIV/AIDS (Phillips, 2000). This can be a normal reaction to the possibility or notification of HIV. Some authors (e.g., Farran et al., 1995) have identified fear as a characteristic of hopelessness, suggesting that anxiety and fear may go along with the construct hopelessness. Interestingly, in her ground-breaking work with hope in counselling, Jevne (1993; 2005) identified hope as an antidote to fear. Hafen et al. (1996)

have also identified hope as an antidote to fear. Thus, there seem to be links between hopelessness and fear as well as an important relationship between hope and fear.

Hope and Counselling

There has been an ongoing debate as to which psychotherapeutic models of change (e.g., cognitive-behavioural, humanistic) and which specific techniques (e.g., progressive muscle relaxation, systematic desensitization) produce the most effective outcomes in terms of client change (Hubble, Duncan, & Miller, 1999; Yalom, 1998). Numerous researchers (e.g., Ahn & Wampold, 2001; Lambert & Bergin, 1994) have suggested that psychotherapeutic models of change and even specific techniques of counselling produce similar counselling outcomes. Furthermore, Ahn and Wampold noted that it is difficult to determine if specific techniques actually produce the desired counselling outcomes. More recently, there has been a focus on the common factors of counselling that create desired therapeutic outcomes (Ahn & Wampold; Hubble et al.; Yalom).

Wampold (2001) reported that specific common factors of counselling and psychotherapy account for almost nine times more of the variability in counselling outcomes in comparison to specific counselling techniques. Similarly, as previously mentioned, many researchers (e.g., Ahn & Wampold, 2001; Lambert & Bergin, 1994) comparing theoretical orientations suggest similar outcomes between orientations. This suggests the importance of examining factors that are common across theoretical orientations and techniques. There have been many trans-factor models suggested (e.g., Frank & Frank, 1991; Hubble, et al., 1999; Lambert, 1992; Yalom, 1995; 1998), several of which label hope as a common factor. For example, Yalom (1998) noted "the instillation and maintenance of hope is crucial in any psychotherapy" (p. 9), and labeled one of his 11 primary therapeutic factors the instillation of hope. Lambert identified a four-factor model and labeled one of these factors as placebo, hope, and expectancy. Talley (1992) noted that in examining the predictors of brief psychotherapy, the single most effective factor in predicting satisfaction of treatment was the counsellor encouraging the client to believe he/she could improve his/her own situation. Edey and Jevne (2003) interpreted this as the "client reclaiming hope about the situation" (p. 45). Hope seems to be a common factor that exists in counselling regardless of the orientation or technique being employed.

Farran et al. (1995) reported that "hope functions as a protective mechanism, whereas the presence of hopelessness on a long-term basis threatens a person's physical, psychological, and spiritual health and quality of life" (p. 39). Thus, it seems the development of hope is an important component of well-being and mental health. Numerous researchers (e.g., Cannon, 2005; Edey & Jevne, 2003; Edey, Jevne, & Westra, 1998; Frank, 1968; Kraatz, 2003; Kuyken, 2004; Ruvelson, 1990; Yalom, 1995; 1998) suggest that hope is an important component in counselling. Creating and maintaining hope in counselling has been reported to be an integral role of the counsellor (Bernard, 2000; Edey et al., 1998; Jevne, 1997; Miller, Duncan, & Hubble, 1997; Westburg & Guindon, 2004; Yalom).

Over the past 15 years work has been done to explore hope focused counselling approaches. Massey (2003) reported that these hope-focused counselling approaches typically include an eclectic modality. For example, areas of emphasis have included cognition, systems, social learning, and existentialism (Massey). Edey et al. (1998)

reported that narrative therapy is also an important orientation within hope-focused counselling. Typically the hope-focused counsellor will listen for stories and instances of hope in order to help re-author problem narratives (Edey et al.). Massey reported that the most common modalities within a hope-focused approach consist of narrative (e.g., externalizing the problem), cognitive-behavioural (e.g., identifying core beliefs and inappropriate thoughts and utilizing hope to help redefine problems with thoughts and beliefs), and existentialism (e.g., life meaning being connected with hope).

Regardless of the underlying orientation(s) employed, the central tenet of hope-focused counselling is intentionally working with hope as the central theme within counselling (Edey & Jevne, 2003; Edey et al., 1998; Massey, 2003). Hope focused counsellors utilize hope-focused questions (e.g., what would I have to know about you to understand your hope) to help clients perceive options and hope as opposed to singularly focusing on the problem(s) (Edey et al.). Hope-focused counsellors also recognize the importance of the therapeutic alliance, and relationships with significant others, in terms of influencing clients' hope levels. This has been especially noted in research with those living with HIV (Keen, 1994; Wong-Wylie & Jevne, 1997). It is important to note that hope-focused counselling is not a separate counselling modality, but rather an approach with a hope-focus that occurs within any therapeutic modality (Edey & Jevne, 2003). The difference is a hope-focused approach intentionally utilizes this hope-focus when it is required, or may be helpful, making hope an integral, explicit, and key component of the counselling process. Other differences that exist include: (a) goal-setting (e.g., it would be appropriate for the counsellor and the client to set the goal of increasing hope and it would be appropriate to check on this goal of increasing hope periodically during the process), (b) counsellor stance (e.g., the counsellor would be aware of fluctuations in his/her own hope levels as the relationship unfolds and would take deliberate steps to keep it as high as possible), (c) counsellor strategies (e.g., the counsellor would use strategies which could be specifically identified as hope-focused and would be able to say what those were such as framing the problem in the context of hope, using language to project a hopeful future, and/or making associations between hope and symbols which a client might use to later recreate the experience of hope in other circumstances), and (d) counselling outcomes (e.g., the client would adopt the practice of framing situations in the context of hope and recreating the experience of hope) (W. Edey[6], personal communication, September 2004). Cutcliffe (2004) also reported that bereavement counselling should contain a focus on hope. He noted that counsellors in his study reported that hope was largely implicit and inextricable within bereavement counselling. Cutcliffe suggested that clients who felt they were cared for by the psychotherapist were simultaneously helped to experience hope. Thus, counsellors who cared for and supported clients facilitated their clients' hope. Borenstein (2003) suggested that hearing and acknowledging clients' dreams and aspirations is also an integral component of psychotherapy which can lead to experiences of hope.

It is also important to note that numerous authors (e.g., Cutcliffe, 2004; Hannah, 2002; McGee, 1984; Ruvelson, 1990) suggest that attempting to demonstrate or elicit hope prematurely in clients experiencing hopelessness can be counterproductive and lead to increased isolation and hopelessness. Thus, part of hope-focused counselling includes recognizing when to engage in other activities that can be non-hope related or may be

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[6] W. Edey, M.Ed (chartered psychologist), Director of the Hope Foundation of Alberta, develops, writes on, and practices hope focused counselling.

precursors to a hope-focused discussion. Specifically, the client needs to feel heard and understood which can then facilitate opening a hope-focused discussion. Upon surveying the research literature, I was unable to locate any research that explores the hope components or mechanisms within a counselling or psychotherapy context for those individuals experiencing the high-risk period following an HIV diagnosis. This highlights the need for research in this area, and thus offers support for the present study.

Sources of Hope in Serious Illness

There have been several studies conducted exploring sources of hope in the face of serious illness. These studies have occurred with people living with HIV/AIDS, but also with groups of other people dealing with serious illness (e.g., cancer). Farran et al. (1995), in reviewing the hope and cancer literature, suggested that there may be a relationship between hope and treatment settings, level of physical health, style of coping, and how information is being communicated. They reported that these variables may impact on the likelihood of hope for the patient.

Relationships are a key source of hope repeatedly identified in research (e.g., Cutcliffe, 2004; Cutcliffe & Grant, 2001; Dufault & Martocchio, 1985; Duggleby & Wright, 2005). Indeed, several theories of hope (e.g., Dufault, & Martocchio, 1985; Farran et al., 1995) have highlighted how hope can develop from relationships. Kruijver, Kerkstra, Bensing, and Van de Wiel (2000) noted, based on a review of hope literature, that the nurse-patient relationship is a key component in the communication of hope. Part of this relational-hope process may interact with the concept of caring, as hope and caring appear to be intimately related constructs (e.g., Cutcliffe, 1996, 2004; Jevne, 1993; Jevne & Miller, 1999; Miller, 1989; Vaillot, 1970). Cutcliffe (1995), Jevne (1993), and Herth

(1990) have noted several important factors related to human caring which may facilitate hope, such as accepting another person and empathizing with another person.

Hope has also been connected with receiving help (Dufault & Martocchio, 1985; Lynch, 1965). These studies suggest that the process of offering help to another can facilitate the process of hope. Cutcliffe and Grant (2001) have also noted that empowerment is related to hope, illustrating the importance of empowering clients in order to facilitate hope.

Researchers (e.g., Edey & Jevne, 2003) have noted the power of humour and laughter in the facilitation of hope among people with serious illness. Researchers (e.g., Edey & Jevne) also suggest that offering hopeful stories can be a powerful means of encouraging hope among people with serious illness. Jevne (1993) cautions that while story can be shared with patients, special care should also be taken to hear the patient's story as well (Jevne, 1993). Hunt (1992), in reference to oncology patients and others with chronic illness, suggested that the most common strategies and means to facilitate hope included: (a) staying busy, (b) praying and religion, and (c) maintaining family relationships. Miller (1989) suggested that having a sense of control and having a belief that life has meaning inspires hope. Hinds and Martin (1988) suggested that distraction techniques (i.e., as a means to distract from the threat of the illness) facilitated hope. Ersek (1992) noted that in dealing with threatening information, while maintaining hope, there needs to be a dialectic process. According to Ersek, this dialectic process involves incorporating the threatening information (e.g., a diagnosis of HIV) into a broader context (e.g., meaning-making) in order to reduce its negative impact.

Jevne (1993) noted several additional strategies which could promote hope in people with serious illness such as: (a) identifying and facilitating hope rituals, (b) providing and listening for hope images, (c) identifying hope models, and (d) creating hope symbols (see Jevne for a review). Herth (2005) reviewed the research literature exploring populations impacted by various health problems (e.g., cancer) and identified several hope-fostering strategies: (a) becoming connected to others, (b) developing goals, (c) having beliefs (e.g., spiritual), (d) recognizing personal attributes (e.g., courage), (e) remembering uplifting memories, (f) utilizing cognitive strategies (e.g., hope stories), (g) gaining a refocus on time (e.g., measure time by relationships), and (h) becoming lighthearted. Salander, Bergenheim, and Henriksson (1996), in their study of patients with malignant brain tumors, found that most patients utilized cognitive strategies to increase hope (e.g., interpreting their sense of feeling good and healthy as doing okay). Holtslander, Duggleby, Williams, and Wright (2005) reported several sub-processes of "hanging on to hope including doing what you have to do, living in the moment, staying positive, and writing your own story" (p. 288) for informal caregivers of palliative care patients. Additionally, obtaining support (e.g., family, friends, professionals) and connecting with something larger than oneself (e.g., spirituality) facilitated hope movement (Holtslander et al.). The next section explores research directly related to hope, hopelessness, and HIV/AIDS.

Hope, Hopelessness, and HIV/AIDS

The threat of AIDS places one's future in immediate question. Connections have been noted between fearing a possible diagnosis of HIV, fearing HIV/AIDS, and hopelessness (Akande & Ross, 1994; Ickovics, Morrill, Beren, Walsh, & Rodin, 1994).

Kylma, Vehvilainen-Julkunen, & Lahdevirta (2001) reported that participants in their study (i.e., caregivers of people living with HIV from Finland) working with people suspecting an HIV diagnosis, perceived these people as struggling with the diagnosis and having their hope challenged. According to participant caregivers, these people, dealing with the possibility of HIV, experienced serious consequences as a result of losing their hope, such as hurting oneself (e.g., suicide attempt). It has also been noted that people living with HIV/AIDS may experience increased levels of hopelessness (McEnany, Hughes, & Lee, 1996; van Servellen, Padilla, Brecht, & Knoll, 1993). Research has demonstrated that HIV-positive gay men have experienced higher levels of hopelessness than HIV-negative gay men (Catalan et al., 1992; Catalan & Pugh, 1995) and HIV-positive individuals living with haemophilia have experienced higher levels of hopelessness than HIV-negative individuals living with haemophilia (Catalan et al., 1992).

There have also been connections noted between hope and living with HIV. For example, Harrison (1993) noted a connection between experiencing hope and maintaining a health-promoting lifestyle in individuals living with HIV. This is an important consideration in the present study as developing a health-promoting lifestyle potentially suggests a reduction of high-risk behaviours. Similarly, Cousins (1989) as well as Dufault and Martocchio (1985) reported that individuals who are experiencing hope are more likely to make healthier choices. Dufault and Martocchio noted that hope can also lead to increased social responsibility. Again, this seems to suggest a concern for others and thus a potential reduction of high-risk behaviours. Farran et al. (1995) reported that in contrast to hope, hopelessness has been connected with increasing levels of "sociologically oriented destructiveness and violence" (p. 39). Wong-Wylie (2003) suggested that counsellors working with individuals living with HIV who engage in high-risk behaviours (i.e., unsafe sexual practice, risky drug sharing behaviours) and refuse to disclose their HIV status to their sexual or drug sharing partners need to seek ways to maintain the client's level of hope in the face of challenging confidentiality issues (i.e., breaking confidentiality was seen as a mechanism of destroying hope). Offering an ethical decision making model when faced with HIV and confidentiality issues, she further suggested that maintaining hope would lead clients to make healthier choices (i.e., reduction of high-risk behaviours or informing partners). Ultimately, this may benefit the HIV-positive individual involved as well as society in general, to a greater degree than prematurely breaking confidentiality and disclosing the high-risk behaviour information.

Numerous researchers (e.g., Chammas, 1999; Heinrich, 2003; Huotari, 1999, as cited by Kylma et al., 2001) reported that hope is an important internal resource for helping individuals living with HIV to experience increased well-being and to survive with HIV. There was also a positive relationship noted between spirituality or existential well-being, hope, and positive correlates of HIV (e.g., fewer HIV related symptoms) (Carson, Soeken, Shanty, & Terry, 1990; Coleman, 1997; Coleman & Holzemer, 1999). Heinrich (1999) noted that hope influences perceived and actual health among individuals living with HIV. Watts (2001) noted that hope is positively related to emotional adjustment in individuals living with HIV. Meredith, Delaney, Horgan, Fisher, and Frasier (1997) reported participants living with HIV wanted to be treated within a setting that offered opportunity to discover hope.

Concluding Thoughts

The previous discussion has highlighted the importance of studying the potential high-risk behaviour period preceding or following an HIV diagnosis in relation to hope and counselling services. There is a clear rationale in the research literature suggesting that hope and counselling services can play a significant role in reducing this potential high-risk period. In addition, there is a lack of research that explores participants' experiences of hope during this time period. As noted in Chapter One, the research question for the current study is: "What are the experiences of hope and counselling services for those who have gone through the high-risk period immediately preceding and/or following an HIV diagnosis?". As will be discussed in the results and discussion sections, this study adds to this body of research literature in several significant ways. The next chapter focuses on the guiding methodology and research considerations for the present study.

Chapter Three: Methodology

Researching the Problem

The present study was a qualitative case study design which involved interviewing 12 people who continued or increased their high-risk behaviours following a diagnosis of HIV. In the initial part of the chapter I highlight the theory surrounding qualitative case study research, the guiding method of the current study, along with philosophical hermeneutics, which describes important processes of interpretation and understanding. The next section of the chapter includes key components of the application of the method, including: (a) community-based research, (b) population and site selection, (c) interview procedure, (d) transcription and analysis, (e) critical evaluation of the interpretations, and (f) ethical issues.

Case Study Research

Qualitative case study research was the guiding method in the current study. Qualitative case study research "is an intensive, holistic description and analysis of a single instance, phenomenon, or social unit" (Merriam, 1988, p. 21). Case study research involves defining clear boundaries which encompass the phenomenon under study. This phenomenon becomes an enclosed and integrated system (Smith, 1978; Stake, 1995), which allows the researcher to understand the phenomenon as being contained within boundaries. The phenomenon selected for study can be an instance of some concerning issue, which the researcher wants to understand in greater depth (Merriam, 1998). Qualitative case study research is (a) particularistic, focusing on a particular phenomenon, (b) descriptive, offering an end product which is rich with description, and (c) heuristic, illuminating the reader's understanding of the phenomenon (Merriam). In addition, the intent of the study will help guide which specific case study research approach will be utilized. Merriam defines descriptive and interpretive case studies, the approaches taken in the current study, as research which presents detailed accounts of the phenomenon along with interpretations of the phenomenon (e.g., conceptual categories highlighting possible relationships among characteristics of the phenomenon). Case study research does not narrowly define the data collection method or analysis procedure (Merriam); thus, allowing for flexibility in how the researcher studies the phenomenon. Importantly, the researcher is the "primary instrument of data collection and analysis" (Merriam, p. 42), making self reflection, interviewing and observation, and interpretive skill sets important aspects of researchers' abilities.

Qualitative case study research contains important benefits for researchers. Merriam (1998) reported that qualitative case study research is well suited for researchers "interested in insight, discovery, and interpretation rather than hypothesis testing" (p. 28-29) as this approach to research focuses on context and interactions between important characteristics of the phenomenon under study. Within case study research the researcher is able to investigate complex interactions among variables that exist within the boundaries of the phenomenon. The case study has the potential to expand the researcher's as well as the reader's understanding of the phenomenon (Merriam), which can help inform solutions to the problem or lead to future research hypotheses.

As with any approach to inquiry, there are certain limitations with qualitative case study research. Merriam (1998) outlines potential concerns when employing a qualitative case study approach including that the approach: (a) is time and resource intensive, (b) can provide an end product that contains too much detail and length to be reviewed, in a time efficient manner, by people who require the information, (c) oversimplifies or exaggerates findings, potentially leading readers to make incorrect or overly generalized conclusions, and (d) can contain biases which can effect the researcher's and the reader's abilities to convey and interpret the final product of case study research.

Qualitative case study research has guided the current research study. Philosophical hermeneutics has also contributed to my understanding of how interpretation and understanding transpire. What follows is a description of key concepts associated with philosophical hermeneutics.

Philosophical Hermeneutics

Philosophical hermeneutics is a conceptual framework which helps to enlighten and prepare researchers endeavoring to do interpretive inquiry research. Philosophical hermeneutics provides the researcher with important ideas, metaphors, and understandings of the processes of interpretation and advancement of understanding (Ellis, 1998; Gallagher, 1992; Smith, 1994). Given that the role of the researcher in qualitative case study research is that of the primary instrument in self-conscious interpretive work, philosophical hermeneutics can help the researcher to further understand the processes involved in interpretation and understanding (Packer & Addison, 1989). Philosophical hermeneutics elucidates several important elements involved in interpretation and understanding such as language, questions/dialogue, historical consciousness, hermeneutic circle, importance of part/whole relationships, and fusion of horizons. These processes are discussed below.

Language enables and limits the understanding that is possible (Aylesworth, 1991; Teigas, 1995). Interpretive researchers (e.g., Denzin, 1997; Gallagher, 1992; Smith,

1994) have highlighted the importance of allowing the dialogue within conversation to naturally unfold, which includes asking questions that simply arise from the conversation. These questions help guide the process of understanding. Of importance, our language and questions contain preconceived notions of the world, limiting us from reaching an objective place due to our inherent prejudices (Gallagher). These prejudices/historical consciousness or horizons contain ideas about the topics we hope to understand. Questions can be developed from these horizons so that there is a starting place in the process of understanding and also so that these horizons can be opened up to new possible avenues.

Interpretation occurs through evoking the hermeneutic circle (Collin & Young, 1988; Packer & Addison, 1989; Teigas, 1995). Mayers (2001) reported that the hermeneutic circle is "interpretive inquiry's way of letting meaning and understanding unfold through the constant renewal of questions and conversation" (p. 12). The researcher, influenced by his/her horizons, moves within the text, fluctuating from the parts to the whole and back to the parts, and so on (Gallagher, 1992). Thus, understanding is circular, from parts to whole and whole to the parts (Ellis, 2006).

The hermeneutic circle is like a spiral, with multiple loops, with each loop representing a deeper engagement with the interpreted (Ellis, 1998). Within the hermeneutic circle, the researcher attempts to get closer to what it is he/she hopes to understand (Ellis). Packer and Addison (1989) reported that the circularity of understanding within the hermeneutic circle is based on the notion "that we understand in terms of what we already know" (p. 34). Thus, we project what we know into the interpretation from the very beginning, and then work toward increased understanding.

Packer and Addison noted the forward and backward movement within the hermeneutic circle. Within the forward movement, the interpreter's horizons allow him/her to reflect on the phenomenon and apply his/her beliefs, values, and interpretive framework within the spiral in order to understand the participant. Following this initial movement, the interpreter's backward movement allows him/her to evaluate and examine his/her initial interpretation and attempt to perceive what was initially missed or mistaken (Ellis; Packer & Addison). This movement process continues throughout the spirals of the hermeneutic circle, with each spiral offering the opportunity to uncover unexpected findings (Ellis). These uncoverings enable the researcher "to understand the problem or question differently and so to reframe it usefully for planning the next step in the inquiry" (Ellis, p. 22).

This process of interpretation, and thus understanding, involves the fusion of horizons. The fusion of horizons is a process that allows knowledge and understanding to fuse and emerge through the connection and reconnection of horizons (Scott & Usher, 1999; Teigas, 1995). Scott and Usher see the "horizon" as one's standpoint or position in terms of time, place, gender, ethnicity, culture, and the topic under consideration. In other words, horizon is one's current perspective in terms of what is being explored. "Fusion" occurs through the developing of understanding between people, which comes from multiple horizons coming together (Scott & Usher). With fusion there is an opportunity to see another's perspective on the topic of inquiry, which can help to enlarge our own horizon. Interpretations continuously open to connect with additional horizons, allowing for the opportunity to reinterpret and reach different understandings as horizons shift (Scott & Usher; Teigas).

The previous discussion has highlighted several important aspects of interpretation and understanding elucidated by philosophical hermeneutics. The next part of the chapter explores key components of the conduct of the study.

Community-Based Research

The present study followed a community-based research approach. Within this research project, the "community" refers to all stakeholders of community-based research and HIV/AIDS issues. Community-based research requires adherence to specific guiding principles: (a) there is community member involvement and understanding of as much of the project as possible, (b) the project is community relevant, (c) there is a focus on equality within the partnerships of the project, (d) the research activities adhere to scientifically accepted research standards, and (e) the research needs to meet ethical guidelines (Harris, 2006; Health Canada, 2002). Within the present study I have involved community members through the design of the study, identifying the research questions to be addressed, structuring and restructuring question/interview formats, site selection, and some of the methodological issues (e.g., qualitative interviews). As the community members have defined relevant and important areas of research for this community, the study is very community relevant. There has also been a focus on equality within the community partnerships in the present study. All stakeholders (e.g., community workers, participants, academic researchers) in the study have had the opportunity to voice their perspective on different aspects of the study. Finally, the study has utilized qualitative case study research, a scientifically accepted research approach (Merriam, 1998; Stake, 1978, 1995) and the ethics component was examined and accepted by the ethics committee of the University of Alberta, Faculty of Education.

Population and Site Selection

Within case study research the case or phenomenon under study is pinpointed and boundaries are defined. The present study was conducted with individuals living with HIV/AIDS who had experienced high-risk behaviours (e.g., suicidal ideation, intravenous drug use) immediately preceding/following their HIV diagnoses. The sampling method that was used for this study was that of a criterion technique where participants were selected based on specific criteria (Osborne, 1994) (i.e., participants needed to be living with HIV/AIDS for at least two years, had to have continued their high-risk behaviours following diagnoses, and had to have received counselling services following their diagnoses). These participants were also connected with an HIV community-based organization, either HIV Edmonton or Living Positive. These boundaries which surrounded the phenomenon under study are consistent with case study research. In addition to the above sampling criteria, Van Kaam (1969) reported that it is useful for participants to have six specific abilities/experiences: (a) ability to linguistically express themselves, (b) ability to sense and express internal affect, (c) ability to express organic sensations that co-occur with the affect, (d) have relatively recent experience with the phenomenon in question, (e) have natural interest in their own experience, and (f) ability to note what was occurring within themselves. Importantly, the purpose of qualitative research is often to interpret and understand the topic or experience; thus, participants who are aware of their experiences and capable of articulation will potentially offer the richest description, which will potentially lead to a richer interpretation.

The chosen sites for participant recruitment were HIV Edmonton and Living Positive, because of the large number of potential participants and the agencies' interest in the study. HIV Edmonton was very active in recruiting participants for the study. Furthermore, HIV Edmonton was interested in the process and results of the project in order to learn about the high-risk period following an HIV diagnosis.

Participants were recruited by HIV Edmonton staff by giving potential participants informed consent forms with a detailed description of the study (see Appendix B) and letters outlining the study (see Appendix C) in order for them to be able to make an informed choice to participate or not participate in the study. In addition, HIV Edmonton presented the study to a group of HIV Edmonton clients. All of the clients received an informed consent form, letter outlining the study, and researcher contact information. Clients were then in the position to either disregard the study (i.e., if they were not interested) or contact me for more information. They also had the option to indicate their interest in participating in the study to HIV Edmonton staff if this was what they preferred. Regardless, HIV Edmonton clients were able to make their own decision regarding their interest in the study and were able to choose who they felt more comfortable in approaching to obtain more information (i.e., myself or HIV Edmonton staff), without compromising their privacy. Following tentative agreement to participate in the study, participants were given demographic questionnaires (see Appendix D) several days prior to the interviews. They were also given the option of receiving the guiding interview questions (see Appendix A) several days prior to the actual interview; however, none of the participants opted to receive the questions in advance. Many participants reported that it would be “more spontaneous” and “more natural” to receive the questions during the interview. Interested potential participants who met the basic criteria were invited for a research interview. Participants were given $30.00 per interview in order to cover travel expenses and their time.

Interview Procedure

Participants were interviewed to learn their perspectives on hope and mental health experiences during the high-risk period following their HIV diagnoses. Within the present study I interviewed 13 participants. Merriam (1998) reported that multicase studies involve collecting and analyzing data from multiple cases, and often result in more compelling and precise interpretations. The number of interviews that were conducted with each participant varied. I began with a pilot interview, and then interviewed this first individual a second time. These interview data were not included in this study, as the focus of these pilot interviews was on testing the interview format. I interviewed three of the remaining 12 participants three times each as this was needed for me to gain enough information and a sense of clear understanding. I interviewed seven participants twice and the remaining two were interviewed once. The reason two participants were interviewed once was because these participants reported several reductions in high-risk behaviours shortly following diagnosis and one was unavailable for a second interview. However, the participants reporting reductions in high-risk behaviours shortly following diagnosis still felt that they met the criteria for inclusion in the study. Thus, although they reported several reductions shortly following diagnosis, they still were noting that they experienced high-risk behaviours immediately following diagnosis.

The interviews were recorded and transcribed verbatim. All participants either chose, or were assigned, pseudonyms during the initial meeting (i.e., prior to any recordings/interviewing) for confidentiality purposes. As the purpose of the study was to describe and interpret, as opposed to generalize cause and effect, the interview was the most appropriate method. A guiding interview format using mainly open-ended questions related to certain knowledge and experience domains, such as living with HIV/AIDS, experiences with the potential high-risk period following an HIV diagnosis, hope elements, and counselling considerations (see Appendix A) was used. However, I was especially interested in the interview unfolding in a non-specified manner. Thus, the conversation between the participants and myself unfolded in a natural, non-directive manner. Interview questions were used as a general guide, but took second place to the natural unfolding of the conversation.

Transcription and Analysis

Interviews and Analysis

Interviews were recorded using two audio-recorders to ensure I obtained the entire interview verbatim. Following the interviews, the audiotapes were transcribed verbatim by a trained transcriber. I then initially listened to the tapes while reading along with the transcription text. This helped me to become even more engaged with the topic, assisting with the interpretation process. I initiated a conversation with the texts of the participants' narratives. In other words, I spent time reading and re-reading the interviews, asking myself questions (e.g., What did this participant mean when he said this?, How does this statement relate to this feeling?, How do the pieces come together?), journaling and taking notes, and developing maps of the interview(s), to ensure increased understanding, and to allow myself time to reflect on the interview content. This occurred within the hermeneutic circle[7] and helped to create a fusion of horizons. Analysis always leads to more questions in the pursuit of interpretation and understanding (Meyers, 2001). Thus, during and following the initial analysis, I developed additional questions based on my changing understandings of the topic, including specific uncoverings that were being discovered (Ellis, 1998). I then utilized these questions during follow up interviews with participants.

I then returned to the interview process to re-engage the participants. I re-interviewed participants starting with specific questions that I developed from my engagement with the initial interviews and the textual analysis. I had several questions for each participant, some overlapping and some unique, as there were similar and different issues emerging between participants. As was the case with my initial interviews, all subsequent interviews flowed naturally, and were not dependent on structured interview questions. Again, I taped interviews verbatim, had them professionally transcribed, listened to tapes while reading transcripts, and re-read transcripts numerous times. I made notes, wrote in my journal, and asked myself questions all in the process of interpretation and analysis.

Interviews and Analysis: Illustration of Journal Writing and Note Taking

Journal writing and note taking occurred regularly and helped me with the interpretation process. The following participant quote was taken to illustrate my journal writing and note taking.

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[7] My engagement with the hermeneutic circle occurred following the development of my entry question. The first loop was to continue to engage with the literature in the forward and backward motions, along with some volunteer work at HIV Edmonton, working with the agency and its members. The second loop included multiple pilot interviews, which also helped me to engage with the topic (Kezar, 2000).

> *Bursts, I mean like the roller coaster, I go ballistic and I really just go to the limit until I either lost everything or just [became] mentally, physically exhausted. Usually it was jail or a psychiatric hospital, you know, that would put a stop to my madness and I'd have to take a little reprieve or break and then I'd get all this support.*

I made several notes during journaling and note taking concerning the above participant quote. For example, I asked myself questions: "What does he mean by ballistic? How intense is this? How does he understand madness? What is his interpretation of support? What is the relationship between support and madness?" I tried to imagine myself in the participant's life: "What would it be like being on a roller coaster not knowing what was coming next, feeling out of control, overwhelmed, terrified. How would I deal with this? What repercussions would this have on a person's life, on a person's sense of self?" "Consider the experiences of going to such extremes within myself and within the world. What would this be like?" "…Would I take support? How would I interpret support in this situation?..." I also reflected on how my pre-understandings impacted my analysis and interpretations: "…How are my values showing up here? How is my reaction to this influencing me?...My beliefs…".

Development of the Categories and Themes

Through the interpretation process several overarching contextual areas were identified within the text of the participants' stories and descriptions. These areas were tracked through writing and reflection. They included areas such as: hope in the context of HIV and high-risk behaviours in the context of HIV. Within these broad contextual areas I placed various topics that seemed to fit within the contextual areas. For example, within the broad contextual area of hope in the context of HIV I placed participant quotes and my own reflections on areas such as: hope and story and experiences of hope in the face of HIV. Further analysis, reflection, and interpretation gave way to common threads which seemed to offer connections between and within the various topic areas. In developing the themes I separated key sentences, statements, and emotions into the different topic areas. These were then explored and played with in the formal development of the themes or connections within and between the topic areas. This was a process of connecting my participants' perspectives, or horizons, with my own horizons, helping me to see their perspectives and enlarge my own horizons. I began to note several thematic areas of rich importance which participants had, in part, highlighted and which I believed, in part, could be central themes. For example, in listening to participants' stories there were many references to hope, some direct and some more subtle. Participants talked about multiple objects and experiences of hope in their lives such as: relationships, counselling services, and educational opportunities. These objects and experiences seemed to fit within the broad topic area of hope in the face of HIV. These thematic areas, along with others, became the central points of the project and were constantly being open to re-interpretations and changes.

Reflection and re-engagement continued until I had a satisfactory interpretation and understanding. Importantly, this did not mean that I had reached a true objective understanding, only that I had reached an understanding that was satisfying for the participants and myself. Clearly, the participants' understanding, and readers' understanding, can, and will, shift with the addition of new horizons.

Development of the Narrative Accounts

Following the second and third interviews, and during the development of thematic areas, I created written depictions for each of my participants. In writing these accounts I spent time reviewing the interview transcripts along with my own interview notes, which contained rich context and detail surrounding the interviews and of the participants' lives. I initially created separate outlines for each participant account, which included key pieces of information I wanted to include for each participant. Once I was satisfied that I had a detailed outline I began the process of crafting the narrative depictions. I included detailed context, circumstances, and emotions, highlighting the life histories of each participant, including their journeys and struggles with HIV/AIDS. I wrote these narratives as if I was responsible for documenting their individual stories and lives. After completing a draft copy of an individual's narrative account I spent time away from the account, allowing myself time to reflect on the process and outcome. Following this reflection, I returned to the account, re-reading it and relating it back to my notes and memories of the individual participant. In some instances, I was even able to have the participants themselves review the narrative account. In these circumstances minimal changes were suggested. Writing these narrative depictions of each case allowed for the development and addition of increased context. It allowed me to conceptualize the lives and experiences of each of my participants. Although I was not able to include these rich contextual depictions in the formal write up and dissemination of the present research project (i.e., due to confidentiality issues) I have included brief written narrative portraits for each participant. These will provide the reader with a written description of, and introduction to, each of the participants and will help to provide context and understanding for the reader. It is my hope that these descriptions will help to make the participants distinct and real as the reader reads the themes and composite depiction. Following the development of the narratives I continued with the formal development of the themes. The narrative development helped me to see and understand the emerging themes within the context of each of the participants' lives.

Analysis, Interviews, and Self Reflection

Journal writing also assisted me in the process of self reflection, an important aspect within qualitative research. For example, I was interested in tracking and reflecting on the impacts of being both a counsellor and a researcher. During interviewing, my clinical skills were highly useful, helping me to analyze the accounts, formulate non-directive and directive purposeful questions, and create a safe and open atmosphere. I did encounter some challenges during interviewing related to my clinical background. For example, differentiating my role as a researcher as opposed to a professional helper was difficult at times. I needed to be very cognizant and aware of my stance (i.e., therapeutic versus inquiry) toward the participant, my questions, my responses, and my introduction of the purpose and limitations to our interactions (e.g., this is a research interview and not a direct therapeutic intervention/interview). During analysis, I found my clinical and analytical skills useful in formulating hypotheses and future directions to inquire about with the participants. These skills actually helped me to maintain a clinically relevant research project and also informed my research skills (e.g., basic interviewing skills).

Critically Evaluating the Interpretations

In critically evaluating the interpretations that were developed within the present study, there had to be a focus on typical standards of qualitative research. Numerous qualitative researchers (e.g., Beck, 1994; Conklin, 2001; Leininger, 1994; Lincoln & Guba, 1985; Osborne, 1990) have suggested that qualitative research needs to be evaluated differently than quantitative research in terms of appropriate standards.

Osborne noted that qualitative research focuses on subjectivity, understanding, and exploration in the description and interpretation of experiences, whereas quantitative research searches for objectivity and generalizability of facts. Thus, in critically evaluating qualitative case study and interpretive inquiry interpretations, specific considerations relevant to qualitative research needed to be considered. Interpretations were evaluated at different times throughout the study, often during the backward arc of the hermeneutic circle (Ellis, 1998). At the conclusion of the study, several specific criteria were used to evaluate the final interpretations. Ellis reported that a useful criterion is if the interpretation is consistent with other sources of information, for example, if the interpretation fits with the interpretations of others who have had the experience. Thus, the interpretations are held against external evidence (Packer & Addison, 1989). Second, a useful interpretation has attempted to incorporate multiple voices and possibly reach some consensus among researchers (Ellis; Packer & Addison). "An interpretation that can be called convincing should be communicable to others, should make sense to them and enable them to interpret new material in its light" (Packer & Addison, p. 285). Third, it is important to recognize the practicality or importance of the interpretation in terms of changing the way something is done, shifting the researcher's understanding on the topic, and/or fostering new solutions or directions to something (Ellis). A final criterion for consideration is if the interpretation is believable and coherent (Packer & Addison). These criteria have been considered throughout the present study.

Ethical Issues

Confidentiality

Confidentiality was a very important part of the present study, especially given the vulnerable nature of people living with HIV and AIDS. Confidentiality has been, and will continue to be maintained, in part, by storing data in a locked filing cabinet. Participants were asked if they would like to generate an alternative name, as to avoid the connection of their data to their identity. Those participants who chose fictitious names then utilized these names in all written materials and correspondence throughout the duration of the study and following its completion. My supervisor and myself were the only ones who knew the participants' identities, and the only ones able to link participants with their data. Five of the participants in the present study chose an alternative name for this purpose. Remaining participants did not chose alternative names for the study. In these cases, I created an alternative name for the participants. The tapes of the interviews were then destroyed following the completion of the project, and actual written transcripts will be destroyed five years following the completion of the project.

Informed Consent

As previously mentioned, participants were recruited through HIV Edmonton by giving potential participants informed consent forms with a detailed description of the study (see Appendix B) and letters outlining the study (see Appendix C). Following agreement to participate, participants were given demographic questionnaires (see Appendix D) and the option of receiving interview questions (see Appendix A) several days prior to the interviews. First contact occurred from the agency (i.e., the agency presented the study to a group of clients and then these clients had the option of contacting myself or the agency, on an individual basis, for more information), by a counsellor or a care worker mentioning the study, to protect potential participants who did not want to be involved in the study or have their identities revealed to an outside researcher. Interested participants who met the basic criteria were invited for an interview. During the initial contact (i.e., prior to the actual interview) the study was explained verbally to ensure it was fully understood by the potential participant. Furthermore, any questions were immediately and fully answered. Prior to the commencement of the actual interview, the study was fully explained again and it was ensured that the participant understood all aspects of the project. The informed consent form was then signed by myself, the participant, and a witness (i.e., the contact community worker from the agency) prior to the beginning of the interview. The informed consent form was written in simple, plain language to ensure understanding.

Minimizing Harm and Protecting Participants

Participants were informed, in advance, that if they wanted to stop the interview at anytime they would still receive the full 60.00 dollars (i.e., for both interviews). There would be no repercussions for the participants if they wished to withdraw. All of their data would be pulled from the research project. Participants were informed about the purpose of the study and were told in advance about the research study questions. To ensure that consent was as informed as possible, participants were also given the option of receiving the questions several days prior to the actual interview. This was partially to allow the participants time to think about the questions, but also to give the participants time to reflect on the nature of the questions and tentatively decide if it was something they really wanted to be involved with. It is also important to note that specific selection criteria were developed to help reduce any risk for prospective participants. These selection criteria included: (a) potential participants were all involved with HIV Edmonton or Living Positive, which suggested that all potential participants were connected to a service provider and had access to ongoing support, (b) all potential participants had received counselling services following their HIV diagnosis, which suggested that they had all had an opportunity to address some of their potential distress, and (c) all potential participants needed to have been living with their HIV diagnosis for two years or longer, which suggested that they had had some time to deal with their HIV diagnosis, and would be less likely to be at high-risk during actual interviews. Before commencing the actual interviews the potentially sensitive nature of these questions was again discussed along with informed consent and the study purpose. During the actual interviews the participants were given numerous opportunities to withdraw if they were uncomfortable in anyway. Furthermore, if the participants had felt they had needed to talk with a psychologist during, or following the interview they would have been directly referred to Dr. Lynda Phillips (i.e., Dr. Phillips is the registered psychologist employed by the HIV program at the University of Alberta Hospital and had agreed to see any participant in this study, free of charge, who needed services due to something that came up during an interview). If this was not preferred, for any reason, the participants would have been given a list of additional counselling resources, and I would have helped the participants utilize this list. In the unlikely event that counselling had of been needed immediately, I would have notified one of the on-site (i.e., HIV Edmonton) counsellors to help with the situation. However, it is important to note that during the interviews I also utilized my own communication skills to deliver these questions in the most sensitive and non-threatening manner possible. Furthermore, I used these skills to monitor the participants' reactions to my questions and the overall interview. Thus, if the participants were experiencing distress I would "slow down" or "close" the interview, as well as respond to the participants' distress. Following this, I was prepared to take appropriate action to ensure the safety of the participants (e.g., see an on-site counsellor, refer to Dr. Phillips) if this had been required. No participants in the present study withdrew early from interviewing, asked for their data not to be included in the formal analysis and write up, nor asked for a referral for services from a psychologist or counsellor.

Concluding Thoughts

Within this chapter I have highlighted key considerations within qualitative case study research, the underlying method of the current study, along with philosophical hermeneutics, which describes important processes of interpretation and understanding. I also focused on key components of the application of the study such as defining boundaries surrounding the phenomenon under study as well as collection and analysis of the data. What follows is a series of chapters which focus on the results of the study. These chapters include the narrative portraits (chapter four), the topics and themes (chapters five, six, and seven), and the composite depiction (chapter eight). Results chapters have been divided into the different categorical and thematic sections, to represent the breakdown of the parts and comparison with the whole as elucidated by philosophical hermeneutics. Chapter eight, the composite depiction, represents a return to the whole. What follows next is a focus on the narrative portraits of the participants of the study.

Chapter Four: Introducing the Research Participants

This chapter introduces and describes the 12 individuals who participated in this study. These descriptions are intended to provide the reader with participants' background information and life experiences necessary to create a contextual understanding for the remainder of the results and discussion sections. These introductions are provided to paint a picture of the participants' individual stories, which are rich with the actual themes presented in later chapters.

Before introducing the participants, a brief comment on confidentiality is important. The participant descriptions are brief and have been altered in some ways to protect the confidentiality of the research participants. HIV/AIDS community-based agencies are extremely small and close knit, with members often knowing many details about others' personal lives. Hence I have taken care not to include unique personal information. Presenting personally unique information can compromise the confidentiality of the individual participants. This is especially the case because one of the focuses of community-based research is on disseminating results to community members. Thus, within the study, care has been taken to avoid presenting too much identifying information on the various participants. In short, confidentiality must take precedence over the presentation of the individual participants' identifying information.

Ralph

I remember first meeting Ralph. He was an insightful person, very eager to share his story and learn more about himself through the interviewing experience. He told me about his experiences growing up in a religious household under the love of a caring family. He remembers being well taken care of by his mother and father. During the interviews this was apparent as Ralph's eyes swelled and he became choked up as he talked about his parents. Some topics during the interviews were difficult for Ralph. He sometimes looked around the interview room, avoided eye contact, focused on the floor and walls saying "it can be hard to talk about these early times". Although Ralph found it challenging, he wanted to continue. Ralph told me that as he grew up he learned the value of a dollar and the importance of being able to look after his family. He developed and owned his own business, which turned out to become very successful. He became a middle class citizen and spent time with affluent and financially well-off people. Ralph placed a lot of value on this type of lifestyle, buying nice material objects and rarely being without what he wanted. He had a significant other with whom he had long term plans of children and marriage. Ralph loved her very much.

During the interviews, Ralph slowly began describing another side of his life which he labeled as "problematic"; he was struggling with a strong alcohol habit and he was occasionally doing drugs such as morphine and cocaine. Ralph spent a lot of time partying prior to becoming HIV-positive. He was spending a lot of time with friends who lived on the streets and he was also selling some drugs. Ralph described this part of his life as being "out of control". At that time he says he did not realize the seriousness of his problems. One day, close to Christmas, Ralph became very sick and went to the hospital. He remembers becoming ill and being very uncertain as to what was wrong. He was scared, and for the first time in a long time, he began to realize how serious his problems with alcohol and drugs were becoming. Hospital staff conducted many tests on Ralph, but it was not until they were running out of testing options that they conducted an HIV test. Ralph left the hospital and shortly afterwards started to feel physically better. This newfound health propelled Ralph back into his alcohol and drug habits. It was not until several weeks later that Ralph was given the news of his HIV status. He remembers receiving the telephone call right in the middle of the Christmas holidays. As Ralph puts it, his worst nightmare had become a reality.

After his diagnosis everything changed. He lost his partner and his business. He lost his will and courage to go on his chosen life path. He plunged himself into numerous and intensive high-risk behaviours. He believed he had six months to live, and that he had been handed a death sentence. He stopped caring. He was angry and “out of control”. His high-risk behaviours included: speeding in cars, getting into car accidents, picking fights with people bigger than him, and drinking alcohol and doing drugs. Ralph wanted to die. Part of him believed that these risky behaviours would kill him. To get money after his diagnosis Ralph started engaging in criminal activities such as house break-ins. He really did not care. Ralph believed that there was nothing else that could be taken from him; he had lost everything. He had given up his will to live.

Diagnosis had the effect of isolating Ralph, forcing him into a lonely self-defeating existence. He became reclusive, telling no one of his HIV status. As he became more and more focused inward on himself he came to believe that he was alone and he had no options to save himself. Entrenched in his self-protective shell of “not caring” seemed only to foster more risky behaviours.

Ralph had an ingrained belief that he needed to have a family. This was one of his central hopes in his life. The reality of HIV cast doubt over Ralph’s dream to have a family. Today, upon reflection, Ralph believes that this dream has died, along with many of his other hopes and dreams such as financial security. To make things even worse for

Ralph, he felt that after he became diagnosed with HIV he did not really fit in anymore with his own family. Shattered was Ralph's dream of having his own wife and children. He was left with the broken reality of no longer feeling as if he had parents and siblings. He felt alone. Sadly, his brother and father have now passed away leaving him no chance to "mend broken relationships". Regret and sadness compound his longing to have a family to call his own. HIV seems to have stolen his dearest dream.

Despite HIV's blows to his dreams and hopes, Ralph tries to find purpose and renew his hope as a peer counsellor in local community-based agencies. He still struggles daily with finding hope and purpose in his life even though he is involved in these agencies. Being around people at these agencies helps him to find support. Without support, he wonders if he could continue to fight against HIV.

Ralph has some regrets about not taking his own advice 14 years ago. He frequently tells newly diagnosed people to just keep living their lives and work toward their goals. He often wonders what his life would be like today if he had just kept going forward in his life. Today, Ralph is 42 years old and has been living with HIV for 14 years. He says he has learned a lot from having HIV. He has learned to be grateful and appreciate life and now knows what is really important—family and health. In this sense, he says he is glad he has HIV.

Ted

Ted lived on the streets of Edmonton for many years. His lifestyle consisted of homelessness and poverty. Prior to living on the streets, Ted lived with his caring family who had sheltered him. In early adulthood he left this family to return to the streets and his previous lifestyle. He still maintains contact with his family, especially in times of need. Ted always had a desire to help people, which came from his caring, eternal hope, and spiritual convictions. Today he is a peer counsellor and even has completed courses in professional helping.

On the streets, Ted met a partner and fell in love. He cared very deeply for her, and wanted to provide for her and begin a family. One day, his girlfriend became ill. It turned out that she had HIV and was becoming sick. It did not take long for her to pass away. Ted discovered following her death that she knew of her HIV status prior to her becoming sick. He was very upset that she did not tell him and angry that she may have infected him with the virus. Ted recalled being stuck between competing emotions--betrayal for her lies and loneliness as she was gone. He did not know how to deal with these feelings, but managed to seek out HIV testing services. Ted had many tests only to discover that he had HIV.

Ted was shocked and in disbelief after the news of his HIV. He was faced with a lot of strong emotions like anger, denial, grief, and guilt. One of these emotions, anger, was directed at his partner for carelessly infecting him with the disease and then, through death, leaving him to deal with it on his own. He was enraged at her, and did not know if he would ever be able to forgive her. He said "it just made me mad that she could, just in a sense, give it away and not care". In time, Ted worked on forgiving his partner through religion and spirituality. He also matured, realizing his anger and hatred toward his partner were not helping him move forward in his life, which helped him to forgive her.

Following diagnosis, Ted needed to actively and consciously search for hope. It was just not there like it usually was; he needed to make a strong effort to find it. He says that recognizing hope and using hope are two different things. You may see it, but you need to work at using it. For him, he needed to find it and work at using it.

Although Ted did not deny the HIV diagnosis for long, as he suspected it prior to getting the news; his anger was overwhelming, as if feeling robbed of everything good from inside of him. When Ted first thought he might be HIV-positive, it was a few months before he even got the testing done. At this time he thought to himself, "If I ever got a diagnosis of HIV, I would completely lose my mind..." At that time he foresaw himself getting a gun and killing as many people as he could or going to another province to just completely go nuts with high-risk behaviours and enjoy his final period of life before he withered away to nothing. To his amazement, he did not desire to follow through with these extreme plans when he did finally get tested and got the news. He attributes this to his family's support and his upbringing. He explains "well, my parents were a big part of it, like how they raised me, it just wasn't in me to go nuts or completely over the deep end". Ted still found himself acting dangerously and even "went a bit crazy" as a result of the news and due to his overwhelming feelings. He spent a lot of time drinking alcohol and using harsh substances. Ted believes that this was largely in an attempt to numb or reduce the emotions that he could not control. He would go to bars and get drunk and then pick fights with the biggest people he could find.

For Ted, hope has been available and apparent in varying degrees. Ted recalls going through rough periods when his hope was challenged, but even then, he remembers there was still some hope. Following diagnosis his hope was "put on the back burner" and was not immediately available. This was when he lost control for a while. Even here, with hope fleeting, there was still some hope available. He attributes this largely to his family and especially his parents, who taught him to have faith. His family would sometimes even "hunt him down off the street" to take him home and give him love and food. For Ted, "as long as you're walking and talking and breathing there's always hope". In this sense, Ted believes that hope is about being alive and that life can continue.

Presently, Ted is on his second regime of medications. Medications give him hope, as they help him stay alive. He believes they will keep him healthy and living for as long as he needs to be here to accomplish his life purposes. He also feels concern and apprehension for his future, as he believes that when he gets to the end of his medications this may challenge his hope. Stigmatization is something that challenges his hope and Ted has devoted much of his recent years to fighting against stigma directed toward people with HIV and AIDS. This stigmatization caused Ted to turn inward, not telling others about his HIV status, leading to him feeling isolated and alone.

Ted's dangerous behaviours after his diagnosis only lasted a few months before he found himself wondering what else he could do with his life and thinking about how he was really going nowhere with his present behaviours and attitude. Ted needed to find ways to build on his fleeting levels of hope and deal with the strong emotions he was experiencing. He was getting very tired of his unhealthy lifestyle, and of his tendency to lose control when under the influence of alcohol and drugs. He began to realize that the only way he could get out of his cycle of destruction was to make the decision to get healthy for himself, as opposed to for anyone else in his life. He made an effort to begin learning about HIV and AIDS as well as Hepatitis C. He completed formal courses offered by local HIV organizations and did a lot of reading on the topic. He talked with other people who were living with HIV to learn about their experiences and gain their knowledge on the disease. Ted was adamant that the best way to become empowered to deal with a disease like this one was to learn about it and how to defeat it. He learned that he needed to make major lifestyle changes such as sleeping regularly, eating a proper diet with essential vitamins and nutrients, avoiding alcohol and drugs, and staying out of trouble (e.g., fights, high-risk situations).The groups at a local HIV organization, counsellors, and the peer supporters helped him to stay on track. These groups also helped him to fight and survive, as well as to build relationships and feel less isolated. Through learning and building relationships came glimpses of hope for his future.

Today Ted is 35 years old and has been living with HIV for six years. He trained to become an HIV peer counsellor, which helps him feel useful and hopeful about his future. Ted tries to help newly diagnosed people to understand that they are not alone and there are many others just like them. He likes to look back on his experiences and what he has learned. He has, and has always had, a strong conviction and belief in hope. He believes we need hope to get through tough experiences, especially HIV. For Ted, "if there is no hope, then there's nothing, we may as well be dead". He also believes that to get through the HIV diagnosis you need to get through denial and anger, and you need to make meaning out of the HIV diagnosis.

Randy

Randy, age 42 and living with HIV for 14 years, remembers back on a life full of music. Randy says that much of his hope comes from this music, which he loves so much. He spent much of his adolescent and adult life playing music and being involved in a band. He said part of this lifestyle was high-risk behaviours such as heavy drug use and multiple sexual partners. Before HIV he had a lot of hope in his life; his life was exactly the way he wanted it to be.

In the face of dreams fulfilled, Randy's life took a profoundly life-altering turn. One day Randy became ill. He went to the hospital and had several tests, including an HIV test. He had a lot of risk factors for HIV like risky needle sharing, so he suggested to hospital staff that they do an HIV test. The doctors believed it was mono, but this came back negative. At this point he remembers "just hoping it was not HIV". This was the only thing giving him any hope at this time. He was terrified, the thought of being HIV-positive seemed insurmountable. Tremendous anxiety and fear flooded his body and mind while he waited for the phone call from the doctor's office.

When the doctor called and invited him in to discuss the test results he recalled feeling terrified and hopeless, as if being trapped in a dark hole with no prospects of escape. When he got the diagnosis of HIV, he described it as being "sheer hell". There was no hope after this. Suicide was the first option, but several things helped him fight off the desire to die. Randy remembers feeling fear toward dying and experiencing major depression with no energy, each preventing him from making a suicide attempt. He did eventually attempt suicide several months after the diagnosis. Randy began using more and more alcohol and drugs after the news. He describes falling into a major depression for the first few months after the diagnosis and alcohol and drugs helped him to numb the painful and overwhelming emotions that he could not seem to purge from himself. The doctors only gave him two years to live, which put him into a very dark, suicidal, and high-risk place. He completely "lost it", for many months after the diagnosis, which lasted for roughly two years into living with the virus. Randy dwelled in a place where life did not matter and he had no concern for what might have happened to him. Life was guided by an image of a sickly, dying person who was unable to care for himself. Terrified people would find out and stigmatize him for having HIV, Randy desired to speed up the dying process. So afraid was he that he even told some people he had cancer as opposed to HIV. His anger, pity, and contempt flooded him like a tidal wave, ravaging his very being, compelling him into submission.

Despite his tremendous hopelessness Randy remembers looking for help. He remembers beginning to recognize his strengths after the "two year prediction of life left to live" that doctors plagued him with when he was diagnosed. Peer counselling, support from local community agencies, professional counselling, friends, his sense of humour, methadone, and maintaining hope for the future all contributed to helping him get his life back on track. Finding purpose through playing music, helping others with HIV, and helping to reduce the spread of HIV helped him to deal with the diagnosis and offered him hope. Randy said it was largely outliving the doctor's prediction of two years and meeting others who had been living for a long time with the virus that helped him to start caring again and get his life going. He felt more positive and able to fight against the virus. This prompted him to learn about HIV and become empowered to stand against the virus. Randy remembers, "It helped me to stop dying of HIV and start living with HIV".

Randy refuses to take any of the present-day HIV medications as he believes this will prevent him from obtaining critical medications later in his life which will turn the HIV virus into a chronic condition. Doctors trying to get him to take antiretroviral medications challenge his hope as his hope is largely connected to his beliefs that new medications will be developed that will reduce HIV to a chronic condition. He believes that these medications will be developed out of existing HIV medications, and resistance to any of these existing medications will preclude him from any new medications which could turn HIV into a chronic condition. When he thinks about the potential of these medications he feels very positive and hopeful.

Today Randy is very hopeful and takes good care of himself on a holistic level (e.g., mind, body, nutrition, sleep, exercise). He plays sports and is in very good shape, even playing rough sports such as football and rugby. He believes that HIV is a beatable disease and that through a positive hopeful attitude, and good relationships, people can live a healthy, normal life with the condition.

Derek

Derek is 39 years old and has been living with HIV for 12 years. During the first interview I saw Derek as someone who had been through a lot of difficult and challenging times and was himself very tough. As the interviews progressed Derek let down his guard and began to show a compassionate and caring side as well as a genuinely concerned side for the well being of others, especially those with HIV. Prior to HIV Derek had a girlfriend, children, and a good job, and he was looking forward to his future. He remembers feeling good about how things were going in his life. Yet, Derek says he also had his share of problems. There were financial concerns that caused him tremendous stress and he used cocaine on a regular basis. Derek recalled his pre-diagnosis drug use. There was a regular group of 10 people who all chipped in to get a supply of drugs which they would then use together. Although his partner also had problems with drug use, and was aware of Derek's cocaine use, she was not involved with this group of users. Derek contracted the HIV virus through his involvement with this group. In the group someone had been living with HIV for several years. Sharing needles with all of the members of the group eventually lead to Derek, and some of the others, contracting HIV.

A cloud of disbelief, denial, and anger descended following his doctor's news of the HIV. Derek felt alone without options. Uncontrollable chaos fell around him. It was as if he was plunging toward the ground in a crippled aircraft, watching his final seconds of life being erased in terror. As he puts it, he completely lost control. He left his partner, his family, and his job. Fear won the fight, as Derek was too scared to tell those he loved most about the HIV. Fear of his family's rejection, homophobia, and disgust turned Derek toward isolation. He hid the news from his parents, thinking they would not understand. Heavy alcohol and drug use consumed him. His way of life became that of a "suicide mission". "Yeah, it was fucking nuts, I made an excuse and I broke up with my partner, I just left her in the dark, went nuts. Took all of the money out of the bank and started partying and went on a suicide mission. See how big of a hit [drugs] I could do..."

Derek stopped caring after his diagnosis of HIV. Life was over and there was no hope left. Dying a normal painless death, not a scary humiliating death like he had seen on television and heard about through others, became his wish. "It's the funniest thing, I just didn't care anymore and I wanted it to end and I didn't want to end in a hospital in a bed and suffering and 35 pounds, 50 pounds or something like that, you know like some of the pictures you see, and any other way to die would be better. It didn't matter how it was as long as it happened." For Derek, his high-risk behaviours were directly related to him wanting to die, to avoid the fear associated with his beliefs of the type of death HIV/AIDS leads to. His became a suicide mission, as he saw his dreams and future destroyed. “There was no hope…my life was over, I destroyed everything that ever happened, every good that was happening to me was gone and I had fucked everything up, all my dreams and aspirations were destroyed, there was no chance on ever building any of it again. Growing old and family and grandchildren and you know all kinds of things about all that, that was gone. I didn’t think I’d last long enough to see my kids be 10 or 12 or 15, I never thought I’d see them.”

This “suicide mission” and the high-risk behaviours went on for almost two years. Derek continued to destroy his body and act dangerously, believing there was nothing else to live for and his life was over. He had pushed everyone out of his life and was alone. Wrapping himself in a blanket of misery, hiding away from the world. One day he became connected to a local HIV community-based organization, where he met others living with HIV and he began to see that quality life was possible after the diagnosis of HIV. He saw things such as the living quilt (i.e., a quilt representing hundreds of names of people living with HIV/AIDS and how long they have survived with HIV/AIDS). This changed his perceptions and his beliefs about his future and his aspirations, he began to feel and experience hope. He started to learn about HIV, which he found empowering, and further contributed to his sense of hope.

During this time Derek also met another partner and has been with her ever since. He has a new child with her and now has contact with his older children from his previous relationship. He says he is getting his hopes and dreams back. Seeing through the dense fog of HIV into what can be a sunny future.

Today Derek talks to newly diagnosed people and tries to give them hope. He does this by helping them to see that they can have a future with HIV, and that HIV is not an immediate death sentence. He is very creative and invested in helping others with the disease. Derek told me during our second interview that for him, hope is highly related to his family and his children. These are his hope and his future. He said that without his family, he could never have survived HIV. These people were the very people he pushed away after he received the news about his HIV status.

Steven

Steven remembers having a "great life" before HIV. His main goals were met as he had a job and financial security. After diagnosis, this was all gone; HIV destroyed much of this for Steven. Steven is 39 years old and has been living with HIV for about seven years. I found Steven as private, and even shy, during the initial interview, not going into too much detail. Steven told me that he usually keeps to himself in many situations. He relies on his relationships at local community-based agencies to be himself and share with friends and fellow workers. Before HIV, Steven lived on the streets and used a lot of drugs. He was into using, and sometimes sharing needles. This placed him at risk for HIV. Yet, getting his blood work done and learning he had HIV was still shocking. During the interview Steven told me that part of him was expecting it to be HIV, whereas a big part of him was hoping it was not. In fact, Steven said that when he was waiting for more test results on his HIV status, the only hope he held was that it was not HIV. A hope that would soon vanish, with the reality of HIV looming overhead.

When Steven was given the blow of the HIV diagnosis he was terrified and very uncertain about his future. The fear was blinding, as if caught in a spotlight with no direction for escape. He did not know where to turn, where to find help, or even who he could talk to. Steven remembers being alone, alone with a death sentence that he did not understand. He felt judged and condemned, like some divine force was casting sentence on him for all his wrongs, and now the world could watch him suffer and die. He told no one of his HIV status, not wanting others to know, for fear of further judgment. Steven recalls that when he first received the diagnosis a big part of him denied that it was HIV, while a small part of him allowed a glimmer of this tragedy to enter into his awareness.

Shortly after Steven found out it was HIV, his drug use significantly increased. His loss of hope, his despair led to high-risk behaviours to help him forget his problems. When he was high on drugs, which was almost all of the time, he did not think about risks that could cause him or other people problems. He simply did not care about what would happen to himself. Curiously though, he remained concerned about others. Steven became very cautious in his drug use, so as not to infect other people with HIV. He tried to maintain safety with his needles so others would not stick themselves. Yet, Steven really did not care very much about his own well-being. He thought his life was pretty much over so he did not really take care of himself; he engaged in a lot of drug use, and was not very safe when it came to his own personal drug use (e.g., dirty needles he used).

It took several months after Steven's diagnosis but he eventually connected with a local community-based agency. At these agencies, Steven saw a lot of people living long and healthy lives with HIV. It was not until he met others living with HIV and saw how they were living positive, healthy lives with the virus that he began to learn about HIV and make changes in his life. This helped him to feel encouraged and hopeful that he could live a long, healthy, and meaningful life. Steven became a highly dedicated volunteer for several community-based agencies that serve people living with HIV or AIDS. He became trained in peer counselling, peer education, and many other important areas of helping the agencies and clients (e.g., fundraising). One of Steven's goals is reducing the spread of HIV. Volunteering helps him to feel good, find hope, and have purpose in his life. It helps him to feel as though he is making a difference and helps him to forget about his own problems and concerns for a little while.

Another source of hope comes from his family (i.e., mother and brother), especially his mother. Steven told me during the interviews that his mother is very supportive toward him and he visits her whenever he gets the chance. He does not get to see his family very much as both his mother and brother live in other geographical regions.

Today Steven hopes for changes in his life such as a steady place to live, meals he can count on, and the opportunity to permanently get off the streets. He also has a lot of hope for a longer quality life. At the time of the interviews Steven was not taking antiretroviral medications but was considering beginning them based on his doctor's suggestion. This was a stressor and a challenge to Steven's hope levels due to the side effects of these medications and what it means to begin taking them (e.g., declining health, using up your options). He feels that he needs change in his life, especially more stability. He has hope that this will happen and things will get better.

Bob

Bob is 42 years old and has been living with HIV for about six years. He has experienced a long standing addiction problem for the majority of his life. This has been a huge threat to his hope and his belief in the possibility of a good future. Before HIV, Bob hoped for a drug free existence and more self-esteem. When asked about a time in his life when he was hopeful for his future, Bob replied that he could not think that far back in his life. He was hopeless for a long time.

High-risk behaviours were part of Bob's life before he became diagnosed with HIV (e.g., risky needle sharing) and he also had a partner who had HIV. Bob did not realize his trusted partner had HIV until after she became sick with HIV-related illnesses. The two of them stayed together and helped each other for several years until she died of AIDS-related illnesses. Bob told me during the interviews that this relationship was very unhealthy for him, and he did not really want to talk about it. Bob was not completely sure if he contracted HIV from his partner through unprotected sex or from his partner through unsafe drug use, but was sure it was contracted through the relationship.

When Bob became diagnosed with HIV, his hope diminished further. He says he was "absolutely hopeless". Anger, as if erupting from a volcano, initially dominated and ruled his feelings. He learned to deal with this anger by suppressing it, as if building walls around the hot spewing lava. Bob pushed the anger deep inside of himself, denying its existence with the help of alcohol and drugs. Bob recalls that this just made it worse. He became angrier and angrier until holes began to break through his walls of denial and the anger erupted with renewed intensity. He also pushed others away, out of his life after diagnosis. Not wanting others around to see his misery, he came to live a very lonely existence, which only worsened with more and more isolation.

After diagnosis Bob's drug use and high-risk behaviours gained a dimension beyond what even Bob could imagine. For Bob, being around others who used drugs (e.g., cocaine) made it much harder for him to quit using drugs. He said that after diagnosis he just did not care, and was not at all concerned with the needles he used or what happened to him. “Yeah, especially the needles part, like I used a lot of others’ needles, well I’m already fucked so it doesn’t matter if I use somebody’s syringe or whatever, you know it was much later that I learned about you know all the other things that you can [contract]…Others’ shit can make you a lot sicker too”.

Bob told me during the interviews that he did not think others would be “stupid enough” to use his needles, but he did not actively try to deter people from sharing his needles. He was struggling with overwhelming feelings of hopelessness and despair, suffering from a long-standing drug addiction, and was facing the loss of his partner. As he recalls, he was not able to always control his high-risk behaviours that may spread the virus, especially during times where he was high. Bob was also involved in a lot of other high-risk behaviours, such as fighting, for which he even spent some time in jail.

Everyday living is hard for Bob. He is still living on the streets and takes shelter wherever he can find it. He sleeps in different places, on the streets or in shelters, and takes meals if he can find them. He told me during one of the interviews that spending time on the street is terrifying and slices away at his hope. As if leaving nothing but the hazy image of what once was a glimmer of hope, Bob experiences a sense of utter emptiness when on the street. He wakes up, is thankful for his survival, and finds renewed hope to move on. Hope for Bob means doing something productive with his life (e.g., helping others), making changes in his life (e.g., getting completely off of drugs), and having a decent shelter.

Local community-based agencies and community members helped him to deal with HIV, as they were there to listen to him and help him out. As he recalls, they helped him to stay alive and helped him to reduce his high-risk behaviours such as IV drug use.

These agencies also gave him hope by being there for him and showing him that quality life was possible after a diagnosis of HIV. These agencies have helped him realize he can survive, and this has helped him to feel hope and made him believe that he has a future. For him, this future is largely about helping others with HIV. He does not volunteer, but does talk to others living with HIV. Bob believes for him, it is too late in a lot of ways. Serious problems with addiction and health have overtaken any beliefs that he will live a long and healthy life. Hope and encouragement are found when Bob allows himself to think about helping others to either prevent HIV or help someone struggling with HIV. Although Bob has stated that for him it is too late in many ways, he does find faith in religion which also gives him hope.

During the interviews Bob told me that he is much more willing to let others into his life today, which is important in successfully dealing with HIV. He also said that for him, dealing with HIV and increasing his hope are connected to hearing the stories of others who are surviving with HIV.

Jake

Jake is 40 years old and has been living with HIV for ten years. Before HIV, Jake had a successful business and was financially secure. He had a wife and a family. Jake made it clear during the interviews that in the past, before HIV, money and material objects were very important to him. Following HIV these possessions became much less important. He focuses on what is in front of him and what he and his family need to survive. For Jake, family is the most important thing in his life and his family brings him much hope for the future and himself. Growing up, Jake had it very hard and he experienced difficult times. He recalls being abused by his father, who had a bad temper. He highlights physical health problems which have resulted in additional stressors.

Before Jake was diagnosed with HIV, he was also struggling with a drug addiction. His wife, at the time, was also living with a drug addiction. Jake's struggles with drugs lasted many years, at times becoming more and more intense and then fading away. Ups and downs in his drug use have plagued him for many of his adult years. His wife eventually left him, and he ended up losing everything, including his family and his business. He decided to seek treatment and spent several months getting help for his addiction. Things began to look better as he was fighting his problems and staying away from drugs. Shortly following his treatment he began seeing someone else. She was also dealing with a drug problem. The lure of this relationship was strong despite its potential to lead them both back into the cycle of addiction. Unfortunately, their ability to fight the temptation of addiction was not strong enough. Falling backward, in an uncontrollable tumble plagued by addiction and high-risk behaviours, the couple plummeted into a high-risk lifestyle. This went on for several years, and eventually led to each contracting HIV. Shortly before Jake learned of his HIV status, his partner had died from AIDS. When Jake found out about his diagnosis, he lost control. He acted dangerously and lost any real care for life. Believing his life was over and his future finished, he became entrenched in a dark world of depression and hopelessness with suicide as the only available answer. He was not taking medications, eating properly, or sleeping, and his drug and alcohol abuse had reached new heights. This led to more high-risk behaviours as he was not thinking clearly when he was high and drunk.

He ended up at a local HIV community-based organization and met others living with HIV. He quickly began to see how they were living normal and healthy lives. He met several counsellors and psychologists who helped him to deal with the diagnosis and gain accurate information on HIV. This propelled Jake to get more help and treatment and try to make long lasting changes in his life. He began to feel hope and encouragement for his future. He began to believe more and more in the higher power of God and today attributes much of his success over adversity to his beliefs in God. He now has a large supply of hope and sees a future. Much of this hope grew through his new family (i.e., he met another partner and has a new child within this relationship) and his volunteer work at several different agencies. He spends a great deal of his time helping people living with HIV.

Today, Jake also hopes for a cure and hopes he can live long enough to see his child grow up. He told me that God gives him the strength to go on and deal with the struggles that exist within HIV. "He gives me the strength, the Lord is my shepherd and every time I start feeling down and out or worried I just think that over and over in my head, the Lord is my shepherd, I shall not want, and He's there. I never have a bad day, I pray in the morning and ask Him for help through the day, I thank Him every night for what He's done for me through that day, and when I do that prayer in the morning, I have a good day. There's nothing in my day that can happen that is going to make me sicker or make me want to use drugs or alcohol again. I have to have strength and I have to be lackadaisical inside because of my immune system, stress breaks it down, so I have to keep the strength up. So no matter how bad things get, God will make sure everything's okay for me as long as I keep believing and trusting in Him and asking Him for help".

Jake avoids focusing on the past or dwelling in the past, and believes in focusing on the future. He has consistency in his life and is happy to say his family has a place to live.

He told me during the interview that his message to newly diagnosed individuals is: “Don’t ever give up”. “If I can help somebody walk out of the office when they come in feeling like I did, hold their head back and smile, it makes me feel I’ve done something worthwhile. These counsellors…saved my life because I [wouldn’t] be here now if I hadn’t had HIV Edmonton and Living Positive… you can make a choice, you know the choice is yours. I remember living on the streets, I remember having to go to the Mission Center and the Mustard Seed Church for a bowl of soup. I don’t have to do that anymore. Why? Because here we go again with that word ‘hope’. Come on Jake, you can get yourself out of this. Doesn’t matter I’ve been down many times, but I’ve never been down and out because when you’re out, that’s it, you know that’s just total giving up, and I don’t know if you’ve ever seen it but there’s this picture of a crane trying to swallow a frog, his feet are hanging out the crane’s mouth and his front flippers are around the crane’s throat so he can’t swallow him and there’s a big slogan on top it says don’t ever give up…don’t ever give up”. Jake tells newly diagnosed clients his story of adversity and hope and helps them to realize that people can survive and be happy. Jake believes you need hope to get through HIV and you need to work for hope and not take it for granted.

Sam

Sam is 48 years old and has been living with HIV for 19 years. He is gay and has been living with a significant partner for several years. Before Sam was diagnosed with HIV he lived a very unsettled life with a lot of high-risk behaviours such as risky needle sharing and unprotected sex. He told me that he contracted HIV through putting himself in these high-risk situations. At the time Sam remembers struggling with a serious cocaine addiction that really made it hard to practice safe behaviours.

Sam recalls being diagnosed in the early 1980's, a time when HIV testing was still in its early stages. Doctors told Sam that the tests were not 100 percent accurate. This helped him to find some hope, in an otherwise hopeless situation, as he thought "maybe it was not HIV". He frantically underwent several HIV screening tests, some even under different names with different doctors. With each positive test result, Sam's hope faded, as if a sinking ship drowning into the sea. Sam held onto disbelief, refusing to accept that it was HIV. Convincing himself that the tests were not very accurate he maintained denial of the seriousness of his reality. He continued obtaining tests, until one day it hit him hard, what if the tests are correct? This threw Sam into a tailspin, one he was not prepared to face at the time. Although he had accepted that the tests may be accurate, he continued to fight, within himself, about whether he had HIV. He denied the severity of his situation, that HIV would kill him. He denied the need for precautions to keep himself and others safe. He believed he was going to die a slow, painful, and humiliating death. Any hope that existed was now buried in a pit of pain and fear.

Sam did not believe that HIV could be spread through sex, so he was not very careful about protected sex. When diagnosed, doctors knew very little about HIV and how to successfully treat it. There were no medications and very few options. Many of his friends were dying painful, humiliating deaths with HIV and AIDS. When he got diagnosed, he was not "thinking straight" and he went into shock. "I was not clear, doing a lot of drugs, I was not thinking straight…I was shocked at first…" Denial was in control. It led his lifestyle and his behaviours. This denial was everywhere. It even challenged his thoughts that he could be infecting others. As he puts it, "[I] went through a lot of denial, denying the fact that I could be infecting others..." Sam's drug use skyrocketed, even beating his old records that easily met the threshold for diagnosable addiction. A strong sense of not caring emerged, feeling as if he was going to die anyway, he wanted to at least die numb and doing the drugs that he thought he loved so much. Believing it was a death sentence, his high-risk behaviours were a means to a quick, painless death. As if wanting to choose how it would end and be in control of the final move, Sam continued to abuse his body and put others at risk. He believed that drugs and other high-risk behaviours would speed up the dying process. Sam continued with this high-risk lifestyle for several months following diagnosis.

It was not until months later when he started to learn more about the virus that he was able to stand up against the denial and begin regaining control. In time, he also surpassed the two year prediction of death that many doctors were making. This gave Sam hope. In fact, the longer he survived the more hope he gained. Sam struggled without the support of his family for several long years. Being HIV-positive and gay became a secret, one too terrifying to share with family. Fearing discrimination and rejection by society and his family he became reclusive and hidden in his HIV status and sexuality. It was not until the death of his father and a major drug overdose, two very serious and personally meaningful events in his life, where he was able to find the courage to tell his family about his secrets. His family offered some support and acceptance despite their apparent apprehension. Sam focused on the support and this helped him to find the energy and strength to continue making change in his life. Through perseverance and support Sam gave up his drug addiction. Getting off drugs helped him to see his life more clearly, regain his hope, and stop his high-risk lifestyle.

Today, Sam is very interested in the helping professions. He is a peer counsellor helping people living with HIV or AIDS. He is very interested in people, especially helping them to live healthier and longer lives. Sam is also working at a job and continuing his education. He believes he is here for a purpose, and that until this purpose is complete he is going to live. He has a strong attitude and belief that HIV will not kill him. Part of this comes from his overall internal belief captured in a phrase he shared in his interview, "I Can Survive!" He hopes for a cure and believes that hope for him is a very special and personal thing. He puts his hope in himself, as opposed to God. He says hope gives people strength. You need to believe in yourself to have hope and you need hope to get through HIV. He is also adamant that you need to let people believe in something and that there is no such thing as "false hope". Sam also said that hope sometimes will build from drastic things happening in a person's life. It is related to pain, suffering, and transformation. "For some people to feel their hope they need something very drastic to happen... I had overdosed and then found out my dad died… you know, I'm missing too much. I missed a lot in my family". Sam's advice to someone just diagnosed with HIV includes: knowing that it is not a death sentence, understanding that it is HIV and not AIDS, understanding that you need to take care of yourself physically, mentally, emotionally, and spiritually, and understanding how you can survive for a long time if you have hope and believe in yourself.

Ryan

Ryan is 41 years old and has been living with HIV for ten years. He has spent many years living on the streets with little shelter, has been involved with drugs, and has spent time in jail for fighting. Today he works several jobs and has a wife. The two have a steady living space and are doing much better than they were in the past.

When first diagnosed he thought it was the end of his world. There was an avalanche of emotions. Fear, uncertainty, chaos buried him alive. He was suicidal, feeling as if time and life were running out, as if his air supply was coming to an end. He checked himself into a local hospital, knowing that supervision was all that would keep him alive. Telling his wife and family was too much to even consider, as he was terrified they would leave him. Death was inevitable and was going to be fast, humiliating, and painful. As he remembered back, he said one of his biggest problems was he knew nothing about HIV, so he was not empowered or prepared to fight against it. Following diagnosis, his fighting, thoughts and urges for suicide, and use of alcohol became much more intense. He thought, "I am going to die anyway, so who cares". There was no hope after diagnosis. Anger, denial, and hopelessness fuelled his high-risk behaviours. The alcohol and drugs helped him to numb the painful fears of HIV and the hopelessness, despair, and uncertainty that overwhelmed him. Denial was his first response. Following diagnosis he says he "brainwashed" himself into believing it was not HIV.

HIV services were very scary for him. He did not understand them and did not understand the HIV itself. Most people in his life alienated him after he told them about his HIV status. It was not until several years later that he learned many of his family members also had HIV, and several of them were dying from AIDS.

Today he has a positive attitude and deals better with the diagnosis. He volunteers and works a few jobs. Although he has lost several family members to AIDS and this scares him, it does make him feel a need to get information on HIV and begin fighting against it. Following diagnosis, he saw peer counsellors and a psychologist. These people helped him to deal with HIV and get into a stable environment.

His wife also has HIV. He thinks that he gave it to her through sex. Both work together to help and look after each other. They make sure each other maintains a healthy lifestyle and follows their medication schedules. Both he and his wife fervently hope that they will get their daughter back from the legal system. She was taken from them while they were still living on the street. Ryan's attitude is that it is up to him whether he lives or dies. He believes you need to have a positive outlook to survive. Although at first he did not take his medications regularly, he now does and he believes they are saving his life. These medications give him a lot of his hope.

Sarah

Sarah is a 38-year-old woman who has been living with HIV for six years. During the interviews, Sarah recalled back to her earlier years. She told me that she remembers coming from a good home. She had good parents who were supportive and cared for her. Sarah told me that she moved around a lot and spent time in different cities growing up. She ended up getting into the drug scene at an early age, although this did not last very long. At the age of 19, she met a man who would eventually become her husband. Becoming pregnant pushed the two into marriage. With marriage came major problems in the relationship. She remembers him becoming very abusive toward her, causing her fear and self blame. This went on for several years, until she eventually found the courage to leave.

Sarah had some major health complications and actually ended up having a miscarriage a few years later with a second partner. Physical pain, due to her health problems, became a regular part of her daily life. Even strong coping eventually gave way to illicit drugs to help her control the pain. During these trying years, Sarah eventually learned that she had cancer. The unbearable life she was living seemed to only become worse with more and more bad news. She faced challenging times in treating the cancer and became very focused on hoping the cancer would go into remission. Severe fatigue and vomiting were among a long list of devastating symptoms. She remembers her symptoms becoming too much to handle and going to the hospital for more testing. When the doctor saw her a few weeks after these tests, she recalls that it was not good news. The cancer was still active and she also had HIV. This was a double blow to Sarah, who amazingly found the strength to survive.

One of her ways to cope was to immediately deny the HIV, as she did not really know very much about it and she was focused on the cancer. The denial worked for her for a short period of time as it gave her an opportunity to deal with her cancer and get her life on track. But as Sarah remembers, "it eats away at you". Her fear of it was largely due to her lack of knowledge regarding the HIV. She believes she contracted HIV from her husband, who had been cheating on her. She said she was able to hold it together for a few months following diagnosis, but then completely lost it for awhile. At the time of diagnosis and during the year after diagnosis she had no hope. With the loss of hope she was back into drugs in a major way, trying to numb and deny the pain, the fear, and the overwhelming feelings of despair. Drugs and denial helped her to temporarily derail the overwhelming emotional rollercoaster that she was trapped in.

Prior to HIV, Sarah was a very careful person with her drug use and never used others' needles. After diagnosis she just did not care what happened to her. Life was over and risky behaviours just did not seem to matter any longer. She used others' needles thinking "I am going to die anyway so who really cares". She was alone and did not tell anyone about her diagnosis, as she was scared to hurt them and send them running. Despite her lack of caring about what happened to her, she was able to find a way to care enough to keep her needles away from others who may try to use them.

Sarah became connected with a local community-based agency, which gave her the opportunity to learn more about the virus and talk to others who had been living with HIV for a long time. She found this to be very empowering, helping her to feel better about her diagnosis. She used this strength and knowledge to make some significant changes in her life. It also helped her to discover hope. Sarah seems to find hope through being healthy, knowing she has HIV and not AIDS, and helping others to learn about HIV and AIDS.

Sarah is now a volunteer at a local community-based agency and does some peer counselling work. Finding purpose has helped her in dealing with her HIV diagnosis. She has found this purpose in being around the community-based agency. Her mother is very supportive of her and is a large contributor to her hope. Sarah told me that having her mother in her life helps her to feel love and acceptance, two feelings that can sometimes be hard to find when you first get diagnosed with HIV. She says hearing stories and experiences from people who are HIV-positive is so important to her and helps her to have hope. For Sarah, the HIV is now part of her and she accepts that. This helps her to deal with it and move on in her life.

Jackson

Jackson is a gay man who is 40 years old and has been living with HIV for eight years. He was married for many years and has a child from that marriage. Prior to HIV, Jackson was engaging in a lot of risky sexual behaviours and was abusing alcohol. This was putting him at risk for HIV. Jackson described the process of his diagnosis as being agonizing. He needed to wait several weeks for the test results. He was tipped off that he may have HIV by an insurance agency doing blood work to see if he was insurable. He received a letter stating that they could not give him insurance and he should seek blood work, but no indication as to what the medical concern was. He needed to wait for two long weeks with the thought that it may be HIV and with the uncertainty of his family's HIV status. He kept wondering if he had passed it onto his family. Jackson became unresponsive to his world as a means to deal with all of the strong emotions that he was experiencing. He numbed the pain by almost dissociating from reality. As the fear, guilt, and uncertainty continuously plagued him, he emotionally separated from his world, his reality.

Following the traumatic news of HIV, Jackson's high-risk behaviours did not increase to any extreme degree. In fact, shortly after the news, Jackson's high-risk behaviours actually decreased. For him, high-risk behaviours were largely the result of alcohol abuse, so he worked hard to stop his alcohol use. He was honest with his wife and the two separated. He became connected with a local HIV community-based agency and learned a lot about HIV. He became empowered to fight against the virus through learning about it.

Presently, Jackson is in a serious relationship that has lasted for several years. His partner is HIV-negative and the two are very careful. The two are quite spiritual and they have a deep connection through their spiritual beliefs. This gives Jackson much hope for his future.

Jackson is on antiretroviral medications and has become resistant to many of the medication combinations. He recalled during our interview, one day receiving the results back from testing to see if he was resistant to specific HIV medications and seeing almost all of the medications being listed in red as opposed to black. Red ink means that you have developed resistance. In part, Jackson is resistant because he has volunteered for many of the pilot studies for new antiretroviral medications. He was immediately receiving new medications as they were being approved for use with humans. Today his doctor has prescribed him several unique combinations of the medications, which has resulted in some severe side effects. This has challenged Jackson's hope.

Jackson told me that his partner and his daughter give him much hope and help him to go on in life. He said during the interview that due to HIV he has learned the value and preciousness of life. He has found purpose in his life (e.g., educating and helping others) which helps him to feel inspired and hopeful.

Andy

Andy is 40 years old and has been living with HIV for about five years. Andy was very suicidal a few years before he became diagnosed with the HIV virus. He was actually engaging in a lot of high-risk behaviours with the hopes of contracting the virus so he would die. He had a rough life and a rough childhood, which largely drove him to feel poorly about himself and his future.

After several years of these suicidal feelings he eventually met a woman with whom he fell in love. They were together for several months and she meant a lot to him. They were both into doing drugs, and would sometimes get high together. One night Andy was given some drugs which turned out to be very dangerous. After ingesting the drugs the couple became sick, vomiting and becoming unconscious. The two were left unconscious for over a day. As Andy eventually woke, he noticed his partner was lying face down in vomit. She was dead. This had a huge impact on Andy. He had lost his very special person. The women he loved dearly.

Shortly after this excruciating loss he learned that he was HIV-positive. He had stopped using drugs because of his partner's horrific death. In fact, he had moved away from drugs due to this experience and also tried to clean up his life. For him, this was an act of love for his girlfriend who had recently died. After diagnosis, he became connected to a local community-based agency and began trying to help people deal with HIV as a peer support educator. Andy remembers not having much hope at the time, but also not being overly depressed regarding the diagnosis. He was very upset about the loss of his girlfriend and had a strong desire to fight back against the HIV. Indeed, this fighting back seemed to increase his hope. Albeit, this hope is not for himself. For Andy, his hope is connected to helping others as opposed to hope for himself or for his future.

Today Andy has a very positive attitude and believes he will live a long life helping others. He has a lot of purpose (e.g., educating others) and actually goes into classes and talks to kids about the risks of HIV. A lot of his hope is tied up in the memory of his girlfriend and preventing the spread of HIV. Andy also has a dog which brings him happiness. He told me that he enjoys going into the wilderness by himself with his dog, which gives him time to think and be at peace. He believes this helps him to deal with HIV and the loss of his girlfriend.

Concluding Thoughts

The present chapter has highlighted the narrative portraits of the participants in the current study. Although these portraits have been abbreviated from their original form (i.e., for confidentiality purposes) they still contain important contextual detail in order to help the reader understand the following categorical and thematic findings.

Chapter Five: Themes

Understanding High-Risk Behaviours

Within this chapter I present the themes of the 12 participants' interviews that relate to high-risk behaviours. Although there is overlap between the different theme chapters, as these are interconnecting experiences, the main focus of this chapter remains on high-risk behaviours. Chapter eight, the composite depiction, will explore the interconnections of the various topics covered throughout chapters five, six, seven, and eight. As discussed in chapter one, high-risk behaviours refer to behaviours that could place others at risk for injury (e.g., reckless driving, fighting) or contraction of HIV (e.g., unsafe sex, risky drug sharing activities) and behaviours that could be harmful to the individual living with HIV (e.g., suicide). The intent of this chapter is to identify and increase understanding of the high-risk behaviours that were experienced by the participants in the present study. To accomplish this, I discuss several areas related to, and encompassing of the high-risk accounts provided by participants. These include participants' accounts of: (a) emotions experienced following their HIV diagnoses, (b) specific high-risk behaviours immediately preceding or immediately following their diagnoses, (c) differences described between high-risk behaviours prior to their diagnoses versus high-risk behaviours following their diagnoses, (d) risks for high-risk behaviours, (e) denial, (f) relationships between denial and high-risk behaviours, (g) influences on high-risk behaviour choices following diagnosis, and (h) hope and high-risk behaviours following their diagnoses. As mentioned, the purpose of this study is to describe the experiences of the participants living with HIV/AIDS as opposed to making generalizations or drawing causal conclusions. In addition, pseudonyms have not been included with the participant quotes in the results chapters as to protect the confidentiality of the participants.

Emotional Experiences of an HIV Diagnosis

Within this section I present a composite narrative of the experiences and emotions of receiving an HIV diagnosis and dealing with this news. I present this in the first person in an attempt to capture some of the emotional experiences of participants in this study and to draw the reader into my interpretation of some of the lived experiences of the participants.

The phone rings… My heart stops… This could be THE call… It has been two weeks of waiting, waiting for my HIV test results. I answer the phone. It is the nurse in charge of infectious disease treatment, from the clinic. She is the one who took my blood. My heart sinks and I feel numb all over as she asks me to come down to the clinic to talk with her and the doctor. Disbelief and shock sits in. My thoughts shift back and fourth between "I've destroyed my life, my children's life, and my partner's life" to "I don't have HIV, there's no way that this would happen to me". Denial is the only thing that brings me hope. I don't care that it's hope created through denial. In fact, in the moment there doesn't seem to be any feelings at all. Numbness and shock seem to be setting in. I get onto the bus to begin my trip to the clinic. Sitting alone with my unshakable thoughts of a slow, painful, humiliating death with AIDS is unbearable. I don't even know anything about it, only the pictures of absolute horror burned into my mind…Photos of emaciated people, their blotchy skin hanging loosely over bones now far too apparent beneath their skin. Feelings of being lost and hopeless grow like uncontrollable infestation of a tree. Feeling as if death is already knocking on my door. I quickly go back to “It can’t be, I can’t have this”. There is a sense of hope, only for a few seconds. The bus stops, the clinic building is in sight from my seat. I just sit and stare for what feels like minutes. Somehow I make it off the bus. Entering the clinic, it immediately feels cold and sterile like an old hospital. The waiting room is full of firm, uncomfortable chairs, worn out magazines, and a reception area behind two inches of glass, with a receptionist who seems to hate her job. She is cold and tells me to have a seat, fill out some forms, and wait for my name to be called. Does she not know what I am here for? How could she be so cold…It feels isolating and lonely. I look around the room at all the people, they all look alone. Fear takes over. My heart beats quickly; I feel a lump in my throat as I try to choke back the tears. Sobbing quietly, I am able to pull it together for a second. Repeating words to myself “remember my family, my children and partner” helps me to feel a sense of calmness. I remind myself that this is all a big mistake. How could I have this thing? Again, I feel a bit better. I just sit and focus on my family for what seems like hours…

Finally, the doctor himself enters the reception area. He looks at me and invites me down to his office. I follow behind him through a maze of corridors. He takes me all the way to what feels like a hidden back room. A room lost from time and the realities of daily life, where peoples’ dreams are shattered in an instant. As I sit down I notice my tension, I am stiff all through my arms, back, legs. I look up and see the nurse come into the room. The doctor looks at me and says “There is no easy way to say this, so I am just going to tell you. You have something called the Human Immune Deficiency Virus”. It’s all silence. No one says anything. I immediately lose it. I start crying uncontrollably. I cannot even breathe. I am gasping for air. My family, my children, my partner, my job, everything is over. I fall over, out of my chair. I am screaming. The doctor and nurse try to comfort me, they are talking about options and seeing a counsellor; I hear them but not really. I cry and roll up into the fetal position on the floor. I have lost it… The doctor gives me a shot of something, my tears stop, my urge to yell goes away, but now I feel empty. I go into complete shock. I am numb all over. I spend some time listening to the nurse who tells me about my options and a bit about HIV. I don't follow her very well. I feel dopey from the doctor's shot, and am really not remembering and understanding much. I feel lost in a cloud of shock and disbelief. As I leave the doctor's office I feel as if I am walking the green mile, I have been sentenced to the worst form of death anyone could be sentenced to. Slow and painful. Humiliating and horrific. In my head I believe that I will slowly die and wither away to nothing. I will lose control of my bodily functions and need to wear a diaper. Even to be carried to the bathroom. I am going to die. I am scared. I return home. I am completely alone. I do not tell my family or friends. I am anxious and worried that they will think I am a freak or contagious. That I will infect them.

I feel a deep sense of doom, like life is over. I think that I have lost everything in my life, my dreams and aspirations, my family and friends. I have no direction or purpose. Most everything I know about HIV I've seen on TV. I feel powerless against it. Everything will change, everything has changed. I will be stigmatized. I am going to die. I am just so overwhelmed with hopelessness.

I begin to become more and more reclusive. I hide away and start drinking much more than before. I find myself using more and more drugs like weed and even cocaine. This helps me to numb all of the overwhelming feelings that I have. They make me feel a bit better, like I do not have HIV, like I am not dying. I pretend I don't have HIV for awhile, but reality always comes back. It seems to come back with more force every time. I drink and use even more drugs to numb the overwhelming pain. Self pity becomes intense and encompassing. Despair becomes my way of life. But I can't stop it, it's all out of control. When sober and even when stoned the fear returns. It is a tremendous fear, being alone and having HIV/AIDS. I know nothing about HIV and all I can think about is death. I stop caring, I don't care what happens. The drugs become my closest friend and the only way to find freedom from HIV. Enslaved to the drugs and to my fears, I attempt suicide. My family leaves me; I lose my job. Gradually my life crumbles. I want to die quickly. I feel angry. How did I become infected? Who the fuck is responsible? Who gave this to me? I want to hurt someone badly. I start fights, partly to get killed. I want to die. I want to strike out at the world for taking my life away from me. I feel trapped inside a sinking ship, a ship with no real hope, direction, or future. I resent people around me. Even with all this anger and resentment I feel only guilt and disgust with myself. I hate myself. I loath myself and what I have become—a freak with a contamination. I feel as though I have the black plague and everyone around me knows it. I feel judged. I have so much overwhelming pain and yet I have no way to make it go away. It is out of control, I am out of control. I feel pity for myself, as if everyone should feel sorry for me, yet I also feel worthless and undeserving of condolences.

I am not able to ask for help. I don't know how, I don't deserve it anyway. A big part of me just wants to speed up the process of dying. I try to kill myself but it never works. A small part of me thinks maybe there is some purpose here for me, but that part is so small in comparison to the lost and hopeless part of my soul. Every now and then I catch a glimpse of a part of me who wants to find help. Odd though it may seem, I think that this part of me gets into trouble and acts risky so others will notice me and give me help. It's not working. No one sees me crying out. I feel overwhelmed and if I don't get help soon I will surely die or hurt someone else.

It's not until I get connected to services and begin meeting others with HIV who are surviving that I begin to feel hope. I talk to counsellors and peers who help me to start working through the hurricane of devastating emotions that have battered me for so long. I start to feel better, like maybe I will be okay. It seems that getting into contact with other people that have encouraging things to say helps to bring me out of it, all the negatives, but sometimes it still feels fleeting. It is a long time before I actually feel a more stable sense of hope and it is still an everyday struggle to keep moving forward. It is becoming much easier than before.

High-risk behaviours following an HIV diagnosis can be a common experience for some people receiving the diagnosis. The following section highlights high-risk behaviours and unhealthy behaviours experienced by participants in this study.

High-Risk Behaviours Following Diagnosis

Participants discussed several risky or unhealthy behaviours that they engaged in following their HIV diagnoses. Not all participants engaged in all of the following behaviours and several decreased behaviours that would spread the HIV virus (i.e., unsafe sexual practice and allowing others to inject drugs with their used needles); however, all participants did commence or increase their engagement in at least some of the following behaviours that the participants described as high-risk or unhealthy:

1) High-risk driving (e.g., fast, reckless): "...if you maintain the lifestyle you were living, you know drinking and driving...". "Driving especially, I rolled a whole bunch of vehicles, sometimes with passengers, sometimes with not... My friends said I was just demonic or demented".

2) Fighting (e.g., picking fights with large individuals) and assaulting others: "I was just angry, got in trouble for fighting, went to jail for assault". "...I'd go to parties and pick fights with the biggest guy, biggest person at the bar, biggest person at the party, I'd just get under their skin and go for a beat, you know. Maybe they'd kill me. Who knew? You know I didn't care, right...".

3) Suicide ideation and attempts: "Most people that are diagnosed with HIV or AIDS were probably like me the day I got diagnosed. I had a gun at home and I was going to go and kill myself because I was told I wouldn't have a normal life again".

4) High-risk sexual activity (e.g., multiple partners, no condoms): "I didn't care, I didn't care anymore until I got associated with HIV Edmonton, Living Positive, and found out that people do live. I figured I had a death sentence, I don't know, and when I realized that I stopped doing the high-risk sharing needles and unprotected sex and things like that...". "...I was extremely promiscuous because I didn't believe at the time that it was sexual habit that it was spread by...".

5) Increased drug and alcohol abuse with associated high-risk use (e.g., needle sharing): "I was pretty well going full steam with my drug use at that point, just didn't care what happened...for awhile there, after I found out [about HIV] it even got worse". "Oh, it increased, after all the times I finally knew, accepting it [that it was HIV]

and going, 'well, I'm going to die anyways', you know, stupid attitude, then I go "I'm going to die anyways" so my intake of drugs got larger".

In addition to high-risk behaviours, there were several unhealthy behaviours that participants also engaged in following the diagnosis:

6) Refusal to consume HIV medication on a regular schedule: "...or I won't take meds anymore, oh fuck it, you know, what's a day? I'm dying anyways. You go through that phase". "...when I first got my meds I used to throw them away. I was totally suicidal...".

7) Refusal or inability to eat or sleep properly: "Well, after I got diagnosed I wasn't eating properly and I wasn't sleeping".

8) Drain bank accounts and engage in reckless spending (e.g., on drugs, alcohol, partying): "Oh fuck, when I got the news [of HIV], I just partied all the time, spent all the money we had...". "...if I'm going to go, let's go...all the cash I had you know 'wsht'! Straight into the arm this arm here is worth I'd say about two houses".

9) Engage in criminal activities (e.g., break and enters). "...turned to crime, did a lot of break and enters, started getting a lot of assault charges, ended up in jail a few times. I just didn't care, it didn't matter anymore. There was nothing else they could take away from me that I hadn't already lost...".

These high-risk or unhealthy behaviours lasted between four days and three years for the participants. The average time was roughly six to 24 months. Most participants experienced some increases in high-risk behaviours during the window period (i.e., the time period when they were waiting for the test results); however, most did not experience the full extent of the high-risk period until after their diagnoses were confirmed. In other words, although participants showed increases in high-risk behaviours after they suspected an HIV diagnosis, most did not experience the full range and intensity of these behaviours until after formal diagnosis. Many seemed to hold onto the hope that it would not be HIV, until testing demonstrated that HIV was the problem. Thus, hopes to be HIV free gave way to the despair of the reality of HIV.

In interpreting participants' accounts of high-risk behaviours, there seemed to exist, underneath these high-risk behaviours, different motivating circumstances or purposes which facilitated the behaviours. Some of the participants described the high-risk period as being out of their control. These participants experienced an inability to limit or reduce their engagement in risky behaviours. As can been seen with the following participant, one of the only factors that slowed down his high-risk behaviours, was external intervention.

> *Bursts, I mean like the roller coaster, I go ballistic and I really just go to the limit until I either lost everything or just [became] mentally, physically exhausted. Usually it was jail or a psychiatric hospital, you know, that would put a stop to my madness and I'd have to take a little reprieve or break and then I'd get all this support.*

Others seemed to engage in high-risk behaviours (e.g., alcohol and drug abuse, suicidal ideation) as a means to numb themselves against HIV and the strong painful emotions that many experienced in relation to the diagnosis. Participants were, through many high-risk behaviours (e.g., alcohol and drug abuse, unsafe sexual practices), also able to try to deny their reality of having HIV. This, in part, helped them to numb strong overwhelming emotions. As can be seen in the quotes below, participants became emotionally detached from themselves and from their situations.

> *Yeah, well, when you're drunk you don't care about anything. Your problems just disappear for a while. As soon as you sober up they're back again so you start drinking again so they'll go away again which is no answer, no solution.*

> *I would do anything and take anything and everything to forget. I didn't, I couldn't even look at myself in the mirror. Cause I'd look in the mirror and I was just like, what am I going [to do], you know, you're gonna melt you know....*

Others seemed to experience high-risk behaviours as a way to cry out for help, as they did not know how else to ask for assistance or services. These participants felt as if they had no other way to obtain help, or express their pain, besides engaging in high-risk behaviours. For example, some participants shared their experiences of reckless driving and fighting, which helped them to get arrested and get some attention. However, these high-risk behaviours served several purposes (e.g., numbing emotional pain, fighting back against the world, trying to die a quick death) and occurred for different reasons (e.g., no longer caring what happens). Crying out was only part of the purpose in acting out. "...it's strange, hey, you know maybe they, you know, suicide sometimes is just to cry out for attention...."

> *...I wasn't able to express my fears or grief in regards to the illness so I put myself in situations that would make people take notice, but I think for all the wrong reasons, that I was never really getting the help I needed because when they did take notice, it was either drunk driving or drug related or, you know, criminal involvement, and so the focus was shifted to those behaviours as opposed to the feelings and until I started to deal with some feelings those behaviours just kept on going and going...*

Differences between High-Risk Behaviours Prior to HIV Diagnosis versus High-Risk Behaviours Following Diagnosis

Many participants in the present study disclosed that they engaged in high-risk behaviours prior to becoming HIV-positive. In fact, those participants who said they engaged in high-risk behaviours such as risky drug use or unsafe sex before diagnosis most often said that they also engaged in high-risk behaviours after diagnosis. For many participants, high-risk behaviours prior to HIV were the source of HIV infection in the first place.

> *...Before that, woo-hoo, yeehah. And that's [high-risk behaviours], I know, how I got positive. I took part in risky behaviour. Don't remember with whom or when or anything. So, it can happen to anyone. I never thought it would happen to me but it did.*

There were some differences between high-risk behaviours prior to diagnosis versus high-risk behaviours following diagnosis for participants. For example, many participants disclosed that following diagnosis they no longer cared what happened to them. Thus, they did not care about death or repercussions of high-risk behaviours (e.g., using others' needles as they did not think anything worse could happen). As can be seen with the following quote, some participants welcomed death: "More to the death wish [desiring death following HIV]. I certainly didn't have any fear of death anymore". Serious consequences can arise when those recently diagnosed with HIV do not care anymore. Their sense of self-care seems to disappear in some cases, as can be seen in the following participant quote.

> *...[I used] intravenous drugs for maybe four years [prior to HIV], never contracted any disease though. How ironic is that, through using drugs, living on the streets, never shared needles, was always careful, always clean, knew what to do, watched other people not [being careful with their drug use]... 10-12 years ago you could buy other people's 'fix' they called it, I can't remember what it was called now but it was mixed with their blood and dope and it was not very healthy, not very healthy at all, but people used to do that a lot and so I quit fixing [using others' blood and dope mixture]... Well [after you get diagnosed with HIV] you just don't care, you're going, you feel like you've gotten a death sentence so it doesn't really matter what you do with the rest of your life, you know, as far as the, you know if the drug use it didn't matter if they were clean [would use others' needles regardless of their HIV status]. I had it so it didn't, you know, I'd use other people's [needles]. I would refuse to give mine to anybody, I was quite careful, but I didn't care if I used somebody else's. I just picked it up and cleaned it with water and used it and people would kind of look at me. You get, you think that it's not a big deal, but I now learned that it is a big deal because not everybody is HIV or infectious. The blood is not the same and you can get a different strain [of HIV] so it's not wise to think okay, well I'm going to die anyways. Well, no, it's just picking up the process and doing it a little quicker than you want [dying], you could*

> *live a long time with just the HIV virus. It takes a long time for that to sink in to your head.*

Thus, as can be seen in the above quote, several participants seemed to reduce their sense of caring following diagnosis. Although many of the participants gave accounts of their lives prior to HIV, which, in some cases, hinted toward a degree of not caring about what happened to themselves; there appeared to be qualitative differences in the degree of not caring following diagnosis. The experience of not caring seemed more intense, more apparent, and more direct following diagnosis as compared to prior to HIV entering their lives. This additional reduction of caring following diagnosis could be an indication of the intensity of hopelessness and despair that followed the diagnosis for many of the participants.

Prior to HIV many participants ignored and denied the risks associated with high-risk behaviours. They appeared to ignore these risks as a way to keep living a high-risk lifestyle. Some commented that despite the known risks, there is a belief that it will "never happen to you". As one participant replied "You're aware, you know there are risks, but you ignore, ignore, ignore... You tell yourself whatever to keep going on". Following diagnosis, several participants explained that there is still denial, in spite of the fact that they received an HIV diagnosis. In interpreting the participant accounts of the time period following diagnosis, the nature of the denial seemed to qualitatively change. It seemed to shift from an attitude of "it will never happen to me" to an attitude of "it has happened, but I will pretend it has not happened". The difference for many of the participants was that they experienced *denial of HIV* following diagnosis, as opposed to denying or ignoring the chances of contracting HIV. Many participants maintained their strategies of denial that they utilized prior to HIV (e.g., drug and alcohol abuse);

however, these strategies now needed to intensify in an attempt to deal with the overwhelming news of HIV. Despite this denial, my interpretation of the participant accounts suggests that participants maintained awareness of the HIV. During participants' recollections of their high-risk behaviour periods, they recalled multiple incidents, during the high-risk period, of harboring fear, uncertainty, and anger regarding the HIV diagnosis. Thus, although high-risk behaviours likely helped them to numb overwhelming emotions and experience temporary moments of denial; HIV seemed to be a regular and continuous reality in their lives.

As mentioned above, high-risk behaviours served as a cry for help and attention for some of the participants. These participants did not know how to deal with the intense pain and suffering that they were experiencing. They were also not able to seek out assistance and support. Thus, they were left feeling alone and out of options. In an attempt to help alleviate their suffering they engaged in high-risk behaviours. This can be seen by the following participant quote:

> *I think there are more high profile attention seeking [high-risk behaviours as attention seeking] and I couldn't [tell others of my HIV status]. I had a hard time stating, 'Hey I'm HIV-positive', but I'd drive my trucks into barriers and, you know like, people had to ask like, 'What the hell was he thinking? There's got to be something really fucked up with him', and so I mean I think they [high-risk behaviours] were more attention grabbing. I think I was trying to yell out, 'I'm in pain, I'm suffering', but without being able to state clearly, you know, 'it's an illness'. Instead it was the behaviours, just crazy behaviours. I didn't waste my time with a little bit of pot and hash in my pocket. I'd go after big stuff, I mean I'd take incredible risks where you know like just... Yeah I didn't, wasn't hiding anything. I was blatant and I became sub-human or super human. I just, you know, I would take risks that were just not necessary. I didn't care about anything or what happened. Think about consequences. To me there wasn't any consequences... Yeah, I have to believe that because, I mean, I wasn't able to express my fears or grief in regards to the illness, so I put myself in situations that would make people take notice... but I was never really getting the help I needed, because when they did take notice, it was either drunk driving or drug related or you know, criminal involvement and so the focus was shifted to those behaviours as opposed to the feelings, and until I started to deal with*

> *some feelings, those behaviours just kept on going and going. The only thing that happened was I got incarcerated and that gave me some time to reflect and seek help.*

Lacking control was also a common experience for many participants following diagnosis. Although some participants did see themselves as being out of control prior to HIV, this did not seem as intense of an experience for participants prior to the HIV diagnosis as it was following HIV. Their sense of being out of control appeared to intensify following the diagnosis, seemingly contributing to high-risk behaviours in some cases. For several participants, pre HIV was like being in a fog or a downward spiral. There was a sense of being out of control and heading toward destruction. HIV was the catalyst that actually led to the destruction, that actually led to the crash.

The severity of high-risk behaviours also seemed to vary before and after HIV. Nearly all participants described increases in the amount and severity level of their high-risk behaviours following the diagnosis. As one participant put it, "After HIV they [high-risk behaviours] just got worse and worse, got completely out of control..."

Experiences that Influenced the Likelihood of High-Risk Behaviours Following Diagnosis

Participants talked about several parts of their experience that seemed to increase their likelihood of engaging in high-risk behaviours (e.g., unsafe sexual practices, risky drug sharing activities) following an HIV diagnosis. In many cases these experiences have been interpreted as "risk factors" or "risk experiences" from my interpretation of the participants' accounts. These risk experiences varied between participants and not all of the participants experienced all of the reported risks. However, these risk experiences were common among participants and appeared to influence high-risk behaviours immediately preceding or following their diagnoses of HIV. These factors are presented below in broad overarching categories and underlying thematic areas.

Risk Factors Immediately Surrounding the Diagnosis

Delivering and receiving the diagnosis. The way in which the diagnosis was presented to participants when they were diagnosed seemed to have repercussions for the chance of high-risk behaviours. Some participants suggested that if newly diagnosed individuals perceive HIV as AIDS, this has the potential to increase their levels of fear and lead the individual to believe that he/she is going to die a slow and painful death. Many people do not understand the differences between HIV and AIDS. In some cases this crucial information may become lost in the communication between the newly diagnosed individual and the health professional, as the client may enter a state of crisis and shock, not hearing the information accurately. In addition, sometimes the distinction between HIV and AIDS may not be explained sufficiently to the newly diagnosed individual. Several participants highlighted the emotional crisis that can occur following the news of HIV. In interpreting participant accounts of the time period surrounding diagnosis, perceiving HIV as AIDS seemed to set the stage for strong emotional reactions, including despair and hopelessness.

> *I gave them hope because they had no hope, they had like "you're going to die"...and they didn't understand that HIV is not AIDS. You're not on your death bed yet; you've got a lot of years to live with it. You've got a lot of years to hopefully find a cure, or something to put it into remission, or something, you know....*

The emotional aftermath. Painful, strong, and overwhelming emotions following diagnosis were common among all participants in this study. Participants felt uncontrollable hopelessness, pain, anger, self-pity, fear, and despair. These feelings, if unaddressed, may have contributed to high-risk behaviours for some of the participants.

> *...You know, I'm crawling the walls here going crazy...drinking, pills, cranking up – everything. Because you've got that attitude, okay I'm going to die anyways. No matter what I do, crime, anything, fighting, that don't mean nothing because you're*

> *going to die anyways. You know you're going in and so what, I'm going to die. That's the attitude people get. You get a real big pity pot; it's all a pity trip. And I said, "Well, oh well if I'm going to die, fuck it; I'll do whatever the fuck I want".*

For example, drug and alcohol abuse helped several participants to numb or avoid dealing with strong overwhelming emotions related to the HIV diagnosis. As can be seen by the following participant's statement, drugs temporarily took away the pain.

> *...It kept going and giving me a false sense of security because I was high so it didn't matter especially on coke...you don't have many fears and everything, yeah, well....*

Interpretations of other high-risk behaviours (e.g., reckless driving, reckless spending) that were directly or indirectly related to numbing the powerful emotional pain suggested that these behaviours occurred for several reasons such as: (a) believing these behaviours would lead to death which would end the overwhelming suffering, (b) feeling as if these behaviours led to control over the emotions and the HIV, and (c) believing that this lifestyle detracted from the reality of HIV and the strong emotions. As one participant put it, "...Even the other behaviours [high-risk behaviours] helped get over the bad feelings...".

Despair and Hopelessness Following Diagnosis

Challenges to hope and experiences with hopelessness. Two strong emotional reactions following diagnosis consisted of hopelessness and despair. Participants talked about challenges to their hope in several different ways, which they saw as an experience that influenced high-risk behaviours. For example, some had experiences where hope for them was completely gone or not obtainable after the news of HIV. Consider the following accounts of the time after diagnosis. "There is no hope. No hope at all. You have to find someone that can get through to you". "I just gave up, gave it all up, hope and all, figured that was it".

Some participants felt that they were able to hold onto some form of hope during the time period preceding the official diagnosis. This hope typically consisted of hoping it was not HIV. However, following the positive test results, this hope was typically gone or unobtainable. "Well, hope of not having HIV was gone. I had it, you know".

Others suggested that hope was temporarily lost, misplaced, or on the "back burner" for awhile. In these cases, the participants suggested that hope was always there, it was just not obtainable at those times.

> *...Yeah, that was...hope was just kind of put on the back burner for a bit and I kind of went over the edge, but when you have to take a good hard look there's no room for that, so hope is right there. It's like losing someone, right, the denial, the grief, the anger all works its way all the way to acceptance. It's the same kind of thing.*

As can be seen, many participants talked about connections between hopelessness, losing hope, and high-risk behaviours. Several of the participants said that losing hope was connected to high-risk behaviours.

> *I think it was the loss of hope [that led to increases in high-risk behaviours]. I mean, yeah, I couldn't put hope in there because hope is the only thing that keeps me from high-risk behaviours.*

Participants suggested that no hope for their future or no hope for change was related to fears of a painful and slow death. As participants felt that death was certain their hope diminished. This led many of the participants to try to speed up the process of death, through high-risk behaviours.

> *Oh, absolutely, I mean in the context of HIV and high-risk behaviours, if you have no hope you got nothing. See this is why it's so hard to explain... My high-risk behaviour, because there is no hope and you go, they knew so little about the disease and everything, the only thing that they knew is that you're going to die and die quickly. Where do you find hope in there? I mean, so, for me, I was going to die and I've seen a couple of my*

> *friends, I'd seen friends in the later stages of HIV and AIDS and everything, and I was sitting there. There is not a hope in hell I'm going to look like that when I die. That old saying, the fast die young and leave the good looking corpse. I've seen a lot of people and I don't care what undertakers and everything do, mortuaries do, to make you look better, it never looks like you. So I was on the whole bender of, "Oh, let's just destroy it all now". Major OD will stop it and then I don't have to worry about it, though for some reason I kept surviving, so obviously I must be here for a reason.*

Some of the participants also suggested that a loss of hope can occur with depression. For many participants the combination of losing one's hope and experiencing depression seemed to precede high-risk behaviours. This can be seen in the following participant quote. "After diagnosis, there was no hope at all… There was major depression…And eventually a suicide attempt…".

Some participants actually suffered through a major depression or extreme sadness as a result of the HIV diagnosis. This prompted these participants to engage in behaviours (e.g., alcohol and drug abuse) in an attempt to reduce the depression, pain, and sadness. "…I'm not sitting here all day long like this, you know, wanting to go have a drink because when I was depressed, feeling down, a few drinks man, all my problems are gone temporarily…".

Hope was connected to caring (i.e., for self and others) for many of the participants. Without hope, some saw little need to care for themselves and others. Without concern for self and others, there was a tendency for increases in high-risk behaviours. In interpreting participants' accounts of the time period following the diagnosis, several participants seemed to not care what happened to themselves or others and therefore engaged in high-risk behaviours which helped them to experience numbness and helped them to temporarily forget their HIV status.

> *...Cause, I don't know, felt there was nothing to do anymore. There was no hope, it just crashed. And I think oh, my life's pretty much over, just do whatever and, you know, if I OD on this next hit or whatever I don't give a shit.*

Importantly, many participants expressed a lack of caring toward themselves as opposed to what happened to others. Many felt concern for others and tried to avoid spreading the virus through high-risk behaviours. Some of these participants expressed a sense of hope for others, even though hope was not readily available for themselves.

Experiencing hopelessness led several participants to find ways to numb the pain of hopelessness and try to replace it with "phony hope". Many used alcohol and drugs as a way to numb their pain and suffering. This seemed to allow them to temporarily avoid facing the pain, but it did not help them to deal with the pain. As can be seen by the participant quotes below, alcohol and drugs were temporary solutions with severe long-term consequences.

> *I had no hope. The no hope...when I had the no hope, okay, I drank more to forget and that made me forget what I had, you know, it numbed it. That was my phony hope. Now I can do things. I forgot about...like that thing was completely, I lose the thought of having that disease and I go out and do things, you know. And I'd keep on drinking and doing it more and more, just to keep that way back in the back of my head. That's where my hope came from, a bottle, drugs, pills. So I didn't have to remember... Fuck that, I'd rather take drugs than think about this shit.*

> *Oh, it [alcohol and drugs] just numbed me. I didn't deal with it [pain of HIV], I just denied...You just don't care anymore. You just don't heed the warnings or even think when you are stoned.*

"Phony hope" was found in the distractions of substance abuse. It seemed that this hope was both detrimental and important for the participants. Some suggested that this "phony hope" allowed them to deny potential harms that they may have been causing others. It also temporarily allowed participants to shift their focus away from the diagnosis, thoughts of suicide, and the pain/fear.

Desire for death. Related to a strong sense of hopelessness, when participants experienced an intense desire to die after they received the news of their HIV status, their accounts suggested that they were more vulnerable to the temptations of high-risk behaviours. These high-risk behaviours would consist of behaviours that could lead to death for the participant (e.g., suicide attempts, drug overdose, refusal to take HIV medications, reckless driving). Some participants perceived the high-risk behaviours as a means to end their suffering through death.

> *...Well I felt the shits, I wanted to die... I'd say the increase in drug use was because of the stress factor and being told that you're going to die "fuck that; quick give me a hit"....*

Many of the participants believed and feared that they were going to die a painful slow death from HIV/AIDS. This, in part, appeared to prompt some to engage in high-risk behaviours that could increase the progression toward death and reduce the pain and humiliation that would come from a death of AIDS. It allowed them to feel as if they could die on their own terms and with a sense of dignity. One participant shared,

> *...[I] figured that if I'm going to die, I'm going to take my own life. I wanted to die with dignity... Yeah, I wanted to die with dignity so I figured I'd take my own life; so my hope on that was that I was hoping to die... With dignity because I was given a two-year death sentence and I didn't want to, you know, the vision that I had was you know people wearing diapers getting carried from a blanket into the bathroom, getting put on a toilet to shit and then if they can't make it then they have to shit in a diaper and someone'll have to wipe your butt and, oh man! I wouldn't wish that upon my worst enemy....*

These behaviours also helped give control to some of the participants who felt that they had no power or control against the HIV. For example, several participants felt that suicide ideation, and even attempts, allowed them to feel powerful against the HIV.

> *...and to me I didn't want that to have to, I figured like "if I'm going to die I'm going to die with something" so I slashed my wrists...I tried to commit suicide; you know,*

> *I figured "if I'm going to go, I'm going to go on my terms, not those terms" [reference to HIV's terms]....*

Some participants also said that they did not want their children or family to watch them suffer, which increased their desire to die. Some participants felt that death was better than forcing their families to watch them deteriorate and wither away to nothing.

> *Well, I figured my life was over; I couldn't let my kids watch me suffering. I just, I didn't want my family to know... I wasn't going to tell my old lady, my mother would never understand, I thought. Everybody's going to think I'm gay so... Yeah, it was fucking nuts, I made an excuse and I broke up with my girlfriend, I just left her in the dark, went nuts.*

Lack of caring. Several participants suggested that a lack of caring for the future or what might happen to them was related to increases in high-risk behaviours (e.g., increased drug abuse, risky drug use such as using used needles). Participant accounts provided reference to hopelessness and despair during times of not caring in many cases, illustrating a potential relationship between participants' feelings of hopelessness/despair and not caring about what happens. Participants said that when they did not care what happened, high-risk behaviours increased.

> *I just didn't care, it didn't matter. I lost everything anyway, so who cares. Thought, let's just do whatever, do drugs. I didn't care. I didn't even care if I used somebody's rig [needles], what else could happen to me?*

Some participants also believed that a lack of caring about others can increase the chances of high-risk behaviours, especially those behaviours that can harm others as opposed to just oneself. Some said that if you are self-centered or egotistical and have a "fuck the world attitude", then this will increase the chances of high-risk behaviours. This is problematic, as some of the participants reported that following diagnosis they did not care about others. As can be seen in the quote below, this participant is verbalizing his belief that not caring about others is not a "high-risk" in the emotional sense. Indeed, it is easier to not care than it is to care.

> *But it's not a big risk to become self-centered, egotistical, fuck the world, I can do anything and I don't care. That's not really a risk at all, that I'm so into myself that I'm not considering other people hurting around me. And yet, I don't know.*

For him, a 'high-risk' would have been allowing himself to care about others. It would of involved opening up to friends and family or seeking services. This participant did recognize the seriousness of his previous high-risk actions. As mentioned above, many of the participants disclosed that their loss in ability to care about their own future was far stronger than their lack of concern for others.

Perceptions of nothing to live for. Participants who gave up their will to live and lost all purpose in their lives felt that this was a risk factor for increased high-risk behaviours. Peoples' dreams and aspirations were taken away, which apparently increased high-risk behaviours. As can be seen in the following participant quote, these participants believed that one's life purpose is related to one's will to struggle on in life. Without purpose and a will to survive, several participants fell into behaviours to reduce the pain and suffering they were experiencing. "When you got nothing to live for, what's the point? You might as well do what you want, what helps you forget the bad [high-risk behaviours]…".

Hopelessness and despair were also apparent within the narratives of the participants' accounts during times when they perceived no purpose in their lives. Again, this interpretation suggests a connection between hopelessness and perceiving nothing to live for.

Seeking Help through High-Risk Behaviours

As mentioned above, participants who were not willing to ask for assistance or who did not know how or where to seek help believed that one way they could find assistance was through high-risk behaviours. These participants believed that high-risk behaviours would attract attention to their situation. On some level, there was hope that this would lead to assistance in dealing with their fears and problems associated with HIV and related life stressors. This interpretation of the participant accounts suggests that hope may display itself in unpredictable and unexpected ways, during times when even participants suggested that hope was not obtainable. It also suggests that even if hope is not consciously available, hope may be operating.

Ignoring and Not Knowing the Consequences

Ignoring the consequences. Some participants believed they experienced increases in their high-risk behaviours if they failed to consider consequences. This was common when participants were using alcohol and drugs, as this often led some to not consider the consequences to their actions. Some participants felt that using alcohol and drugs, while not considering consequences, increased the likelihood of other high-risk behaviours (e.g., unsafe sexual experiences). Many participants' accounts of the high-risk period suggested that drug and alcohol use led to poor judgment, an inability to weigh the pros and cons, and not being able to think clearly or rationally. According to participants, these factors sometimes precipitated the occurrence of high-risk behaviours. There was also belief among participants that drug and alcohol use reduced the fear of other high-risk behaviours (e.g., criminal activities, suicide attempts), which, in some cases, precipitated their occurrence.

> *Yeah, you know. You just don't care anymore [when you are drunk and high]. You just don't heed the warnings...That would be it. Yeah. You know, when I'm not high or drunk, I think. I do things with precautions.*

Some participants said that they did not always care about consequences or often would feel impulsive. Each of these appeared to result in not considering consequences. This can be observed in the following participant quotes, "I just didn't care and when you don't care you don't really think about what could happen". "When you get into that place it's almost kind of impulsive, too". As discussed above, based on participant accounts, hopelessness and despair often occurred during times of not caring.

A related risk included "not thinking clearly". A few of the participants reported that following diagnosis, they were in a fog and somewhat out of control, which contributed to high-risk behaviours. "You get hit with the news and just can't think or see anything; you find yourself in a fog, not being able to think clearly...".

Insufficient knowledge and understanding of HIV. Participants believed that a lack of knowledge and understanding of HIV will potentially increase the chances of high-risk behaviours. The belief among participants was that without knowledge and information on what to do or what not to do against HIV you may feel powerless and unable to fight back.

> *...I wasn't scared of needles anymore, it just didn't matter, I could pick a dirty one up and I didn't have the coping ability or the knowledge to realize that I was putting another disease of HIV inside... inside my blood stream, but the caution wasn't there....*

Environmental and Social Issues

Drug and alcohol addictions. Participants said that drug and alcohol addictions prior to HIV typically resulted in increases in drug and alcohol abuse following diagnosis of HIV. Similarly, if participants were engaging in high-risk behaviours prior to diagnosis, they tended to continue to engage in the same high-risk behaviours after diagnosis, to an even greater degree.

> *Well, if you have a problem with alcohol and drugs prior to HIV, that's where you will turn after you get hit with it [the HIV diagnosis]...In my case it just increased a lot more....*

Several participants reported criminal behaviours (e.g., break and enters, selling drugs) following diagnosis to support their drug and alcohol use. "...but along with that comes all the other bad stuff, like you've got to sell drugs to get the money to make the drugs to do the drugs...".

Co-occurring stressors. Many participants' accounts of the time period surrounding the diagnosis suggested there were connections between their co-occurring stressors/stress connected to HIV and their high-risk behaviours. Participants identified several co-occurring circumstances that impacted their stress levels. There were strong beliefs held by several participants that excess stress can cause: (a) physical and psychological problems, (b) increases in the likelihood of engaging in high-risk behaviours, and (c) challenges to hope. "Sometimes it's that extra stuff that puts you off the deep end, makes you lose it, like, it all goes together, HIV, no money, no place to go...".

Participants said that although HIV is stressful, much of the stress of daily living comes through other aspects of life which are difficult as well. For example, the following co-occurring stressors were identified by participants: (a) unemployment, (b) lack of financial stability, (c) employment in stressful and unfulfilling job(s), (d) medication side effects, (e) uncertainty for the future, (f) no home or shelter (i.e., this can result in a lack of stability in one's life which can also lead to other stressors such as not remembering to take medications and losing medications), (g) physical and mental health concerns (e.g., cancer and depression, respectively), (h) fears of medication resistance, (i) friends becoming ill with HIV related health problems, and (j) relationship problems (e.g., family, friends). As one participant described his financial concerns, "...But I'm tired of like living on 850 bucks a month...and not being able to survive...pay rent and don't eat...Money wise it just sucks". Another participant discussed medication stresses, "I was just talking to him [doctor] about meds again, so expecting in the future I'll be into taking more pills, working on it. Some kind of a risk and side effects with pills...". Another participant talks about employment concerns, "...I had a couple of interviews but nothing yet. And that's discouraging. I'm thinking 'what's wrong with my resume' and I don't know if I'm overqualified for the jobs".

Limited family and social support. A lack of family or social support was seen as potentially increasing the likelihood of high-risk behaviours for participants. Without family and social support participants did not have the emotional and physical resources needed to deal effectively and safely with HIV.

> *Well, at first it was scary for me. You know like I didn't have a clue as to what was going on here. What do I do here, where do I go, who do I see?...You know right away I found out I was alienated from my own family, you know, friends, "God", they said, "hey man stay away from him". And that's what I went through and then I just built up my anger and[the] more angrier I got, the more I fought, the more I went to jail, the more I drank. You know I used to drink 50 and 60 of those big bottles of beer in one weekend..*

Understanding Denial

Many participants provided accounts of denying the HIV diagnosis and denial of the repercussions of the HIV following diagnosis. These forms of denial, for many, were a means to continue on with their lives without the intense pain and fears of HIV. This can be seen in the following participant quotes.

> *... When I was diagnosed I didn't quite believe it because they said, well, these tests aren't exactly 100%, we'll do another and another, I did about four or five at different doctors', you know I gave different names and everything....*
>
> *... When you first get it you go through a stage of denial. You talk yourself into believing that you don't have it, that you're okay. That you don't got it. You'll do anything and everything. And you'll brainwash yourself, you'll deny it right to the end, you know. I went through that denial period, maybe three years.*
>
> *...I got away with it [denial] for a little while and then it [HIV] started to eat my head...Got to go to the doctor's, see how sick I am... Pushing to go to [the] doctor's and stuff, than it [HIV] became more of a reality and start to get something done you know... Yeah, kind of pushed it open, so, and then the more people I told, I couldn't quite deny it [HIV] any more. But looking back on it, if I didn't, now with the support stuff I have, I wouldn't be able to do that [deny] so, it's, I don't know. Quite, quite different. But, yeah, I'm glad he [doctor] pushed me, he pushed a little bit. But I don't think I would've left it that long [HIV]. Just long enough to kind of get my bearings back. Because I was in a shelter at the time, too, so I kind of wanted to get stable and get into a house and get cleaned up where I can do this on my own thing you know....*
>
> *...I was good at shutting things off. Because if it's not, like I didn't have to deal with it [HIV] right away so it wasn't an issue. Nobody knew so it wasn't an issue. It was just shut off...Yeah, it is hard to explain but if you don't want to deal with it I guess you just shut it off...I think, it's where you are, like environmentally as well as emotionally and physically. Living on the street it's really easy to shut things off because nobody asks...It's just something that's not spoken so it's just really easy to get away with. I think that it makes sense. Because a lot of people just don't ask those things. You know, they don't ask you where do you live? So you don't have to have a home, like you know what I mean. So you're not questioned so it's not there so you can easily just avoid it... So I think the more you talk about it, the more you [are] reminded, and where your guilt and stuff comes back or whatnot. If it's not talked about, it's something that's just, it's really easy to avoid.*

Participants revealed that they found denial to be beneficial but also detrimental. At first, denial helped participants to temporarily forget the HIV. As can be seen in the following participant quote, denial helped them to continue to function. "Especially at first, you are just hoping and hoping it is not HIV, it is just some big mistake...You don't believe it, which helps you get through...". However, after a while the painful emotions of receiving an HIV diagnosis needed to be explored and dealt with. If participants continued to deny the existence of HIV, then the emotional nightmare was not being dealt with or explored, which could potentially influence high-risk behaviours. In addition, as discussed above, denial following diagnosis was not always effective, and often was only a temporary solution.

> *It [denial] happened for a long time after the news [of HIV]. It just helped me to survive and not get focused on all the bad stuff...But it was not healthy and it just led to a bad situation [high-risk behaviours]....*

Often participants would go numb, or engage in high-risk behaviours in an attempt to ignore or numb the overwhelming emotions and the news of HIV. If they were denying the existence of HIV, this allowed them to deny the guilt that came along with having HIV and also the guilt of engaging in high-risk behaviours.

> *Well, the denial, what purposes for me? It gave me an out, you know. It made me think that I didn't have to be responsible, you know. It's like, lots of people do it as well for lots of things. Parents go "oh, my kid's so good", even though they know their kid is doing something wrong and something illegal, and the denial is because "my child was so good when he was young and now he's older and he's doing things you just can't be"...Denial and the denial thing saves you; it's a saving grace. I can't be doing wrong; there's just no way you are.*

When denial numbed or took away strong feelings, such as guilt, the underlying problem might not be addressed. This could perpetuate the cycle, as illustrated by the following participant quote. "...You denied, denied, denied, drank, and drank, and anything else, but this just led to more deeper emotions like anger and resentment...It got worse and worse...".

Some denied the diagnosis all together, at times even convincing themselves that they did not have HIV. Others denied the repercussions of HIV, accepting they had the disease, but refusing to believe it would affect them. One participant shared, "Denial of the HIV, denial of what it does…".

Some participants suggested that denial could actually increase risky or unhealthy behaviours (e.g., drug/alcohol use). Participants who completely denied the HIV diagnosis, as opposed to the repercussions of having HIV, talked more about the relationship between denial and risky behaviours. For example, one participant made the comment, "Well, when you are in complete denial over HIV, you are doing things that help you deny but are hurting you…".

Denial and High-Risk Behaviours

Many participants felt that reducing denial can reduce high-risk behaviours. Furthermore, some participants believed that denial itself can increase the likelihood of high-risk behaviours.

> *How would I be able to stop [others] high-risk behaviours…I've tried. I've tried with people down here. I know that 90 percent of people, that they deny, and there's a whole lot of denial down there. They're the people that rather point the finger then look at themselves and say "hey I got it [HIV]"… The denial, and denial, it's very gigantic when it hits you. Until you come to the point where, hey, you accept it. Accept what you've got but deal with it. That's where I was, denied it for awhile. It took me a while to get to accept it. Yeah, I've tried to kill myself and you know, jail and that, you know. I've lost family and you know, it's like, it didn't work.*

> *Yeah, off and on for the first year [denied HIV], I held it together for a couple months and then lost it and then went back in to the dope, I was smoking crack, pills, everything, anything to numb. I was alone. I didn't tell my mom, my father had passed away, didn't want to tell family, didn't know how to tell family.*

According to the participants' accounts, denial of HIV influenced high-risk behaviours in several ways:

1) Some participants took few precautions to prevent the spread of HIV when they were denying HIV: "…I was extremely promiscuous because I didn't believe at the time that it was sexual habit that it [HIV] was spread by…".

2) Some participants suggested that there was potential to actually engage in high-risk behaviours to show (e.g., over compensate) that they did not have HIV: "…I wanted people to know I just didn't have it [HIV]".

3) Some participants believed that when they were denying HIV they were less likely to consider the repercussions of their actions. "Went through a lot of denial, denying the fact that I could be infecting others and at that time, especially being a drug addict, I really didn't care how anybody else felt".

4) Some participants indicated that they were unable to tap into more adaptive coping mechanisms or hope due to the denial.

> *I wasn't even thinking. I wasn't even there. I was…no. There was complete denial, no hope, no nothing, I don't think. No, I didn't even know about the disease, you know, enough to do anything about it. You know, I was more scared of it than anything. You know you're thinking of death rates, well AIDS, death, that's where my head was. Not so much HIV. I didn't know the difference between the two, so I thought, I learned it because there is a big difference between the two. But, not then, didn't have a clue.*

Experiences that were Perceived as Influencing High-Risk Choices after Diagnosis

Participants disclosed specific life experiences that they believed helped them to reduce their high-risk behaviours. What follows is a description of interpretations of participant experiences that seemed to offer protection from engaging in high-risk behaviours. These experiences are presented below as overarching categories and underlying themes.

Significant Events

Major life losses. Several of the participants indicated that through significant life losses (e.g., death of a father or partner), they were able to realize and appreciate what they were doing to themselves and others. These losses helped them to begin the process of acknowledging problems, making changes in their lives, and in reducing some of their high-risk behaviours. These participants began to appreciate life and wanted to avoid missing anymore important life milestones or experiences.

> *My mind said "I need to stop"; I had overdosed and then found out my dad died and I said "can't keep doing this", you know, "I'm missing too much". I missed a lot in my family. The births of my nephews and nieces and they're all teenagers now, you know. I mean they're all young adults and I missed them being kids, so I tried with my hope to try and not miss too much.*

Major drug overdose. Another impetus to reducing high-risk behaviours, as explained by participants, was experiencing a major drug overdose. Participants said that having an overdose, resulting in a near death experience, helped them to see the damage they were doing to themselves and the pain they were causing others. It also helped them to regain, or develop, an appreciation for life. This can be seen in the following participant quote. "…I mean when I finally gave up the drugs, the coke and everything, I had to have a major OD and almost not make it".

Support

Family, friends, and professional support. Many of the participants believed family and parental support was very important to help them with their high-risk behaviours. For some participants, if their family was able to support them, and help them to realize that they were better than the high-risk behaviours (i.e., they had too much going for them or too many positives in their lives to allow high-risk behaviours to destroy them), they could slowly start to deal with the high-risk behaviours and the emotional pain associated with HIV.

> *Well, my parents are a big part, you know. Like how they raised me from 11 up and [it] just wasn't in me to go nuts over the deep end. Like I said, my parents were probably the first ones I told [about HIV]. And as far as support, I'm sure they were there. You know, I was already on my own and my mom kind of just made some suggestions and reminded me who I was. Yeah, I think I'll, I'm going to do this now. Yeah, it is. A lot of it had to do with my upbringing. I can't complain.*

Participants also said that having supportive people in their lives (e.g., friends, family members, counsellors) who would continually make their support known was especially important. Participants were often not willing to believe that the support was available or able to accept any support from these people; however, after frequent and continuous attempts by supportive people, participants began to believe it and were more open to accepting the support.

> *It's repetitive or hearing it, sooner or later the crack opens and somewhere in there you're going to start believing. It's like when someone says "you're a dummy" and you constantly hear it all your life, well you start believing it and that's, well that's bad or good, if it's repeated often enough, a person's psyche starts believing on that.*

> *I had to try different ideas and everything to make me whole again and give me that hope and give me the strength to go "I've got to change this and I've got to do that", and if it weren't for friends and even strangers saying "you can do it" and saying it over to me, I would never have believed, I probably would have OD'd and died.*

Being around people who had a positive attitude also apparently helped participants to feel better about themselves and their situation, which some participants believed led to reductions in high-risk behaviours. As the following participant quote suggests, "Finding people in your life that are happy and positive…Not necessarily [living with] HIV, just [having a] positive [attitude]…".

Significant partners. Several of the participants identified their significant partners as reasons they reduced their high-risk behaviours. This was especially true when they had partners who were not engaging in high-risk behaviours themselves. Partners offered support and assistance in dealing with strong overwhelming emotions such as isolation, stigmatization, and self-loathing and gave them a reason to be safe. One participant mentioned, "Having a good partner to help you through it, help you to stop all the bull shit is so important…".

Having partners who became sick and required care was also identified as being an important reason for reducing high-risk behaviours. Being responsible for the care and support of a loved one seemed to act as an "eye opening" experience for several of the participants. It led to the development of responsibility for another human being and also resulted in realizing the repercussions of high-risk behaviours and not taking care of oneself. It also helped participants to feel needed.

> *I had met someone and we were both doing cocaine and everything at the time. We were using condoms when we first met, but we were living together down the line, everything, my risk behaviours started to clean up a bit because I go "well he's sick and we're partners and someone's going to have to take care of him" because by watching so many [people dying from AIDS], how many had nobody there to help them out and I went through a bad time with him in the end, my high-risk behaviours, because he had got phenomena and all these serious problems [AIDS related complexities] and I had to put him on life support… [I said] "You've got to stop [high-risk behaviours]", because I'm standing there and I'm staying healthy even though I was a drug addict. I wasn't getting sick and I was watching a friend of mine and he was deteriorating and I was like, things have got to change, and they got to change for him and his awakening to him to change for his hope and everything was that he had to go on life support but we weren't compatible anymore because he still wanted, after he came out, he still wanted to do coke and I'm going "Man this has got to stop. This has got to stop".*

Obtaining community-based peer support services. Participants felt that receiving peer support services from community-based agencies helped them to slow down risky behaviours. Meeting people living with HIV and AIDS and seeing how they were living healthy normal lives helped participants to realize that life could still go on and that they could survive. This realization seemed to be part of letting go of high-risk behaviours for some of the participants. It helped them to start caring again about their own lives and to realize that they were not going to immediately die a painful and humiliating death from the HIV. It also helped them to find opportunities for meaning in their lives (e.g., volunteer work). Thus, community-based agencies often contributed to the participant regaining a reason to care and discovering meaning and purpose.

Peer counsellor training (i.e., to become peer counsellors) was also seen as being important for participants in reducing high-risk behaviours. This was the case for several reasons such as: (a) participants receiving training and education in the areas of counselling and HIV, (b) participants feeling as if they are making a difference in the lives of others, and (c) participants having something positive and purposeful to focus their lives on (see section on "Peer counselling" for additional discussion and participant quotes).

Utilizing group interventions and individual counselling. Group interventions were also experienced by participants as useful in helping them to reduce risky behaviours. Participants suggested that seeing how others were struggling and dealing with specific issues and concerns was useful for their own growth. Individual counselling was also experienced as useful for participants to help to challenge high-risk behaviours. "Counselling services and talking with peers and stuff was very important; it kept me alive...It was useful at helping me stop my drinking and other risky things also...".

Developing an action plan, goals, and a safety plan were also important for participants in challenging high-risk behaviours. An action plan helped some participants to become orientated in their lives and to get focused on a positive direction. As one participant suggested, "Counselling was really helpful in getting a plan of action together…" Goals helped to remind participants of what they could accomplish if they worked at making changes in their lives. One participant commented, "Major lifestyle changes are needed, a whole change in direction…You need guidance, you need to have goals…". Safety plans helped in creating a safe atmosphere and reducing dangerous behaviours (e.g., suicide attempts, extreme drug abuse). This is demonstrated in the following participant quote, "…Being safe, having a safety plan, this helped to reduce risks of drug use or even suicide problems…". Counselling services also helped participants to develop coping and stress reduction skills, which are discussed as a separate theme under the category "Learning about HIV and Dealing with Problems Associated with HIV".

Reaching out to harm reduction programs. Harm reduction programs (e.g., needle exchange programs, methadone programs) were identified by participants as useful for reducing high-risk behaviours, especially risky drug use situations. Through the reduction of high-risk drug situations, participants also experienced reductions of other high-risk situations (e.g., risky sexual behaviours). These types of high-risk situations and behaviours sometimes developed out of the risky drug use. Participants felt that because of harm reduction programs they were safer and less chaotic in their drug use (e.g., more likely to use clean needles, less likely to share others' needles). One participant noted, "Programs like methadone and that were very good, they help you to get into a better situation, less risks…".

Learning about HIV and Dealing with Problems Associated with HIV

Knowledge and information acquisition. Many of the participants expressed that gaining information and knowledge about HIV and infectious diseases helped them to reduce their high-risk behaviours. This occurred through several avenues. For example, some participants discovered that through high-risk behaviours they could become infected with other infectious diseases (e.g., hepatitis), get other strains of HIV, and become sicker and speed up the process toward death. Participants also learned that they could spread the disease relatively easily, which also seemed to influence their high-risk behaviours in many cases.

> *Yeah, especially the needles part, like, I used a lot of other peoples' needles; well, I'm already fucked so it doesn't matter if I use somebody's syringe or whatever, you know. It was much later that I learned about, you know, other things that you can get. It's not just the end, and you can get other diseases which can make you a lot sicker, too.*

Participants also said that through informational attainment, they learned that HIV is not an absolute death sentence. Many of the participants believed that they were going to die a painful, slow, and humiliating death with HIV. When participants began to learn that they could live a long and healthy life, some experienced changes in their high-risk behaviours. For example, the following participant came to realize that his life could go on. This awareness positively impacted his outlook, offering him hope for the future. "Part of it was just being told that you are not going to die, you can live a long healthy life, and seeing this in others...".

Participants also highlighted that learning the difference between HIV and AIDS was important for helping them to realize that they could live a long and healthy life. Some of the participants were told right away that they had AIDS, or were told they had HIV/AIDS which led them to believe they were going to die. One participant noted, "Understanding the difference between HIV and AIDS is so important to getting through [surviving HIV]...".

Taking responsibility. Taking responsibility was seen as being important in challenging high-risk behaviours. Participants recalled that through blaming others, they engaged in a lot of pity and denial. Denial of HIV was common among participants. As mentioned above, many participants suggested that experiencing denial of HIV may have put them at risk for unhealthy or risky behaviours. Several participants saw their high-risk behaviours as helping them to deny their HIV status. They also experienced a lot of anger toward others. Some participants suggested that this reduced their sense of responsibility for their actions as well as the repercussions of their actions. "I was just so angry at the world, just did not care...I was blaming anyone else but me...I needed to accept some of the blame and move on...". Participants recalled that as they were able to let go of denial, increase their acceptance of the HIV, and accept responsibility for their lives, they engaged in fewer risky behaviours. As can be seen in the following participant statements, acceptance of the HIV and taking responsibility were important. "Just accepting the HIV and getting away from denying it [was important]...". "Once you stop the games you can start looking at who really can make something happen...".

Addressing mental health concerns. Treating mental health concerns was suggested by participants to be an important component in challenging high-risk behaviours. For example, people feeling very sad and depressed can experience suicidal ideation and people dealing with mania or an extreme elevation in mood can experience risky behaviours (e.g., unprotected sex). "You get help with the more severe mental health problems and that can help you with other stuff, like your drug use or your suicide thoughts...". Mental health concerns were addressed through several avenues (e.g., professional counselling/psychotherapy, medication, family/friend support).

Dealing with emotional suffering. Most participants felt that high-risk behaviours helped them to numb and deny the intense emotional pain they experienced following diagnosis. Several participants found that it was not until after they successfully dealt with these emotions in a healthy and effective manner that they were able to move on and challenge their high-risk behaviours. One participant suggested, "It was about dealing with the fear, anger, pity; these feelings were just too much...They needed to be dealt with...". Indeed, several participants believed that these emotions also prevented them from seeking out services and following medication schedules.

Developing coping mechanisms and stress reduction techniques. Learning coping mechanisms and stress reduction techniques to deal with stressors and HIV without engaging in high-risk behaviours was important according to several participants. This seemed to be especially true for participants if they were utilizing high-risk behaviours as a means to deal with stress and overwhelming psychological pain. "...Learning how to cope and handle stress instead of drugs and alcohol [as a means to deal with stress and the HIV}...". Although professional counselling services were often involved in helping participants learn skills to deal with stress, participants also learned skills through other means (e.g., peer support, community-based agencies, friends/family).

Reducing high-risk associations. Many of the participants disclosed that they believed associations and relationships with others who engaged in high-risk behaviours (e.g., drug use, alcohol use, stealing) perpetuated their own high-risk behaviours. For some, the relationships fueled these behaviours. One of the ways participants felt that they reduced their high-risk behaviours was through reducing their associations with certain people who encouraged or facilitated these behaviours.

> *Well, it's from moving. Getting away from people, not telling them where you live. I'm just getting going. Get away from junkies, people who encourage you to use, getting on with your life, which is good. Makes you want to get out of there. So that really helped it. Change your address, change of people. Change your neighborhood. They said "hey, can you still hook me up", and I said, "well I don't do that no more".*

Perspective Shift

Finding hope. An important experience explored in the present study was hope. One of the central findings was hope's influence on participants' ability to challenge their high-risk behaviours. Several participants recalled that when they began to experience hope they noticed changes in their high-risk behaviours. As one participant recalled, "Hope is a funny thing; it makes you feel good and hopeful for the future...It also helps to change your life ways...".

Participants also suggested that with reductions in high-risk behaviours, they experienced increased amounts of hope. Taken together, this suggests several participants experienced a back and fourth relationship between hope and high-risk behaviours. One participant commented, "When I got my life back together, off of the drugs and stuff, I felt much more hopeful...".

People also identified specific things or objects they were hoping for (e.g., getting back a daughter, longer life) which helped them to become focused and make changes to their lifestyle. Future outlook was important. Hope grew as participants began to realize that they could maintain many of their hopes and dreams for the future. Several of the participants found that they could re-connect with future aspirations such as "seeing their children grow up" and "having a family". As one participant shared,

> *I want to live; I made that choice. I want to live; I've got things to do. I got my daughter. We lost our daughter due to our drug use and our drinking and being unstable. You know, she got taken. And I'm saying "hey, I know my daughter wants to see you and I'm going to stay alive until she gets back". And that's the hope I've got. And you know, I*

> *do it for myself. And while I'm doing this, I quit four months ago drinking. Period. I can go bottle pick and find bottles of beer, full cans of beer and I spill them out. Where normally I would just down them. Easy, don't drink anything with alcohol, perfume, shaving lotion, anything. I shot up pure alcohol. I did the chicken [lost control]. I even drank antifreeze. And I started doing suicidal things. I walked across this wooden bridge backwards. I tried to walk across backwards, over the ravine. Stupid things like that.*

The multidimensional nature of hope was apparent through the stories of the participants, suggesting hope was represented in several different realms (e.g., context, cognitions, behaviours). This will be explored in more detail in chapter six.

Finding something to believe in was suggested by some of the participants to be instrumental in facilitating hope and challenging high-risk behaviours. Without guiding beliefs, there was nothing helping them through the emotional turmoil. For some, a belief in God, or some type of higher power, steered them along a positive course. It helped to offer reassurance during a time of total uncertainty.

> *Just having something to focus your energy on, like something spiritual, or something important...This gives you something to believe in, like it's going to be okay...This can get you through hard times after diagnosis, and get you through the drugs, and the suicide....*

Discovering purpose and meaning. Many of the participants in the present study shared that following diagnosis they had nothing to live for. They believed that their lives were over, and purpose and hope were gone. Reducing feelings of loss and despair and helping them find purpose and meaning in their lives seemed to help them to challenge high-risk behaviours and locate hope. One participant shared, "What's the point of life now?...If you have a reason to go on you will go on...".

Some participants also suggested that identifying things in their lives that provided them with meaning was important and may have helped them to reduce high-risk behaviours. The following participant quote illustrates the importance of meaning,

"...Meaning, get meaning, get purpose...This helps you to change your life, like drug use and reckless ways...".

Becoming busy with personally meaningful activities also seemed to help participants influence their high-risk behaviours. For example, many participants volunteered, giving their time to others, which helped them to find meaning. Volunteering at community-based HIV agencies was identified as an especially powerful experience which helped them to obtain meaning. Several participants suggested that this meaning helped them to reduce their high-risk behaviours. "Being a peer educator, just helping out, this helps you to get focused and change your lifestyle...".

Another important aspect of finding meaning in life after HIV was making meaning from the diagnosis itself. According to several participants, finding or making meaning out of the HIV diagnosis was important in challenging high-risk behaviours and effectively dealing with the diagnosis. "...Definitely, you need to make meaning out of it all if you are going to accept it and get over it [HIV], change your lifestyle, be safer...".

Regaining a reason to care. As mentioned above, one of the most common, and intensive, reactions to an HIV diagnosis for the participants was to "stop caring". After diagnoses many just did not care about what happened. Several participants felt that this fuelled high-risk behaviours. Regaining a desire to care seemed to help participants to challenge their high-risk behaviours. Many began to care again for several different reasons. For example, outliving doctors' predictions of death gave them hope that they may not die. A common prediction made by doctors was two years. After these two years elapsed, many of the participants were not only alive, but in good physical shape. This helped them to begin caring and challenge their high-risk behaviours. One participant commented, “Just outliving doctors’ predictions gave you hope and helped you to move on away from bad situations…”.

Desire for longer life. Several participants dreamed for longer lives. Through obtaining health related information they began to realize that by living a healthier life (e.g., emotionally, physically, psychologically), they could improve their health and increase their chances for a longer life. This gave some an incentive to reduce behaviours that were contradictive to health.

> *Yeah, I, I knew that having a compromised immune system, I couldn’t abuse it, kick the shit out of it or, no. I had to live a little more positive. That’s why I started dealing with that agency and this agency. Cause the groups and the training sessions and stuff was just what I needed to stay straight and focused. It was great.*

Finding control. Participants identified control as being important to them. Many found that high-risk behaviours resulted in a loss of control. According to some participants, having a sense of no control propelled them to reduce the high-risk behaviours that resulted in feelings of no control. One participant suggested, “It’s not good to lose that kind of control. I don’t need that. What are you going to tell a judge, ‘oh I was drunk, oh I was stoned’. That doesn’t work. That doesn’t work”. Perceptions of control also seemed to be related to a sense of hope. Although having control was not an absolute necessity for the appearance of hope, perceiving a sense of control did seem to help some participants hold onto hope.

Becoming comfortable with HIV. As participants became more and more comfortable with HIV, some felt that they were able to reduce some of their high-risk behaviours. Some suggested that part of this comfort came from getting to know oneself as “HIV-positive”. One participant commented, “The more you accept it and deal with it the better off you are...You are just more likely to deal with it without all the drugs and suicide thoughts...".

Sense of humour. Developing a sense of humour or regaining a sense of humour was seen by participants as an important component in dealing with the HIV diagnosis and reducing high-risk behaviours. Humour helped participants to lighten the seriousness of the HIV. It also helped them to laugh with others, making them feel good. As one participant mentioned, "...Humour is just so important in being healthy and getting through it...It helps you to realize that it [your life] is not over...". Having a sense of humour was also related to a sense of hope for several of the participants. Humour seemed to reduce the tension and despair which often surrounded HIV, opening the door for hope.

Losing patience with a high-risk lifestyle. Becoming tired and fed-up with the lifestyle of high-risk behaviours was also an important reason for reducing these behaviours according to some participants. It became clear to several of the participants that they were the only people who were able to make the change to reduce these behaviours and move on in their lives. It was the frustration and disgust for the high-risk lifestyle combined with the realization that change could happen if it was self-initiated through self responsibility that helped reduce the high-risk behaviours. As one participant recalls,

> *Well, money and time is probably one of the main factors. But [I was] waking up sick and was strung out and sore and I knew something had to change. And the only one that was going to do it was me. So I...not totally straightened out, even to this day I don't, I really, there's a difference between use and abuse and I just don't abuse. I see others, how they abuse. I can't do that.*

Participants felt that with age and experience they developed maturity or a realization that life is short and what you make of it. There was a realization that things needed to change in their lives, which included a reduction of high-risk behaviours. In this case, it was a combination of becoming older and having different types of experiences, which, for some, helped them to become impatient with their lifestyles. This can be seen in the following participant quote,

> *Over the years, 25 years of injecting, you know what actually made me stop? Was turning 40... well, when I turned 40 years old, that was my goal, was to get my shit together and get off the stuff and start living...and for me it just got to the point where I said "40 years old. Okay. I started when I was 15, that's 25 years sticking needles in my arms", sometimes up to six, seven hundred dollars a day worth of stuff, and some of the ways I got it I'm not even going to say because I probably end up going to jail but, uh, yeah, turning forty, I said "that's it" I wanted to quit for myself.*

More Reasons for Hope Today Following Diagnosis Yet Still High-Risk Behaviours

As previously mentioned, many of the participants indicated that with more awareness of hope they seemed to engage in fewer high-risk behaviours. Interestingly, several of the participants suggested there is more to be hopeful for today when you receive an HIV diagnosis (e.g., more effective medications, more knowledge regarding HIV issues) as opposed to in the past, when little was known about HIV and effective medications were undeveloped.

> *...See it's, that's hard, because when I got diagnosed, it's a lot different from when I got diagnosed to people getting diagnosed now because there's hope with people that are getting diagnosed now where there wasn't hope when I got diagnosed...There was no hope at all you know, you got diagnosed back in the '90's, "you're dead, sorry", you know, which obviously was a lie because I'm still here.*

Some of the participants were able to offer reasons for increases in high-risk behaviours despite the potential for more hope following diagnosis.

> *...You know you have to want to give it [high-risk behaviours] up before it will actually get given up and even though there's the hope now, more hope because people*

> *can last 20 years or whatever...they don't see that, all they see again is those three letters, H.I.V., which equals death sentence.*

It seems that it takes time for many newly diagnosed individuals to learn that there is hope for the future with an HIV diagnosis.

> *Yeah, because they don't know, they're blinded, they think that they've got the disease now and that's it, I'm gone, you know what I mean, like I did. I had no idea of what was. I was blind to my situation and didn't know what was going to happen and within five years I figured I would be dead, within five years, and here it is [a lot more years later] and I'm still healthy as a horse and I'm just starting a new family life. I would have never thought that would ever happen. That was the last thing from my mind, I thought that would ever happen, was like something that I wouldn't believe if you'd told me when I first found out that I was HIV, in [a lot more years later] you're just going to be starting another family, you know what, fuck off, you know what I mean.*

As seen in the above participant quotes, a common theme was being blinded by the HIV diagnosis and thoughts and fears of a slow and painful death. This was occurring despite the existence of new HIV medications and treatments that can prolong healthy life for many years. Again, getting participants information and knowledge, as well as helping them to see others who have lived with HIV for many years, was identified as being important in reducing high-risk behaviours.

> *...Talking to a peer counsellor...I think, yeah, before everybody gets tested they should at least talk to a counsellor before they get their test results so that if they do get a positive result at least they're not going to go out and slash up right away...they've got a little bit of knowledge that they can use before actually getting that diagnosis and that little bit of knowledge could equal a longer life.*

Another reason suggested for the increase in high-risk behaviours, despite the current potential for enhanced hope for a long life following diagnosis, was due to a major identity shift or change to the way one is living his or her life. Following diagnosis of HIV come major changes to one's self perceptions and lifestyle choices. For example, the newly diagnosed individual must often adapt to being labeled as “HIV-positive”, “sick”, and “ill”. In addition, the individual must frequently make lifestyle changes such as following rigorous medication adherence schedules and maintaining increased vigilance surrounding high-risk activities.

> *Well, it might be a death sentence in the way they, their lives, like their lives as they know it certainly is going to change. So maybe the end of one lifestyle and the beginning of another one, I guess.*

As can be seen in the above participant quote, even if HIV is not perceived as a death sentence, it is still perceived of as death to a way of life. This implies a major transition with serious lifestyle changes, often accompanied by devastating stress and uncertainty.

Concluding Thoughts

Within this chapter I have highlighted several categorical and thematic domains that relate to unhealthy and risky behaviours following an HIV diagnosis that existed for the participants in this study. The participants' accounts, along with my interpretations of their experiences, have offered a rich description of the "high-risk period" following an HIV diagnosis. It seems that multiple types of high-risk and unhealthy behaviours can exist following an HIV diagnosis. In addition, various experiences can perpetuate and ameliorate such behaviours. In the following chapter I will explore several categories and themes that relate to hope in the context of high-risk behaviours following an HIV diagnosis.

Chapter Six: Themes

Understanding Hope in the Context of HIV and High-Risk Behaviours

Within this chapter I present the themes of the 12 participants' interviews that relate to hope. Overlap does exist between the different theme chapters as these are interconnecting experiences. Participants' experiences of hope, their high-risk behaviours, and their involvement with mental health services were all connected through the news of the HIV diagnosis. It is not possible, nor desirable, to separate the context and relationships to other experiences such as high-risk behaviours and mental health services, in discussing participants' experiences of hope. However, the main focus of this chapter remains on hope. Through hearing and interpreting the participants' experiences and stories several hope related categories and themes emerged. These areas are discussed in the following sequence: (a) participants' definitions of hope, (b) learning about hope through story, (c) experiences of hope in the face of HIV, (d) challenges to hope, (e) risk of hoping, (f) functions of hope, and (g) hope developed through the research interviews. Hope was seen by most participants as being a central experience in their lives. No participant said that hope was not important for him/her. As can be seen in the participant quotes below, many participants identified a massive threat to hope following their diagnoses, with hope increasing as time passed and life itself becoming more and more promising. Participants began to connect with hope for many different reasons such as experiencing purpose in life and better physical and emotional health.

> *I got pretty lost, you know, I didn't have any real direction [following my HIV diagnosis]...I had fleeting moments of hope but they were fleeting...Those little signs of hope that get my life kind of refocused and going and then as soon as something goes wrong, oh my...I lose that hope, then I go into my little depression, you know, so I mean if I were to like monitor my roller coaster, hope gets me up and, you know, so I mean encouragement, good medical reports, volunteering, appreciation. All of those things*

> *kind of stack up and work towards a health [and hope]. Discouragement, bad numbers, getting the sickness...bring you down. When I was first diagnosed I was a real downer and the hope was not there and there was a lot of despair and fear and I was getting into contact with other people that had encouraging things to say [which] brought me out of [the depression and lack of hope] but like I say it was fleeting. It was a long time before I actually felt hope. And even then it's been rocky.*

Many participants felt as if they had no hope following diagnosis, and were trapped in a place where hope would never exist. The belief was that a meaningful future had died for them and with that hope seemed to disappear. "No, there was none [hope]. I figured I was just locked in to that kind of life forever. You know, I didn't care. Just getting high was the only thing I cared about".

> *There was no hope...my life was over, I destroyed everything that ever happened, every good that was happening to me was gone and I had fucked everything up, all my dreams and aspirations were destroyed, there was no chance on ever building any of it again. Growing old and family and grandchildren and you know all kinds of things about all that, that was gone. I didn't think I'd last long enough to see my kids be 10 or 12 or 15, I never thought I'd see them.*

Participant Hope Definitions

Participants talked about hope in different ways throughout the interviews. Often hope was initially hard to talk about. Participants struggled with finding the language to describe what they meant by hope. As the interviews progressed, participants seemed to become clearer in their own thoughts and words when talking about hope. It was as if given permission to talk about hope, an unconventional topic, allowed them to gain insight into what hope meant for them. What follows is a description of participant understandings of hope.

Future. Hope was temporal and future oriented in many participants' descriptions of their high-risk period following HIV diagnosis. When the future-oriented aspect of hope was experienced, it included a belief or a feeling that things were going to work out (e.g., "You have to keep thinking that it will be okay" and "I just all of a sudden got this sense that it would work..."). This belief/feeling was not necessarily of a cure for HIV, but of other important things working out in their lives (e.g., seeing a child grow up to get married or graduate, getting a child back, accomplishing something great at work, or mending a broken relationship).

Drawing the past forward. Hope was also seen as existing in the past and present. Participants spoke of overcoming past difficulties as evidence that there had been reason to hope in the past and so there could be again. Participants reminisced about difficult times that they had lived through and also remembered positive experiences from the past that could recur.

Behaviours/control. Participants also revealed that certain behaviours (e.g., taking medications, exercise) were a part of hope. These behaviours gave participants a sense of control in their lives and the power to enact a good future for themselves.

Relationship. Hope was also relational. Participants revealed that an important aspect of hope was about their perceptions of, and experiences with, important relationships (e.g., "The relationships, these are so important [for your hope]").

Meaning and purpose. Hope was also vitally connected to meaning and purpose. Areas of life such as family, work, or spirituality offered meaning in life and the prospect of a good future for self or others. Several participants suggested that hope was related to making a positive difference in others' lives and was also about leaving something worthwhile behind after their death.

Hope as a process following diagnosis. Most participants struggled to find any hope immediately following diagnosis and slowly began to re-experience hope with time. One participant described the devastating despair,

> *There was no hope [following the diagnosis of HIV]...My life was over, I destroyed everything that ever happened, every good that was happening to me was gone and I had fucked everything up, all my dreams and aspirations were destroyed, there was no chance on ever building any of it again. Growing old and family and grandchildren and you know all kinds of things about all that, that was gone. I didn't think I'd last long enough to see my kids be 10 or 12 or 15...*

Sharing Hope through Story

During the research interviews hope was often rooted in the participants' life stories. When asked to define hope during the interviews, many participants disclosed stories that represented hope for them. Hope as an abstract concept seemed much harder to define in the absence of giving a personal account. Many of the participants also offered hope to others through sharing their own stories of living with HIV. Hope was embedded in their stories and they felt a need to share that hope with others by sharing stories of living with HIV. In sharing personal hope stories, participants themselves began to feel more connection with others, and also feel more hopeful as a result of remembering and sharing the hopeful stories in the first place. This is a recursive loop that appears to foster hope in the teller and the listener. Indeed many participants recalled how sharing their own hopeful stories also seemed to invite the listener into reciprocating by sharing their own hopeful stories. As one participant put it,

> *...Like I did it, you can do it, so I've gone through this so you can go through this, it's just another challenge that we have and if we can share it with other people, then it's, I don't know, like you said, this hope has to be shared. I think so because I wouldn't be able to live without having to share it...*

Another said,

> *Well, hopefully I can put it in a nutshell for them, where I was, where I was at, where I am now... I just say that, most of what I know is just from personal experience and everybody's story is different, but it's the same....*

Participants told stories during the interviews. These stories were shared when they were invited to speak about their experiences of their HIV diagnoses. Indeed, story was one important way participants described their experiences of hope with me. Transmitting hope through story can be seen in the following two participant quotes, where each shares a story, which represents hope for them.

> *Spreading, I hope it [hope] can be contagious, I hope. I hope it's contagious. I do, with more people who are involved, the more new faces we see, people who are interested to talk to people who have this disease who are not afraid to shake their hand, that's just hope there in itself with the interaction between [people]. Humans, that's getting a hug from a child or an older person, there's hope and that's awesome, totally awesome and here's an example, when I was in the shelter. I didn't tell a lot of people about my disease and one day we were sitting there, there was about nine of us around the table and only one knew [that I was HIV-positive] and I blurted it out [I am HIV-positive] and the look on their faces, three of them started crying, two of them, and only one kind of pushed her chair out real quick but then she caught herself and she came back real slow and I went up to her first and I said "Are you scared of me?" And she said "No." And I said "Don't lie." And she goes "Well, yeah." And you know she used to hug me everyday so it took her a couple days but she did come back and she says "Oh, I still love you, you're not any different." So that was, it was really interesting to see so many different reactions at the same table at the same time, especially the crying, it was like, "Why are you crying? Oh, you're going to die, oh, no I'm not." You know, I was like, I said "No." I gave them hope because they had no hope, they had like, "You're going to die." No I'm not, I'm going to fight this and they didn't understand that HIV is not AIDS, you're not on your death bed yet, you've got a lot of years to live with it, you've got a lot of years to hopefully find a cure or something to put it into remission or something, you know...I guess when we're threatened with a serious illness especially a terminal illness, I say this is my terminal illness and with that life is more precious and so is the relationships that I make and the friends that I make and the people that I see and the people that I talk to, it's [hope] more personal, something that I need to hold on to.*

> *...So we [participant in this study and another person recently diagnosed with HIV] met up and I rode up on my bike and he just went, "You ride your bike?" Yeah, why not? And I have rollerblades at home, too. And I think at that moment he realized it's not death. It's not that. And I think people need to see that right away. That this is not a death sentence. This is a new challenge and it's going to challenge you to your limits but it's certainly not a death sentence, by no means. So I think giving hope...however, me riding up on a bike or me, I walk everywhere I go, so I walk and meet for lunch with him still,*

> *and you know I'm just active. And to me that's part of my purpose is to remain healthy so that I can help others and live a long time.*

Obtaining and spreading hope through story was also common for participants who were peer counsellors. Peer counsellors and those who had received services from peer counsellors seemed to utilize story as an important medium for the transfer and acquisition of hope. Participants, who were recipients of peer counselling services, disclosed that through hearing others' stories they were able to realize that life could go on and that they could be healthy. They developed and found hope through listening to others' experiences and stories. Some of the peer counsellors also seemed to discover and nurture their own hope through telling their stories about their experiences and by helping others deal with HIV.

> *I didn't see peer counsellors at first, it was just people that were HIV [positive] and other people, you know [I] just talk to people and learn their story and [it's about] getting a better grasp on the disease.*
>
> *[What is it about hearing others' stories that brings you hope?] Just knowing that they're living. Like me, I talk to people that have HIV and [I] tell them, I just had a baby...It like blows them away. I had no hopes for another family. And I thought my kids are going to be growing up and that's it and [I will] live alone or I'll have a girlfriend but I'll never have any more kids. I want a family.*
>
> *Great, so I went every Monday for years and there's about seven of us, eight of us and during that period of time over a couple years, three years, I met people who had been positive for years and learned from them how to cope, how they cope, what they did, how they dealt with their emotions. And one of them was going to that group. And being trained as an educator...so yes, weekly group sessions, and through the course of years met many people, all positive. Men, women, teenagers, prisoners, junkies, middle-class, upper class, gay, straight, didn't matter. And it's very inspirational hearing their stories. Just learning how do you deal with this some days.*

As seen in the next participant quote, some participants held hope that they could share their hope with others, through story. "Well, I just hope that, and I hope that I can help more people through experience and through coming across with my story".

Some of the participants said that through hearing stories of peer support counsellors they also felt inspired, motivated, purposeful, and as if they were not alone.

> *When I'm inspired by somebody's story I'm hopeful because it shows me that I'm not the only one going through this. You know, there are others out there. So that provided hope and I also learned that not only was I being a benefactor of people's stories in terms of getting my hope and being inspired to help others. I soon realized that, yes, others were learning from me... So that was my first time really realizing that my presence made a difference to others in a positive way. So that gave me hope and that hope gave me purpose. Now that I have a purpose, I have something hopeful. Hope and purpose [go together]. [One should] inspire to have a purpose which in turn having that purpose, [makes me] hopeful that I can fulfill it.*

> *Hope and purpose. If a person doesn't have purpose for being here then there's nothing to hope for. And if a person has hope then it's probably because they know they have some purpose to perform, you know. Whatever it may be, selfish, unselfish, whatever. But they have a purpose.*

As can be seen by the following participant quote, many participants worked hard to maintain a sense of purpose in the face of serious threats to their future. Sustaining a sense of purpose helped many participants to have hope even during difficult times.

> *I remember I was half through my [education] when I was diagnosed and the course I was in at the time was [professionally helping oriented]. It was just bizarre and there's a purpose here somewhere, I may not know what it is but there's got to be a purpose and I really questioned whether I would finish or not. Whether I'd be alive to finish. How do I go to [another country] to finish my degree being positive? And still on mono therapy AZT which was brutal. How do you do that and do it legally. So I managed, I got my student visa...and then my [partner] just mailed down my meds and I picked them up at the post office and that was it. I was there for a month. Finished my [education] and came back. So that goal that I had, realizing that, okay, do I give up or do I carry on? What if I give up? Why give up? Carry on. Do what you can. If you don't finish it in five years, toodle-loo, big deal. But I knew I would.*

Experiences of Hope in the Face of HIV

This section explains the sources of participants' hope and threats to participants' hope in the face of HIV. It also looks at the interplay between these hope sources and threats to hope. Participants disclosed many experiences, objects, feelings, and thoughts that enhanced their sense of hope. These different hopeful experiences occurred at various times in the participants' lives. As can be seen by the following participant quote, hope was described by several participants as being individual, unique, and not something that could be "prescribed".

> *I haven't changed my ideas about what hope is; hope is what you make it and how each person views it and what they do with that kind of hope...It's very individual....*

As mentioned above, most struggled with hope immediately following diagnosis and slowly began to regain hope as time passed. Participants described various things that brought them hope, which varied tremendously in many cases.

Survivability of HIV and Support

Participants talked about several different experiences which helped them to realize that they could survive with HIV. Sources of support were also important components for participants to realize they could survive with the virus.

The living quilt. The living quilt was identified by many participants as giving them hope in the face of HIV. The living quilt demonstrates the survivability of HIV. It contains the names of hundreds of people who are living with HIV and AIDS and shows the length of years each person has survived with the disease. It acts as a testament to the fact that HIV is not a death sentence, demonstrating that it is a chronic condition that can be managed and survived. As one participant put it,

> *...Years of people being positive. Yeah, right, they live. Makes you realize another 20 years [is possible]. You could live the next 20 to 30 years. People look at that [living quilt] and they see that you don't die after 2 weeks, 6 months or whatever. You could live forever. Or a lot longer than you think.*

Being around others who have HIV. Being around others who have HIV and who have been living long healthy lives helped the participants to experience hope that they could have healthy long lives. "Just seeing that they are living a long time and that they are positive makes you feel positive".

Some participants disclosed that seeing "miracles" occur among others with HIV helped them to have hope. For example, if someone was sick and close to death but then unexpectedly became healthy again then this helped people to have hope. "It was amazing seeing someone who was just on their death bed bounce back because of some new meds or something..."

Community-based agencies. Community-based agencies provided the opportunity to be around others who were HIV-positive and living meaningful and healthy lives, which many participants found hopeful. "This place [community-based agency] saved my life. You just get to be accepted and be around so many great people all the time. You see people living life and being positive, it is hopeful..." Involvement in community-based agencies helped participants to locate hope in several of the other thematic areas in the present category (e.g., living quilt, being around others who are HIV-positive) as well as other thematic areas (e.g., purpose and meaning, learning about HIV and AIDS) in other categories.

Family and friends. Having family and significant partners/friends available often offered a profound sense of hope for the newly diagnosed as they struggled with high-risk behaviours. As one participant put it, "The only hope I have is for my family. If I didn't have kids and family, I just probably wouldn't care. Kids are everything, in my life anyway..."

In addition, thinking about the future and believing that they would be able to survive long enough to witness important milestones (e.g., weddings, graduations) in their families' lives seemed to help them to have a greater sense of hope. "...I want to be around long enough to see the first guy she [daughter] goes out with or when she turns 13...That gave me hope for a new life..."

Memories. Reflecting on the past or keeping cherished memories alive helped some participants to maintain hope. Thus, time orientation centered toward the past facilitated hope for some participants. One participant reflected on an intimate partner who remained important to him though she had died,

> *...I think she'd [partner who died shortly before participant's diagnosis] be pretty proud of me and what I've done and I think she'd probably tell you that in death much like as in life most of my hope was tied up in her....*

Engaging in Meaningful Life Experiences

Participants also found ways to engage in meaningful life experiences which helped them to experience a sense of hope. Engaging in different experiences helped them to become inspired and develop purpose in their lives.

Inspiration. Hope offered the inspiration or drive and energy to do things that participants cared about and were interested in. Inspired by hope, participants began to believe that they could continue with life doing what it was that energized and motivated them in the first place. Inspiration, for some participants, helped them to harness the energy necessary to engage in other thematic sources of hope (e.g., joining community-based agencies).

> *...so that's my hope, my inspiration, my driving force is my music...So we're born with one foot in the grave [and] it's just a matter of when the other one's going to get there so until that other one gets in there I'm going to keep doing what I'm doing and that's writing songs and making music and having fun doing it... and that's my hope, my drive, my tunnel vision.*

Purpose and meaning. Indeed, several participants suggested that becoming involved in HIV work (e.g., public presentations of their stories of HIV, peer counsellor work) brought them hope and purpose. Participants believed that through this work they were making a difference, slowing the spread of the virus, and preventing others from suffering. This, for many, was the best way they could fight against the disease. Finding this purpose in life helped participants make meaning out of their lives and even of the HIV diagnosis. Purpose and meaning often helped set the stage for the appearance of hope. As one participant who does HIV education in the schools shared,

> *...In them [children] is my hope for a better world; for myself, I have no hope for me, I am what I am, I'll live as long as I live. I'll spread my message to as many people as want to hear it and if it helps, I'm glad for it and if it doesn't help, I tried, either way I go to the grave a satisfied, healthy person you know....*

As can be seen in the above quote, one source of hope for participants was contributing to something beyond themselves. This helped them to find meaning, purpose, and hope.

Faith and spirituality. Hope was connected to faith and spirituality for many participants. Through spirituality and religion several participants suggested that they were able to hold onto beliefs that things would be okay for them and their families.

> *I would say to me, as someone living with HIV, hope is a range of things. Hope is being realized every morning I wake up fine and healthy. Hope is something that is spiritual to me as well. There's a faith.*

> *...just want to make a comparison to the word hope and faith, two words that aren't easy to define, that's just going through my mind... Yeah [I see a connection between hope and faith]... Relationships with God....*

Perceiving Options and Learning about HIV/AIDS

Participants talked about becoming prepared to live with HIV by obtaining information and developing options. In this way, preparing for a future, even with HIV, offered hope.

Learning about HIV and AIDS. Participants suggested that learning about HIV and AIDS and learning how to effectively fight against the virus helped them to experience hope. Knowing that they possessed important skills to care for themselves offered a sense of personal empowerment and the sense that, even with HIV, they could create a good future for themselves.

> *Oh, fuck, there was no hope at all, my life was over, that was it, I'm dead. I was a walking dead man [after diagnosis]... After about a year or so, you know, I started wanting to learn more about it and talk to other people, but right off when you find out [become diagnosed] you don't know that this is here or you don't know anything about it, it's just I'm sick and that's it, I'm going to, I have a terminal illness and I'm going to die of it...*
>
> *...I think yeah before everybody gets tested they should at least talk to a counsellor before they get their test results so that if they do get a positive result at least they're not going to go out and slash up right away... they've got a little bit of knowledge that they can use before actually getting that diagnosis... and that little bit of knowledge could equal a longer life....*

Perceiving options. For some of the participants, more and more options (e.g., medication options, treatment options) seemed to help them to have hope, whereas reductions in options seemed to challenge hope.

> *...My hope was starting to build and I got past... really ugly two year mark that people were dying and then more information was coming out about HIV and more options, and they were coming out with new drugs and I'm like "Yeah"....*

Hope in the face of illness. Though participants often found hope in those experiences that supported a longer life with HIV, they also revealed that planning ahead and knowing that they had a good place to go when they became sick helped them hope.

Following diagnosis, many participants were overwhelmed by images of sickness and humiliation by a horrific death of AIDS. Believing that the future held the possibility of a good death offered hope. One participant reflected, "Well I know that I'm going to die...I would hope that it wouldn't be so prolonged and sickening...I hope that I would have a good place to go to..."

Treatment

Participants reported that treatment including medications, counselling, and harm reduction programs supported their sense of hope by helping them to believe that their lives and situations could improve.

Medications. Several participants suggested that medications were linked to their hope. Some of the participants talked about not being on medication as being hopeful. "...I wasn't on medications and I've only been on medications recently, will be three years, so I was without meds for three years..." Those who were not on medication seemed to believe that there were other options available. If they became sick they knew that medications existed that would help them through their sickness. It also meant that they knew they could survive a long time taking these medications which helped them to focus on living rather than on dying and AIDS. Also, participants who were not on medications were relatively healthy which meant the virus was under control. This all seemed to increase their sense of hope. Those on medications and even those running out of medication options suggested that it did challenge their hope for survival; although these participants said they still had hope. Many just obtained their hope from other sources (e.g., faith in God, family), demonstrating how hope sources and threats to hope could co-exist.

> *Oh, some days it's pretty tough [running out of medication options]. I know that there's nothing else right now but I know there's one more I can try, throw into the mix. Not replace but throw into the mix and there's one still at [an early] stage that they're trying... But not much I can do about it. And that's another thing for hope is I try and differentiate what I have control over and what I don't. Because things I don't have control over aren't going to make a difference, whatever I do. So just controlling the things that I do have control over and knowing the difference, just like the serenity prayer....*

Peer support and counselling. Many participants felt that peer support counselling programs (i.e., peers who are living with HIV or AIDS and who have training in counselling/helping) and counselling services (i.e., professional counsellors who usually have graduate training in counselling or psychology and are members of a registration body such as a psychological association) were instrumental in fostering their hope. "Services [counselling and peer support] helped give me something to hope for..." Participants also said that reading stories about hope and hearing others' (e.g., peer counsellors) stories about hopeful experiences were powerful routes to finding hope.

Harm reduction programs. Harm reduction programs such as methadone programs seemed to help participants hope in that these programs offered options and helped them to make healthier choices.

> *...Oh! If it wasn't for the methadone program I'd probably be dead...so what happens if the supply runs out where you don't have the money to get the fix and then you're going through the withdrawal and all of it so this just gives me lots of hope, now I'm living a clean life you know I don't have to worry about nothing, so I love it I think it's a very, very, very good program....*

Life Style and Life Quality

Participants also suggested that their life styles and their quality of life impacted on their experiences with hope.

Quantity and quality of life. All of the participants suggested that hope was connected to longer life and increased or maintained quality of life. This next participant suggested that quantity and quality of life are each important. "Longer life, but also good life is so important..." Most participants felt that they would prefer maintained quality of life over simply increased length of life.

> *...And I've always maintained and believed still for myself that if I can [have] guaranteed five years on this medication that will make me sick constantly and have side effects and really not enjoy it, my five years. Or no drugs and have two and a half years of good quality, strong living. I'd take the two and a half. Absolutely, you know. Just because I make the best of it. And I try and do that on a daily basis, which gives me hope.*

Basic needs. Participants suggested that hope was related to basic needs (e.g., shelter, food, clothing, work). With needs met there was more room for hope in their lives. "You feel better and have some more hope if you have a place to live, food, shelter..."

Health status. Participants believed that their health status (e.g., CD4 counts, viral levels) influenced their experiences of hope. Some suggested that if they were healthy then this helped them to have hope, whereas if physical health was poor then this challenged hope.

> *...My main hope is for my life to continue the way it is and I hope that my health stays as it is now or gets even better; I hope that maybe one or two, three, four years from now if I'm still around....*

Drug and alcohol reductions. According to some participants, reducing their drug and alcohol use helped them to experience hope for a better future. This can be seen in the following participant quotes. "...It's [drug abuse] a tough road to get past, it is, and here's where hope is once you get through that tough road then your hope gets up higher...". "You know, knowing that I'm strong enough to not drink; I'm strong enough to deal with this. So that's hopeful. So, reassurance. Knowing that I'm strong enough to deal with this. That, that gives me hope". Reductions of drug and alcohol consumption often occurred for participants who had received positive sources of support (e.g., peer support counselling, professional counselling, harm reduction).

Overwhelming emotions. Some participants felt that strong overwhelming emotions such as guilt, anger, and disgust challenged their hope. By finding places to talk about, explore, and address these emotions participants felt that emotional space was cleared, allowing feelings of hope to emerge. Addressing difficult emotions was like preparing soil for the growth of hope and re-connection with life.

> *After diagnosis and, uh, you are so fucking depressed and sad, feeling angry, hope is gone... You need help to deal here, get through the anger and get back to life... Finding hope is so important....*

Humour. Humour provided an important window on hope for several participants. Though a recent diagnosis of HIV would seem to obliterate all light-heartedness, humour in the face of HIV was instrumental to hope and getting through the diagnosis. Humour offered a moment of transcendence, of joyfully living outside of the sadness of their personal circumstance. As one participant said, "Being able to make jokes, make others laugh, make myself smile, this was so important to get through the HIV and holding out for something hopeful..."

Challenges to Hope

Participants identified several additional threats to their hope. These included: (a) co-occurring stressors and extreme life stressors without effective coping mechanisms, (b) stigmatization and discrimination, (c) isolation, (d) going to jail, and (e) doctors predictions of death (e.g., expectation of death was usually around two years following diagnosis for several of the participants). Several participants offered quotes to illustrate the common threats to their hope.

"Being stressed and not knowing what to do hurts the hope, takes it away…".

"After I got the news [of being HIV-positive] I was so alone, not telling nothing to no one…This makes you feel empty and hopeless…".

"Went to jail, tell ya, that makes you lose hope, doing something so stupid…".

"The worst being those doctors telling you when you will die…This strips all your hope for anything…".

Risk of Hoping

Most participants suggested that hope was highly important in effectively dealing with, and getting through, the HIV diagnosis. Some participants shared the personal intimate reality that can be hope. The existence of hope is often the one phenomenon, or combination of phenomena, which exist, that can keep one going. Yet, in holding onto hope or putting one's hope out there to be challenged creates a situation where one can be deeply disappointed. The individual is faced with the possibility of a devastating disease, but is able to hope, but in doing so risks having that hope threatened. Participants suggested that no matter what the risk, having hope needs to happen as it serves several functions.

Functions of Hope

Hope was a powerful phenomenon according to many of the participants. It helped them to do important things in their lives. What follows is a description of the various functions of hope, following an HIV diagnosis, as described by participants.

Strength and Options

For some participants hope helped them to find strength and see different ways to deal with the HIV in order to survive. For example, some participants took care of themselves through eating right, getting exercise, and reducing alcohol or drug use.

> *I'm not on medications now, I took those medications for about six months that was my immunity, I just believe if you can take care of yourself, eat properly, do the things you need to do, you can keep your immunity at a normal level...because I don't believe after being diagnosed with HIV you need to go well you're going to have to start medications, I don't believe that, people have their hope, they can find in their hope a different way of taking care of it, rather than just doing the drugs, I mean it's been many years that I've been diagnosed and I don't take medications and the whole belief is within me and what I can do, there's hope, it's not only taking pills or taking care of it physically, it's how you think about it. I have absolutely no desire to die from this disease so I'm doing the best I can, will I in time have to take the medications? I don't know, it's a possibility...*

As can be seen in the above participant quote, some participants perceived medications as being one option or one aspect of having a healthy life with HIV. This participant believed that with hope, it is increasingly possible to see additional options and find the courage to use those options.

Some participants indicated that hope fuels adapting to, and overcoming, the HIV diagnosis and the fear of having HIV. It helped some of the participants to struggle and fight against the HIV.

> *I prefer quality above all else, so if it means not taking medications and their side effects and everything... You know, sometimes I have to struggle, well my hope helps me struggle, what little hope I do have, I mean I just don't know how to explain hope, it's just something in me that says, "I'm not going anywhere yet".*

Similarly, several participants disclosed that hope assisted them to make it through the HIV. According to some, hope came from, and contributed to, inner strength. Hope offered them energy and motivation. "Definitely, yeah [you need hope to get through the HIV diagnosis]...if there is no hope, then there's nothing, we may as well be dead...".

> *I think hope has a strong motivator for a lot of people... just a lot of people have hope and divine intervention and it will give them the strength, but the thing is each person has their own strength, their own divine intervention if they believe in themselves, my own hope is up to a six now [out of 10; though discussing it during interview]...for me every once in a while talking about it [hope] and everything makes me feel stronger*

and so... Absolutely [you need hope to get through the HIV diagnosis], the thing is that because a lot of people in society put a lot of emphasis on hope, it's a four-letter word and we pay attention to hope, I think if you go there... there is no way anyone should take away hope, it would be a very, very sad world because people have to believe in something, so let them hope that things will get better and they do, they actually do, I've been in some ugly, disgusting situations and I had hope, yeah, I've had hope... and you can get through the diagnosis, oh, absolutely and the biggest hope is by doctors telling them straight out you will not die from this tomorrow, that you can live a long life with this disease, it's like you can live a long life with cancer... that gets hope and that has to start right from the diagnosis and the doctor is the one that has to give it to them.

Yeah, I think you do, you need hope [to get through HIV]. If you want to get out of it... Yeah, you do need hope. If you just give up then you got absolutely nothing to rely on. Nothing to look forward to. Yeah, you needed hope.

Positive Changes

Some participants said that after they began feeling hopeful they were able to start making positive changes in their lives. Although other factors were important (e.g., information, empowerment, mental health services) hope was also helpful for participants to start making changes. Participants suggested that when they began experiencing hope, it gave them a sense of what was possible, a picture of what they may be able to do.

Well [after I was feeling more hopeful and had found information on HIV], I was still alive and I had the resources to improve my life. I just knew that if I used what I had I could get better. Not cured, I know there's no cure but it just made me realize that, hey I can have a good life. I can have a normal life. Nobody has to know. In situations where it's better for people to know, I do let them know, or if I can help somebody else. But it just gave me a meaning to live like hey, God spared me, I could have been run over by a truck or I could have overdosed or something but I didn't. And the times that I managed to pull through it. So if I can get through stuff like that and what I went through from my life, I can go something like this, you know. At least it's not cancer. You know, if you've got malignant cancer, you know, you don't have, you've got a bad life to go through. I don't have to go for radiation treatment; I just have to take 20 odd pills a day. And eat a proper diet and get proper rest and exercise. Stay clean and sober. And I'm fine. I'm just as normal as you. Maybe not up here but I was normal as you are physically, you know. Spiritually.

According to the following participant, hope has the power to help people with HIV live meaningful and productive lives. Hope can help people to believe that they can make changes and see a good future.

> *...there's still people here that don't have a lot of hope because as you wander around here you can see that a lot of them are stoned a lot of them are drinking, they're not cleaned, they're not dressed properly, they're just in limbo and they need to come here because they need a place to go but there are a lot of people for example the board of directors, nearly everybody on the board of directors, not everybody but most people on the board of directors are HIV-positive. They drive nice cars, they've got good jobs, they've got nice homes, you can make a choice, you know the choice is yours. I remember living on the streets, I remember having to go to the Mission Center and the Mustard Seed church for a bowl of soup; I don't have to do that anymore, why, because here we go again with that word hope...*

Healthy Risks

According to some participants, hope helped them to take healthy risks which facilitated positive experiences (e.g., letting family know about HIV). These "positive" risks are very different from "high-risk behaviours" such as drug use or unsafe sexual practices. Unlike healthy "positive" risk behaviours, "high-risk" behaviours were seen by several participants as being easy to engage in and did not feel as being that big of a risk at the time.

> *Yeah. I'd let, I'd let other people in. Sometimes that's where the hope came from. Though it was kind of hard to say which came first. Did I have hope and therefore took the risk of letting people in to support me or did I take the risk of letting people support me which gave me hope. It's the chicken and egg. I think they were kind of in balanced in the sense that to take a small risk and if it was with the right people that gave me hope. And I'd continue. But being fragile took a few steps. But yeah, the risks, if I was in despair or resentful I took higher [unhealthy] risks..." [Interviewer: "And what did that do to those feelings of despair when you took the risks?"] "Fed it. Reinforced it. A lack of caring. No, when I had hope, when I had this feeling that, you know, there's a way past this, there again it goes back to what is a high-risk. Because that's when I took my greatest risks of letting people in and trusting and believing and not fearing that I'd be rejected or turned away or shunned through stigma or discrimination. Those are my highest risk times. I couldn't of done it without hope and yet when I started feeling better about myself and I started becoming active in the community and I was taking all those kind of risks, my other high-risk of attention seeking, my crazy driving, my drug use all*

> *went down. So the unhealthy high-risk in one hand went down dramatically when I had hope and inspiration and encouragement... Yeah [hope was an important factor in taking the healthy risks]. I think the difference would be that when I faced my fears, when I faced my insecurities and I took those risks, the real hard ones for me, they're all real because they're all emotion based connected. I mean I knew that if I risked sharing my experiences, my illness that I faced being hurt, abandoned, shunned. I knew that and did it anyhow. Whereas when I wasn't facing my emotions, just going for my own physical pleasure, that risk wasn't there...*

Research Interviews and the Development of Hope

The research interviews seemed to suggest that there is something contagious about hope. Even discussion of what hope is and what hope means can lead people to feel hopeful. This is part of the premise of hope-focused counselling (Edey & Jevne, 2003; Edey et al., 1998; Massey, 2003); talking about hope in a purposeful aware manner can lead clients to experience hope. During the interviews within this study several participants verbalized that they were experiencing hope. This was sometimes disclosed "in the moment" during the interview itself, but mainly occurred during subsequent interviews with the participants. For example, some participants returned during subsequent interviews and immediately told me that they were feeling more hopeful and had been doing a lot of thinking between interviews and reflecting about hope.

> *Actually I gave it a lot of thought, I have been. Believe it or not the first one [interview] has really helped me even go to detox, you know, because of that interview. What am I going to do? What I am doing. What I consider a high-risk. Taking a risk, allowing myself to be loved and cared for. Hoping for myself to get healthy....*

It seems that by introducing conversations about hope with people it helps them think about hope, start using the word hope, and begin to feel more hopeful. Participants suggested that this occurred in several ways. For example, through gaining perspective during the research interview(s) about HIV and hope participants began to experience hope. Indeed, gaining perspective helped participants to learn about themselves and to take time to reflect on themselves and their situations which appears connected to an increased sense of hope. Some participants disclosed that during the interview they learned about themselves which also helped them feel hopeful. This is seen in the following participant quote.

> *"...This is weird; I'm learning things [e.g., why I made some of the choices that I made in the past such as getting connected to services] that I never thought of....*

Several participants talked about insights they had during and between the interviews and how they were learning about things they needed to do in their own lives. This helped them to think about life changes and hope. For example, as noted above, one participant found that during the first interview he realized he needed to enter detox and make some major life changes. He shared this insight and his decision to enter detox when we met for our second interview. Another participant indicated that he contacted an old friend who he lost touch with following a fight. During our initial research interview he talked about the importance of this relationship and how this relationship helped him to deal with his HIV. During a subsequent interview he told me that he contacted this person to attempt to address the fallout they had experienced. This occurred between our first and second interview.

The interviews also seemed to help many participants realize that they had much in their lives to be hopeful for. This fostered hope.

> *...Well, I just realized, yes there are a few things I haven't thought about. People live a long time with HIV. They seem to be happy. So I realize, yeah you can have it. Get partners... You never know, maybe get a girlfriend....*

Many of the participants believed that talking to others about HIV is a significant part of their life purpose. Thus, through talking to me about their experiences with HIV it made them feel purposeful, which seemed to translate into hope for many of the participants.

> *Hope. Hope for me today is like the information I passed onto you. I hope it's of use because I know it's going to be passed on to other people and that's one thing I want to do is make people aware. People need to know what's going on. There's a lot of people out there that see it as just one thing. AIDS, it's not that...They got a totally mixed up perception of it. They need to be more, they need more information. They gotta know what it's about....*

As can be seen in the above participant quote, participants also experienced hope due to their contribution to the research, which they knew would be shared with many people. Several believed that this would have a positive impact on other people, which helped them to experience hope.

Concluding Thoughts

Within this chapter I have highlighted several categorical and thematic domains that relate to hope and the HIV diagnosis that existed for the participants in this study. Through participants' accounts, along with my interpretations of their experiences, I have offered a rich description of the construct hope and how it relates to an HIV diagnosis and high-risk behaviours. Hope was an important experience for the participants in the current study. Hope helped them to survive with HIV and reduce their high-risk behaviours. In the following chapter I will explore several categories and themes that relate to mental health services in the context of high-risk behaviours following an HIV diagnosis.

Chapter Seven: Themes

Mental Health Services: Peer Counselling, Group Work, and Professional Counselling and Psychological Services

Within this chapter I present the themes of the 12 participants' interviews that focus on mental health services. Of these 12 participants, nine were also peer counsellors. This chapter offers linkages with the previous results chapters on high-risk behaviours and hope, but now from the vantage point of mental health services. Although there are several connections between the various result chapters there are unique categories and themes presented in each. Specific areas explored in this chapter include participants' experiences of: (a) peer support counselling, (b) group interventions, (c) community-based agencies, (d) counselling and psychological services, (e) hope and mental health services, (f) factors which prevented participants from seeking services, and (g) positive life changes that resulted from HIV. What follows is a description of the various categories and themes related to mental health services in order to highlight important intervention considerations for working with people diagnosed with HIV and at risk for high-risk behaviours.

Peer Support Counselling: Peer Counsellors' Advice and Interventions for Helping Clients Deal with HIV, Experience Hope, and Challenge High-Risk Behaviours

Participants perceived peer counselling as being beneficial in helping them to deal with the HIV diagnosis, experience hope, and challenge high-risk behaviours following diagnosis of HIV. What follows is a description of the accounts of participants who provided peer counselling (n=9) and received peer counselling (n=11) in terms of the specific interventions that were described by the peer counsellors. These are framed into two main categories: (a) relationship and (b) informational attainment/change in perception.

Relationship

Support and advocacy. Almost all participants suggested that peer support counsellors were able to offer them advice and support and this helped them experience hope and challenge their high-risk behaviours. The following participant accounts highlight some of these participants' experiences of working with peer counsellors and how the peer relationship impacted their hope and high-risk behaviours. "I would say go see someone at [community-based agency], they help you to get a grounding, figure out [life is] not over...You can fight back with a little bit of info..." "Getting connected with people who know what it's like [peer counsellors]...They can help you see a future...Change your ways for the better..."

Some participants, who were peer counsellors themselves, felt that peer support counsellors helped newly diagnosed individuals work through their problems and concerns in a supportive environment. As one peer counsellor put it, "Oh, I try to help them, I would totally support. I would say, hey, this is where you go...".

Many of the peer support counsellors said that they may go with clients to appointments and offer their support. One peer counsellor participant put it this way, "I'd say hey, if you need me to go down there with you, I'll go down there with you and I'll introduce you...". Another participant noted that he can help clients fill out forms and make applications to different types of services. "Assist with paper work and appointments..."

Positive connection. Peer counsellors were understood to provide people living with HIV an opportunity to talk to someone who was also living with HIV and who had a positive attitude about his/her situation. According to some peer counsellors, it is important to be life affirming. Being positive and life affirming is about being inspiring, supporting, encouraging, genuine, and hopeful, showing that life can go on. As one participant advocated, "Try to inspire them, show them what they could get and do…". Another pointed out, "Being supportive, being genuine, being there for someone. Just trying to be encouraging".

Acceptance. Some participants suggested that an important part of peer counsellors' roles was helping their clients to feel accepted. In interpreting the participant accounts, acceptance from peers was important in helping the participants deal with feelings of stigmatization. Receiving peer support helped participants to feel as if they belonged to a group which helped them fight against feeling stigmatized. Acceptance and belonging were important for participants and helped them to have a sense of hope (e.g., feel stronger and see a future through their relationships with peers), deal more effectively with HIV (e.g., acquire information on the virus through their relationships with peers), and reduce their high-risk behaviours (e.g., have safer relationships with peer counsellors that often do not involve high-risk behaviours). Stigmatization seems to have the potential to threaten hope, delay effectively dealing with an HIV diagnosis, and create opportunities for high-risk behaviours. Interpretation of the participant accounts highlights isolation and overwhelming feelings (e.g., disgust, fear) as potential detrimental experiences which may go along with stigmatization, contributing to the above mentioned concerns. There is a strong sense of commonality that can occur between peer counsellors and clients. Specifically, clients, and peer counsellors, do not need to pretend they are not HIV-positive or hide their HIV status due to fears of stigmatization. They are accepted. As one participant who was a peer counsellor put it, "I'd want them to know that uh… there's a lot of people that are living with this disease not dying with the disease you know…Tell them this and let them be who they are…". This commonality and acceptance can break down the stigmatization, isolation, and overwhelming emotions that often come with an HIV diagnosis.

Listen and validate. In some cases, peer counsellors were available to their clients to talk about their clients' emotions. According to some of the peer counsellors, this helped people dealing with the diagnosis by helping them to start to deal with the strong overwhelming emotions (e.g., fear, anger, resentment, guilt, frustration) that often accompanied the diagnosis. Participants felt that peer counsellors were able to listen and validate. They were also able to get them connected to a counsellor or psychologist who could help the client to further deal with his or her emotions. As one participant put it, "Helping them to deal with the emotions of it [HIV]…". "I ask them 'what is the biggest fear, lets talk about that'…This is where to start…"

Empathy and credentials. Both participants who were peer counsellors and those who were not peer counsellors suggested that peer counsellors are able to relate to the newly diagnosed person, as peer counsellors have actually gone through some of what the newly diagnosed person is experiencing. Empathy seems to be an important aspect of this work, having a deep sense of what it is like to receive an HIV diagnosis and being able to convey that to the newly diagnosed individual. Thus, on an emotional level, the peer counsellor is able to convey emotional understanding. There also appears to be a "credential" issue at play here. Participants often perceived peer counsellors as being especially qualified given their own personal backgrounds regarding HIV and related issues (e.g., being gay or having experienced street life). This lent credibility to peer counsellors in many cases.

> *...I know I'm an equal.... It's like seeing a counsellor that never had a drink, seeing a counsellor that's never had a problem. Like, what kind of counsellor is that? Not somebody I'd want to see. I'd want to see somebody that, you know, can relate, on the personal level. And now I can relate in some ways...better, than other ways...I would want somebody that knows. I mean I've always, I've pretty well always been like that.*

Some participants felt that people may feel free to talk with peer counsellors about anything as there is a sense that they will understand as they have already gone through it. One participant recalled, "Those are people I can talk to about anything, right. If I'm having a shitty day or whatever then those are the people I talk to, that's my support system". Other participants suggested that peer counselling is not for discussing private matters as there can be concerns about confidentiality in some cases. Another participant suggested, "I don't talk about anything too personal [with peer counsellors]; you need to be careful about others finding out personal stuff or stories getting around...". This latter point can be especially relevant in small communities (e.g., community-based agencies), as clients may not feel safe disclosing personal information to peer counsellors out of fears that the information will be shared with others.

Informational Attainment and Change in Perception

Informational attainment. Almost all participants suggested that peer counsellors provided important information on HIV (e.g., referrals, healthy living suggestions, medication suggestions such as side effects). Information was a key aspect in helping people diagnosed with HIV to become empowered. Through informational attainment participants were able to understand HIV, determine ways to maintain a healthy lifestyle, and share the information they obtained with others. This seemed to help participants to become armed and empowered in the fight against HIV and challenged participants to realize that their situation may not be as bad as they thought. Obtaining information helped participants to realize that HIV is not a death sentence. Peer counsellors can teach people about HIV, explain HIV medications and their side effects, and also the importance of staying on those medications to avoid complications (e.g., medication resistance). For example, one peer counsellor put it this way,

> *I'd want them [newly diagnosed individual] to know that...there's a lot of people that are living with this disease not dying with the disease you know...Right off the top, don't think that you're dying because you know what? You may be here in 20 years still...Look after your body. There's support groups. Monday nights there's support groups, Wednesday nights uh...email support groups, here's Living Positive, here's HIV Edmonton. Let me introduce you to some of the people down here and then from there...I introduce them to the people here then they can get a general look at the whole, whole scenario and realize that "well maybe it's not as bad as I thought it was".*

Several participants suggested that peer counsellors pointed out differences between HIV and AIDS and highlighted the importance of emotional, physical, psychological, and spiritual health. Peer counsellors can also help newly diagnosed individuals to understand important concepts such as viral load levels and encourage them to get these checked by medical professionals. This is important to do quickly before the person assumes he/she has a severe case of HIV or even AIDS. One participant suggested,

> *With HIV, the difference between HIV and AIDS, that's huge, right there. There's a lot of hope right there. The difference is health, your health concerns, the way you eat, the way you take care of yourself and your drug issues you know, stay clean... My first [advice] would be the difference between HIV and AIDS and there's a huge difference so not all is lost right away when you get first diagnosed. Check to see where your CD4 counts are and how sick you are first before you flip out and think you're going to die tomorrow and deal with it right away and not leave it on the back burner.*

Many participants stated that an important role of peer counsellors was, through providing information, to dispel myths about HIV (e.g., HIV as a death sentence, HIV as contagious through kissing and hugging).

Stories of hope and survival. Several participants suggested that as peer counsellors they shared hopeful stories of their own experiences and challenges and how they managed to get through these difficult times. "Sharing stories… about my experiences, how I got through, showing them it can happen, it can be good…". These stories helped participants to realize that HIV did not mean that life was over. Participants were given hopeful messages through story such as: life can continue and possibilities are endless.

Peoples' stories of hope were also conveyed in other ways beyond narrative. For example, in helping clients locate hope and realize that life can continue after HIV, peer counsellors suggested that clients can be introduced to the living quilt and its purpose and significance can be explained. One participant put it this way, "…Show them the living quilt, show them the names and how many years you can survive with this thing [HIV or AIDS]…".

As seen in the following participants' quotes, peer counsellors can show newly diagnosed people first hand that they can live a healthy and meaningful life with HIV. Seeing others living a long time with HIV offered evidence for the hope to live a long life.

> *The thought of HIV was always, was always there... [I] didn't care so much about anything at all. I figured it was pretty much over. But being here [with peer counsellors] and seeing people and hearing those stories of people living for 14, 20 some odd years, it's kind of encouraging.*

> *...I wasn't even thinking about hope, that was until I got to learn about the people and not so much the disease, then I started looking at the hope and it was like wow, you've had it for 25 years and you look so good, yay... and you know... you can't read that from a book and get the same reaction so it was really cool. That's why when I first came here last year... the first place I looked for was some agency, some place with HIV related [help], some place I can go to because I knew if I [did]...then I'd be okay....*

Several participants felt strongly that peer counsellors, and other health professionals, should never take away hope even if it looks like all is lost in the person's life.

> *...The strongest thing and the most fatal thing I think a person can do to someone who has HIV is take away any hope that they may have, especially after diagnosis. I mean, if they hope that the sun is going to shine for 24 hours then you say "I hope so too". And I'll be watching to see if it does but to take it away or to nullify it or to take away or nullify someone's perception or acknowledgement of their own achievement, you're taking that hope chest and throwing it back in the ocean and it's difficult to retrieve. And to do that is really, really harmful, I would say. That's just in my experience. So that hope factor is so important at a spiritual level for me...gotta have it.*

Humour. Several participants suggested that peer counsellors also helped people to have a sense of humour. Reflecting on his peer counselling experience one participant said,

> *...well if you've got no humor you've got no hope... you know you've got to have humor to get through life otherwise you'd just be bummed out all the time and when you're bummed out all the time that's not good for your health... and especially people like me you've got to keep yourself healthy....*

Dreams and goals. Several participants suggested peer counsellors can help people realize the importance of continuing to live their lives and staying focused on their dreams. Some participants talked about how peer counsellors gave them insight into the importance of living life like they do not have HIV but also to learn to live each moment like it was their last. It seems there is a need to allow oneself to enjoy life (i.e., without letting HIV control one's life) but also to recognize the gift of life and to treasure every moment. Hope is explicit within this process of recognizing dreams and goals. As participants' perspectives began to shift toward living as opposed to dying, specific sources of hope began to be identified (e.g., dreams, goals, living in the moment).

> *Just because you've been diagnosed doesn't mean it's a death sentence, you are not going to die today, you are not going to die tomorrow, you may not die for 20 years, so don't go off the deep end. Live your life, I mean live it the same way you would have or better but don't regress because you're going to have 20 years and if you fuck up everything you've got now there's going to be nothing for the next 15 or 20 years. Live life, like every moment is your last and then when you get to your last moment you'll have no regrets....*

Referral. Some participants felt that peer counsellors connect people to other services that they require (e.g., nutritionist, psychologist) for general/holistic health. This can include services where they can obtain basic needs (e.g., shelter, food). As one participant put it,

> *...I would say, "Hey, this is where you go". I [am] not the best, I don't know everything about this but I can send you to places that can and people...where I found out, okay I can give you references to where you can go, ask your own questions where you can go to experts. I'm not an expert...*

Change in lifestyle. Many of the participants suggested that peer counsellors helped them to change their lifestyle (e.g., eat healthier food, obtain better sleep, reduce high-risk behaviours, find healthy friendships, change drug habits) so they may be able to live longer and healthier lives with the HIV. One participant suggested, "...Just talking about making simple [lifestyle] changes...Diet, working out, getting off of the drugs...".

Peer counsellors help people learn how to be healthy and safe in different ways. They can teach people how to reduce their high-risk behaviours. For example, they may discuss how and where to locate clean needles and the dangers associated with using used needles (e.g., risk of transmitting HIV to someone else, risk of contracting other infectious diseases or other strains of HIV). They may also explain the importance of condoms and how the virus can be transmitted through unprotected sex. One participant noted, “Peer workers can help you be safe, teach you ways to be safe like how the virus can be spread through unsafe sex…”.

As previously discussed, denial is a common experience for many people following diagnosis of HIV. Some peer counsellors suggested that they can play an important role in helping clients change their lifestyle through recognizing and reducing their denial in healthy and safe ways. One participant suggested, “…Helping them to uh, see the denial and get back to reality…” Several participants felt that along with many of the roles of peer counsellors, professional counsellors and psychologists should also be involved in the helping process.

Some peer counsellors felt that they could help people to develop a “moral conscience” or help others realize the need to be cautious and to avoid spreading the HIV virus. As one peer counsellor put it, “…the best thing that I can help somebody do is achieve a moral conscience you know…”. Again, this implies a lifestyle change with important repercussions such as potential reductions in high-risk behaviours and improved healthy behaviours for the individual client (e.g., diet and exercise).

Psychological aspects of survival with HIV. Several peer counsellors also suggested that they can explain to clients how there is a psychological component to living successfully with HIV. Several participants, who were also peer counsellors, suggested that clients need to believe they can survive and be healthy. This illustrates the importance of the client believing that he or she can live with HIV. Maintaining this belief that survival is possible also implies that hope is important to survival.

> *…There are people that come in here and just get diagnosed and I try and sit down and tell them there's a lot more to life then, you're not going to die right off, you're still alive and you're going to be alive for a long time and you could live forever if you want. It's all in your head. You got to put it in your head that you want that [to survive].*

> *You got to follow through. You got to keep your health. Take care of yourself is the big thing, sleeping right, eating right. And, if you keep on those terms, like you know, a good life style... You'll live forever, HIV will probably never even bother you.*

Meaning and purpose. According to some participants, peer counsellors can help their clients to create meaning out of their HIV experience. One participant put it this way, "Getting help with trying to find some meaning out of it all. Like, what [do] I do now? Just finding something...". The creation of meaning out of the HIV diagnosis was a key aspect to successfully dealing with the diagnosis for many of the participants. For many, the HIV diagnosis stripped away the little meaning and purpose that existed in their lives. In time, many of the participants would use the diagnosis to build a strong sense of purpose and meaning in their lives. This took several forms such as: (a) peer counselling, (b) volunteering at local agencies, (c) fundraising, and (d) sharing their stories through public presentations.

Several participants suggested that a big concern for people newly diagnosed with HIV can be a reduction in caring about life. In several instances, this seemed to occur through a loss of purpose, meaning, and hope in their lives. Peer counsellors felt that they can help clients to want to care again. One participant put it this way, "...Help them find things to care about again, what do you care about? If they are not caring this can be bad, they may hurt themselves or something...". Participants often regained a sense of caring through discovery of purpose and meaning in their lives.

Hobbies/activities. Some participants found that peer counsellors can help people remember hobbies that they enjoyed and help them to reengage in these activities. This helped several participants in the process of learning to live with HIV.

> *...Find a bunch of your interests, like for me gardening, cooking , nature, arts, visual arts; get a nice little support group and believe... Cruise with them, you know and*

> *it's like I think that, thanks for asking that question because that's really when I'm doing really well and when I'm in the best position to give help is when my needs are all being met when my energy is high and not depleted and I'm not bringing other people down... That's what I would say...Just don't give up, pick your interest and get involved and just keep going.*

Peer Support Counselling: Benefits for Peer Counsellors from Providing Peer Counselling

Participants who were peer counsellors talked about how providing peer counselling helped them in several important ways. What follows is a description of the benefits of peer counselling for peer counsellor participants.

Distraction and Change in Perspective

Some of the peer counsellors suggested that there is always somebody who is struggling with an issue that is more severe or challenging than they were struggling with. Thus, some participants felt a bit better knowing that they were not in the worst situation possible. Participants seemed to feel better in these types of situations as working with others who were struggling helped the participants to distract themselves from their own situations and employ a different cognitive framework (e.g., my situation is not as bad as I once believed as this person is doing a lot worse).

> *Like, when you think it's all bad and you only got this and that and...no, there's always somebody out there that's got it worse, you know. Life or situations or, there's always somebody else worse off. And when...I just found that it was important to help as much as I could and to help someone else just helped me, you know, made me feel good. And that way I just, to this day I do this [peer counselling]....*

Peer counselling gave some peer counsellors a change from their own life, especially, as some mentioned, the ordinariness of life. Several of the participants felt that through peer counselling they were kept busy and occupied, which reduced boredom and opportunities to get into trouble (e.g., high-risk behaviours). It also helped participants in the process of distraction from their own situations.

> *Lifestyle changes... [Peer counselling] keeps my mind going...keeps me from getting bored right... Coming here it's different, different. Something's always going to happen...Change the day... You know, it's not much but it feels good and it's different... So I don't mind doing volunteering stuff. They seem to appreciate it here too.*

Reward in helping Others

Almost all peer counsellors felt that peer counselling was a rewarding experience. Peer counselling helped peer counsellors to feel good knowing they were helping others in difficult situations. Some suggested that it increased their personal value, or self worth, and gave them meaning and purpose in their lives. It also helped them to make meaning out of their own diagnosis (e.g., through their own diagnosis they were able to help newly diagnosed people).

> *My biggest fear is that, I always felt kind of like a pariah all through life, starting in my childhood because of my dysfunctional stepfather and mother and I carried that with me through most of my adult life, then they told me I had[the] plague of the twenty-first century. I could have done two things at that point. I could have succumbed to being a pariah or I could choose to educate the world and teach them a different point of view on the plague of the twenty-first century, that's my mission.*

Some of the participants felt they had made mistakes in their lives and experienced guilt as a result of these mistakes. Many of these participants found that through helping others they felt as though they were doing something right, which reduced feeling guilty for mistakes committed in the past. "Just feeling as if you are doing something right for a change, a change from wrongs done before...".

Empowerment and Inspiration

Peer counselling, according to most participants, helped them to feel inspired and empowered. Participants seemed to acquire energy and a belief that things were possible with their involvement in peer counselling. This energy and empowerment often seemed to translate into action, which would help them feel useful, productive, and important. As one participant put it, "Well it makes me feel useful and then when I help somebody it makes me feel better and coming into the office and seeing someone that I've helped is a reward...". Another suggested, "...volunteering helps me, peer counselling helps, I look forward to getting up in the morning to come in to [HIV community-based agency]. Just talking to people, being around other people...".

Most peer counsellors experienced encouragement and hope when someone that they helped was doing well. This hope often extended beyond themselves, with a focus on hope for others. "If I can help somebody walk out of the office when they come in feeling like I did, hold their head back and smile it makes me feel I've done something worthwhile". Alternatively, one participant suggested that helping someone else has made him feel bad at times, as he feels he is not living up to his own advice that he is giving others. This may illustrate that there can be a risk for some peer counsellors who place hope in their clients. As clients improve, peer counsellors may be left behind, not making the changes they encouraged in others.

> *Depends, it's not all one feeling I mean, you know, there's definitely encouraging [feelings] and a feeling of I made a positive difference and then there's also the self incrimination that I don't live up to my own, like I don't practice my own preaching.*

Insight and information Regarding their own Struggles

Some participants believed that through helping others work through their problems the peer counsellors were then able to work through their own problems. Some suggested, they could see others dealing with tough situations (e.g., medication resistance issues) and watch how they moved through it, which could help them to move through their own similar problems. Several participants also felt a sense of hope within themselves when helping others as peer counsellors, which also helped them to have the courage and drive to help themselves work through their own problems.

> *Sure, helping other people work through their problems gives me insight into my own problems, helping somebody find meaning in their lives by looking inside themselves instead of looking outside themselves just reinforces what I know for myself. When you see it work and you see positive results how good does that make you feel? It puts me up on the top, you know... And if I feel like that [reference to being up on the top] I am hopeful you know.*

Several participants also suggested that they could learn about HIV and AIDS by talking to other peer counsellors and clients. This was positive, as it can be scary, isolating, and intimidating to learn about HIV alone. By being a peer counsellor the isolation is reduced. As one participant recalled,

> *...I didn't want to learn it by myself because every time I picked up the book I thought I'm already gone and it seemed too surreal, so I just left it, just... So when I was with others there was like a bunch of us looking through it and we would all ask each other questions and it was much more informative that way, it was a good way to deal with it and have other people around and then you didn't feel so isolated.*

Peer Counselling: Problems and Recommendations with the Peer Counselling Model

Some of the participants highlighted concerns with the peer counselling model of helping people diagnosed with HIV or AIDS. However, almost all participants suggested the benefits far exceeded any deficiencies or concerns with this model. Also, many of the concerns noted below happened infrequently and some were noted to have occurred several years ago and were not as frequent anymore.

Building Relationships and the Emotional Risk

Building relationships with others with HIV can be emotionally risky as people can eventually die from HIV, AIDS, or related complexities. This can be difficult for peer counsellors and clients. Some participants suggested that it can cause people to have their hope challenged and also cause them to lose faith in a good future. Many believed, due to advances in medications and treatments that this is less likely to occur today than in the past. As one participant reflected on the past he said,

> *...I started taking structured counselling as opposed to peer support because peer support then was devastating. I mean you couldn't get close to anybody because they were going to die so peer support back then was really, really, really hard and kind of detrimental, a lot of people said that...*

Peer Counsellors' Risk Taking Behaviours and Problematic Attitudes

Some participants felt that peer counsellors would not always "practice what they preached". For example, they may do drugs or engage in some type of high-risk behaviour, which could cause clients to feel as if the peer counsellors were contradicting themselves. This could also cause clients to lose faith and lose confidence in the help offered by peer counsellors. As one peer counsellor reflected,

> *...Down side of [peer counselling was] probably some of the people I met here [community-based agency]. Some of the others were great, but not all. I guess you could say some could get you in trouble. I was one of the people that could get you in trouble too.... Experimented with a couple of drugs that just you know... I just tried to continue on with it... That'd be the downside cause there was a lot of different drugs around here....*

Another peer counsellor shared,

> *...If anything a few of the other peer support workers really let me down, not as far as communication or whatever but setting an example, that's how they let me down, they weren't very good examples. They weren't practicing what they preached; they let me down like that, just let me know that they're people too.*

According to some participants, there were a few peer counsellors who engaged in drug use or other high-risk behaviours that could be a bad influence on clients and lead them into high-risk situations. However, this was not reported to be a frequent concern by participants in the study.

Some of the participants felt that peer counsellors may be struggling with their own problems and may end up pushing their own bad attitude or personal problems on their clients. One participant shared, "...Sometimes it wasn't good to be around here because they were depressed or struggling with their own problems, they could bring you down...they weren't all like that".

Dissimilarity of Service Providers

Some participants felt that connecting to a peer counsellor who was similar to them (e.g., gender, sexual orientation) was especially important, especially right after diagnosis. This was largely due to concerns such as homophobia and wanting to be with others who were dealing with similar problems beyond HIV. Participants suggested that some clients even avoided services out of fears such as homophobia.

> *"For me I avoided coming in [for services] because I was scared people would think I was gay...I did not want to be put in a group or hooked up with someone gay at the time, [though it's] now not so much an issue....*

One of the participants felt it was sometimes pointless to talk to peer counsellors, and to some extent, even professional counsellors, because the HIV is such an individual condition. His beliefs were that no one could truly understand his experiences as he had his own unique issues to deal with. He put it this way, "Sometimes it's [peer counselling] good, but often not, as it is such an individual disease...".

Overwhelming Nature of Peer Counselling

Some participants also suggested that peer counselling can be overwhelming and even scary for some clients if the service is not fully explained prior to its commencement. One participant recalled, "It can be pretty overwhelming, going in to get help and not having a clue what to expect...".

Group Work

Benefits of Group Work

Nine of the participants spoke of their experiences with group work. Participant experiences with group work usually consisted of support groups facilitated by professional counsellors and/or peer support workers. Almost all of these participants saw group work with fellow peers and a professional facilitator as a useful intervention strategy. Some participants felt that they could vent in terms of the problems they were experiencing in their lives. Peers could listen and offer suggestions in terms of their own experiences that were related to what the group was discussing. As one participant reflected, "…I guess that's peer support where we can rant and just try to figure it all out…". Participants could meet others and gain wisdom and ideas from hearing others' experiences. One participant shared, "Cause the groups and the training sessions and stuff was just what I needed to stay straight and focused".

Another participant recalled,

> *[I] attended the support groups… to meet other people and hear their experiences. That was probably the best thing that I did was going to the support groups. Because it kind of keeps you out of death, keeps you from losing it. You think you have problems, well wait until you talk to other people about it.*

Concerns of Group Work

Some of the participants suggested some concerns about group work. Some felt that too many people knew about their personal concerns and there were problems with limited confidentiality.

> *…I go "there's a breach of confidentiality", too many people know and I don't care what anybody says…Too many people know and one or two out of that group generally talk to other people so it's not intentional or anything it's just how people are. One on one, if you were my psychologist I know it'd stay quiet, I've started in group sessions and stopped the group sessions because I'm going just too many people know….*

A few participants had some concerns about mixed member groups (e.g., homosexual clients, drug using clients); however, for many participants this turned out to be a positive growth experience. It helped participants to learn about other groups, look at problems from different perspectives, and increase their acceptance of diversity. One participant reflected, "The mixed groups can be a challenge, can cause problems like if you're homophobic or something like that...But you learn to accept others as the group goes on, you learn that you all share stuff...".

Community-Based Agencies

Benefits of Community-Based Agencies

Community-based organizations can offer a warm and stable place to spend time and obtain services (e.g., shelter, food, counselling, companionship, assistance with medication). Spending time at community-based agencies helped some clients to reduce their feelings of isolation and stigmatization. Simply put, community organizations can offer acceptance. Community organizations can also offer hope through acceptance and the opportunity to safely share emotional burdens with others who understand. Also, by being around others who are living with HIV, seeing how others can live a healthy, meaningful life, and hearing the stories of others living with HIV clients can begin to feel inspired, hopeful, and purposeful. As one participant shared, "...You know, you're not alone and you're not looked at sideways because you are here...". Another mentioned, "Talk to others who are living with HIV, hear what they have done... Learn from example, get some motivation to do something...".

One participant reflected,

> *...That's... the hope, okay. This place is good because it gives you counselling, it feeds you, gives you a place where you can go to be with people that have it okay. It's a place to go unload your tensions and your frustrations. See the counsellors and talk about it. What's your problem? How can I help? How can I stabilize you? That's what they want, that's what they're there for. Plus you've got your 5 bucks [financial support from community-agency] if you wanted to buy a beer with it, that was up to you.*

Problems with Community-Based Agencies

Some suggested that even being associated with an HIV organization was difficult, due to fears of stigmatization and discrimination. This especially occurred during the initial time period when participants just received their HIV diagnosis. This fear and unwillingness to seek out community-based services can lead to isolation. As one participant shared, "...But I had an issue with the HIV sign outside...Look people see you go to the office...you're classified as HIV-positive and, oh, you're HIV-positive, so you must be gay...".

A few participants disclosed that they wished there would be less advertising (e.g., big sign that states "HIV Edmonton") due to fears of discrimination and stigmatization.

> *...That big sign out front, I just hate that sign. 'HIV Edmonton'. I'm honest with people that I'm close to, I let them know I'm sick, I have HIV. And it's important to tell a girlfriend or spouse. But that big ugly sign is just, no, no. Cause everyone walks by and looks at it [and] automatically thinks: "Oh, a bunch of AIDS cases"...That isn't good and there's enough stigma out here that we don't need a great big label or great big sign advertising that.*

Fears of different groups (e.g., drug users, homosexuals) at the group services being offered by community-based agencies was also a concern for a couple of the participants. However, these participants suggested that this was mainly a concern when they were first diagnosed, and was no longer an issue for them. One participant explained, “Just the different groups, like gay people, others would think you were gay you know…”.

Some participants felt that other community-based members or other clients may have a bad attitude and bring you down. One participant suggested, “…Sometime it wasn’t good to be around here because they were depressed…they could bring you down…”.

A couple of participants believed that if the agency is the primary support clients have and then there is a conflict between clients and the agency then this can be problematic. These participants suggested that clients can find themselves without support. To prevent this risk, participants felt that clients should attempt to develop multiple forms of support if possible.

> *Well, a lot of it’s hard, you know…I mean like the very places where you go for support sometimes can be your worst enemy and so sometimes like one of the things that I’ve been looking at this last year has been, I need to establish a base outside of HIV where my support is and then when I got a problem with HIV I can come and confront agencies like this without losing my legs you know, it’s like I haven’t had that, I put a lot of my trust here when my anger and unresolved issues are here so I need to re-establish a new base and I haven’t gotten there, I’m working on it…*

Some participants suggested that they did not know about community-based services; however, were quick to point out that more people are aware of services today. One participant explained, “There just did not seem to be anything around…these problems are not too serious anymore…”.

Counselling and Psychology Services: Characteristics of Effective Professional Counsellors and Psychologists

Participants identified several characteristics of professional counsellors and psychologists that they found helpful. What follows is a list of these characteristics as described by participants. These characteristics have been divided into two categorical sections: (a) caring orientation and (b) facilitator/expert orientation.

Caring Orientation

1) Good listening skills: "They [counsellors] are just good at listening…".

2) Ability to connect with clients: "Yeah I needed it [relationship] back then".

3) Able to help you to develop and locate hope:

> *…Before that, just partying all the time and like I said I really didn't care and I came to realize after talking to a lot of these counsellors, psychologists, psychiatrists, that there was that word 'hope' again and that if I lived a good life style I could expect to live a good and prosperous life and that has all come around, it's all come around now.*

4) Able to listen and respond to sensitive and personal issues: "If you wanted to talk about anything, anytime you could just knock on the counsellors' door and they'll be there for you…".

5) Very flexible in times available:

> *…Well, like I said I started coming here and got to know some counsellors and it was wonderful…We got to be pretty good friends and she said you know, if you want to talk, come in anytime. She knew when I was down.*

6) Make you feel accepted and non-judged:

> *And the counsellors make you feel you know, accepted. They don't make you feel like you're sick pretty bad. They're not, "Ewe, I don't want to be in the same room with you". Not like some of the people you meet on the streets….*

7) Provide some physical closeness (e.g., not afraid to offer a hug): "…Yeah she was really there. When I needed a hug… We never really got too close to them [counsellors]. They [counsellors] were always cheery. I am not really [a] touchy feely kind of guy…".

8) Friendly and inviting: "…I always felt welcome…".

Facilitator/Expert Orientation

9) Knowledgeable and able to provide support for HIV related issues: "...If you needed help with [a] form to fill out, they fill them out. If you need help with the AISH application they were there to help you to do that...Need information on HIV stuff, they could help here...".

10) Ability to solve problems and set goals: "Counsellors can help you to set up your priorities and figure out how you will get to where they [priorities] may be...".

11) Able to provide information on HIV related issues: "...Drugs have an effect...You need enough information about it...a little bit of knowledge about what's going on. It helps a lot...".

12) Able to facilitate empowerment: "She [psychologist] just made me feel like I could go out and deal with all of my problems...".

13) Provide strategies and knowledge to help reduce high-risk behaviours: "They helped me to look at my risks and come up with a plan to slow them down...".

14) Offers the opportunity to help clients create meaning in their lives and out of the HIV experience: "...They [counsellors] were good at helping me see the big picture, what was really meaningful...".

15) Inspirational and a motivator: "Those people [counsellors] could be very inspiring...".

Counselling and Psychology Services: Benefits of Professional Counselling and Psychological Services

Counselling and psychological services provided several important benefits from the perspective of the participants. What follows is a description of categories and themes related to the benefits of professional counselling and psychological services. This section is organized around the following categorical headings which illustrate the multiple forms of what counselling and psychological services can offer clients: (a) elusive benefits, (b) concrete benefits, and (c) outcome benefits.

Elusive Benefits

Elusive benefits included areas that are difficult to pinpoint. They consist of highly important benefits of counselling but are not always directly discussed or explicitly a focus. These included: (a) inspiration, (b) empowerment, (c) hope, (d) validation, (e) life process, (f) self-value, and (g) purpose/meaning.

Inspiration. Counsellors offered inspiration to their clients. One participant recalled, "It [counselling] gave me hope and inspiration…". Counsellors were able to help clients amass resources and energy through their encouragement, suggestions/advice, and the support from the therapeutic relationship. Thus, inspiration and drive became available for the participants.

Empowerment. Counsellors, through educating and supporting clients, set up a situation whereby clients were able to enhance their sense of empowerment. This empowerment helped participants to increase their connections with others, strive to make changes in their lives, and develop meaning/purpose.

Hope. Counsellors helped clients find hope in different ways. For example, education regarding HIV, understanding that HIV was not a death sentence, being supported and accepted, and assisted to find meaning and purpose all helped participants further regain a sense of hope. Hope helped clients to see possibilities and a future for themselves.

Validation. Several participants suggested that just talking to professional counsellors to obtain insight into their situations was beneficial. As one participant recalled, "They [counsellors] can help you to see things you did not see before and understand complex stuff...". Having someone listen and validate clients' experiences and feelings was very important. Participants felt that counsellors and psychologists typically understood what their clients were experiencing. Several of the participants felt that professional counsellors could do this despite not living with HIV themselves. One participant shared, "Just knowing that someone understands and they can explain it in a way that I'll understand...".

Life process. Some of the participants felt that they learned about "life processes" through counselling. These participants suggested that counselling helped them to appreciate the "journey" through life as opposed to being solely focused on the "destination" or the end. For example, some participants talked about appreciating the day to day living, being focused within the moment, as opposed to being solely goal directed and future oriented.

Self-value. Some participants felt that counsellors had played a key role in helping the participants to feel more valuable and to not feel worthless. As one participant put it, "They [counsellors] can make you feel better about yourself, feeling bad from the past is one thing, they can make you feel better about yourself". As participants became connected with counsellors within the context of a safe therapeutic relationship they felt accepted and valued. According to many participants, counselling increased feelings of acceptance and helped them to experience non-stigmatization by others. One participant noted, "...the counsellors make you feel...accepted. They don't make you feel like you're sick…". Clients were helped to feel accepted, which helped them to see that they were worthwhile and to learn to accept themselves.

Purpose and meaning. Some participants suggested that counselling helped them to locate purpose and meaning in their lives. Counselling and psychological services offered an opportunity to talk openly about different life directions participants could follow. Counsellors helped some participants to prioritize their lives, including their life purposes and goals. One participant shared,"…Finding out what's next, getting organized…". Counsellors also helped participants to make decisions on important areas of their lives (e.g., how to spend time in meaningful activities).

> *Oh, absolutely. It [counselling] helped me piece together all these earth shattering, like three earth shattering events within months. I was a mess, shit. But I still wasn't drinking so that said to me, you can still get help. And I thought, I gotta talk to somebody. And so I was recommended to this person and I went and chatted. It was good. And it was a third party I'd never met in person and you know, I knew nothing about them really, other than that they were ready to listen and offer some feedback on what I was saying. And helping you piece it altogether and what is the friggin' purpose of staying. All these things just….*

Counselling helped participants to develop their own purpose as opposed to following some pre-defined script of what they should be doing with their lives. Some of the participants even suggested that through counselling they were helped to realize that they did not have to give up those aspects of life that offered meaning prior to when they were diagnosed with HIV.

> *…It [counselling] helped me see a purpose. Develop my own purpose, not be told this is your purpose, this is what you gotta do. But rather, you know, maybe… helping a person on a discovery of what can their purpose possibly be now that they're HIV-positive. Well, what was their purpose before? Why has that changed if at all? And see that they don't need to give up their purpose just because of this. And still realizing those purposes they had prior to diagnosis are still there. They're not going to go away just because of this. They might get rearranged and it might get reprioritized but they're not going to go away. You know, you might want to put HIV information at the top for a little while and read up about it and learn about it and think about it but don't let it take over*

> *everything. Like that movie 'Jeffery'...Anyway, it's hilarious. It's a gay movie but it deals with HIV and one of the lines in there is, "hate HIV don't hate life". And it's so true, you know, so true. I hate this thing, I hate what it's doing to me and I hate what the drugs do but I'm still here and I have a purpose.*

Concrete Benefits

Concrete benefits included specific and explicit areas within counselling. In this area, participants were often given explicit information and direction, which they perceived as being highly beneficial. Concrete benefits included the following thematic areas: (a) advice, (b) referral, (c) education and information, and (d) options.

Advice. Counsellors and psychologists were often seen to offer good advice. One participant explained, "Like if you were my psychologist, I would ask you, what do I do when guys are giving me a hard time? Or get your advice...". Some participants suggested that counsellors were also good at helping their clients find their own answers as opposed to only offering advice and direction. As illustrated in the following participant quotes, counsellors helped participants to take responsibly for making their own change happen. "They [counsellors] are good at helping you look for your own answers instead of just telling you what to do...". "They [counsellors] help you to look at yourself to do what you need to do, take responsibility...".

Referral. Several participants suggested that counsellors helped their clients get connected to services (e.g., dietician) and learn about resources (e.g., funding for assisted living). As one participant explained, "Well, they [psychologist] said to see a dietician [and] get on a proper diet, I require 2500 calorie high protein diet, junk food wasn't doing it...". Thus, counsellors were able to facilitate holistic care/services for the HIV-positive individual.

As one participant suggested,

> *...Well like I said she [counsellor] was there whenever I needed [someone], you know she helped me get on my AISH, she helped me get the paper work and stuff done, she'd help me find an apartment... Whenever I was feeling bummed out and you know like if I wanted to slash up uh you know because I was really depressed back then.*

Education and information. Some participants suggested that counsellors provided information to participants and helped them to find answers to their questions. One participant reflected, "...Drugs have an effect...You need enough information about it...a little bit of knowledge about what's going on. It helps a lot...". This information was instrumental in helping participants to understand HIV and co-occurring problems. The information helped participants to make important decisions and to increase their sense of empowerment and hope. Counsellors also helped participants to learn the truth about HIV and break down the myths that they learned along the way (e.g., transmitted through touch and kissing, death sentence). Again, this helped participants to realize that HIV was not a death sentence and that life could continue.

> *When I, I saw a counsellor right away and she just explained all the stupid things that I had been told. You mean, I can kiss my wife, I can hold hands with her, it's stupid that I can just spread it like that and then I got sent to see a psychologist...and she straightened me out, she, I was sitting here I think pretty much on a weekly basis....*

Options. Some participants suggested that counselling created multiple options in their lives. For some, possibility/choice was connected to seeing hope for the future. Counsellors helped participants see options through discussing their problems, offering encouragement and support, providing them with education and skills, and fostering purpose, meaning, and hope.

> *...there's options that was a big one, you know I'm not stuck in a rut, I'm not you know I'm not forced into a path that...and I could choose to get out of it, move on. I could also choose to follow the path and see where it took me and I had the awareness that those were choices.*

Outcome Benefits

Outcome benefits consisted of specific outcomes that occurred as a result of the counselling and psychological services. These included: (a) acceptance of the diagnosis, (b) co-occurring stressors, (c) emotions, (d) reduction of high-risk behaviours, (e) quality of life, and (f) mental health issues.

Acceptance of the diagnosis. According to some participants, counselling was useful to help them to deal with and accept the HIV diagnosis. Within counselling, participants were able to openly discuss the diagnosis, including their angers, fears, uncertainties, and confusions. This was able to occur in a supportive therapeutic relationship, whereby the counsellor was able to offer perspective and support. The counsellor was able to help the client to accept the HIV diagnosis. Again, this occurred through open discussions of the clients' fears and uncertainties, education regarding HIV/AIDS, relationship building, and fostering meaning-making activities.

Co-occurring stressors. Counsellors helped clients to deal with co-occurring stressors (e.g., poverty, death of loved one, homosexuality, drug addictions). As one participant put it, "Counsellors could do that, yes, help you to see options and deal with extra problems and stuff, poverty, illness, they could help...They could teach you coping tools and stuff...". These stressors often contributed to the stress of the client, making life increasingly unbearable. With support, a change and perspective, and newly developed skills (e.g., stress reduction, relaxation, assertiveness) clients were able to deal more effectively with co-occurring stressors.

Some participants suggested that counselling helped them to create stability and balance in their lives. Stability was often destroyed for many of the participants following the diagnosis. For example, many were struggling with a transient lifestyle, including no permanent shelter. As a side note to the interview accounts, I remember arriving at one of the HIV community-based agencies during a cold December morning. Outside the agency doors was a large piece of cardboard wedged between two concrete walls. Several clients were huddled together under the makeshift cardboard roof in a desperate attempt to have shelter. Counselling was a useful resource to improve stability (e.g., physical and psychological) in their lives.

> *...We woke up with this much snow on top of us [several feet]. And I used to lose all my pills because I had no stable environment. When I went to get help, we started making connections, counselling and then we got a stable environment, we've had a stable environment now for years....*

Emotions. Participants felt that counsellors were important in helping them deal with strong overwhelming emotions that came in response to HIV. Several participants recalled that counsellors helped them to deal with these emotions in positive ways (e.g., discussing, teaching coping skills) as opposed to through the coping techniques that the participants were often using following diagnosis (e.g., drug and alcohol abuse, denial). One participant shared, "...I don't think I took it right away, Yeah I'd say with the counselling was when I first started to get past all the fears...".

Reduction of high-risk behaviours. Many participants felt that counselling can be useful to help reduce high-risk behaviours. This can occur through several avenues such as: (a) helping newly diagnosed people realize it is not a death sentence, (b) providing them with information and knowledge, (c) empowering them and making them feel hopeful for their futures, and (d) helping them to start caring about self and others again. As one participant shared, "...Counselling was useful [as] it helped me to get back on track and find out what to do next...". Several participants felt that counselling helped them to challenge their drug and alcohol use, which in itself reduced high-risk behaviours (i.e., drug and alcohol use), but this also contributed to reducing other risk behaviours that sometimes co-occurred with drug and alcohol use (e.g., risky sexual activities). One participant recalled, "I think so [counselling reduced drug use] because I still use but it's like nothing, nothing compared to what it was before...". Following diagnosis, participants needed someone knowledgeable and hopeful who could listen to their fears and concerns and help them through the diagnosis. Participants needed to get their questions answered and locate key resources to help them deal with the diagnosis.

Quality of life. Almost all participants suggested that counselling helped them to improve the quality of their lives (e.g., dealing with stressors) in areas such as dealing with substance abuse and finding stability. As one participant explained, "Working through my problems with a counsellor really just helped in so many ways, feeling better, being happier, having options…".

Mental health issues. Some participants felt that professional counselling was more desirable than peer counselling for dealing with certain issues. In these cases, participants preferred professional counsellors to discuss issues that they saw as serious such as suicidal ideation and mental health concerns such as depression. One participant explained, "…[Counselling was important to] work out my deep seeded mental problems…". Another suggested, "Talking to a psychologist could be helpful, just for those mental health issues…". Several participants also preferred a professional counsellor to talk about sensitive issues such as the side effects of sexually transmitted diseases and highly emotional struggles. This was important in order to maintain complete confidentiality. As one participant put it, "…Generally if I'm coming to a staff it's highly emotional and I don't want to share that with somebody that I see on the street who might use it in someway against me…". Counsellors and psychologists were also helpful to connect participants with psychiatrists to help them obtain medications to deal with mental health issues. One participant explained, "…she sent me to see a psychiatrist so I could get medication for my depression and within a couple months I was right up there, I was just feeling great…".

Counselling and Psychology Services: Negative Aspects of Professional Counselling and Psychological Services

Some participants suggested that the process of obtaining counselling could lead to feelings of isolation and not belonging. The perspective was that counsellors were professionals, which meant that a true relationship and connection would not be formed.

> *…But it [counselling] had its faults too, because there's still the stigma and you still weren't included in that circle [of counsellors] so you kind of, you're torn either way, you couldn't get in to that circle of people so you're basically excluded with hope [as services were helpful]…*

One of the participants felt that psychologists and counsellors were not that useful, especially immediately following diagnosis. This participant believed that counsellors and psychologists were not capable of truly understanding what people with HIV were experiencing. This same participant also believed that he was not able to connect with counsellors or psychologists because they just did not have the experience of being HIV-positive. He explained, "I went to one counsellor and I just didn't feel, it just wasn't… [Interviewer: "No connection?"] Yeah, exactly". He went on to suggest, "You can't just talk to somebody when you're HIV fresh like that to somebody that's not HIV and expect them to understand how you feel". Another participant also felt that he had seen one counsellor in the past and was unable to form a connection with her, which resulted in him stopping the counselling until he found another counsellor whom he could connect with. He recalled, "With that counsellor there was just no emotional hook-up, it was about business with her". One participant suggested that for him counsellors and psychologists needed a deeper sense of empathy.

> *You have to learn to accept it yourself and talking to someone about it that doesn't have it isn't going to help at all. Didn't help me. I went through that. I've seen a psychologist, psychiatrist, psychologist twice. It was a waste of time...*

Another participant shared his frustration when medical doctors, and other health professionals, tell him that they *really* understand and know what it is like to be living with HIV or AIDS.

> *You know, I can live a normal life and you know what, and what makes me, you know, kind of angry is sometimes doctors will tell you, hey, you only got so long to live, you know. You're not fucking God. You could be normal like, you could be normal just like you are, you could go out there and get hit by a car. Hey, it's up to God, not up to the doctor. And who the fuck are you to tell me how long I got left to live when you don't know what I'm fucking going through? Who are you to tell me what it's like to live with it...?*

Hope and Mental Health Services

Many participants felt that mental health services (e.g., individual professional counselling, peer counselling) helped them to see hope following diagnosis.

> *...But, being around HIV Edmonton and Living Positive has given me more hope with the new programs that are coming out and the people's support and then you wake up one day and you think you have a lot of hope....*

According to participants, mental health services impacted their hope in several important ways. It helped participants to realize they could survive a long and healthy life with HIV and helped them to increase their desire to live by helping them to find reasons to stay alive. Many of the participants' initial reactions to HIV were that of a death sentence, which shattered their hope. As one participant put it,"...Through this agency...

and through other people… and you have a general ability to put two and two together you can think it's not so bad after all, find hope, you can survive…". Participants suggested that services helped them to find purpose in their lives which influenced their hope. One participant recalled, "Talking to counsellors and peers, it was good, I mean they can like help; get you thinking about just what are you going to do in your life…". For several of the participants hope and purpose seemed to be related constructs. "…I've learned that hope and purpose are similar things…". Mental health services also helped participants to become focused and get their lives back on track. One participant suggested, "They keep the vision of my purpose clear in my head; they make sure my feet are going in the right direction".

Dealing effectively with HIV and accepting HIV were important. They were related to hope for participants. As one participant described, "…The more you accept it [HIV] and deal with it, well then the more hope you have for yourself, you can live…". Participants suggested that mental health professionals helped facilitate this acceptance. "When you are talking to these people [professional helpers and peer counsellors] you start to realize that, 'Hey, I can get through this shit [HIV]. I can be okay here'…". Some participants felt that working through strong overwhelming emotions could help hope. "If you can get through the harsh reaction to HIV then this can get you focused on the future, you can begin to see straight again, which is hope…".

Peer support services showed participants people who were living with HIV for long periods of time and who were helping others deal with HIV. Hope was found in seeing that others had HIV and still had a future. One participant stated, "Just seeing other people who live longer, you know they don't die after six months. They can live 20 years...this [peer counselling] is hopeful...". Mental health and peer support services helped to reduce stigmatization and discrimination for participants by helping them feel accepted by service providers. Participants suggested that this helped them to have hope.

> *Being helped and accepted is so important, you know these people will not look at you like you got the plague, you are okay...This makes you feel good, like things will be okay, like you are not a freak, it can be hopeful....*

Mental Health Services and the Loss of Hope

Participants described hope as fluctuating over time. For participants, hope was influenced by external events and, specifically, perceptions of these events. If participants had a bad experience at a community-based agency or counselling session this could challenge their hope. Some participants suggested that being involved with services with peers and seeing those peers die challenged their hope. As one participant shared, "...I've seen it the other way too, people that have got really, really sick too. This can hurt your hope...". Some participants felt that poor services or being unable to connect with the service provider led to challenges in hope.

> *Well, if you have a bad experience or can't have a good relationship it is frustrating, and this can hurt hope in some cases, but hope is inside and outside...More inside, so it is dependent a lot on how you see stuff...Still, [it] can hurt your hope...*

Barriers to Seeking out Services Following Diagnosis

Participants experienced several factors that prevented them from seeking out services following diagnosis. What follows is a description of these factors and comments from participants briefly illustrating the themes.

1) Lack of actual services or supports: "Truth to it, there was not too many people around offering supports or help".

2) Lack of knowledge and information regarding available services: "If somebody had told me [I would have used services earlier]...I didn't have the slightest idea [services were available]". "I didn't know about the existence of this place [HIV community-based agency], I didn't know Living Positive existed, I didn't know anything existed". Another participant explained,

> *Not knowing, not understanding. I think it's not understanding the whole process. Like I said before AIDS/death, you know. I didn't, there was this process, like the whole process and stuff. I mean there's years and years and years before death comes. Knowing that I don't think I would have done that [high-risk behaviours] as quickly as I did because I wasted a year. I wasted a year of not getting the proper health, of not getting, you know, not knowing anything, not understanding it.*

3) Fear of stigmatization and discrimination of becoming connected to HIV services and also of others finding out that you are HIV-positive and believing that you are gay: "I don't think I took it right away, Yeah I'd say the counselling was when I first started to get past all the fears...".

4) Homophobia (i.e., believing that many people with HIV are gay and any services offered will be geared toward gay people): "...[I was] not wanting to be seen as gay...".

5) Not caring what happens to yourself: "You just don't care, so why bother trying to get any help?...".

6) Actually desiring death: "...Like I said, wanting to die, so why get help...".

7) Strong overwhelming emotions (e.g., fear, anger, pity): "You be on the pity pot, or you're so damn angry, you're not thinking 'get help'"...".

8) Denial of HIV and/or denial of the repercussions of HIV:

> *Now it's okay. Now it is, Yeah. Now that I understand the disease, it's not something to be ashamed of; it's not something to run away from. I mean you have to live with it, you have to be part of it and I think part of the solution would be. Okay, like being a drug addict, right, for example, first of all you have to admit you're one before you can get any help and before you can take care of yourself. So if I went around and didn't admit that I was HIV-positive, I don't think I would have the supports I have. I don't think I'd be able to excel as much as I do because then I'd be taking a part of me away. Has to be involved in what I do because it's what I have right. So I have to.*

9) Belief that others will not understand or be able to help. Trust was also difficult for some of the participants.

> *No, no I was [all grown up], I knew it all, I could take care of myself, I don't need any help. Yeah... the less people knew the better, going to a doctor, they don't have it, they don't know what I'm going through. It was really hard to, the trust issue, the trust factor, I wanted somebody who knew, who had been there, who was going through it....*

Positive Outcomes and Major Life Changes that Occur Through Becoming HIV-positive

HIV helped several of the participants to find meaning in their lives. Many suggested that before HIV they did not have a lot of meaning and purpose in their lives. With the HIV they were able to create and find new meanings and purposes. As one participant shared, "With HIV I do things to help it not be spread... I fight against it... This gives me focus and purpose".

Further, many participants suggested that through HIV they were able to shift their focus away from material objects toward the things in life that are really important (e.g., family, being alive and taking time to enjoy life, not wasting time, live in the moment). This illustrates the change in life perspective and the focus of hope which can occur with an HIV diagnosis. Several participants shared evocative stories illustrating this theme.

> *Or even when I'm homeless, I've been homeless five months now, I didn't give up hope, I seen it as a transition where I had to go homeless, my life was chaotic and the*

only way to get out of the chaos was to actually just pick up and walk away and no matter how much I had around me and I had a lot, it wasn't healthy and one day I just said "to hell with it" and I walked away. I lost everything on one hand; I gained my sanity on another. I got back to nature, gave me a lot of time to think about like what's important, the computer and the stereo or mental health. I might be homeless with no electricity but my mental health is coming back and before that I was just all into material possessions you know and then I get trapped and sometimes it's real easy to turn off the emotions by focusing on external toys and to be quite honest that's not very good....

So, I really don't have time to put up. I'm not going to do a job I'm not happy at. Life's too short. So I guess in that respect it's given me the hope chest itself. Whereas before I was hopeful for different things, now I'm just hopeful that tomorrow is as good as today, if not better.

I think with any illness though. And there's a lot of blessings in illness that are really hard to describe to someone that hasn't had it. I mean there's a certain spirit that comes with being diagnosed that a lot of people don't get. And you kind of wish you could tell them like wish you could just grasp the concept of how valuable life is without having to be diagnosed. With anything, cancer or HIV. If people could just grasp, you know like, some things are not worth arguing about. Let it go. I mean if it takes an illness to get those concepts through your head, well I'm glad that I have it because it sure changed my life. I'm not after the sports car or the fancy house. I know what I'm not taking with me and I know what I'm leaving behind.

...Your life doesn't stop... oddly enough, I guess when we're threatened with a serious illness especially a terminal illness, I say this is my terminal illness and with that life is more precious and so is the relationships that I make and the friends that I make and the people that I see and the people that I talk to, it's more personal, something that I need to hold on to.

Many participants suggested that they consumed alcohol and drugs prior to HIV. This continued following HIV (i.e., often increased); however, many participants indicated that after they realized they could survive with HIV they made a shift toward a healthier lifestyle. This often included reducing and even stopping drug and alcohol use. Many participants believed that if it was not for the HIV they would have continued using the drugs and alcohol.

Through it [HIV] I've stopped drinking. I've stopped using the drugs. I've gotten my family back together. I've got some responsibility in the community. I'm living a healthy, normal per se life. In some way the HIV is a blessing because I'd probably, I'd still be drinking and drugging. You know I'm just...drinking and drugging I didn't know

> *when I was going to die. But with HIV and not taking proper care of myself I knew I'd have a short life coming. Then I really, I really never give up. I've been down but I've never been down and out. And this made me realize, hey God spared me now, give something back, give yourself, you know, rebuild the temple that he's given you. And that's what I've done.*

Some participants suggested that becoming HIV-positive helped them to learn new coping mechanisms which helped them to deal with the HIV and other problems in their lives (e.g., taking it one day at a time, avoid stressing over little things in life, make positives out of HIV, accept things you cannot control). One participant shared, "Getting HIV forced me to learn how to deal with stress…".

> *…I mean I have it so why don't I live with it with a positive attitude and you know educate myself and others to live with it with a positive attitude because I can't change it, I can't get rid of it, it's not going to go away so why get depressed about it and why stop living? I'm not going [to] stop living. I think I enjoy life more now, how oddly that is, than I ever have because I'm not taking it for granted and I didn't care before and now I care a little more, so it's a big difference.*

Some participants felt that through HIV they realized the need to make changes in how they were living such as personality changes and changes in their beliefs. As one participant put it, "It was hard to be accepting before, now things are better… You don't step on my toes, I won't step on yours… I have gay friends now, too".

> *"I guess, I was my father, my father had a temper like you wouldn't believe, I came from a very, very abusive family, my parents didn't use drugs or alcohol but my father was very abusive. I was scared to death of my father, I hated him all my life and he'd hit me continuously for nothing, I was the oldest one, I was the black sheep and you know he was very, unless you were white you were garbage, my father would roll in his grave right now if he found out that my wife was [not white], if he found out that my grandson was [not white] you know, and that's how I grew up, with a very bad temper, people would say you're going to have a heart attack and then when I got AIDS, when I came to believe in God and I got into the program I had a complete 180 you know, I've got nothing against anybody of any race, creed, colour, sexual orientation, I had a lot of problems especially until I got here because most people I deal with are gay you know and that's their lifestyle just don't push it on me, don't flaunt it on me you know and nobody has, I know some really, really great people, one time I would have said "you fag get away from me" and [now] I hug them.*

Concluding Thoughts

Within this chapter I have highlighted several themes that relate to mental health services and unhealthy/risky behaviours following an HIV diagnosis that existed for the participants in this study. The participants' accounts, along with my interpretations of their experiences, have offered important information and understanding of mental health services following an HIV diagnosis. Specifics about participants' experiences with peer counselling services, group work, and individual counselling/psychological services have been explored. In addition, hope and mental health services have also been a focus within the chapter. It seems that mental health professionals can have a significant impact on people struggling with an HIV diagnosis in terms of helping them discover and refine hope as well as to deal with the HIV diagnosis. In the following chapter I will present a composite depiction of the experiences of receiving an HIV diagnosis for the participants in this study.

Chapter Eight: Composite Depiction

This chapter presents the composite depiction of the results from the study. It returns to a narrative account based on a summary of the main themes presented in the previous results chapters. These earlier results chapters presented different components of the accounts of the participants in this study. This chapter is a return to the wholeness of these accounts in order to illustrate the interconnections of the various experiences of the participants. Although it is written in first person in order to better capture and present the accounts, this narrative is a fusion between the participants' stories and my own interpretations and pre-understandings.

Narrative Composite Depiction

I am sitting, waiting for the phone to ring. I am waiting for the call that will undoubtedly change my life. I am entrenched in despair. How will I tell my family, my friends, my partner? How will I tell all these people that I have HIV? That I have contracted a deadly, life changing disease. What will they think of me? Will they still love me? Will they accept me, and treat me in the same ways that they did before I was diagnosed? I was told I would need to wait for 14 days to get the results; how will I wait for this length of time, how will I make it? It is so hard to act normally around my partner, to be okay with the possibility that it may be HIV. My partner has no idea that it may be HIV. What if it is HIV? Will I die quickly? Will I die a slow, painful, humiliating death? I know nothing of this disease. I am so scared, but know nowhere to turn for answers or help. I can't tell anyone. I feel so alone, all alone and by myself. What should I do? I wish there was someone I could talk to, someone who knows, someone who understands what I am going through. I can't concentrate on work, I can't concentrate on any conversations I have. All I think about are those three letters H-I-V.

Each time the phone rings, each time someone calls, all I think about is "HIV and death". I experience dissociation, like my body is here but my head is in a thick fog and I cannot see through it. I feel as if my emotions are becoming detached from my heart, at times I feel nothing and other times I feel everything at once. Finally, the call comes. It is a nurse who wants me to come in to talk to the doctor. Why won't they just tell me over the phone, why won't they tell me I do not have it? All I want is for them to tell me that "I do not have HIV". They will not, I must have it. In my mind, I go back and forth... The reality, it must be something serious, it must be HIV. If it wasn't they would have just told me over the phone. I hope... I hope so much that it is all a big mistake, that it is not HIV. I do not want to die; I do not want it to be HIV. I go into the hospital. It's a clinic. It's a clinic that reminds me of death. Its sole purpose is to test peoples' blood for infections and diseases. I check in to the front counter. The receptionist looks at me, and looks away quickly. She knows, she knows I am diseased and am going to die. She almost looks as though she has contempt for me, thinking, "I feel sorry for him", on the one hand, but thinking, "he must deserve it", on the other. She will not even make eye contact as she points for me to sit. I wait, and I wait, and I wait. Every second goes by so slowly. I feel as if Father time has banished me to an eternity of waiting. I see the pictures on the walls and the expressions on the peoples' faces. Although I sit in shock, and experience a sense of surrealment, I suspect I will never forget these moments. Everyone looks upset. It is a somber place of being. I wonder if these people are dying. I feel sick to my stomach and full of anxiety. I am so tense. The time goes by so slowly. It feels like the seconds turn to minutes, and the minutes turn to hours. I see a clock on the wall, the second hands just barely move, they tic as if time is pushing against them, slowing everything down. It must be the shock I feel.

A nurse and doctor approach me, and ask for me to follow them. I can barely stand, my knees are weak, and I feel faint and scared. I follow them, all the way to the back office, away from everyone else. It feels like a cell. I have been marched to my execution. They close the door behind me and ask me to take a seat. The doctor looks at me, and looks away, toward his feet. Even he cannot bring himself to say the words he needs to speak. He says "I wish I had better news for you, I do not. Your test results came back HIV-positive. You have HIV/AIDS". I am shocked into disbelief. I feel as if 1,000 volts of electricity were just jolted through my body. I am speechless. What does this mean? Am I going to die? How long do I have before I deteriorate and wither away to nothing? What will happen next? Where can I go for help? Please, someone tell me what I should do next! Before I can ask anything, the doctor tells me they will run the test again to make sure it's not a mistake, he means to ensure that it is not some cruel joke. He says that the hospital has a psychologist I can see, and also that they offer something called "post test counselling". He asks me if I have some time to talk to someone now. I am so upset and so shocked, I do not know what to say. If I had someone to tell me to keep hope and that it would all be okay then I think I would be okay, maybe, maybe not... I really do not know what to expect. It's like I was just given news that I know is horrible, but I really cannot comprehend it because I don't know what it means and because my body has taken over and placed me in complete shock. I wait around for a while at the hospital, but nobody shows up... I could wait longer, but the smells and the noises of the hospital are making me sick. I just need to leave, to get out of here for now.

I turn to the only thing that will help me to get rid of all of the bad feelings I have. I am so scared and so upset. I go to the bar and start drinking, drinking a lot. I drink to the point where I do not even know where I am. I feel better for a little while. I forget my reality. I do not care. I mean who really cares anyway. I have just been handed a death sentence. I have, what, a couple of years to live, maybe a couple of months. I do not want to die like the people I saw on television, completely helpless and not able to care for themselves. I just don't fucking care anymore! I get stoned and drunk. I want to die now. I want to make it all go away. It has to just all go away. I can't tell my partner, my family, my friends, they will never understand. What about my child? He will grow up thinking his father was gay or something. He will never accept me, and he will be ridiculed by his friends if they find out. How can this be? What can I do now? I just want to drink and get stoned, again and again. I want to die. As I drive home drunk, speeding, I wonder if this will kill me. I start to lose control of the car. Bang, hit a tree. As I lay there in shock the emotions sink in for a little while. I am so sad and scared...I am also still alive... Sitting drunk and stoned in my car. I just lay there, upset and wanting to die...The police come and give me a breathalyzer...Gone to jail, to "sleep it off". I think this police officer should feel bad for me. "Feel bad for me police officer, I have a deadly disease, let me go, let me die". They let me go the next day, after my partner has to post bail. I have a court date set for four weeks away and now a suspended license.

My partner does not understand, does not get it, why I am acting this way. No one does. She "puts up" with me for a while, and tries to help and understand. But I push her away, continually push and push. In time, she leaves and takes our child. Everyone leaves, no one understands. I need to drink to get rid of these bad feelings. I am so lonely; I need to feel close to someone. I can meet people at the bar, people like me, people who like to drink and do drugs too. I need to feel connected to people. I still want to die. God please kill me…

It's not until several months have past that I meet someone who tells me about a local agency that helps people who are HIV-positive. It's hard, but I work up the courage to go to the agency. I talk to a counsellor there who really seems to know what he's talking about. He seems to have all the answers. But how does he know? How can he really understand? It's not until 20 minutes into our conversation that he tells me he has been living with HIV for about 12 years. I am absolutely blown away—12 years! He tells me about his stories and experiences. He introduces me to others who have been living with HIV a long time—one guy had it for 18 years, and he looks great. Everyone seems so nice and accepting. I can't believe that I am being welcomed, despite my HIV. I start to feel better—even hopeful about my future. I start asking more and more questions. I talk to a professional counsellor who also helps me. She makes me feel hopeful as well. I feel empowered.

It is not long before I start doing some peer counselling courses to try to learn how I can help others dealing with their HIV diagnosis. It makes me feel good, like I have a lot of purpose for being here now. Maybe this is the reason why HIV came into my life, to help others. After the course I am actually invited to do some peer counselling at a local community-based agency. This is great. My first client comes in to see me; I sit across from him and ask him "how he is doing?" He says "horrible, I need some fucking advice, some help, how do I get through this shit?" I think to myself "wow, how do I help him?" All of a sudden I feel scared. I think, the best I can do is tell him my story, my experiences, how I dealt with it myself...I start talking, telling him my story...

As I look back on my experiences I realize that it was no easy thing dealing with HIV. I share this with him, my client. "The diagnosis and everything, that's something that you just don't forget", I tell him. Looking at my feet now, I can't even look him in the eyes. I just start talking... "You know, there are times in your life, like defining moments, that was one of those moments. December 27th 1991, 2:36 pm. I lost it. Just totally lost it at first. All of those emotions. Anger, fear, sadness. I needed to deal with these first, needed to find ways to talk about those emotions". I find myself starting to make eye contact with him, I am starting to feel more secure. I think, "maybe I can help this guy". I tell him with new found confidence, "I wanted to have those feelings validated after they were spoken out loud. Medications to deal with stress and strong overwhelming emotions can also help; I will help get you connected to a psychologist and a psychiatrist". I can feel the emotion starting to surface within myself, it sometimes still has a hold around my neck. I share with him my feelings. "I still struggle with getting through it almost every day. But it does get better, it gets easier. Having something to believe in makes it easier. For me, it was religion and God. I guess ultimately it is about being spiritual and believing in something of a higher power. This just makes you feel safe and that it has not all been a waste. Like there is something else, some larger purpose to all of the madness of life. If you have beliefs then this can also help you to find meaning and purpose in your life". I decide to share some personal future plans, "For me, I am planning on going to some different schools and talk to the children about HIV and the need to be careful with sex and drug use. I'm also doing some of this peer counselling stuff, like we are doing right now. This makes me feel as if my own HIV has not been for nothing. Like, I got HIV, but if I had not got it, then maybe someone I helped would have got it. It feels hopeful to tell my story to people. I tell them about my experiences and my strong fighting spirit. You need to be strong and keep looking forward to get through HIV".

I tell him that I also try to learn about HIV, even though it was really scary at first. Trying not to overwhelm him, I explain, "I take courses, read books, and listen to others' stories of how they dealt with HIV. Information is one of the best ways to fight against HIV. The more you know the more you can help yourself. It is empowering to be able to understand HIV and know how best to deal with it. It helps you to take control of your life. Part of this comes from hearing others' stories and part of it comes from my own experiences".

"Finding things that empower you, give you purpose and inspiration, and hope are very important", I tell him. "For me, it's my family. That's one of the biggest. It was not until after I started coming here that I was able to stop some of my high-risk behaviours and get my family back. I finally got up enough courage to tell them, and they actually accepted it, they accepted me. Besides this, it's my volunteer work, helping others with HIV and trying to prevent HIV. Creating meaning out of the HIV experience and out of your life in general is so important".

"I make others laugh and smile. It makes me feel happy and hopeful when I can make others, especially those with HIV, happy. Having a sense of humor is so important for me. If I can laugh off stresses in my life, or just have a good laugh once in awhile then this makes me feel so much better".

I also share with him my little coping things that I do. I start by telling him "I have just learned these over my life. It helps me to deal with HIV, to feel better about it. I have learned these things from counsellors, peers, friends and family, and from myself—trial and error". He seems okay with this, so I continue. "I try to avoid thinking and worrying about HIV stuff. Part of this was coming to terms with HIV and realizing that I could not let HIV destroy me. I try to find ways to just throw stress away or disregard stressful things. I walk away from stressful situations, ignore stuff that makes me feel stressed out, I make a point to realize what I can and cannot control in my life, I don't sweat the small stuff, I avoid taking life too seriously, and I focus on one problem at a time. I also try to stay positive and spend time with positive people. It's hard though, because having people in your life is so important, but it's not always easy finding people with positive attitudes. I also learned some good skills from talking to my counsellor. I learned about thinking problems through all the way, breaking problems down into smaller problems; avoid living in the past, especially focusing on guilt and remorse—or focus in the moment, and trying to use problem-solving skills. Taking one day at a time, having goals, and a plan of action are also very important. One of my favorites though is just allowing myself to take a mental break or even a vacation. I get away camping with my dog".

I also tell him about hope and how important it is. "Most of us don't really think too much about hope, but you need to make an effort to really focus on it and think about it. It's there for you, its there for me, but you need to be willing to grab it and work for it.

You know, hearing others' stories of living for like 15, 20 years, that is hopeful, realizing this thing called "HIV" is not a death sentence, that's hopeful... I also have hope for better drugs and a longer life, but mostly just a quality life. But hope is not only about the things that we look forward to or hope will happen, it's also about the different dimensions of life that exist day to day that shine rays of hope on us. Our family, friends, our beliefs of spirituality, our emotions, our struggles, suffering, and pain all contribute to our experiences of hope".

"Staying busy, focusing on hobbies that you love, volunteering, doing work or activities, it's all important. Keeps your mind off of HIV and focused on more hope-filled things. It's also important to stay busy with healthy things to keep you away from unhealthy things, like high-risk behaviours such as drinking, using drugs, partying all the time, or unprotected sex".

"Another really important thing is getting on HIV medications if your viral levels are high and CD4 counts are low. We will get you checked out. But if you do go on these medications, it's really important for you to listen to the doctors and stick with them on a regular basis...You don't want the virus to take over and become immune to the drugs. Part of this is also looking after yourself—all of yourself, take a holistic approach. Get sleep, spend time with good friends, get rid of stress, eat right, no alcohol or drugs, and be active. I take tai-chi to gain energy. Just look after yourself and you will be okay".

"You need to have a fighting attitude" I tell him— "You need to believe you will survive and you must have faith. Do this, even if you need to totally change your attitude. For example, "I am living with HIV as opposed to dying with HIV". This helps to get me through. Part of this is about finding positives in your life and focusing on these. It is also important to acknowledge the negatives, but keep your focus on the positives. Just remember: All of the aspects of life that draw you in that give you hope don't die with an HIV diagnosis".

"This is my stuff that works for me. It may not work for you. One of the biggest things with dealing with HIV is knowing that you need to be ready and willing to make some major changes in your life...Think about it, it is really all up to you..."

Personal Reflections

The previous narrative represents my composite depiction of the results for my dissertation. Writing this composite depiction was a valuable experience in that it helped me to bring together the different aspects and pieces of the interpretations I formulated through this study. It also helped me to further the interpretation process. It helped me to continue to connect my horizons with the participants' horizons.

This process was also quite challenging and emotionally draining. Bringing together such powerful accounts of the experience of receiving an HIV diagnosis, dealing with the aftermath of the diagnosis, engaging in high-risk behaviours, discovering hope, empowerment, and meaning, engaging in peer counselling, and receiving mental health services is a personally life changing experience but also an experience that brings with it a risk--a risk of having one's own hope challenged. As I listened, read through, and reflected on the participants' accounts there were times when I felt anger, sadness, discouragement, and fear, which impacted on my own personal hope as the researcher. Having said that, there were also times during this process where I experienced joy, humour, empowerment, and courage, which also impacted my hope. As I reflect on this research process I realize that my feelings and my hope, at times, became connected with those of my participants' feelings, as they reflected on and recalled their experiences of receiving and dealing with the diagnosis. This has been a powerful journey, one filled with meaning-making, learning, and empowerment—ultimately hope.

The following chapter offers a general discussion of the results of the current study. Specific connections with the existing research literature and implications of this study are highlighted.

Chapter Nine: Discussion

High-Risk Behaviours, Hope, and Mental Health Services

This chapter highlights the main findings of the research, along with the interrelationships with the available research literature. It also identifies specific practical and programmatic implications. The content of the chapter includes a discussion of the relationships between three main areas addressed in this research: (a) high-risk behaviours, (b) hope, and (c) mental health services. Given that there is considerable overlap among these three broad topic areas, the discussion explores the relationships between these areas as opposed to focusing on them separately. Importantly, the central organizing principle underlying this discussion is that of hope. Aspects of hope have been pervasive throughout the findings of this study. Thus, the discussion is framed around hope and specific sections within the chapter include: (a) potential high-risk and unhealthy behaviours, (b) experiences underlying high-risk and unhealthy behaviours, (c) mental health care services and high-risk behaviours, (d) hope and healthy lifestyle choices, (e) defining, communicating, and characterizing hope, (f) transcendent and object-focused hope, (g) hope, adjustment, and coping, (h) relationship and hope, (i) meaning, purpose, and hope, (j) inspiration and hope, (k) inspiring and facilitating hope, (l) peer counselling and inspiring hope, (m) hope and story, (n) hope, survivability, and support, (o) hope, perceiving options, and learning, (p) diagnosis delivery and hope, (q) perceiving control, (r) hope, treatments, and lifestyle/life quality, (s) positive outcomes as a result of HIV, (t) threats to hope, (u) hope and current day experiences with HIV, (v) false hope and false despair, (w) health care services, and (x) response team.

Potential High-Risk and Unhealthy Behaviours Following HIV Diagnosis

Although most people who receive an HIV diagnosis reduce or cease their high-risk behaviours, a small percentage continue or even increase their high-risk behaviours, putting themselves or others at risk. The present study suggests there are several types of high-risk behaviours that can happen following an HIV diagnosis, as well as several experiences that may influence the likelihood of the occurrence of these high-risk behaviours.

The main high-risk behaviours identified following an HIV diagnosis have tended to include: (a) suicide, (b) alcohol and drug use, and (c) risky sexual practices (Erickson, 1993; Hook & Cleveland, 1999; Sarwer & Crawford, 1994; Siegal & Ilan, 1999; Sherr, 1996). Although these types of high-risk behaviours had occurred for several of the participants in the present study, additional types of risky and unhealthy behaviours were also identified by participants in the current research, including: (a) high-risk driving, (b) fighting, (c) refusal to take HIV medications, (d) refusal to engage in self care activities, (e) reckless spending, and (f) criminal activities. This research highlights the importance of considering high-risk behaviours as a broad cluster of risky behaviours which can result in harm for the individual and for others in his or her environment. Thus, high-risk behaviour can be conceptualized as any behaviour that poses a threat to the individual, to others, or, more likely, to both the individual and others. This can help widen the observational lens of what constitutes high-risk behaviours. For example, refusal to efficiently follow an HIV medication schedule can create harm for the newly diagnosed patient, but it can also result in increased likelihood for HIV transmission during other types of risky behaviours (e.g., sexual intercourse) due to viral counts being unsuppressed. Thus, not only is it important to define high-risk behaviours broadly, but it is also important to realize the interconnections between high-risk behaviours. These interconnections can create high-risk behaviours (e.g., drug addictions can precede criminal activities), maintain high-risk behaviours (e.g., alcohol abuse can result in high-risk driving), and increase the dangerousness of high-risk behaviours (e.g., refusal to follow an HIV medication schedule can result in increased risk for HIV transmission during high-risk sexual activities). Of particular importance is understanding the experiences that underlie the above-mentioned high-risk behaviours.

Experiences Underlying High-Risk and Unhealthy Behaviours

Several experiences may have contributed to high-risk behaviours for participants in this study. The following is an examination of several of these experiences, along with considerations for health care professionals.

Overwhelming emotions. Diagnosis led all participants to experience a strong emotional reaction. These emotions were powerful and consisted of feelings such as: (a) anger, (b) hopelessness, and (c) fear. Some participants seemed to become lost and out of control within these emotions. Although strong overwhelming emotions are common following an HIV diagnosis (Bartlett & Finkbeiner, 1998; Zegans, Gerhard, & Coates, 1994), little research exists which examines emotions following diagnosis and how these emotions might relate to high-risk behaviours. Many people who receive an HIV diagnosis and have a strong emotional reaction do not engage in high-risk behaviours; however, as seen in the present study, some do increase their high-risk behaviours and attribute these behaviours, in part, to overwhelming emotions. Several possibilities may explain the potential relationship between emotions and high-risk behaviours. For example, one explanation of how overwhelming emotions may relate to the increased likelihood of high-risk behaviours has to do with peoples' need to cope with their emotions. With few effective coping skills in place, people may increase their engagement in high-risk behaviours in order to deal with their emotions. Indeed, research (Osowiecki & Compas, 1998; Stanton et al, 2000) has suggested that ineffective coping mechanisms, such as avoidance of the stressor, can lead to higher levels of distress and maladaptive outcomes. Another potential explanation could be that the emotions themselves impact individuals' abilities for rational thought in some situations. Thus, with high levels of affect, peoples' ability to reason and consider consequences could be affected, resulting in potential high-risk situations. Research (e.g., Kaufmann, 2003; Spering, Wagener, & Funke, 2005) has suggested that strong emotion can influence peoples' ability to reason and solve problems, although less research is available on exploring the relationship between strong emotion and cognition associated with high-risk behaviours. Ladouceur, Arsenault, Dube, Freeston, and Jacques (1997) reported correlational research findings related to problem gamblers, suggesting that this group experienced (a) strong emotions (e.g., depression), (b) cognitive distinctions (e.g., problem-solving differences as compared to the general population), and (c) increased likelihood of engaging in risk behaviours (e.g., gambling). Although this research was correlational in nature, it did highlight correlational findings related to (a) emotion, (b) cognition, and (c) risk taking. Siegel and Meyer (1999) have reported that following diagnosis of HIV, "panic and mental disorganization may ensue" (p. 53), which can create risk opportunities for suicidal ideation. Thus, some researchers have highlighted potential relationships between (a) emotional experiences, (b) cognitive restrictions, and (c) high-risk behaviours.

Given participants' accounts of overwhelming emotions being related to high-risk behaviours, it seems there is a need for health professionals to help newly diagnosed HIV-positive patients address these overwhelming emotions. This can be accomplished through several avenues such as: (a) having open discussion in the context of a safe and therapeutic alliance, (b) keeping a journal, (c) focusing on acceptance of the diagnosis and forgiveness in terms of the route of transmission, and (d) obtaining support (e.g., peers, family, friends) (Blechner, 1997; Cadwell et al., 1994; Green, 1996). Although counselling in general can help patients deal with strong emotions, some specific counselling modalities may be especially useful following an HIV diagnosis. Experiential counselling modalities (e.g., existential, gestalt, person-centered) maintain a primary focus on connecting and dealing with emotional experiences. In addition, these modalities often focus on consolidation and wholeness, which may be important for newly diagnosed individuals who can be experiencing a shattered sense of self and scattered emotions (Corey, 2001).

Hope, hopelessness, and despair. Little research exists on the experience of hope following an HIV diagnosis and how this may relate to high-risk behaviours. The present study suggested that hope may be an important aspect in understanding peoples' experiences of receiving an HIV diagnosis and engaging in high-risk behaviours. Although some researchers (e.g., Farran et al., 1995; Hall et al., 1999; Kelly et al., 1998) have suggested that hope and hopelessness may impact behaviour choices, little research has been conducted to examine these relationships, especially with an HIV population.

According to participants in the present study, hope and hopelessness seemed to be related to high-risk behaviours. As participants' hope became challenged, some reported engaging in more and more high-risk behaviours. At diagnosis, HIV took away whatever hopes existed for many of the participants, leaving them feeling a strong sense of despair and seeing a future of suffering and death. In contrast, at the time of our research interviews, participants' current and future hopes helped them see a future and believe that life could work out.

Heckman et al. (1998) suggested that the reduction of high-risk behaviours among HIV-positive individuals needs to include the development of interventions that focus on: (a) encouraging the protection of others and (b) highlighting personal responsibility. Many hope theorists (e.g., Cousins, 1989; Dufault & Martocchio, 1985; Farran et al., 1995) have highlighted the role of hope in facilitating social and ethical behaviour choices, including the protection of others and personal responsibility, illustrating its potential benefit in reducing high-risk behaviours following an HIV diagnosis. Indeed, participants in the current study suggested that hope helped them to maintain a sense of responsibility, which often led to reductions in high-risk behaviours. Wong-Wylie (1997) offers an example of how hope in counselling may be maintained among HIV-positive individuals who are engaging in high-risk behaviours. She highlights the importance of maintaining the therapeutic alliance and the client's confidentiality. Through this counselling relationship, containing trust and respect, comes an opportunity to invite the client to develop hope and social responsibility. Participants in the present research identified relationships with service providers (e.g., peer counsellors, professional counsellors) as helping them build a sense of hope in their lives, which impacted their high-risk behaviour choices. This hope was often facilitated through specific aspects of the relationship such as: (a) trust and (b) acceptance.

HIV knowledge. Many participants had insufficient knowledge of HIV and were left wondering what would happen after they received the news of their diagnoses. This uncertainty was overwhelming and dehabilitating, often beginning immediately following diagnosis. In some cases, crucial information on HIV and how it differs from AIDS was lost as participants described entering a state of shock, making it impossible to consume valuable information offered at the time of diagnosis. Bradley (2005) reported that patients receiving medical diagnoses (e.g., cancer) can feel overwhelmed and have a difficult time retaining information, which is why it is important to give patients information that can be reviewed at a later time. According to participants in the present study, helping newly diagnosed individuals obtain information and knowledge regarding HIV can be an empowering experience. Some research (e.g., Mattson, 2000; Purcell et al., 2004) has illustrated that providing information is one aspect of intervention and prevention programs which can facilitate empowerment; however, little research exists exploring how informational attainment can facilitate empowerment following a medical diagnosis such as HIV. Participants in the current study suggested that information can help newly diagnosed individuals feel a sense of control and increase their desire to live in a healthy manner. Clearly, according to participants in this study, timing, repetition, complete and accurate information, and manner of communication are all important considerations in the delivery of HIV information.

Drug and alcohol addiction. Participants suggested that drug and alcohol addictions contributed to high-risk behaviours. Several researchers (Kennedy et al., 1993;

Robins et al., 1994) have suggested that substance abuse can result in high-risk behaviours among people living with HIV. Indeed, research suggests that drug and alcohol use can increase following an HIV diagnosis (Caba, 1994; MacGowan et al., 1997). These serious concerns related to substance abuse and high-risk behaviours indicate that harm reduction and substance abuse treatment may be important treatment options for newly diagnosed individuals. Participants in this study suggested that dealing with addictions helped them to reduce their high-risk behaviours and regain control over their lives. In addition, developing effective coping skills can help newly diagnosed individuals deal with the diagnosis without a reliance on substances.

Coping skills. Research also reveals that high-risk behaviours following an HIV diagnosis may be related to poor coping skills (Robins et al., 1994). Participants in the present study indicated that their high-risk behaviours served several important purposes, including, (a) a way to numb the pain associated with HIV, (b) a means to deny the HIV, and (c) an avenue to seek help. Thus, for many of the participants, their high-risk behaviours were attempts to cope.

Researchers have reported that effective coping skills can help people to adapt to stressors and maintain a healthier lifestyle (Osowiecki & Compas, 1998; Stanton et al, 2000). Teaching more effective coping skills to deal with the distress of the diagnosis could be beneficial for newly diagnosed individuals. Helping newly diagnosed individuals address overwhelming emotions following diagnosis, directly offering them support and hope for their futures, and teaching coping skills (e.g., distraction, meaning-making exercises, relaxation), can occur through counselling and HIV community-based agency services.

Support. Health professionals can also connect newly diagnosed individuals to various resources in their communities in order to help them deal with co-occurring stressors, such as financial concerns or medication problems. Research suggests that prevention or intervention programs would be benefited through further involvement of community agencies (Crepaz et al., 2006). Participants in the current study reported benefits from being connected to community services, such as helping them deal with co-occurring stressors in their lives. Additionally, health professionals can help patients connect with family and friends, which can also be beneficial for newly diagnosed individuals and people who have been living with HIV/AIDS for longer periods of time (Bastardo & Kimberlin, 2000). Indeed, participants in the current research highlighted the indispensable role of family and friends in helping them to survive with HIV and reduce high-risk behaviours. These social connections helped participants to reduce the loneliness and isolation that often accompanies a diagnosis of HIV.

Mental Health Care Services and High-Risk Behaviours

Mental health care workers have a valuable role to play in helping people diagnosed with HIV to reduce any existing high-risk behaviours. An important recognition for HIV care professionals is that some segment of this population engages in high-risk behaviours prior to becoming diagnosed with HIV. These patients' abilities to cope with this incredibly difficult news may already be compromised. A realistic awareness of the struggles facing many newly diagnosed individuals is important, and maybe daunting, for HIV workers. It is important to recognize that this can be different than delivering a life threatening, chronic or terminal diagnosis to individuals who already have healthier coping strategies in place, who are aware and able to access services (e.g., are familiar with hospital or community services and have the interpersonal skills necessary to feel comfortable accessing these services), and who are not engaging in high-risk behaviours.

Most participants in this study of high-risk individuals suggested that high-risk behaviours became especially intense following notification of the diagnosis. This is an important observation for health care professionals involved in delivering the HIV diagnosis, as preventing high-risk behaviours among newly diagnosed individuals provides an important opportunity to reduce the spread of HIV and to keep newly diagnosed individuals healthy and safe. Research suggests that prevention of high-risk behaviours needs to include several specific target areas (Fisher & Fisher, 1992; Purcell et al., 2004). According to Fisher and Fisher, clients need information, motivation, and behavioural skills. For example, information can include: (a) HIV transmission routes, (b) identification of high-risk behaviours, and (c) identification of risk contexts which increase the likelihood of high-risk behaviours. Motivational areas can include: (a) pros and cons to change, (b) steps involved in making change, and (c) self monitoring exercises. Importantly, for participants in the current research, differences existed between motivation and hope. Although hope fueled motivation for many of the participants in the present study, motivation alone was not sufficient to lead to hope. Motivation could exist in the absence of hope, but this motivation was often not sufficient to create major lifestyle transformations. For example, when participants described being motivated in the absence of hope, the motivation often came from negative experiences such as fear of illness, which often led participants to seek medical testing. Thus, this motivation was often fear based and focused on avoidance. With hope, often came the motivation necessary to make major lifestyle and behavioural transformations such as (a) becoming connected to support services and (b) reducing high-risk behaviours. The third area, according to Fisher and Fisher, is behavioural skill sets, which can include teaching skills such as: (a) assertiveness, (b) negotiation, communication, or disclosure, and (c) technical skills (e.g., using condoms) (Carey et al., 2004).

Within the present research, participants highlighted the importance of each of these broad areas. For example, participants suggested that informational attainment was a key aspect of learning how to be safe and fight back against the virus. Empowerment, inspiration, and hope were discussed as motivating and energizing, giving the participants the motivation needed to initiate positive transformations in their lives. Other researchers have also highlighted the importance of empowerment in high-risk behaviour prevention programs (Purcell et al.). Previous research indicates that empowerment is an important component of helping people with HIV effectively deal with the diagnosis (Harris & Alderson, in press; Harris & Alderson, 2006; Purcell et al., 2004; Webb, Horne, & Pinching, 2001). In addition, some researchers have utilized empowerment within their prevention models with reported increases in pro-social attitudes (Purcell et al.). Within this study, participants suggested that empowerment and hope were often enhanced through a peer mentoring system, involving people with HIV in treatment programs. The relationship(s) between empowerment, inspiration, and hope were complex. According to participants in the current study, empowerment and inspiration may have been specific aspects of the hoping process itself. For example, with hope, people may be empowered and inspired to believe that an improved future is possible and obtainable (Hannah, 2002; Miller, 1991; Snyder et al., 1991). An implication of the current study is that empowerment and hope are important aspects of helping people diagnosed with HIV to obtain the necessary motivation and perspective to make healthy transformations in their lives. In addition to empowerment and hope, prevention programs should also consider a focus on other aspects of positive psychology, as positive psychology capitalizes on the human strengths and virtues inherent in human beings (Emmons, 2006; Seligman, 2003). These variables include areas such as (a) self motivation and (b) inspiration. Participants in the present study noted that motivation and inspiration were important in helping them deal with HIV and high-risk behaviours. Returning to Fisher and Fisher's (1992) three prevention foci, which were (a) information, (b) motivation, and (c) behavioural skills, participants discussed different avenues (e.g., through professional counselling) for learning specific behavioural skills (e.g., coping skills such as distraction) to reduce their high-risk behaviours. Thus, within the present study, participants struggling with high-risk behaviours following diagnosis reported being helped through (a) education, (b) motivation, and (c) skills training.

In terms of health care services, research has also highlighted the importance of broader contextual factors in the prevention of high-risk behaviours for HIV (Ewart, 1991; Crepaz et al., 2006). For example, exploration of (a) peer and familial support relationships, (b) peer networks (i.e., including high-risk networks), (c) environmental considerations (e.g., support groups, sources of stigmatization and discrimination, governmental supports and resources), (d) involvement of community-based agencies, and (e) development of a sense of community within networks are important aspects of prevention programs. Participants in the present research indicated that broader contextual factors were key aspects to high-risk behaviour reduction among this population. For example, social programs (e.g., support group, community-based agencies) were seen as an important element in reducing high-risk behaviours following a diagnosis of HIV. These social groups can foster social support and help the newly diagnosed individual reach out and connect with others. In addition, reducing harmful peer networks was seen as an important intervention for participants in this study. Peer counsellors are in a unique position to facilitate changes to peer networks, especially behavioural norms within these networks. In a study of high school and college students, Winslow, Franzini, and Hwang (1992) demonstrated the importance of targeting peer norms in high-risk behaviour reductions among people not living with HIV/AIDS. In this study, perceived peer norms and behaviours regarding HIV/AIDS/risk transmission were a better predictor of high-risk behaviours than HIV/AIDS knowledge among high school and college students (Winslow et al.). Participants in the present study suggested that receiving peer counselling helped them to connect to a helpful peer group and be influenced by the norms of that group. It is possible that peer counsellors have the opportunity to influence others living with HIV by introducing the newly diagnosed to experienced peers, thereby fostering healthy behavioural norms (i.e., high-risk behaviours are inappropriate or unacceptable), which may contribute to safer behaviour choices.

Harm reduction programs are also considered important components of treatment, as these services are instrumental in reducing high-risk behaviours (Crepaz et al., 2006). For example, needle exchange programs can reduce the likelihood of sharing used or dirty needles. In addition, methadone programs can help patients reduce illicit and dangerous (i.e., high-risk) drug use. Methadone programs also provide a steady source of methadone that is obtained in a legal and safe manner and can save patients large amounts of money that is expended on illicit drug abuse. These programs were highlighted by participants in the present study.

In considering the above-mentioned findings, health professionals need to be able to provide (a) support, (b) options (e.g., community-based services, counselling), (c) information, and (d) hope following the diagnosis. Participants highlighted the importance of the role that hope played in helping them to find balance and stability in their lives and in contributing to the reduction of high-risk behaviours. Having a sense of balance meant that participants were able to perceive possibilities and healthy choices in their lives. The opposite of balance, non-balance, consisted of (a) the absence of hope, (b) perceived threats to the future, and (c) high-risk behaviours. Importantly, according to participants in this research, hope can be developed through many of the avenues illustrated above (e.g., information, support). In addition, practitioners need to become aware of resource people (e.g., HIV community-based agencies, peer support workers, mental health professionals) who can become involved in treatment and case management of newly diagnosed individuals in order to ensure availability of services. This is especially relevant due to the possibility that some newly diagnosed individuals who continue to engage in or increase high-risk behaviours following diagnosis may not be receiving sufficient services. Many of the participants in the present study suggested that their high-risk behaviours were severe following diagnosis, especially when they were not connected with services. Thus, ensuring availability of appropriate services may be an important component of reducing high-risk behaviours.

Another important consideration is the focus of counselling with the newly diagnosed individual. The current study has suggested that several of the participants maintained a self focus versus a social focus following diagnosis. Thus, several participants engaged in high-risk behaviours with a focus on personal reasons for continuing these behaviours (e.g., wanted to die, was in denial). Given the findings of the current study, the clinician should consider the importance of fostering a sense of social awareness and social responsibility in dealing with high-risk behaviours. However, the importance of keeping a focus on the client's current position is also important, as attempting to prematurely shift the client's perspective may be counter effective.

Hope and Healthy Lifestyle Choices

According to participants in this study, hope is an important component of effectively dealing with HIV and AIDS. Participants suggested that hope was also important in helping them to reduce and eliminate high-risk behaviours and to strive for a healthier lifestyle. Hendricks et al. (2000) noted that hope was a predictor of healthy behaviour choices among adolescents. Harrison (1993) noted a connection between experiencing hope and maintaining a health-promoting lifestyle in individuals living with HIV. Cousins (1989), as well as Dufault and Martocchio (1985), reported that individuals with hope are more likely to make healthier choices and have a sense of social responsibility. Farran et al. (1995) reported that in contrast to hope, hopelessness has been connected with increasing levels of "sociologically oriented destructiveness and violence" (p. 39). Participants in this study suggested that with hope they were able to reduce high-risk behaviours and improve their lifestyles. It was following diagnosis, during times of high-risk behaviours, that participants had difficulty in locating hope. During this time, participants were struggling with fear, despair, and hopelessness.

In their study of caregivers of people living with HIV in Finland, Kylma et al. (2001) reported that following an HIV-positive test result, participants saw their patients typically become distressed, hopeless, and despairing. This resulted in the patient becoming emotionally shut down (Kylma et al.), which was noted to have helped some patients deal with the overwhelming situation of receiving the news. Participants in the present study reported despair and hopelessness, as well as fear, following the diagnosis of HIV. Participants continued or increased their high-risk behaviours, partly as a means to deal with the overwhelming emotional impact of the diagnosis. In Kylma et al.'s study, following the initial reaction, caregivers suggested that many of the patients' hopelessness and despair turned into hope, though the process by which this happened was not fully explored (Kylma et al.; Kylma, 2005). Similarly, Siegal and Meyer (1999) reported that in their study of gay and bisexual men, some participants experienced suicidal ideation and suicide attempts following notification of HIV-positive status. Several of the participants experienced intense fear of death and suffering following diagnosis, which prompted some individuals to consider suicide as a potential option. These cases of suicidal ideation and attempts appeared to actually help some participants to temporarily cope with HIV. In time, several participants in their study progressed from suicidal ideation toward a desire to live. Siegal and Meyer highlighted multiple tasks that needed to occur in order for participants to make this transition toward a desire to live, including: (a) finding control in life, (b) developing internal and external coping resources, and (c) redefining life meaning and goals. Suicidal ideation acted as an impetus to facilitate several of these positive tasks. Consistent with Siegel and Meyer's findings, several participants in the present study suggested that their high-risk lifestyles were, in part, an initial attempt to invite death. In time, this high-risk behaviour lifestyle acted as an impetus to make positive changes in their lives. This occurred through several avenues such as (a) becoming dissatisfied with current unhappiness and lifestyle choices and (b) acknowledging the pain associated with HIV and life circumstances. These realizations helped some participants to begin the process of making changes in their lives, including re-connecting with hope. In time, through several avenues (e.g., peer support counselling, professional counselling, family or friends, significant events such as death of a loved one, information on HIV, volunteer work), participants built on their sense of hope. According to participants, this hope helped in the process of changing their lifestyles, including reducing and eliminating high-risk behaviours. Thus, with hope, a sense that a meaningful and productive quality life is possible can become realized, leaving little room or need for a high-risk lifestyle.

Research suggests that professional caregivers have a responsibility to consider hope when working with their clients. Indeed, the present study has highlighted the importance of the role(s) that professional caregivers assume for their HIV-positive clients in facilitating hope. Wong-Wylie (2003) suggested that counsellors working with individuals living with HIV who engage in high-risk behaviours (i.e., unsafe sexual practice, risky drug sharing behaviours), and who refuse to disclose their HIV status to their sexual or drug sharing partners, need to seek ways to maintain the client's level of hope in the face of challenging confidentiality issues. This is because breaking confidentiality is seen as a potential threat to hope due to the likelihood of fracturing the therapeutic alliance with disclosure. Offering an ethical decision making model when faced with HIV and confidentiality issues, she further suggested that maintaining hope can lead clients to make healthier choices (i.e., reduction of high-risk behaviours or informing partners). Thus, maintaining the therapeutic relationship, a potent avenue for the development of hope, becomes an important goal when navigating ethical decisions during clients' periods of high-risk behaviours. Ultimately, this may benefit the HIV-positive individual involved, as well as society in general, to a greater degree than prematurely breaking confidentiality and disclosing the high-risk behaviour information. Maintaining the relationship and developing hope may potentially result in clients' self choices to reduce high-risk behaviours. The present study offers support for Wong-Wylie's contention that hope helps to foster responsible behaviour. According to participants in this study hope helped to facilitate ethical and healthy behaviours following diagnosis. In addition, many of the participants in the present study reported that trusting and supporting therapeutic relationships with caregivers (e.g., counsellors, peer support workers) were important aspects of their overall treatment and fostered hope. A point in keeping with Jevne and Nekolaichuk (2003) who assert that healthcare professionals have an ethical responsibility to sustain and support hope for their patients.

Looking beyond HIV related literature to healthcare research more broadly several researchers have suggested that hope can facilitate behaviours and attitudes aimed at prevention of illness, highlighting hope's influence on healthy lifestyle choices (Barnum, Snyder, Rapoff, Mani, & Thompson, 1998; Floyd & McDermott, 1998; Harney, 1990, as cited by Cheavens et al., 2005; Tennen & Affleck, 1999). For example, Harney reported that people with high levels of hope are more likely to engage in physical exercise than people with lower levels of hope. Further, Floyd and McDermott noted, in their study of gay men, that those with high hope levels were less likely than those with low hope levels to engage in sexual behaviours which could lead to sexually transmitted infections. Participants in the present study suggested that with increased hope they were more likely to reduce high-risk sexual behaviours which could put themselves or others at risk, and they were more likely to make healthier choices overall (e.g., follow medication schedule, reduce alcohol and drug use, increase exercise).

Defining, Communicating, and Characterizing Hope

Participants in the present study initially struggled to find the words to talk about, describe, and define hope. It seems that the word hope, although often used in health care conversations (Eliott, 2005), is complex and difficult to define in the abstract. Interestingly, despite initial difficulty to explicitly define hope, all participants were able to engage in conversations about their experiences of hope. These conversations involving hope varied, with some participants talking about hope through personal stories and with others talking about specific characteristics of hope (e.g., hope being related to family). Larsen, Edey, and LeMay (in press) differentiate between implicit (e.g., subtle aspects of the conversation that imply hope) and explicit (e.g., aspects of the conversation that directly address hope) forms of health care conversations. For example, relationships and caring are often implicit contributors to hope, while direct hope-focused questions are explicit aspects of hope conversations. Given participants' difficulty with initial explicit discussion of hope, researchers and clinicians may be wise to adopt an implicit-explicit perspective on interviewing and counselling, whereby both implicit and explicit forms of hope are employed.

Although multiple definitions and models of hope exist, researchers have not yet created cross disciplinary perspectives on hope or a universal definition (Jevne, 2005).

Many researchers have suggested that people experience hope in unique ways, suggesting that a broad, singular definition may not be a feasible goal for hope researchers (Eliott, 2002; Jevne & Nekolaichuk, 2003). Participants in this study highlighted unique characteristics of hope, and some even suggested that hope was an individual experience. Other researchers have suggested both unique and universal aspects of hope (Morse & Doberneck, 1995). In a comprehensive review of nursing research on hope, Herth (2005) suggests that questions still remain as to hope's composition of unique and universal aspects. Within the present study, participants described hope as both an individual experience and as an entity that shared common elements with other participants. For example, like many hope researchers (e.g., Farran et al., 1995; Herth, 1991; Miller & Powers, 1988), participants suggested that hope was often multidimensional. Participants described various components of what hope was for them. They often highlighted hope as containing (a) relational (e.g., relationships with friends and family), (b) affective (e.g., feeling a sense of hope), (c) cognitive (e.g., thinking about hopeful future outcomes, creating meaning), and (d) behavioural (e.g., adherence to medications, volunteering) characteristics. Some participants also discussed hope as containing (a) temporal (e.g., considering hope in terms of a past, present, and future orientation) and (b) spiritual (e.g., locating hope in spirituality) characteristics. This illustrates the complexity and multidimensionality of the construct "hope" for participants in this study. It also suggests that uni-dimensional definitions of hope may not fully capture the complexity of participants' experiences of hope. Thus, the present study lends support for the unique and shared experiences of hope, as well as the shared multidimensional aspects of the construct.

Some participants suggested that the manner in which hope was communicated was a unique experience. This can be observed through both modality and content. For example, participants shared hope through different modalities such as (a) stories, (b) explicit-implicit aspects of conversations, (c) non-verbally (e.g., body language), (d) actions (e.g., seeking treatment between research interviews), and (e) journaling or drawing. In addition to various modalities, hope was also shared through varying types of content within messages. For example, some participants talked about their specific job while others talked about specific characteristics of their unique daily routines as relevant to hope.

Duggleby and Wright (2005) reported that definitions and focuses of hope will vary between different groups of people. Specifically, palliative care patients will often hope for the "avoidance of suffering, a peaceful death, and life after death" (p. 72), whereas other patient populations may hold hope for improving health and extended life. Thus, the composition of hope may be even more complex, varying between different populations of people. In the present study, participants' experiences with hope seemed to vary at different times in the process of learning to live with HIV. Initially, hope seemed to be greatly impacted by participants' perceptions of (a) the HIV, (b) their chances for survival, and (c) their perceived level of control over their fate. Participants' beliefs about the HIV, their coping mechanisms, and their prognoses impacted the nature of hope adopted by the participants. Thus, for many of the participants, hope was absent following diagnosis. Once participants began to reconnect with hope, the form that hope took seemed to depend on the above-mentioned characteristics (e.g., beliefs about HIV, perceptions of control). These characteristics and beliefs regarding HIV changed over time (i.e., often with connections to support services), which impacted participants' experiences of hope. One of the key aspects of the evolution of hope following diagnosis appeared to be related to the differences in experience between object and transcendent hope.

Object and Transcendent Hope

Two common experiences of hope, as embedded in participant accounts and represented in hope literature, consisted of object and transcendent hope. Hope, for the participants, was often focused on specific objects of hope or goals. As various hope researchers have noted, this aspect of hope most often appears as a verb in participant language, e.g., "I hope that …" (Farran et al., 1995; Eliott, 2005). In the current study, participants illustrated object hope through talking about hope for a longer life and meeting their basic needs. Snyder and colleagues have been prolific in researching this aspect of hope (Eliott). Snyder (1995) defines hope as "the process of thinking about one's goals, along with the motivation to move toward and the ways to achieve those goals" (p. 355). Participants in the present study who actively thought about goals, considered ways to achieve goals, and experienced energy or motivation to move toward goals reported experiencing hope for their future. Importantly, diversifying one's "hope portfolio", with multiple and diverse hope objects and goals, can improve the likelihood of having some of these hopes realized (Snyder) as well as buffer against the disappointment of hopes that do not materialize. Following diagnosis, participants in the present study suggested that few of their previous hope objects or goals appeared to exist in their lives (e.g., hope for long life, hope to have children), leaving them with no readily obtainable hope. As time past, participants began to develop hope objects and goals (e.g., volunteer/employment) which facilitated experiencing hope for their futures. Although hope objects and goals were important for participants in the current study, hope that existed during times when specific goals were unobtainable was also important.

Transcendent hope is not focused on any specific goal or outcome but suggests a general belief that the future can hold good, though the particulars are currently unclear. Jevne (2005) talks about hope that is not singularly directed toward goals or expectations. This hope can exist even when specific goals do not materialize. As she puts it, "It is about not losing sight of the goodness of life, even when it is not visible" (Jevne, p. 267). Further, transcendent hope, as defined by Gabriel Marcel (1967), embraces uncertainty and finitude, celebrating surprise, play, novelty, and mystery, in the moment. This hope includes trusting that hope always remains a possibility and that purpose exists though its manifestation may not immediately be obvious. For Marcel, transcendent hope is often, but not necessarily, connected to a sense of spirituality and religion. Thus, transcendent hope contains a meaning-making component. It suggests that regardless of outcome, something meaningful can become of a situation. "It [hope] is not the conviction that something will turn out well, but the certainty that something makes sense regardless of how it turns out" (Havel, 2004, p. 82). Transcendent experiences of hope offer possibility even in the presence of difficulty, but the outcome is less clear than that of specific goals. Researchers have uncovered aspects of transcendent hope under many health threatening conditions (e.g., Benzein & Saveman, 1998). Davies (1997) suggested that people living with HIV, who adopt a position of "learning to live with the uncertainty of the future" (p. 569), keep their possibilities open and this assists in helping them to live and enjoy the present moment. These people, implicitly or explicitly, found meaning and purpose in their lives, despite the realization that they may not survive long-term (Davies). Smith and Sparkes (2005) highlighted some of the differences between specific and transcendent hope in their qualitative study of 14 men with spinal cord injury. They maintain that hope existed, in part, through the participants' life stories. Participants' experiences of hope were shaped by the narratives that they used to understand their lives. For example, the restitution narrative (i.e., "Yesterday I was able-bodied, today I am disabled, but tomorrow I'll be able-bodied again" p. 1096) shaped concrete hope or hope focused on specific goals while the quest narrative (i.e., "...meet suffering head on; they accept impairment and disability and seek to use it" p. 1099) shaped transcendent hope (Smith & Sparkes). Participant accounts from the current study suggested that transcendent hope developed over time, following their HIV diagnoses.

Several avenues to transcendent hope were described by participants in the present study. One of the most common invitations to transcendent hope in the face of difficulty was the belief that something was to be learned. For some it was the learning of a very important life lesson. For others it was learning that they had the power to help others and to make the world a better place. Another common aspect of the transcendent hope was its embodied quality – its felt experience. Participants spoke of quiet moments such as a special moment shared between a father and son. Such hope is often found to exist through spirituality, religiosity, and familial relationships. In these cases, hope was not about a future goal but about living fully in appreciation for what each moment might have to offer. Third, participants frequently talked about their experiences of helping others (e.g., offering peer counselling to others dealing with HIV) and how this facilitated their own personal sense of hope. Psychiatrist Victor Frankl (1984) offers a poignant example of this aspect of transcendent hope from his own experiences as a prisoner in a Nazi concentration camp. He defined his perceptions of having faith, arguably consistent with hope, as crucial, and often situated in caring and hoping for good things for other people. Thus, transcendent hope is often made possible through the good-will and hopes we hold for others. For many of the participants, helping others also facilitated the development of a strong sense of meaning and purpose. For participants in this research, meaning and purpose and experiencing hope entwined. Previous research has highlighted relationships between hope and meaning (Duggleby & Wright, 2005; Frankl, 1984; Herth, 1989, 2005; Mascaro & Rosen, 2006; Michael & Snyder, 2005). All invitations for transcendent hope, including opportunities to learn, deeply experience a relationship, help others, and construct meaning, helped participants develop a deep sense of hope.

Contemporary multidimensional models of hope support the contention of specific and transcendent forms of hope. Dufault and Martocchio's (1985) model of hope includes two spheres of hope, generalized hope and particularized hope. Generalized hope refers to a general outcome (e.g., my life will change into something positive for me) and particularized hope refers to a "particularly valued outcome, good, or state of being, in other words, a hope object" (Dufault & Martocchio, p. 380) (e.g., through counselling, I will reduce my depression and be happier). The present research is consistent with Dufault and Martocchio's model, as participants described hope as both particularized (e.g., goal) and generalized (e.g., transcendent). Although both types of hope were experienced by participants in the present study, it seems that transcendent hope was able to exist even in the face of illness, whereas particularized hope was more commonly focused on good health outcomes. This has implications for clinicians as obtaining generalized or transcendent hope can be an important therapeutic goal of counselling during times when particularized hope objects maybe more difficult to realize. Hope can still be present even when a specific hope object seems threatened.

Hope can also be considered as a process, at times interconnected with despair. Several researchers have suggested that true hope exists in the face of despair, as would be expected during a diagnosis of HIV (Dufault & Martocchio; Marcel, 1967; Miller 1991, 2000). Thus, according to Miller's model of hope intensities, the hope described by an individual with an HIV diagnosis would likely reach level three, or a level of hope developed through suffering or a state of captivity. Interestingly, many participants in the present study suggested that immediately following their diagnoses of HIV, hope was largely unobtainable. This was often when high-risk behaviours became intensified. This would suggest that although a state of suffering may open the door for hope, it may take time and support before hope can become fully realized for some people. It also highlights that hope is a process that shifts and evolves following diagnosis. Hence, those working with the newly diagnosed HIV patient, experiencing high-risk behaviours, will benefit from remembering that a current state of hope is likely to shift with skilled support.

Hope, Adjustment, and Coping

Research suggests that hope can facilitate coping with health problems, including adjustment to health problems (Farran et al., 1995; Herth, 1989; Irving, Snyder, & Crowson, 1998; Morse & Penrod, 1999; Snyder, 1996, 1998; Wineman, Schwetz, Zeller, & Cyphert, 2003). Stephenson (1991) suggested that hope helps facilitate and maintain health, and it also helps the patient to accept an illness. Duggleby (2000) reported that palliative care patients in her study described hope as a means to cope with their suffering. Some have suggested that hope can be a coping strategy in itself, or it may facilitate the use of other coping strategies (Farran et al.; Korner, 1970). Stanton, Danoff-Burg, & Huggins (2002) focused on hope and coping strategies and how these mechanisms facilitated adjustment in newly diagnosed breast cancer patients. These authors suggested that hope and coping strategies interacted to produce positive results. For example, the authors reported that hopeful women in their study obtained greater benefits, as compared to women with less hope, from utilizing specific coping skills such as social support and positive reinterpretation of experiences. The authors suggested that this effect may be due to the hopeful women's positive outcome expectancies. Indeed, participants in the current research seemed to obtain significant health promoting benefits and coping abilities through hope. Consistent with previous research, hope helped participants to see a future and realize that life could continue. Hope helped these participants to have a reason to make healthy lifestyle choices and want to learn and engage in healthy coping strategies. Other researchers (Farran et al.; Jevne & Nekolaichuk, 2003) have also suggested that hope and coping interact, and that each is highly important in dealing with life stressors and health problems. Participants in the present study suggested that hoping and coping were two related processes that helped them deal with the diagnosis of HIV. Other researchers have suggested that hope can be an antecedent to coping (Weisman, 1979) or an outcome of effective coping (Miller, 1983). Overall, Jevne (2000; 2005) suggests that hope helps people recover from, cope with, and adjust to, many serious life problems.

Research indicates that higher levels of hope are correlated with enhanced coping when people are faced with a serious health problem (e.g., fibromyalgia, spinal cord injuries, arthritis) and people will cope and adjust better than those with lower levels of hope (Cheavens, Michael, & Snyder, 2005; Barnum et al., 1998; Laird, 1992; Tennen & Affleck, 1999). In the present study, participants suggested that as hope became more apparent and obtainable they found it easier to deal with, and adjust to, their HIV diagnosis.

Longitudinal research reveals that higher hope individuals are more likely to use effective coping skills (e.g., finding meaning) as opposed to people with low hope, who are more likely to use avoidant coping skills (e.g., denial) (Chang & DeSimone, 2001; Tennen & Affleck, 1999). Participants in the present study often described utilizing high-risk behaviours, arguably avoidant behaviours (e.g., alcohol or drug abuse), as means to deal with the HIV diagnosis, especially immediately following the diagnosis. Several researchers have noted that coping strategies aimed at avoiding stressors typically result in higher distress levels, and poorer overall adjustment, as compared to strategies which result in active engagement with the stressor (Osowiecki & Compas, 1998; Stanton et al, 2000). However, several researchers have also suggested that initial avoidance (i.e., during and shortly following diagnosis of cancer) as a coping mechanism actually predicted decreased distress (Stanton et al., 2002). This suggests that avoidance can be an adaptive coping mechanism over the short term, but not the long term. Earl et al. (1991) reported different types of denial responses (i.e., secondary denial and denial without benefit) typical of people recently diagnosed with HIV, resulting in the possibility of high-risk behaviours such as unprotected sexual intercourse. Earl et al., as well as Sawer and Crawford (1994), noted some forms of denial can be important coping characteristics in reducing anxiety following the initial diagnosis of HIV. For some participants in the present study, avoidance and denial following the diagnosis helped them to not focus on the diagnosis, death, and the overwhelming fear and despair that accompanied this news. This seemed to help some of the participants survive immediately following diagnosis; however, it was also a time of high-risk behaviours. With hope, participants described being able to engage in more beneficial coping skills (e.g., meaning-making, problem-solving), which led to overall healthier lifestyle choices. Additionally, some research suggests that people with higher levels of hope may be more likely to be connected to larger networks of family and peers, potentially explaining part of the relationship between hope and adjustment (Barnum et al., 1998; Cheavens et al., 2005). Indeed, in the present study, meaningful social connections were apparent for many of the participants during times of (a) hope, (b) positive lifestyle choices, and (c) reductions in high-risk behaviours. The following section explores the connections between relationship(s) and hope.

Relationships and Hope

Several hope theories (e.g., Dufault, & Martocchio, 1985; Farran et al., 1995) suggest that relationships are an essential component in building hope. In addition, researchers have highlighted the importance of facilitating relationship development in working with people with HIV/AIDS, as HIV/AIDS can have the detrimental effect of isolating and stigmatizing people (Getzel, 1991; Kendall, 1994). Specifically, people with HIV who are socially isolated may be at an increased risk for reductions in hope, due to few relationships. According to participants in this research, peer support counselling helped to facilitate the development of relationships between people living with HIV/AIDS. These relationships have the potential to reduce social isolation. Indeed, participants in this study reported that peer support counselling helped them to experience hope, partly through the development of relationships with others living with HIV/AIDS. Thus, forming relationships with peers helped reduce isolation and cultivate hope through meaningful human connections.

Both participants who were peer counsellors and participants who had received peer counselling indicated that they experienced hope as a result of peer counselling. Several participants noted various aspects of the relationships which facilitated hope such as: (a) caring, (b) supporting, (c) connecting, (d) belonging, (e) inspiring, (f) empowering, (g) encouraging, (h) understanding (i.e., deep level of empathy), and (i) authenticity. These relational characteristics helped participants to become grounded in a therapeutic-caring relationship which helped them to (a) regain purpose in their lives, (b) feel cared for and supported, (c) have a sense of a hopeful present or future with potential and possibility, (d) identify options, and (e) hear others' stories of hope.

Aspects of the relationship, such as caring, helped participants to become connected to and feel a sense of trust within the peer counselling relationship. Participants, whether peer counsellors or clients, suggested that they felt cared for and supported within the peer counselling relationship. Thus, the relationship felt genuine and equal, containing little power imbalance between service provider and user. Participants also felt that their peer counsellors had a deep sense of empathy and understanding for their situations, as the peer counsellors had experienced, firsthand, the struggles with which they were dealing. Other counselling researchers have highlighted the importance of relationship variables in fostering hope. Cutcliffe (2004), in his study of bereavement ex-clients and counsellors, highlighted overlap between the conditions necessary for inspiring hope in bereavement counselling and the core therapeutic conditions of counselling put forward by Carl Rogers (1951/1986). Interestingly, Cutcliffe further suggested that inspiration of hope ought to be an additional core condition of counselling. Jevne (2005) has also highlighted the importance of Roger's core therapeutic conditions in fostering hope. Rogers, the founder of person-centered therapy, identified what he believed were the three main components of counselling: (a) empathy, (b) congruence, and (c) unconditional positive regard. He believed these core conditions facilitated the development of a therapeutic relationship and led to client change. The present study lends support to Roger's core conditions as therapeutic agents, and also suggests that peer counsellors, in this study, utilized aspects of these core conditions to facilitate hope in their clients.

Koopmeiners et al.'s (1997) study on the impact that healthcare professionals had on hope among people with cancer found that the healthcare professionals' routine caring activities had the power to positively impact their patients' hope. Wong-Wylie and Jevne (1997) also illustrated the power of relationships on fostering hope in their study of physician-patient interactions. Further, Cutcliffe (1996) suggested that nurses often inspire hope in their patients through their (a) demeanor, (b) character, and (c) caring. Participants in the present study suggested that relationships fostered hope not only through peer counselling, but within relationships with other health professionals as well (e.g., psychologists, professional counsellors, physicians). The relational characteristics (e.g., empathy, understanding) that facilitated hope with peer counsellors were often described by participants as operating in relationships with health care professionals as well.

Duggleby and Wright (2005) noted that supportive relationships were one of several avenues which facilitated the transformation of hope for participants in their study of how palliative patients live with hope. Transforming hope involved making a "conscious decision to change or transform their [palliative care patients'] hope" (p. 76) so they could have new forms of hope in their lives. With the transformation of hope came new patterns of hope (e.g., focusing on family) as opposed to older patterns of hope (e.g., finding a cure, living longer) (Duggleby & Wright). Participants in the present research suggested that relationships were important aspects of facilitating the hoping process, and, like Duggleby and Wrights' findings, included changes in the form of hope (e.g., focus on family relationships as opposed to a cure) experienced by participants.

Meaning, Purpose, and Hope

Researchers have suggested that peoples' abilities to make meaning (e.g., discover or create a rationale that is significantly meaningful for them) out of experiences in their lives (e.g., losing a partner to AIDS) may be beneficial in preventing negative expectations and acting as a buffer against deteriorating health in HIV-positive individuals (Bower, Kemeny, Taylor, & Fahey, 1998; Kylma et al., 2001; Taylor, Kemeny, Bower, Gruenewald, & Reed, 2000). This illustrates the importance of meaning-making in dealing with the HIV diagnosis. As discussed below, the development of hope is another potential benefit that can occur from creating meaning.

Meaning and hope were related for participants in the current study. Developing meaning helped participants to experience hope and maintaining hope helped participants to develop meaning in their lives. Conversely, if participants lost a sense of meaning and purpose in life, this was a threat to their hope. Relationships between hope and meaning have been identified within hope literature (e.g., Frankl, 1962; Herth, 1989, 2005; Marcel, 1978). For example, Duggleby and Wright (2005) reported that searching for meaning helped palliative care participants in their study to transform hope (i.e., developing new patterns of hope). For participants in their study, searching for meaning consisted of several activities such as finding value within their lives and leaving something of value following their death (e.g., contributions from work). Purpose and meaning were found in many different ways in the present research. Participants found meaning and purpose in life by contributing to something beyond themselves such as (a) peer counselling, (b) HIV prevention campaigns, or (c) public speaking about their experiences. Some even suggested that through being involved in the research interviews for this study, they were fulfilling their purpose, which was to fight against the virus. Several acknowledged that this purpose helped them to have a sense of hope in their lives. Similar to Duggleby and Wright's findings, many of the meaning-making exercises employed by participants in the present study contributed to the participants finding value in their own lives and offered the opportunity for them to leave something of value following their eventual deaths.

Several participants in the present study talked about the benefit of finding purpose and meaning in their lives as a result of being a peer counsellor. Peer counselling helped participants to rediscover or develop meaning in their lives through the pursuit of helping others. Jevne (2005) noted that hope can be developed through declaring and committing to a mission. This mission, rich in purpose, involves the work in which one chooses to engage and contains the potential to positively impact or change the world. This is consistent with peer counsellors' experiences of purpose and hope in the present study. Additionally, peer counselling has the added benefit of facilitating meaning-making for the receivers of the service as well. Clients are given the opportunity to talk with experienced peer counsellors and are able to see what may be possible for them as newly diagnosed individuals (e.g., helping others deal with the diagnosis, becoming involved in prevention services, and surviving a long time with HIV). Eliott (2005) noted that there is "power attributed to hope" (p. 38) which can change peoples' lives. She goes on to suggest that part of this power may exist through the "imparting of meaning or purpose to human existence" (Eliott, p. 38), illustrating the meaning-making aspects of hope. Again, meaning and hope can be constructed through relationship and open discussion between peers.

With a meaning to life and a meaning ascribed as to why HIV was contracted, participants were able to have hope for themselves and for others. Although previous research has highlighted relationships between hope and meaning (e.g., Herth, 1989, 2005; Mascaro & Rosen, 2006; Michael & Snyder, 2005), as well as relationships between living with HIV/AIDS and the importance of developing meaning and hope (e.g., Plattner & Meiring, 2006), the relationship(s) between meaning-making, hope, and high-risk behaviours have not been explored within the context of receiving an HIV diagnosis. Further research into the role that meaning-making plays in developing hope following an HIV diagnosis and its impacts on the likelihood of engaging in high-risk behaviours could have important implications for effective prevention and intervention with this population. According to participants in the present study, finding meaning within the HIV diagnosis itself and finding meaning for their lives following the diagnosis were important in experiencing hope and reducing their high-risk behaviours. Finding meaning also helped several to deal with the diagnosis itself. Importantly, this process of finding hope in meaning-making seems to be a gradual process that takes place over time. Thus, this provides support for the contention that hope, through the pursuit of meaning, is a process that evolves over time.

Inspiration and Hope

Participants in this study described a connection between inspiration and hope. For participants, inspiration was finding the drive and energy to do things that they cared about and were interested in doing along with a focus on creative thinking in relation to the above mentioned activities. Miller (1991) has noted that energy is a necessary component within the hoping process, as it partly facilitates the hoping process. Thus, inspiration appears to be an important component of the hoping process. Indeed, inspiration may be one aspect of hoping itself. Unfortunately, little research exists exploring the relationship between hope and inspiration, especially in relation to receiving an HIV diagnosis and dealing with high-risk behaviours. In the current research, inspiration and engagement in life activities were held against the existential backdrop of not being and death for the participants. The reality of death and the knowledge of the fragility of life strikes especially poignantly when individuals are faced with a terminal illness. The individual living with HIV, through stark awareness of his or her own mortality, may experience a renewed appreciation of the importance of enjoying and appreciating life while it is still possible. Paradoxically, it is the undeniable threat of "not being" that may ultimately offer a profoundly strong invitation to hope. With hope comes both the energy and inspiration to engage in life fully and appreciatively – all lived against the real understanding that life is a time-limited gift. Hence, health care professionals and peer support counsellors may be able to play a key role in this process, through helping clients remember and reconnect with those aspects of life that bring inspiration and engagement with life.

Inspiring and Facilitating Hope

Research has suggested several interventions or methods for fostering and inspiring hope, such as: (a) developing meaning, (b) finding relationships, (c) living in the present, (d) developing and utilizing inner strength and a determined mental attitude, and (e) developing spiritual beliefs (Herth, 1990, 1995; Miller, 1989; Post-White, Ceronsky, & Kreitzer, 1996). Participants in this study highlighted various experiences that inspired hope in their lives. Many of these areas have been reported within the research literature as inspiring hope in different populations of people (e.g., terminally ill, youth, elderly). Thus, the present study lends support for the use of specific hope fostering strategies among newly diagnosed individuals dealing with the high-risk period. What follows is a discussion of hope inspiration strategies as experienced by participants in the current study.

Participants in the present research highlighted the importance of relational variables (e.g., personal connections, empathy) in fostering hope. Cutcliffe (1995) developed a model of hope inspiration based, in part, on his research with patients terminally ill with HIV. This theory contained multiple core variables, several of which contained a focus on relationship development. Further, Benzein and Saveman (1998) explored the perspective of hope with cancer patients and found that participants in their study perceived several variables as contributing to their hope: (a) having inner strength and energy, (b) receiving family support, (c) perceiving confidence in treatment, and (d) experiencing significant events. Similar to Benzin's and Saveman's findings, participants in the present study suggested inspiration was an important aspect of hope, which included having an energizing component. In addition, having family support and experiencing significant life events (e.g., death of a family member) also helped participants in the current research to turn their lives around and experience hope. Using humour has been shown to foster hope in adolescents dealing with health problems (Hinds, Martin, & Vogel, 1987). Indeed, humour was also an important experience in facilitating hope for several participants in the present study. Although several hope fostering strategies have been noted within the present study, researchers have suggested that research needs to shift further toward developing hope focused interventions (Jevne, 2005). This is especially important within the area of hope focused intervention studies (e.g., clinical control studies); as few studies have been conducted (Herth, 2000, 2001; Rustoen & Hanestad, 1998) to explore hope-fostering interventions.

Peer Counselling and Inspiring Hope

Hope scholar, Jevne (1993), suggests that mental health professionals can play an important role in inspiring hope among people living with HIV. This was also suggested by participants in the present study. Unfortunately, despite the demonstrated effectiveness of peer counselling (Downing et al., 1999; Hughes-d'Aeth, 2002; Madray & van Hulst, 2000; Molassiotis et al., 2002), previous research has not explored the role of peer counsellors in inspiring hope among newly HIV-diagnosed individuals. In the current study, peer support counsellors played an important role in inspiring hope for their clients. Peer counsellors accomplished this in several important ways: (a) building relationships and helping clients to express emotion, (b) acting as hope mentors and providing information, and (c) sharing their own personal stories of living with HIV.

Peer counsellor participants in the present study suggested that being (a) genuine, (b) supporting, (c) caring, and (d) empathizing helped them to inspire hope in newly diagnosed individuals. Thus, findings of this study suggest that peer counsellors, working with people living with HIV, can inspire hope by establishing meaningful relationships, which can help reduce feelings of isolation and loneliness. Participants noted that peer counsellors listened to them talk about their feelings, helping them to express themselves and facilitate a connection with mental health professionals. Cutcliffe (2004) noted that the inspiration of hope, in bereavement counselling, involves a cathartic release of emotion, following the development of a therapeutic relationship. Peer counsellors, in the present study, were often involved in the facilitation of this emotional expression through listening to their clients and by connecting their clients with mental health professionals.

Peer counsellors acted as mentors and helped participants to see what was possible and what was obtainable. Jevne (1993) suggested that hope can be enhanced through finding hope models. “Everyone has a real person, a storybook character or a television personality, who can act as a hope model…By aspiring to the hope model, patients may take on its attributes…” (Jevne, p. 128). Several researchers (Kirkpatrick, Landeen, Byrne, Woodside, Pawlick, & Bernardo, 1995), exploring hope in a psychiatric patient population, noted that hope, among this population, developed through access to role models and educational programs. Participants in the present study highlighted the development of hope through peer counsellors, who often acted as role models, and who provided information to their clients. Peer counsellors are in a unique position to act as role models due to their life experiences, credibility, and triumphs over the HIV.

Peer counsellors also inspired hope by sharing their own personal stories, and, especially by disclosing experiences of their survival though hopeless and challenging times in their lives. Eliott (2005) noted that, based on review of hope literature to date, hope is an ingrained component of the stories we share with others about ourselves. If sharing stories is a central component of hope, and the ability to inspire hope in others, then peer counsellors have an important and unique opportunity to foster hope in their clients. One of the central interventions that peer counsellors utilize with their clients is the sharing of story, stories of their personal experiences, triumphs and hardships, with HIV. Indeed, participants in the present study suggested that hope was fostered through the sharing of story.

As seen, peer counselling is an important aspect of facilitating hope among people diagnosed with HIV. If the newly diagnosed individual is willing to see a peer counsellor, this research appears to suggest that this access should occur quite quickly following diagnosis. Peer counsellors may even be usefully involved in the pre-delivery and delivery of the diagnosis. Peer counsellors may be helpful for newly diagnosed individuals by modeling that a good life can continue after the diagnosis of HIV, which can potentially be instrumental in facilitating hope and reducing high-risk behaviours. Peer counsellors, with their training in lay-counselling and their personal experiences of living with HIV/AIDS, are in a unique position to be able to help newly diagnosed individuals experience hope.

In engaging in this research, I have found myself wondering about peer counsellors' roles in hope inspiration: "Who better to inspire hope than someone who has walked the treacherous path of the virus; who has seen its effects firsthand and realized that life can go on, that hope can exist despite no cure?". As health professionals I believe that we can lose sight of hope, not having lived in the shoes of our patients. Hope is central to the human condition, and if it is lost, then all may be lost. Vaillot (1970) reminds health care providers that if we fail to inspire hope in our patients then we have not lived up to our duty to care. Inspiring hope among people living with HIV can require a human connection often best provided by another who is also living with the virus.

Hope and Story

Defining hope proved to be quite challenging for the participants in this research. However, recent hope scholarship reinforces that hope is often transmitted and shared through life story. Stories of hope are now common in the literature (e.g., Bardi, 2005; Elledge, 2003; Lake, 2003; Larner, 2004) and focus on specific life stories which represent hope in the context of specific life experiences. Indeed, Snyder (1994) has reported that hope partially develops through the creation of internal stories (i.e., from Snyder's perspective, stories focused on goal-directive behaviours), suggesting story is an integral aspect of hope. Further, Smith and Sparkes (2005) reported in their qualitative study of 14 men with spinal cord injury that hope existed, in part, through the participants' life stories. In the present study, hope stories were often shared as a means of inspiring hope in others. Hope was also found through sharing stories of living with HIV and in breaking the isolation that so often accompanies the diagnosis. What follows is a discussion of how, according to participants, story inspired hope in both the story teller and the listener.

Telling stories of hope seemed to involve a recursive loop that fostered hope in both the listener as well as the teller. Participants who shared their hope stories not only gave others hope, but they also seemed to experience hope as a result of telling their story and being heard. Participants who shared their stories also seemed to inadvertently encourage others to share their stories. After listening to another's hope story, participants suggested that they were often more likely to share their own story, specifically framed through the lens of hope. This may be an important consideration for group therapy and other group modalities. It suggests that sharing hope stories may have several benefits, including facilitating others to frame their experiences as hopeful and share this with others.

Participants appeared to experience hope in several ways when sharing their stories. First, several participants, including some who were peer counsellors, reported that by sharing stories they were able to help others, especially newly diagnosed individuals. Sharing stories helped listeners, who were newly diagnosed, obtain information about HIV and other important issues as well as to learn that life can continue with HIV. Thus, obtaining information and recognizing that both quality and quantity of life were possible helped listeners to experience hope.

Second, since participants often believed that helping others was a main purpose in their lives, and sharing stories helped participants to help others, story sharing may have facilitated participants' sense of purpose, which also seemed to enhance hope. This was observed in several different contexts. For example, participants shared hope by offering their stories (a) at HIV community-based agencies with clients and staff, (b) during peer counselling sessions with newly diagnosed individuals, and (c) during presentations to the public on HIV prevention. In sharing their stories, participants sought to inform and enhance the lives of others who face HIV. Hope was also experienced in other contexts through story, such as during the research interviews in this study. Specifically, participants talked about how sharing their stories during the research interviews helped them to contribute to their purpose (e.g., informing others about HIV) and offered an experience of hope.

Finally, participants also seemed to experience hope through sharing their stories as a means of connecting with another person, being heard, and being known. This illustrates a connection between hope and relationship, with the hope story potentially fostering relationship.

Several implications from this research are suggested. Specifically, services offered to people diagnosed with HIV should contain an opportunity for people (e.g., peer counsellors) to share with clients their experiences of living with HIV in relation to hope. This can be hopeful for newly diagnosed individuals, but also for the service providers or peer counsellors. It is also important for service providers to recognize clients' stories as containing hope. In this way, service providers can be in a better position to recognize the presence of hope in clients' stories and support this hope in their clients. For example, service providers can ask clients to share stories and then listen for messages of hope embedded in the storylines of everyday living.

The present results also have implications for hope researchers as well. Hope researchers can ask participants to share stories, and then look for hope embedded in this story context. Indeed, some hope researchers (e.g., Smith & Sparkes, 2005) have focused on narratives that constitute “hope” stories. Telling life stories appears to be a relatively simple way for participants to discuss hope. Hence, encouraging stories of hope can facilitate hope discussions as hope can be a difficult construct for participants to discuss in the abstract. Given the apparent importance of story in understanding hope these findings suggest the importance of research methodologies in hope related research that encompass a narrative focus which may offer especially valuable avenues for the study of hope. Indeed, given the importance of story for the open discussion of hope for the participants in this study it is possible that with another methodology, by not allowing for the sharing of stories, some key information on hope may have been missed by the researcher.

Hope, Survivability, and Support

For participants, hope was often connected to the belief that a longer or better life was possible, illustrating particularized hope. Participants grasped this belief in several different ways. Some talked about the “living quilt”, containing concrete stories of others’ survival, as being a reminder that many people survive with HIV for long periods of time. Others talked about meeting people with HIV and hearing their stories of long and healthy living with the virus.

Importantly, participants were more interested in hearing stories of “possibility” rather than “probability”. Hope lived within the realm of possibility for many of the participants. Thus, statistical odds, probability of survival, and being told that a good outcome was “unlikely” all had detrimental effects on hope, whereas hearing stories of what was possible helped fuel hope. Other researchers and scholars have also noted the importance of stories of possibility when dealing with difficult news. In a review of hope and health literature, Hafen et al. (1996) draw the conclusion that the possibility of good things, including good health, must not be denied for patients with serious illness. Suggesting that the medical profession must be humble about its ability to estimate life span based on prognosis, they review literature highlighting factors, such as hope, that have shown power to beneficially impact physical health. The authors close their review concluding that it is unwise to deny the "fact" of a serious diagnosis but that the implications of a serious diagnosis (i.e., such as HIV) are ambiguous, leaving room for plenty of hope and hope-filled action on the part of the patient. They further suggest that patients benefit most from accepting legitimate diagnoses while being cautious of accepting, with absolute certainty, the negative implications of a diagnosis (e.g., specific life expectancies) (Hafen et al.).

Hope, Perceiving Options, and Learning

Learning about HIV was important in becoming empowered to fight against the virus and in experiencing hope for participants. Many participants knew little about HIV when they were diagnosed. Several held stereotypes and misconceptions which caused them agony and despair. In a study of women not living with a terminal illness, those with high levels of hope, as compared to those with low levels of hope, were more informed about healthy lifestyle choices regarding cancer prevention and were more likely to utilize this knowledge to help themselves avoid cancer (Irving et al., 1998). Westburg and Guindon (2004) reported that psychoeducation is an important intervention for people living with HIV/AIDS and can help people living with HIV to become accurately informed regarding their options. In the current study, participants with accurate knowledge began to see hope for their futures and to experience a sense of empowerment and control over their lives. Similar to Irving et al.'s findings, information and hope were related. Through accurate information, participants in the current study were able to realize that HIV was not a death sentence and that life could continue, that they could be healthy and maintain quality of life, and that there were ways they could fight back against HIV. Thus, while little research has been done on the potential beneficial effects that accurate health knowledge may have on patient hope, the current research findings suggest that patient education can have a very beneficial impact on hope. Seemingly, accurate information delivered in a timely fashion in therapy can open windows of possibility that had been unrealized by patients. This is consistent with research on cancer (Hagerty et al., 2005; Salander, Bergenheim, Bergstrom, & Henriksson, 1998), which illustrates the importance of conveying accurate and relatively prompt diagnostic information to patients.

Diagnosis Delivery and Hope

Specific to providing information, the manner in which the HIV diagnosis is delivered can have major implications for the patient's well being and sense of hope. Research has illustrated the importance of conveying accurate and relatively prompt diagnostic information to the patient dealing with a cancer diagnosis (Hagerty et al., 2005; Salander et al., 1998), and this suggestion seems to pertain to patients receiving diagnoses of HIV/AIDS as well. Several participants in the current study believed they were going to die after the diagnosis. They did not understand HIV/AIDS, and had been given predictions of how much life they had left (e.g., two years was a common prediction). The current research suggests that the diagnosis needs to be given in a way that maintains hope, as hope appears to be an important component of learning to live with HIV and reducing high risk behaviours. Indeed, this suggestion is in keeping with a developing body of research on how to deliver medical information with hope (Hagerty et al.; Wong-Wylie & Jevne, 1997).

Perceiving Control

Several participants in the present study noted that following an HIV diagnosis they experienced a loss of perceived control in their lives, making it difficult to cope with the diagnosis and reduce high-risk behaviours. Some researchers have suggested that continuation of high-risk behaviours, following an HIV diagnosis, may be related to feelings of losing control (Joseph et al., 1990; Ostrow et al., 1993). Importantly, some participants seemed to maintain control through high-risk behaviours (e.g., suicidal ideation) immediately following the diagnosis. Several participants noted that effective coping ability and a sense of hope were largely absent during this time period.

Researchers have suggested that control and hope are intimately connected. For instance, Farran et al. (1995) noted that one aspect of maintaining hope is having perceived control in one's life. Similarly, Miller (1989) suggested that having a sense of control can inspire hope. This would seem to suggest that fostering a sense of control is an important aspect of facilitating hope and adjustment following an HIV diagnosis. However, the relationship between control and hope is complex. Frankl (1984), through his survival as a prisoner in Nazi concentration camps, has demonstrated the possibility that hope can be maintained with little or no overt control in one's life. Thus, perception of control, and maintaining control over what is possible to control (e.g., thoughts), may be more important in facilitating hope then actually having control in all aspects of one's life. Perceived control was an important aspect of hope for participants in the present study. As participants began to perceive control in their lives they often reconnected with hope. This helped them to find increasingly productive and healthy ways to survive with HIV, as opposed to a reliance on high-risk behaviours.

Hope, Treatments, and Life Style/Life Quality

Adherence to medications is considered highly important in HIV treatment. Participants in the present study suggested that following diagnosis, one type of unhealthy behaviour was refusal of medical treatment, including following an HIV medication schedule. Some researchers have suggested that having hope is related to adherence to medical interventions (e.g., children and adolescents' use of inhaler medications to deal with asthma) (Moon, Snyder, & Rapoff, 2001; Seaton & Snyder, 2001, as cited in Cheavens et al., 2005). Westburg and Guindon (2004) conducted a study of 94 healthcare providers and found that these participants named imparting hope during counselling as the most important intervention for increasing the likelihood of the patient's adherence to treatment. In the present study, participants reported that hope helped to improve their adherence to medications, suggesting that healthcare workers provide an important intervention in terms of fostering patient hope. Having a hopeful attitude often encompasses a desire to survive, and a belief that survivability is possible. Participants who had hope for their futures believed that they could survive and had things in their lives that helped them want to survive (e.g., volunteer work, family). Thus, these participants were willing to follow medication schedules.

Another issue related to medications is when people do become resistant to available medication options. Importantly, participants in this study, who were running out of medication options, were able to locate hope elsewhere (e.g., family, religion), suggesting the potential for transcendent hope to emerge in the face of major threats to specific hope outcomes. This finding offers potentially important clinical implications – Hope is possible in one way or another. Thus, even in the face of medication resistance exist opportunities for hope to emerge. This is consistent with other research which suggests hope is possible even in the extreme of facing death (Hagerty et al., 2005; Jevne, 1993).

Positive Outcomes as a Result of HIV

Most participants felt that through contracting and living with HIV, they had experienced some positive outcomes. In addition, finding the positives in HIV helped some participants to actively cope with difficult experiences in their lives. Several participants noted that one positive outcome of living with HIV was that they were able to find purpose in their lives. This purpose came in several forums, such as fighting against HIV through helping others deal with the virus and through public speaking in order to facilitate HIV prevention campaigns. Consistent with the findings of the current research, Harris and Alderson (2006) and Schwartzberg (1994) have suggested that living with HIV can lead to positive experiences such as the development of purpose and meaning, for gay men living with HIV/AIDS. Another example of a positive outcome reported by participants was that they found ways to reduce their high-risk lifestyles. Many of the participants were engaging in high-risk behaviours prior to HIV. Several participants suggested that without the diagnosis they would still be engaging in high-risk behaviours and would not be taking care of their physical and mental health. Thus, in an important way, HIV ultimately helped some to become healthier and transform their lives. HIV fostered these changes, as a healthy lifestyle is a highly important aspect of building a healthy immune system and surviving with HIV. Participants also seemed to adopt a healthier lifestyle due to changes in their perspectives and feelings toward life. Prior to HIV, many of the participants reported threats and challenges toward hope and meaning in their lives. With HIV, participants were eventually able to develop new meaning in life and connect with a stronger, more enduring, sense of hope. Several participants felt that without HIV they would not have developed this meaning and hope in their lives. Thus, HIV was the impetus, for the meaning and hope, which actually helped participants adopt a healthier lifestyle.

Some participants also commented in terms of HIV being a gift, which gave them new perspective on their lives. This new perspective helped them to treasure the life they had left to live and what was really important in life such as family. It seems that for many of the participants, an HIV diagnosis transformed their identities. Over time, many of these participants adopted different perspectives, goals, roles, and hopes that often seemed more meaningful to them. Some authors have suggested that HIV, cancer, and other traumatic experiences can result in the opportunity for change and growth in perspectives (Fosse, 2005; Harris & Alderson, 2006; Jacobsen, 2006; Schwartzberg, 1994).

Threats to Hope

HIV, along with other serious illnesses, can significantly threaten hope (Ingram & Hutchinson, 1999; Jevne & Nekolaichuk, 2003). Participants in the present study highlighted several threats to their hope following the diagnosis of HIV. For example, participants felt that isolation threatened their sense of hope. Getzel (1991) and Kendall

(1994) have reported that HIV can lead to isolation for people living with HIV/AIDS. In addition, researchers (e.g., Herth, 2005) have noted that isolation and loneliness can challenge hope, while relationships have been found to foster hope (Farran et al., 1995).

Another threat to participants' hope following diagnosis was that of stigmatization. Fearing stigmatization, participants often became isolated as a means of avoiding others' scorn. Cadwell (1994) reported that people with HIV are at an increased risk to experience stigmatization and this stigmatization can significantly threaten their sense of well being. Stigmatization can result in the destruction of trust that the HIV-positive individual has for society. Trust is an integral aspect of hope (Farran et al., 1995), and the demise of trust can result in threats to hope. Trust helps maintain a perception of safety and can facilitate the development of a relationship. These are critical aspects of the development of hope. Alternatively, a lack of trust can result in perceived threats and the failure to develop a relationship, potentially threatening hope (Ozag, 2006; Talley & Knight, 2005).

Fear has been postulated by some as the opposite of hope and hope as a key antidote of fear (Hafen et al., 1996; Jevne, 1993; 2005). Similarly, some authors have suggested that despair exists on a continuum with hopelessness and that hope is not possible without despair (Eriksson, 1994). Many of the participants' threats to hope (e.g., stigmatization, isolation, death) often contained an underlying aspect of fear and despair. For many of the participants, fear and despair were significant threats to hope. Although fear and despair were often part of many of the participants' threats to hope (e.g., stigmatization, death), fear and despair also existed during times of hope. Thus, fear and despair threatened hope, but also helped set the stage for the appearance of hope. Some authors have suggested that true hope exists in the face of fear and despair, when threats to hope are very real and apparent (Elliot & Oliver, 2002; Farran et al., 1995). Hope is often understood against a backdrop of fear or despair. It is in the face of fear or despair that we either understand the life sustaining value of the hope we hold or we understand the desperate need for hope so that we can go on. For participants in the present study, immediately following the diagnosis was a time of fear and despair, plagued with high-risk behaviours. In time, hope was regained or discovered, but with full awareness of the fear and despair that accompanied the diagnosis. It appears that the fear and despair actually helped alert participants to the need to make changes in their lives.

Hope and Current Day Experiences with HIV

Some participants suggested that there is more to be hopeful for today when diagnosed with HIV than there was in years past. For example, some suggested advancements in medications, increased knowledge of HIV, and more acceptance of HIV are all reasons to have hope for the future. This was different from when several of the participants in this study were diagnosed, at a time when (a) medications were less effective, (b) knowledge of HIV was scarce, and (c) stigmatization of people with HIV was the norm. However, most participants suggested that even today, when people get diagnosed, they still hear, and become fixated on those three letters, H-I-V. Participants suggested that the newly diagnosed still become fixated on death and dying from the virus. Receiving an HIV diagnosis elicits fear, despite medication and medical advancements. Hope becomes significantly threatened. Participants felt that it is difficult to comprehend and assimilate the medical advances as the fear and confusion surrounding the diagnosis are often so intense. Thus, there is still a serious threat or challenge to peoples' hope following diagnosis, despite (a) treatment developments, (b) increased information, and (c) less stigmatization. This speaks to the importance of actively fostering hope, during, and following, the diagnosis process. Health care professionals need to be aware that newly diagnosed HIV-positive individuals may have not internalized these hope promoting messages illustrating that a long, full life is possible. In addition, given the significant changes in lifestyle and identity that accompany a diagnosis of HIV, peoples' sense of self and lifestyle choices must undergo significant transitions, which can also threaten peoples' perceptions of their futures. Research has illustrated that with HIV comes the need for major changes in lifestyle and also significant changes to one's sense of self (Gore-Felton et al., 2005). Thus, despite advances in medical and psychological treatments, HIV is still a significant threat to hope.

False Hope and False Despair

This section explores the constructs false hope and false despair in relation to the results of the present research. Most participants in the present study suggested that following diagnosis, hope was gone, hidden, or unobtainable. Several felt that they were left to deny the severity of their problems, at a time in life when they were already tempted by high-risk behaviours (e.g., alcohol and drug abuse). This relationship between denial and high-risk behaviours, following diagnosis, was complicated for several of the participants. Although, for some, denial of the diagnosis was destructive, for others it actually facilitated a sense of relief. Some even referred to this denial as "phony hope", or hope that was not real. At first glance, this appears to be similar with what some researchers have labeled false hope; "hope" that exists through pathological and complete denial of the problem (Hafen et al., 1996; Reff et al, 2005). False hope suggests that if one is completely denying the existence of the problem then there is no room or need for hope, as the individual has not acknowledged a problem exists (Hafen et al.).

Although participants in this study used the terms “phony hope” and “denial”, most acknowledged that the reality of HIV was looming in their lives. Accordingly, HIV would come in and out of awareness, potentially illustrating the complex processes of accepting or integrating an HIV diagnosis into life as well as the process of how hope becomes refined and changed over time. Participants would use denial and high-risk behaviours (e.g., substance abuse) as a means to cope with the diagnosis. Participants in this study seemed to have some awareness of the diagnosis, and even had some early hopes in relation to the diagnosis (e.g., wanted to die a quick, painless death). Given participants’ early hopes regarding a painless death and secrecy regarding the HIV, it seems that participants were not engaging in pathological denial as they indicate that they were aware of the severity of their situations. Indeed, with “false hope”, participants would have had little reason to utilize coping strategies, would have had no specific hopes regarding the diagnosis per se, and would have not experienced such awareness of the diagnosis and its severity. Thus, my interpretation of the participants’ accounts is that they were experiencing denial as a coping mechanism; however, they were still aware, at some level, of the diagnosis and its severity. This propelled the additional coping strategies of increased high-risk behaviours and led to specific early hopes in relation to the diagnosis. This research suggests that for participants in this study, “false hope” is not an accurate description of participants’ experiences following diagnosis. Although participants experienced moments of denial, the HIV seemed to be firmly rooted in their awareness, which necessitated attempts at coping and finding hope outcomes through avenues such as secrecy and a painless death.

In comparison to false hope, Jevne (2005) has highlighted the notion of false despair. False despair occurs when one is completely focused on probability rather than focused on any kind of possibility; indeed, false despair often precludes any possibility of a desired or good outcome. Thus, the individual refuses to consider any possibility beyond whatever probability of survival or health has been given to him or her. People struggling with false despair can completely shut down in hopelessness. False despair has particular relevance within the history of HIV/AIDS. Prior to the advent of antiretroviral medications, the life expectancy of someone with HIV was very short. Many people diagnosed would be given predicted quantities of time left to live. Indeed, several of the participants in the current study had been told to expect a relatively quick progression toward death following their diagnoses. Some were given a "two-year death sentence", which they accepted and believed. Several of these participants talked about thinking life was over and that they were going to die a painful death following diagnosis. Thus, false despair ruled their lives for a long time. In fact, for some, it was not until after they survived past these death predictions that they began to challenge the false despair and regain a sense of hope. This can be an important consideration for health care professionals. Specifically, although probability is often based on science and research, possibility is inherent within the human condition. Throughout history, human beings have continuously lived beyond or outside of standard knowledge accessible through science and research and, reaching well beyond what was perceived as possible in years past. Thus, possibility should always be an option, even if it seems unlikely at the time.

Simpson (2004), in her work on hope and vulnerability, has highlighted the importance of maintaining a focus on imagination and possibility, despite what is probable, when working with people struggling with serious health problems. Participants in the current research demonstrated that possibility for a longer quality life was a true option for them, despite research and science's probabilities.

Health professionals' behaviours and interactions with their patients can potentially influence their patients' hope (Jevne, 2005). If health care professionals give up hope and attempt to challenge or over-ride the hopes of the patient, perhaps even calling it false hope, this will potentially impact the patient's hope. This may even have the potential to destroy so called vulnerable sense of hope and fuel perceptions of false despairs. Participants in the present study suggested that health professionals should not challenge patients' hope, whether that hope is shared by the professional care provider or not. Keen (1994) noted that there is a "living hope" which develops and exists between the caregiver and the patient. This hope is part of the relationship established between the patient and the professional. When a patient's hope is not respected, the relationship has the potential to falter and destroy the possibility for a "living hope" shared in the context of a caring relationship.

Jevne (2005) suggests that researchers and clinicians need to examine their own assumptions regarding false hope and false despair in order to avoid the devastating consequences of transmitting these perspectives to others. She is critical of these constructs and offers a new perspective on how these constructs can be conceptualized. According to Jevne, "contested hope" allows for more recognition of what may be possible in difficult situations. Contested hope recognizes that situations can change and that things do sometimes work out better than may have been expected. Thus, the patient's hope need not be considered as false simply because it is disputed by a caregiver (Jevne). Oliver (2005) suggests that the individual can have a subjective sense of hope, which does not need to be maintained by "objective" hope given by the doctor regarding probability. For example, someone given a terminal diagnosis and a specific period of life left to live (e.g., two years) may hold hope for a change in health which would prolong life. In some situations (e.g., a diagnosis of HIV prior to antiretroviral therapies) this type of hope for prolonged life may have been challenged by people in the patient's life. The same could be true for people living with HIV today, who may be holding onto hope for a cure or for a medication to turn HIV into a chronic disease. Contested hope would allow for the patient to hold onto hope for prolonged life, or a cure, despite a lack of objective probabilities for this hoped-for-outcome given by medical professionals.

Health Care Services

"Hope is a crucial therapeutic factor helping us co-habit with uncertainty" (Jevne, 2005, p. 268) and deal with health related issues such as HIV. Participants talked about health care services and how these services contributed to their hope for a better life. Peer support counselling and individual counselling with professional counsellors, as well as other types of services (e.g., harm reduction programs such as methadone maintenance and needle exchange), all helped participants to have hope for an uncertain future. This occurred in several different ways such as: (a) hearing others' stories, (b) seeing others survive, (c) obtaining insight and assistance into their situations, (d) being given skills and resources to cease their high-risk lifestyles and fight against HIV, and (e) being sent hopeful messages such as, "I believe you can survive" from counsellors, peer counsellors, and other health care professionals. This demonstrates the importance of helping to empower individuals with HIV and AIDS to deal with the virus and their personal situations. It also highlights the need for professional psychosocial support availability following a diagnosis of HIV.

Participants highlighted several characteristics of effective professional counsellors. Several of these characteristics were consistent with a counsellor caring orientation such as having good listening skills and helping clients to feel accepted and non-judged, while others fit more with a counsellor facilitator or expert orientation such as facilitating empowerment and providing information or teaching skills. Counsellors working with an HIV population require an ability to be flexible and caring, while offering specialized expertise in various areas of counselling (e.g., problem-solving) and HIV services (e.g., information regarding HIV and safe behaviours). Researchers have suggested that offering counselling services in a caring and respectful manner can lead to improved service uptake among people living with HIV/AIDS (Cadwell, 1994; O'Dell, 1997). In addition, Antoni et al. (2000) as well as Weinhardt and Carey (1999) have highlighted several benefits such as anxiety reductions through offering expert oriented interventions to people living with HIV/AIDS. Thus, counsellors working with people dealing with an HIV diagnosis need to consider various styles of counselling such as caring and expert orientations. Participants in the current research also highlighted several benefits of professional counselling, such as: (a) developing purpose, (b) working toward accepting the HIV diagnosis, and (c) dealing with strong overwhelming emotions. These benefits are consistent with previous research examining the benefits and purposes of HIV counselling (Hoffman, 1996; Weinhardt & Carey, 1999).

Hope is a central aspect of professional counselling, operating in many, if not all, counselling modalities. Indeed, research has clearly demonstrated that hope is an important aspect of counselling (Cannon, 2005; Cutcliffe, 2004; Edey & Jevne, 2003; Edey, Jevne, & Westra, 1998; Frank, 1968; Kraatz, 2003; Kuyken, 2004; Ruvelson, 1990; Yalom, 1995; 1998). Participants in the current study suggested that an important benefit of professional counselling was that of professional counsellors helping patients living with HIV to find hope. This occurred through several avenues, including: (a) counsellors' relationship orientation, (b) counsellors' connecting clients with other services, (c) counsellors' helping clients to locate purpose in their lives (e.g., helping clients become connected to community-based agencies), (d) counsellors' sharing stories of hope with clients, and (e) counsellors' various interventions which facilitated hope (e.g., setting goals, providing information, teaching skills).

It is also important to note that numerous authors suggest that attempting to demonstrate or elicit hope prematurely in clients experiencing hopelessness can be counterproductive and lead to increased isolation and hopelessness (Cutcliffe, 2004; Hannah, 2002; McGee, 1984; Ruvelson, 1990). This is an important consideration in the present study, as many of the participants reported experiencing hopelessness following the HIV diagnosis. Thus, part of counselling and hope-focused counselling following an HIV diagnosis may need to include recognizing when to engage in other activities that can be non-hope related or may be precursors to an explicit hope-focused discussion. For example, focusing on helping the client to feel heard and understood can facilitate hope implicitly and may open the window for explicit hope-focused discussion later. Upon surveying the research literature, I was unable to locate any research that explores the hope components or mechanisms within a counselling or psychotherapy context for those individuals experiencing the high-risk period following an HIV diagnosis. Given results of the present study, further research in this area is recommended.

Response Team

Several participants in the current study talked about the possibility of some form of "response team" in which a team of HIV workers are immediately provided to the individual just receiving the HIV diagnosis (i.e., possibly even prior to the individual receiving the news). The team would be comprised of peer counsellors, professional counsellors or psychologists, and other health related professionals. Participants believed this type of service would reduce high-risk behaviours immediately following diagnosis and would also offer the opportunity for people living with HIV to be involved with the team, which could add purpose to their lives. Some participants also suggested that people who are about to receive an HIV diagnosis should speak to a professional counsellor or psychologist and a peer counsellor prior to receiving the news. This way, patients can be given information and some hope that life is not over before they become flooded with the news of HIV and all of the overwhelming emotions that go along with the diagnosis.

Mobile crisis response teams have been demonstrated to be effective in dealing with crisis issues with some populations (e.g., youth with schizophrenia) (Singer, 2005a; Singer, 2005b). However, specialized HIV diagnosis delivery teams have yet to be developed. Some success has been found with telephone crisis services among people living with HIV (Safran & Waller, 1996); however, during diagnosis it is unlikely to be a utilized service. Thus, mobile crisis intervention may be an important consideration with some newly diagnosed individuals with HIV. Specifically, during pre-test counselling, if specific risk factors for high-risk behaviours emerge, this could be a warning sign that mobile crisis intervention may be required. Mobile crisis intervention does not always need to be delivered outside of the clinic or hospital. This team could be utilized during the diagnosis process within the diagnostic setting. Hence, they could also be involved prior to the diagnosis being delivered.

Study Limitations

Several limitations should be acknowledged with this study. These limitations can inform the reader's interpretation of findings of this study as well as guide directions for future research in this area.

Qualitative research is typically focused on description and exploration, as opposed to generalization to other groups (Goetz & LeCompte, 1984; Morgan, 1986). While small sample size (n = 12) permits qualitative researchers to explore accounts of participants' experiences, it can also be considered a limitation due to restraints on transferability of findings. Any generalizations of these results should be considered cautiously as they will not apply to every newly HIV diagnosed individual. Future research could include a larger sample size to further explore specific (a) high-risk behaviours, (b) risk factors for engagement in high-risk behaviours, and (c) experiences of hope following an HIV diagnosis.

Qualitative case study research has been utilized as the guiding methodology within the present study. This approach of inquiry places large demands on the researcher given the intensity of the interviewing and analyses processes. This coupled with the intensity of the interview topics resulted in a concentrated, rigorous, and exhaustive research process, often depleting my own energy levels. I found that I needed to address this energy depletion through self care activities. It was important for me to reflect on my experiences of conducting this research, during the research process, in order to assess my own energy and internal resources in order to continue with the project. I needed to find ways to recharge my energy and internal resources while staying engaged with the participants' accounts. I relied on family and friends' support, a healthy lifestyle, and engagement in my hobbies.

For this research project, participants retrospectively recounted their experiences of their high-risk behaviours following diagnosis. All participants had been diagnosed for at least five years. This was an important ethical consideration in conducting this study, as I did not want to compromise participants by interviewing anyone very recently diagnosed with HIV who may be actively struggling with high-risk behaviours. Nevertheless, participants were not living in the moment with their high-risk behaviours; they were recalling these experiences from memory. This was both a strength and a weakness. For example, it is possible that participants may have experienced problems in recalling specific details about their experiences, though no one articulated this to be an issue. Rather the benefit of time since diagnosis seemed to help participants reflect insightfully about their high-risk behaviours following diagnosis. They had had time to reflect on their behaviours and had come to some personal understandings about how their behaviours had happened.

Participants were recruited on the basis of several criteria, including engagement in high-risk behaviours following diagnosis. Although two participants reported a decrease in high-risk behaviours fairly shortly following diagnosis, no participants were purposely recruited who did not engage in high-risk behaviours following diagnosis. From a positive psychology perspective, future research could explore a population of newly diagnosed HIV-positive patients who do not engage in high-risk behaviours in order to further our understanding of the processes involved in reducing this high-risk behaviour period. In addition, future research could also explore the experiences of people engaged in high-risk behaviours prior to diagnosis but who cease their high-risk activities at the time of diagnosis.

The study participants were primarily men in their 30s and 40s. Given gender and age impacts on the present data, more research should be conducted looking at females' experiences with high-risk behaviours following diagnosis, as well as youths' experiences following diagnosis including current HIV treatment differences among various genders and ages.

Concluding Thoughts

The present chapter highlighted several of the research findings in relation to the importance of hope following an HIV diagnosis in order to help newly diagnosed people deal with the diagnosis and reduce high-risk behaviours. Specific high-risk behaviours following an HIV diagnosis have been identified in the current study, several of which have not been sufficiently discussed in the existing research literature. Clinicians need to consider high-risk behaviours broadly, along with the context in which high-risk behaviours exist. As suggested in this chapter, prevention and intervention strategies need to include a focus on the individual living with HIV as well as the broader contextual-social considerations that exist in his or her environment. Several intervention considerations have been suggested, notably aspects surrounding hope. Hope's therapeutic value is well indicated, and has been highlighted extensively by participants in the current study as both a therapeutic agent and as capable of contributing to the reduction of high-risk behaviours. Hope's value for people struggling with a diagnosis of HIV and high-risk behaviours is a unique contribution, of the current study, to the existing research literature. The following chapter offers a reflective epilogue to the study.

Chapter Ten: Reflective Epilogue

Transforming my Pre-Understandings

What follows is my reflection on the 12 previous participant narrative accounts along with the thematic and categorical findings. The following personal reflection may serve as an epilogue to the study, highlighting my reflections on the main findings. I present this reflection in the form of a timeline of the participants' lives, which begins prior to their HIV diagnoses. Their history, before receiving the diagnosis, as well as their experiences during and following the diagnosis, are central aspects of understanding their lives including their struggles with the diagnosis and high-risk behaviours.

The following reflection also encompasses the notion of balance. I have come to understand that many of these participants were struggling with balance in their lives both preceding and following the diagnosis. My interpretation of balance is that it consists of perceiving possibilities, making healthy choices, and maintaining a healthy and stable lifestyle. With balance, high-risk behaviours were reduced and the perception of possibilities was enhanced. Without balance, there were increased high-risk behaviours, a lack of perception of possibilities, and perceived threats to one's future. I see hope as having the ability to offer balance to the individual.

Non-Balance	Balance
Perceived threats to future	Perception of possibilities
Risky choices	Healthy choices

Prior to HIV

For many of the participants hope was variable, and for some, not well established, prior to HIV. Most of the participants were struggling with some combination of stressors (e.g., financial, relational), substance abuse and dependence, or identity crises (e.g., homosexuality versus heterosexuality) in their lives. Any hope that did exist was often challenged and threatened. Many seemed to engage in high-risk behaviours as a means to cope with life problems, ignoring, and even not caring about the consequences, in some cases. Indeed, these high-risk behaviours were the mode of HIV transmission for many of the participants. This helped me to understand the frame of reference, prior to the diagnosis, for many of the participants in this study: High-risk behaviours and challenges to hope were apparent prior to HIV.

Although participant hopes were often challenged, most did make attempts to maintain some hopes during this time period (e.g., hope for material possessions or specific aspects of employment). Some participants also suggested that their families helped them to try to hold onto hope, although family was not always a clear priority, at this time, in many of their lives. During this time, participant hope often seemed to exist on a continuum with wishing. Hoping and wishing can be contrasted in several important ways: (a) hoping is open to difficult and painful emotions while wishing is closed to such feelings, (b) hoping maintains an expanded cognitive frame of reference while wishing maintains a constricted set of cognitions, (c) hoping is active while wishing is passive, and (d) hoping allows for flexible outcomes while wishing is inflexible (Farran et al., 1995).

Major Health Changes and other Abrupt Signals

This lifestyle, characterized in part by high-risk behaviours, continued for many of the participants until abrupt changes in their lives were noted. For many, this was a qualitative change in health status such as a serious viral infection. For others it was some other form of abrupt signal (e.g., blood test results, sexual or drug sharing partner becoming diagnosed with HIV). Most participants suggested that at this point HIV was not a concern. Participants underwent many tests, exploring different potential causes. Most were also tested for HIV. As early non-HIV test results returned negative, many participants began to focus more and more on the possibility that unexplained health changes were due to HIV. At this time, there was often a shift in focus for many of the participants: The hope focus became hoping it was not an HIV diagnosis. Again though, here hope existed on a continuum with wishing. In addition, participants engaged in whatever coping skills they had available. This took the form of high-risk behaviours (e.g., substance use) and denial in many cases. Participants were often isolated at this time, fearing others' reactions to their potential HIV diagnosis. Although I had some understanding of the "window period" prior to this research, this study helped me to transform my pre-understandings in important ways. For example, I became aware of the role of participants' coping skills (e.g., substance abuse) in facilitating the risky behaviours and the importance of hope and how the focus of hope changed for participants during this time period (i.e., toward hoping it was not HIV) as the study progressed.

Positive Diagnosis

The positive HIV diagnosis destroyed all perception of hope, or rendered it unobtainable, for many of the participants. The balance obtained through hoping it was not HIV had been destroyed. This threw many participants into a tail spin resulting in chaos and uncertainty. Participants perceived the diagnosis as a death sentence, often believing they had AIDS, and thinking there was nothing that could be done to help. This lack of participant understanding and information about HIV helped me to understand their reactions to the diagnosis. Participants often utilized the coping mechanisms they had available with intensified force. Attempts at denial and engagement in high-risk behaviours became their lifestyle. Despite denial though, the reality of the HIV diagnosis frequently returned to their awareness, which helped me to understand their continuous distress regarding HIV. Thus, although moments of denial existed, participants could not permanently shake their awareness of HIV. Many became further isolated and rejected support services. I initially struggled with understanding participants' movement toward further isolation and rejection of support services following their diagnoses. However, new understandings became clearer to me as I came to learn the significant risks that the newly diagnosed perceive when disclosing an HIV diagnosis to others and when seeking out support services.

Immediately following diagnosis participants did hold some specific hopes related to the HIV diagnosis, although these hopes were not conducive to balanced lifestyles. For example, some participants held hope for quick painless deaths and secrecy regarding their HIV infections. Ultimately, many of these participants were holding onto the hope to end their pain and suffering.

Positive Shift

Participants encountered some form of significant event which helped them to re-evaluate their lives and become connected to a support system. This event was often external (e.g., death of a loved one, meeting someone with HIV who challenged their personal perceptions of the virus), although was sometimes internally focused (e.g., risk to physical health through drug overdose, survival beyond their life expectancy as predicted by health professionals) and resulted in an opportunity for a cognitive and emotional restructuring. Participants had the opportunity to begin to perceive and emotionally experience HIV differently as a result of the event. This opportunity manifested itself in participants' willingness, and even motivation in some cases, to seek out connections and support services. This cognitive/emotional restructuring and willingness to seek out support represented an initial move away from denial. Participants began the process of accepting the diagnosis and taking active steps toward obtaining healthy support and assistance. In short, participants began to re-connect with hope. In this instance, hope was real and active, in contrast with wishing. At this point, hope was largely focused on a better way of life, on what might be possible in life. With hope, came the willingness to take new and different risks. Participants needed to take hope-based risks in order to become connected with services, which would help to further the process of accepting, and dealing with, the diagnosis. In this instance, there is a perceived risk/threat to hope because the participants needed to expose their HIV status in order to access support. In being involved in this research I have come to understand that contacting support and becoming labeled as HIV-positive is considered by many to be dangerous, uncertain, and overwhelming due to fears of stigmatization, rejection, stereotypes surrounding HIV, and a lack of knowledge/skills. All of these aspects have the potential to destroy the newly visible hope, sending the individual back to the chaos that surrounded the time of the diagnosis. Thus, I understand this time period as holding the possibility of a spiral back and forth between hope and despair.

Connection

Over time, participants became connected with community-based agencies, peers, counselling services, and health care. Participants actively risked/utilized their visions of hope in order to facilitate the connections with others. In this way, participants began to "realize" hope. They allowed themselves to move in a positive direction, despite fears of stigmatization and uncertainty. They were introduced to others with HIV, and began to see that HIV was not a death sentence. They saw possibilities, were inspired and empowered through learning and hearing others' stories of hope. As time passed, participants moved toward the "acceptance" of hope. This represented a faith that hope would remain and that things could improve, even when encountering difficulties. Participants began to find meaning and purpose in their lives through volunteer work, peer counselling, and developing a mission in life—to fight back against the virus. In this way, many participants began to develop something that they never had in their lives (for some, they regained something they had prior to HIV), meaning and purpose. They began to experience inspiration, empowerment, and meaning. Participants were also able to further develop a sense of hope. In this instance, hope was often "transcendent", going beyond the virus and even themselves. It was often focused on others and larger initiatives such as the fight against the virus. Participants experienced increased balance with each of the different forms of hope, although seemed to progressively increase balance (i.e., reduced and eliminated high-risk behaviours and increased perceived possibilities) with each step toward transcendent hope (i.e., transcendent hope represented an advanced sense of hope that was capable of survival in the face of existential concerns) on the continuum. These continuums of balance and hope, along with the participants' accomplishments and experiences, are my understanding of how participants' hope became realized in their lives. It represents a dynamic process that began prior to HIV and will continue to evolve long after the completion of this study. The following continuum of hope highlights my understanding of the various forms of hope experienced by the participants in this study.

Continuum of Hope

Initial vision of hope/ Hope utilized/ Hope realized/ Hope accepted/ Hope transcendent

Initial vision of hope/hope utilized. The initial glimpse or vision of hope helped participants start to shift away from denial. Participants attempted to make connections with support services, peers, and community agencies. The hope was "utilized/risked" in an attempt to expand the experience of hope through connections and services, despite fears of stigmatization and isolation. This created an opportunity to move participants further along the continuum of hope, provided some support for hope was experienced.

Hope realized. Hope "realized" occurred following the participants' successful use of the initial vision of hope. There was a realization that hoping was a possibility which may serve some important functions. In taking small risks to hope for something better, participants were rewarded with a hope realized. These experiences supported participants' willingness to hope further and to risk more in seeking a good and meaningful future for themselves.

Hope accepted. Hope "accepted" represented a faith that hope would remain and that things could improve, even when encountering difficulties. This represented a deeper sense of hope. Participants went beyond realizing hope was a possibility to accepting that hope was a very real stable option. Participants identified hope objects and were open to the cognitive, emotional, and spiritual aspects of the hoping process.

Hope transcendent. Hope "transcendent" went beyond the virus and even the individual participants' lives. It represented an advanced sense of hope that was broad and non specific. It was capable of survival in the face of existential concerns (e.g., death, uncertainty).

Concluding Thoughts

These reflections illustrate the complexity and challenges of receiving an HIV diagnosis, struggling with high-risk behaviours, and developing/refining a sense of hope.

The reflections contained in this chapter also illustrate how my own pre-understandings have shifted, how I have come to understand the time period surrounding an HIV diagnosis, and how I have come to understand hope and high-risk behaviours for the participants in this study.

Throughout this study I have had the opportunity to engage in conversation with people living with HIV/AIDS who have experienced the high-risk period following their HIV diagnoses. Their accounts, along with my own reflections and interpretations, have been presented within this document. The experiences of crafting the narrative portraits, elucidating themes and categories, developing interpretations and reflections, and integrating the composite depiction have been intensive and life transforming. The study has ultimately facilitated profound changes in my own perceptions and ideas of people living with HIV/AIDS dealing with the high-risk period following diagnosis. These changes in perceptions will help guide me through my future clinical and research work with people dealing with high-risk behaviours following HIV diagnosis. Importantly, my own interpretations and ideas regarding the high-risk period following diagnosis will continue to develop and grow.

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Appendix A

Guiding Interview Questions

I would like to start off by **thanking you** for agreeing to do the interview. Before we get started lets review the **informed consent form** and the **ethical guidelines.** It's very important that we **go at your pace** during the interview, I **don't want to go too fast.** So, during the interview just let me know if there is a **question you don't want to answer** or a **question you would like to skip.** The **questions below are to help get us started**, and we **probably won't talk about all of them.** I am most interested in **hearing about your experiences**—these questions are intended to help **guide our conversation today.**

General Questions:

1) Please tell me a little bit about your life now.

2) Sometimes people talk about how they have a story; can you begin by telling me a little bit, starting after you thought you were HIV-positive, about your story?

3) If you can, please tell me a little bit about what it was like for you after you thought you may be HIV-positive. And what it was like, for you, when you first found out about it?

4) What were some of the things that helped you after you thought you may be HIV-positive?

5) What did you do after you found out about it (e.g., first months following the diagnosis)?

6) How did the news about the HIV change your life?

7) How has it changed over the years? How is it different today? How has it remained the same?

8) Sometimes people say that their life has gone through 'stages', or they can remember really important periods of time that happened in their life. If you could describe your 'life stages', or really important periods in your life, what might they be?

9) What were some of the things that you did to cope?

Hope-Focused Questions:

1) What are small things that sustained your hope (after diagnosis of HIV)?

2) On a scale of one to ten (i.e., one being no hope and ten being highly hopeful), what was your level of hope before you were diagnosed (e.g., one year, six months, two

weeks)? After your diagnosis? Now? What have been some of the things that have changed it over time?

3) What are things that challenged your hope (after diagnosis of HIV)?

4) What gave you hope? (likely ask in relation to various events or experiences)

5) What took your hope away? (likely ask in relation to various events or experiences)

6) Was there anyone that helped you get hope? (likely ask in relation to various events or experiences)

7) What happened the day you were diagnosed? If you can, please tell me about your hope then. How did it change? Were there any people involved that helped you to feel hope?

8) What would others who know you say about your hope? What would others say about your hope when you first heard about your HIV diagnosis, during the time following this?

9) Please tell me about your hope and your actions just before and just following diagnosis.

10) If you were to meet someone newly diagnosed, what would you want them to know so that they could have hope?

11) If you were to meet someone newly diagnosed, what would you do to make them feel hopeful?

12) How would you have defined your 'hope' just before and following your HIV diagnosis? What happened to your hope following notification of your HIV diagnosis?

13) What are some things you hope for now? Is there anything else?

14) What does hope mean to you? OR What is hope for you?

15) What do you think about hope?

Counselling and Related Questions:

1) What types of high-risk behaviours have you engaged in following your HIV diagnosis (e.g., suicidal ideation, unsafe sex practices, and increased drinking/drug use)?

   (I anticipate that this information will unfold naturally; however, as it is important for the research, I am adding it as a direct question and I will directly ask the question if I do not get the information indirectly).

2) What was most helpful about your counselling? Was there anything that was less helpful?
3) Do you see a relationship with your experiences in counselling and your behaviours? Yes, what were they?
4) Can you please tell me about your experiences of hope during counselling?
5) After you were told about your HIV diagnosis, were you involved with peer support programs (or any other type of mental health service)? If yes, how did that help? Not help?
6) How have counselling and peer support groups helped you to feel hope?
7) What have you learned about hope through this interview?
8) What was it like to get these questions before the interview?
9) What else would you want me to know that is important?
10) What has it been like to participate in this interview?

Appendix B

Sample Informed Consent

Research Project Title: Hope and the Potential High-Risk Period Following an HIV Diagnosis: A Hermeneutical Interpretation

Investigator: Gregory E. Harris

The purpose of this study is to learn about the potential high-risk period following an HIV diagnosis in relation to hope and mental health services. In this way, service providers (e.g., HIV Edmonton) can offer services that are increasingly more relevant and useful to the clients that they serve. This study will focus on the potential high-risk period following an HIV diagnosis. Accordingly, participants will need to have experienced one high-risk behaviour or situation (e.g., increased alcohol or drug use, suicidal ideation, unsafe sexual practices) following their HIV diagnosis. The study will specifically focus on the perceptions of people who have experienced the high-risk period first-hand. This way, participants will be able to comment on their own personal experiences as it relates to hope and mental health services.

The study will include: (a) reading and signing the informed consent form, (b) completing the attached demographic survey, (c) returning these two forms to myself at the time of the interview, and (d) meeting with me, the interviewer (i.e., Gregory Harris, graduate student, University of Alberta), at a mutually acceptable time, to discuss your experiences of the high-risk period following an HIV diagnosis in relation to hope and mental health services. The interview will last for approximately one and a half hours and consist of questions that are directly related to your experiences with the high-risk period, hope, and mental health services such as counselling and peer support programs. Following the interview, and after I listen to the interview again, it would be helpful to meet a second time to review some of the information we discussed. This will likely be a shorter interview, to review our previous conversation and discuss it further. It also gives you an opportunity to clarify things from the first interview. Participants will each receive $30.00 per interview (i.e., $60.00 for both interviews) for their time. Since the focus of this interview will address potentially sensitive issues, it is important for you to know that your participation is completely voluntary, and if at any time during the interview you feel uncomfortable, you are free to leave. Furthermore, if for any reason during the interview, or after the interview, you feel the need to talk to a counsellor about something that has come up during the interview then my co-supervisor, Dr. Lynda Phillips, Chartered Psychologist, will be available. Also, a list of additional counselling resources will be available upon request.

Strict confidentiality will be maintained with the data obtained from the interview. You will have the opportunity to create an alternative name for yourself in order to ensure that your identity and your data cannot be connected in any way. Only the interviewer (i.e., myself) and my supervisor (i.e., Dr. Denise Larsen) will have access to your data and your identity. Furthermore, if at any time during the study you feel that you no longer wish to participate, you can request that your data be destroyed. An audiotape will be used to record the interview, and it will be transcribed for the purpose of data analysis. All data (e.g., transcripts, notes) will be kept in a locked file cabinet in the interviewer's office and then shredded after five years. It is important for you to know that there are some limitations to confidentiality. Specifically, I would need to break confidentiality if either yourself or someone else was in danger of being harmed, a minor was in danger of being harmed, or if the courts subpoenaed my records.

For those interested, a general summary of the study results will be made available to HIV Edmonton and other interested agencies. Furthermore, results will be made available to any individual participant upon request. However, there will be no information reported publicly that could be linked to you. Strict confidentiality will be maintained through using pseudo-names and leaving all information that could identify you personally out of the report.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. Your signature below also provides permission for the researchers to use quotes and stories in presentations, published articles, and in any other future publications. If you have further questions concerning matters related to this research, please contact:

Gregory E. Harris (780) 492-5245
Dr. Denise Larsen (780) 492-5245 (supervisor)

This study has been reviewed and approved by the Faculties of Education and Extension Research Ethics Board (EE REB) at the University of Alberta. For questions regarding participant rights and ethical conduct of research, contact the Chair of the EE REB at (780) 492-3751.

This consent form, a copy of which has been given to you, is only part of the process of informed consent. It should give you the basic idea of what this research project is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to carefully read this form and any accompanying information.

Participant's Signature Date

Investigator and/or Delegate's Signature Date

Witness' Signature Date

A copy of this consent form has been given to you to keep for your records and reference.

Appendix C

Sample Invitation Letter to Participants

Dear potential participant,

I would like to invite you to participate in a study regarding your experiences of hope and the period of time following your HIV diagnosis. The purpose of this study is to learn about hope and the potential high-risk period following an HIV diagnosis. In this way, service providers (e.g., HIV Edmonton) can offer services that are increasingly more relevant and useful to the clients that they serve. I am looking for participants who

- have been living with HIV/AIDS for two years or longer,
- have experienced a high-risk behaviour or situation following or immediately before your HIV diagnosis (e.g., increased alcohol or drug use, unsafe sexual practices, or suicidal thoughts),
- have received a counselling service following your HIV diagnosis.

The reason why these criteria have been set is so participants who are interviewed will be able to comment on their experiences within these areas. The overall goal of this research project is to provide information from community members to service providers so that they may improve their programs and counselling interventions to better meet your needs.

There will be no cost to participants, and each participant will receive $30.00 per interview for their time. At any time if you feel uncomfortable we will stop the interview immediately. Furthermore, participants who feel the need to talk with a psychologist about anything that has come up during the interview will be able to talk with my co-supervisor, Dr. Lynda Phillips, Chartered Psychologist, free of charge. The research interview will last approximately one and a half hours and will consist of a conversational style interview with some initial questions about your experiences following your HIV diagnosis in relation to hope and mental health services.

The interview will be **strictly confidential**. For more information, please contact Gregory Harris at (780) 492-5245 or skinnygreg@aol.com. The interview session will likely be sometime during mid September to mid November, depending on your availability.

Thank you,

Gregory Harris B.A., M.Sc, Ph.D. student

Appendix D

Demographic Questionnaire

1) Age _____

2) Gender: male _____ female _____ transgender________

3) I identify my sexual orientation as: ______________________

4) I identify my religious preference as: _____________________

5) If there is a religious preference, are you currently practicing this religion?

   yes __ no__

6) What race/ethnicity do you define yourself as? ____________________

7) What is the highest level of education you attained? college/university_____, high school graduate____, some of high school______, less than high school_____, do not care to respond_____

8) What is your occupation? __________________

9) If you have had to leave your occupation, what was your previous occupation?

   ____

10) What is your annual income? Over $50,000_____, between $30,000-49,999______, $20,000-29,999 _____, below $20,000 _______, do not care to respond_____

11) What year did you learn about your HIV diagnosis? ______

12) What types of counselling services have you accessed since your HIV diagnosis: individual counselling (i.e., yourself and one mental health professional such as a counsellor, social worker, and/or a nurse) ______, peer support programs_______, group counselling, other __________.

13) How often have you used these services: individual counselling (i.e., number of times you have used individual counselling over how many years)_______, peer support programs_______, group programs, other________.

14) Is there anything else you would like me to know prior to our interview together?

____

____

____

____

Appendix E

Oath of Confidentiality

Research Project Title: Hope and the Potential High-Risk Period Following an HIV Diagnosis: A Hermeneutical Interpretation

Investigator: Gregory E. Harris, M.Sc., Ph.D. Student, Department of Educational Psychology, University of Alberta

Supervisor: Dr. Denise Larsen, Ph.D., Department of Educational Psychology, University of Alberta

You are being asked to sign this Oath of Confidentiality form due to your involvement in this project, as a transcriber of the interview tapes. You will be listening to highly confidential and personal information. This information needs to be kept strictly confidential. This means that under no circumstances will you repeat or disclose any of this information to anyone at anytime. By signing this form you are indicating that you understand the ethical principle of confidentiality and you are agreeing to uphold this principle of confidentiality. Failure to strict adherence to this ethical principle of confidentiality can result in serious legal repercussions to both you and the researcher.

____

Transcriber's Signature Date

____

Investigator and/or Delegate's Signature Date

____

Witness' Signature Date