McGILL UNIVERSITY

A CASE STUDY OF A ONE-WEEK RECREATIONAL CAMP FOR PEOPLE AFFECTED BY HIV

A Research Report Submitted to
The School of Social Work
Faculty of Arts
Graduate and Post-Doctoral Studies Office

In Partial Fulfillment of the Requirements
for
The Master's Degree in Social Work
by
Naomi Hyba
Montreal, August, 2013
Adviser: Jill Hanley

Table of Contents

Introduction

Approximately thirty years after the first known case of HIV, the Public Health Agency of Canada (PHAC) estimates that over 65,000 Canadians are living with HIV, representing an increase of 14% from the previous data collection in 2005 (PHAC, 2010). PHAC estimates that HIV prevalence rates in Canada will continue to rise due to two reasons: first, with the advent of improved medication regimes, HIV has become a chronic, non-terminal disease (meaning that those with HIV live longer to remain part of the statistics); and second, rates of new HIV infections are rising, although minimally. HIV has a unique social context, described by many researchers as a "social disease" due to the stigma associated with the illness (e.g. Mavandadi, Zanjani, Have & Oslin, 2009; Friedland, Renwick & Mccoll, 2010; Brown & DeMaio, 2008). At the intersection of this stigma are the diverse social groups and social locations that are disproportionately affected by HIV. Within the HIV-positive Canadian population, 48% identify as men who have sex with men; 17% identify as injection drug users; 17% identify as heterosexual, 8% identify as Aboriginal; and 14% originate from countries where HIV is endemic (PHAC, 2010). The effects of marginalization and stigma represent a significant challenge to the well-being of the neighbours, friends and family in our communities who are living with HIV (CATIE, 2009).

This case study seeks to examine the experiences of campers and volunteers at a one-week recreational, residential camp for individuals and families affected by HIV in Ottawa, Ontario. This study was initiated with the author's hypothesis that three social factors associated with HIV would prove particularly relevant to how this camp is experienced by both volunteers and campers: stigmatization within greater society versus a sense of community and social support among camp participants. The data presented was gathered during the camp session held in July, 2013, and was derived from twenty-six interviews with campers and volunteers, as well as from a self-administered survey available on the last day of the camp session. This data highlights five outcomes: the camp as a “family”; the camp as a unique and diverse, yet cohesive community; campers’ and volunteers’ experience of navigating their identity in a setting in which their HIV status is normalized; the psychological continuity of the camp experience beyond the single week that camp is held; and altered family processes while at camp and after the camp session.

This report will begin with a literature review of stigmatization, social support and family processes as experienced by individuals living with HIV (Part I). In Part II of the literature review, recreational experiences – in particular camps – will then be explored as a way to boost psychosocial support and sense of community. Lastly, the data from the case under study will be presented: a case overview, review of the methodology, results, and a discussion linking these findings to the existing scholarly literature.

Literature Review: Part I

This section will first review stigmatization and social support as experienced by individuals living with HIV. A brief overview of their impact on family processes for families with HIV will also be provided. Following this will be a literature review on recreational experiences – in particular camps –as a way to boost psychosocial support and sense of community. Literature on HIV-specific camps is sparse; the few articles available focus almost exclusively on camps for children and youth affected by HIV. As such, this section will also include literature on more general, non HIV-specific medical camps.

HIV and Stigma

This sction presents a short review of the literature on HIV and stigma, highlighting the relationship between stigma and, respectively, identity and secrecy. Stigma is defined as the effects of labeling, stereotyping, status loss, and discrimination (Link and Phelan, 2001). These processes require certain human differences to be linked with negative attributes which are then used to create an "us" and a "them" (p. 370), whereby the "them" group then experiences status loss and discrimination, both individually and structurally. The role of relational power is crucial to the definition of stigma, as "it takes power to stigmatize" (p. 375).

In their discussion of HIV and AIDS-related stigma, Parker and Aggleton (2003) also underscore the importance of power in the creation and maintenance of stigma, conceptualizing stigmatization as a social process that draws on the dynamics of power and domination. They note the role of stigmatization in devaluing HIV-positive individuals and relationships with these individuals. The authors contend that to understand the relationship between stigma and HIV, one must consider "the workings of social inequality" and "think more broadly about how some individuals and groups come to be socially excluded, and about the forces that create and reinforce exclusion in different settings" (p. 16). The stigma associated with HIV is also linked to the stigmatization of groups that are disproportionately impacted by HIV: sexual minorities, injection drug users, street-involved individuals, and sex workers (Parker and Aggleton, 2003; Bogart et al., 2008; Fielden, Chapman & Cadell 2011). In the Canadian context, one might also consider the elevated prevalence rates among Aboriginal peoples, as well as among refugees and immigrants of colours, groups that also experience other forms of social exclusion (PHAC, 2010).

A factor that is linked to the stigma of HIV, perhaps both as a cause and as an effect, is the secrecy surrounding the illness. Brown and DeMaio (1993) explore the complexities of this secrecy, noting that it can at times be adaptive by reducing anxiety about the illness, and respecting psychological defenses such as denial. However, secrecy may be an important barrier in discouraging positive medical and psychosocial interventions (such as attending group activities for HIV-positive individuals), preventing individuals and families from accessing social support. As noted by the authors, "secrets feed into a sense of isolation and stigma" (p. 98). In Bogart et al.'s study of 33 American families affected with HIV, the authors emphasize the importance not only of direct stigma, but of courtesy stigma, or "prejudice and discrimination against individuals who are associated with stigmatized others" (2008, p. 245). Both forms of stigma were found to act as significant barriers to individuals' adherence to their medication regimes. Within the sample, 100% of HIV-positive mothers felt they had experienced stigma, as did 88% of HIV-positive fathers, 52% of children, 79% of adult children, and 60% of caregivers (Bogart, 2008). This is especially salient for work with families in which one or family member is affected by the illness.

HIV and Sense of Community/Social Support

While sense of community is a distinct concept that is discernable from social support, no studies were found that specifically linked this concept – a key finding of the current study – to HIV. This section seeks to define sense of community, while focusing more on the available literature on social support and HIV.

McMillan and Chavis's widely-cited work on sense of community (1986) defines this concept as "a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members' needs will be met through their commitment to be together" (1986, p. 9). Sense of community is determined by four elements: membership, or "a feeling that one has invested part of oneself to become a member and therefore has a right to belong" (p. 9); influence, or the bidirectional effect of the individual on the group and of the group on the individual; reinforcement, which is alternately defined as the "integration and fulfillment of needs" (p. 12); and shared emotional connection, which is related to the sharing of a common history or values.

Barrera adds that social support must be conceptualized in terms of three distinct categories (1986). The first, social embeddedness, is defined as "the connections that individuals have to significant others in their social environments" (p. 415). Social embeddedness can be operationalized by measuring the presence of social connections, e.g. marital status, friendships, and participation in community organization. The second category, perceived social support, is defined as "the cognitive appraisal of being reliably connected to others" (p. 416), and includes the appraisal of both the availability and adequacy of these connections. The third and last category, enacted support, is defined as "actions that others perform when they render assistance to a focal person" (p. 417).

Norbeck’s model of social support (1981) clarifies its application to social sciences, in which properties of the person and properties of the situation combine to inform the need for social support. This is then compared to the actual social support available. Norbeck poses five questions aimed at improving social support for those who judge theirs to be inadequate, as is often the case for individuals affected by HIV:

> 1. What is the capacity of the network to change?
> 2. Does the individual have the interpersonal skills and attitudes required to establish and maintain contact with network members?
> 3. Is the individual receptive to existing self-help or support groups or to having contact with a person who has coped with a similar experience?
> 4. If help from the indigenous social support system cannot be made available or acceptable, exactly what support does this individual require to cope with the current stressors or illness?
> 5. What long-term help would be required to assist the individual to establish and maintain an adequate social support network? (Norbeck, 1981, p. 564)

Numerous authors have specifically examined the role of social support in the well-being of individuals living with HIV. However, the need for up-to-date research will continue as medical advances continue to make HIV an increasingly chronic, not terminal, illness (Ashton et al., 2005). Mavandadi, Zanjani, Have and Oslin (2009) studied the role of social relationships in determining the psychosocial wellbeing of 109 adults aging with HIV in Philadelphia. The authors found that compared to younger adults, older adults reported greater perceived social support and more “vigor”, which was linked to more positive affect and less depressive symptoms (p. 94). This social support was hypothesized to account for older adults’ greater self-rated psychosocial well-being, despite older adults experiencing greater medical challenges associated with HIV. The mitigation of depressive symptoms is significant, as HIV has been linked to higher rates of depression, which is in turn linked to the progression of HIV, as indicated by markers such as viral load, hospitalizations, and life span (Manvandadi, Zanjani, Have & Oslin, 2009).

Ashton et al. (2005) longitudinally examined social support as a predictor of physical health in 65 HIV-positive individuals in California. The authors found that satisfaction with social support was a “robust predictor” (p. 587) of HIV-related health symptoms, as measured by CD4 T-cell count, AIDS status, opportunistic infections, and other common HIV-related physical health symptoms (p. 591). In a study of 78 HIV-positive individuals in Texas, Clingerman (2004) noted that the developing chronicity of HIV can serve to deplete social support resources over time, while the ability to access these resources is affected by HIV treatment regimes and their side effects. Clingerman found that social support – from friends in particular – was highly correlated with health-related quality of life (2004).

Friedland, Renwick and Mccoll studied the roles of social support and coping in determining the quality of life for 120 HIV-positive individuals in Toronto (1996). The authors note that effective social support for individuals living with illness must be tailored to the illness. For example, living with HIV affects both the type of social support needed, and the ability to access various forms of social support. Perceived social support, particularly emotional support, was found to be a significant factor in determining the quality of life for individuals living with HIV (Friedland, Renwick and Mccoll, 1996). While the participants perceived that the emotional support they received was of sufficient quality, they wished for greater quantity of emotional support.

Bekele et al. (2013) examined the role of perceived social support in determining the quality of life for 602 HIV-positive adults in Ontario. Perceived social support was found to directly affect physical health. It was also found to indirectly affect both physical and mental health by serving as a mediator of depressive symptoms. In addition, social support was significantly associated with a variety of other factors that may affect quality of life: employment status, income, and housing-related discrimination (p. 340). Ashton et al. (2005), Friedland, Renwick and Mccoll (1996) and Bekele et al. (2013) all cite as an implication the need for increased "informal support" services, such as buddy lines and drop-in centres (Ashton et al. p. 28).

HIV and Family Processes

As with many chronic illnesses, HIV affects not only the infected individual but the entire family system (Kmita, Baranska & Niemiec, 2002). It is therefore important to briefly review the literature on HIV and family processes: the social contexts of families affected by HIV; the internal problems experienced by these families, such as child mental health or behaviorual problems; non-disclosure and secrecy both within and outside of the family; and resiliency factors for children, youth and families affected by HIV.

In discussing families affected by HIV, it is important to note the "social ecologies" linked to HIV (Gillard, Witt & Watts, 2011, p. 1509) as well as the difficulty in separating these factors from the HIV illness itself in discussing their impact on mental health and functioning. These factors may include substance use, poverty, racism, and unstable family structures; it is therefore important to compare HIV-affected children and youth to demographically-matched populations (Betancourt, Meyers-Ohki, Charrow & Hansen, 2013; Steele, Nelson & Cole, 2007).

Children and youth affected by HIV may be at greater risk for a variety of mental health problems. For example, a 2011 study that sampled 416 children and youth found a prevalence rate for diagnosable mental illness of 38% for children and youth exposed to but uninfected by HIV, and 29% for HIV-positive children and youth (Malee et al., 2011). Children and youth whose caregivers had psychiatric disorders, problems with limit-setting, or health-related disabilities were found to be more at risk for mental health problems, as were children with a younger age and with a lower IQ (Malee et al., 2011). Marhefka et al. (2009) also found an elevated prevalence rate of emotional and behavioural problems among HIV-positive youth. In their sample of 164 youth, 31% displayed symptoms of psychopathology; 27% of these youth had received no mental health care or treatment. These extremely high prevalence rates may be contextualized by the finding that HIV can alter normative family processes, such as the child's transition into adolescence and his/her family's ability to foster autonomy and independence in spite of illness (Kang, Mellins, Ng, Robinson & Abrams, 2008, p. 277).

In 2006, Rotheram-Borus, Stein and Lester conducted a randomized controlled trial with 288 HIV-positive parents and their adolescent children in New York City. Adolescent outcome was measured in terms of emotional distress, substance use, and risky sexual behaviours. Adolescents who lost a parent to HIV were significantly more at-risk, whereas those who reported a strong parent-child bond experienced more positive outcomes. The authors conclude that interventions that support and model appropriate parent-child interactions may be especially effective in promoting positive outcomes for adolescents with HIV-positive parents.

Disclosure within the family unit is an important process that is often difficult to navigate. In Bogart et al.'s sample of 33 American families with at least one HIV-positive parent, both parents and children frequently cited concerns about children experiencing stigma due to having an HIV-positive parent (2008). Due to this fear, many parents in the study chose not to disclose their HIV status to their children, with some viewing this as a protective mechanism. However, the authors note that this secrecy served to prevent family members from accessing HIV-related social support from outside the family.

Many HIV-positive children and youth who are aware of their status choose not to disclose their status to their friends, for fear of stigma or rejection (Kang, Mellins, Ng, Robinson

& Abrams, 2008; Fielden, Chapman & Cadell, 2011; Shermann, Bonanno, Wiener & Battles 2000). In other cases, they may develop “two primary peer networks, one of which is aware of their serostatus and the other, which is not” (Kang, Mellins, Ng, Robinson & Abrams, 2008, p.231). In some cases, youth may make a calculated decision about disclosure, weighing the potential rejection and discrimination against the potential for additional sources of support and wellbeing (Fielden, Chapman & Cadell, 2011). Service providers may serve as “mediators between the silence and telling of the ‘secret’, both between parents and children, and between youth and significant others (Fielden, Chapman & Cadell, 2011, p. 273).

In a study of 64 caregiver-child dyads, Sherman, Bonanno, Wiener and Battles found that children who had disclosed their status to friends experienced better health than those who had not, as measured by an increase in CD4 cell count (2000). This held regardless of the child’s age or medication regime. There was no statistically significant difference in self-concept or psychological well-being in children who had disclosed versus those who had not. This supported previous evidence that disclosure of HIV status typically has a positive impact on physical health. The authors hypothesize that this finding may be explained by the burdensome “inhibitory processes” required to keep physical illness a secret, as well as the possibility that disclosure may promote “reschematization”, or the individual’s ability to integrate his/her illness into a more adaptive cognitive structure (2000, p.245).

Recent research points to the minimization of the impact of HIV on children and youth due to the efficacy of modern HIV medications, high-active anti-retrovirals (HAART). Di Risio, Ballanytne, Read and Benadayan’s 2010 study of 9 HIV-positive youth in Toronto and Ottawa revealed that for the large part, youth were not medically affected by HIV. Youth discussed a number of salient support system: access to anti-retrovirals; supportive role models – usually parents; attendance in HIV support groups for youth; and a self-identity that positioned themselves as someone with expert knowledge of HIV. In addition, participants' long-term dreams and ambitions were not found to be significantly affected by their HIV-positive status (2010).

As demonstrated by this research, many children, youth, and families are highly resilient in the face of HIV. In a 2013 literature review and meta-analysis of resilience in HIV-affected children, Betancourt, Meyers-Ohki, Charrow and Hansen found three categories of resiliency factors. Among individual factors of resilience, coping strategies, self-esteem and hope for the future proved most significant. At the family level, resiliency factors include parental monitoring, secure attachment, and family coping in response to parental impairment. Lastly, community resilience factors include access to education, social support and information sharing, peer support, and participation in mental health interventions.

Literature Review: Part II

This section will explore recreational experiences and camps for individuals affected by HIV as a way to address the social problems summarized above, included lack of social support, stigma, and secrecy surrounding the illness.

HIV and Recreation

One intervention that is often proposed for stigmatized populations who lack psychosocial support is group recreational activities. This section explores recreational activities for individuals affected by HIV, focusing on accessibility of recreational activities as well as on the benefits derived from participation: sense of control, social support, and the navigation of both individual and group identity.

Caroleo (2001) contends that mainstream recreation and leisure activities may be difficult to access for individuals living with HIV, as "the stigmatization associated with an AIDS diagnosis affects one's ability to socialize" (p. 156). In addition, the various medical and psychosocial factors linked to HIV – physical factors, such as loss of strength and endurance and fatigue; mental factors, such as loss of short-term memory or concentration, and depression; and structural factors, such as job loss, decrease in income, and complicated medication regimes (Sausser, Dattilo & Kivel, 2000) – may result in a general "neglect" of leisure, as leisure activities become low priorities in the face of the daily challenges of HIV (Caroleo, 2001, p. 156) or simply become less enjoyable (Sausser, Dattilo & Kivel, 2000).

Caroleo (2001) posits that recreational activities may nevertheless benefit individuals living with HIV in four ways: by increasing a sense of control and self-determination; by directing energy into positive outlets; by providing continuity of social or group activities after diagnosis; and by fostering social support systems (p. 156). Caroleo derived four main findings from his qualitative review of a drop-in recreational program for people with HIV in New York: participants perceived that their human needs were being “stripped away” due to their HIV status, and that these needs were filled through the recreation program (p. 160); the social support afforded by the recreational program was instrumental in decreasing participants’ anxiety; participants developed a sense of community and of family; and participants were given “a purpose in life and a reason to get up and get out of the house” (p. 163).

In their qualitative study of eight HIV-positive individuals engaging in a variety of leisure activities, Sausser, Dattilo and Kivel (2000) found similar benefits to those listed by Caroleo (2001), with an added benefit of the negotiation of “perception of self” through leisure activities (2000, p. 48). The authors note that participants navigated the formation of self-identity through participation in leisure activities, which were particularly salient in forming self-concept as many participants had experience a decrease in paid employment or informal social support networks. Therefore, participating in recreational programming provided participants with a strong sense of accomplishment and pride.

Caroleo (2001) and Kelly (2010) also point to the importance of group identity through group and recreational activities for individuals living with HIV. Caroleo labels this the “same boat” phenomenon that unites participants despite considerable diversity (2001, p.163). This is echoed in Kelly’s discussion of group work and HIV, with the finding that the single bond of HIV status is sufficient to create a community, as the group is “united by the desire to find a safe place to deal with AIDS in [their] lives” (2010, p. 284).

Medical Camps

As described earlier, very few scholarly articles exist on HIV-specific camps, perhaps because HIV remains a relatively “new” illness. However, a significant array of literature is available on more general medical camps and their effects on social support and sense of belonging. General medical camps differ from HIV-specific camps in a few salient ways: increased stigma associated with HIV versus, for example, cancer; the role of disclosure and non-disclosure with HIV that may not be present for more visible illnesses or disabilities; and the diversity of the populations that are disporportionately affected by HIV. However, salient themes for HIV-specific camps – social support, sense of community, and reprieve – are likely also salientfor more general medical camps. One limitation here is that the scholarship on medical camps focuses primarily on camps for children and youth.

Henderson, Bialeschki and James note in their review that the design of medical camps reflects two different philosophical approaches to the meaning of camp for individuals affected by illness: camps created by clinicians tend to focus on health and treatment outcomes, while medical camps created by camp professionals tend to focus on preserving the "sanctity of the camp experience", focusing much less on the illness itself (2007 p. 763). Prior to the widespread development of medical camps in 1980's, there were concerns that segregating campers by illness could actually lead to detrimental effects (Balen, Fielding & Lewis, 1996; Goodwin & Staples, 2005). These concerns have not been empirically supported by the literature, which has consistently found overall positive benefits of these camps. This highlights the need for research on less traditional forms of psychosocial treatment, such as camping experiences. It is important to note that much of the available literature focuses on camps for illnesses with much less social stigma than HIV (e.g. juvenile diabetes, cancer, and cystic fibrosis).

In their study of 27 adults who had attended a cerebral palsy camp, Dawson and Liddicoat (2009) found that camp created a therapeutic community, defined by the authors as "an informal and communal atmosphere that is homelike rather than institutional" (p. 21).

Participants identified that “camp is home” (p. 16), affording them a sense of belonging, the opportunity to be respected members of a community, and the chance to develop friendships. Participants also identified the importance of mutual support, with the authors finding that camp allowed campers to “play a therapeutic role as auxiliary therapist in which they influence the behaviours of others” (p. 21). Based on these findings, the authors recommend the camp experience as a therapeutic modality for building community and thus enabling growth, as drawn from sense of community theory.

In a study of 15 adult participants of a disability sports camp, identity formation was a key outcome of the camp experience (Ashton-Shaeffer, Gibson, Autry & Hanson, 2001). Participants reported facing “surveillance” from the mainstream in their daily lives (p. 104), with their identity dominated by their disability. Stigma was located as central in the process of negative identity formation. Camp, in turn, afforded participants the opportunity to construct an alternate identity and to engage in resistance against the stereotypes of disability that permeated their self-identity. This more positive sense of self was facilitated through opportunities for participants to engage in physical activity, form supportive relationships with other campers, and “be themselves in a context that accepted their abilities and disabilities” (p. 110). Similar findings were reported in Goodwin and Staple’s interviews with 9 youth who had participated in summer camps for youth with disabilities (2005). Like adults, youth engaged in a significant process of identity formation through group discussions and activities at camp. The camp provided what the authors termed a “therapeutic landscape”, defined as a “personal, physical and social landscape” with “restorative qualities for individual, environmental and social reasons” (p. 173).

In their 2009 study of 22 participants at a camp for children with asthma, Nichols, Williams and MacLusky, 2009 also emphasized the importance of illness-specific education. The asthma camp focused on teaching children self-care and health management, with activities and education tailored to their shared illness. This focus on health as well as illness was part of a larger balance between “normalizing the camp experience yet offering targeted health management” (p. 218).

Other camps for children with illness focus less on the illness, with a primary emphasis on the development of supportive staff-camper, and camper-camper, relationships. For example, Thomas and Gaslin’s study of a camp for children with hemophilia identified enhanced independence and self-worth as the main outcome of the camp, a process the authors termed “camping up” self-esteem (2001, p. 253). Hill and Sibthorp’s 2006 study of autonomy support at a camp for juvenile diabetes located relationship formation and mutual support as the main outcome of the camp, with relatedness viewed as a “basic human need” (p. 119). Sawin, Lannon and Austin studied 20 campers at a camp for children with epilepsy, where the focus was recreational with the main goal to “allow kids to be kids” (2001, p. 59). While no significant differences in attitudes about epilepsy were found in the overall sample, children with more frequent seizures nevertheless reported a more positive attitude about the illness after attending camp.

HIV-Specific Camps

The scholarly literature on camps for individuals affected by HIV is scant, with very few recent studies available (Gillard, Witt and & Watts, 2011; Swartz, 2009). Hrenko (2005) describes her experiences as a volunteer art therapist at Camp Dreamcatcher, a camp for children with HIV on the East Coast of the United States, focusing on her integration of art therapy activities into the camp setting, such as creating memory-boxes, drawing favourite memories, and creating a group mural. Hrenko's article – like much writing on HIV-specific camps – is informative but purely anecdotal, offering little in the way of empirical scholarship on these camps.

Pearson, Johnson, Simpson and Gallagher (1997) provide a detailed description of the Hole in the Wall Gang Camp, a camp for hemophiliacs that began offering a special "Immunology Session" for children with HIV in 1990 (p. 710). Written in 1997, this article focuses on the medical management of AIDS and the minimization of risk of transmission in a camp setting, reflecting the prevalent discourse of HIV/AIDS in the mid 1990's. In 2005, a similar article by Bergman, Kinsella, Kenny, Barbor and Zeltzer examined the safety level of summer camp for immunodeficient, HIV-positive and hemophiliac children. The authors found no differentiation in medical needs or visits to the nurses' cabins for HIV-positive children versus their non-immunodeficient counterparts.

Apart from these articles, only three studies were found in which the authors studied process or outcome in camps for individuals affected by HIV. Gillard, Witt and Watts (2011) undertook a study of a recreational camp program for youth with HIV in the Southern United States. The authors found that this camp experience addressed several challenges faced specifically by youth with HIV, such as dilemmas around disclosure and problems linked to the demographics associated with HIV, such as poverty, parental drug use, and change in primary caregivers. The authors found three main outcome themes of this camp: the formation of "caring connections" for campers, thereby breaking the isolation; "feeling reprieve and experiencing recreation", which created a sense of freedom; and increasing youth knowledge, skills and attitudes in areas including problem-solving, communication, and management of anger and conflict. (p. 1515).

The centrality of staff-camper relationships was highlighted, with the authors noting that this factor was more significantly associated to the outcomes than were the camp activities themselves. This echoes the authors' previous study examining the organizational culture at a camp for youth with HIV in Texas, in which they found that "camp can be understood as being contingent on relationships between people" (Gillard, Witt & Watts, 2010, p. 63). In this study, the authors discussed the need for camp goals to reflect a balance of recreation and education. The authors found that while counsellors presented with differing levels of knowledge and understanding of HIV, with some understanding little about, for example, the processes around disclosure. Some counsellors displayed an over-emphasis on the "fun" aspects of camp; however, in this camp, the educational activities were led not by counsellors, but by a team of medical and psychological staff (Gillard, Witt & Watts, 2010).

Kmita, Baranska and Niemiec (2002) compared clinical outcomes for Polish families affected by HIV who received a therapeutic camp intervention, a standard medical/clinical intervention, or both. The therapeutic camp intervention consisted of a one-week camp for children and parents, which included therapeutic interviews with parents and children separately, group sessions for children, and support groups for parents. The authors found that the families who received both types of interventions displayed the most positive outcomes, operationalized as "better emotional functioning of parents and children, more people in a family's social network, less silence about those who died, more differentiated and flexible coping" (p. 283). The authors found that the group experiences facilitated by camp were particularly powerful: "parents could share their experiences, discuss important problems and provide each other with support and respect"; and children "could safely reveal or express such emotions as anxiety, anger or a feeling of loss" (2010 p. 283). The authors conclude that medical intervention for HIV-affected families can be made more effective when supplemented with non-medical interventions, with more research needed on effective collaboration between these types of interventions and service providers.

An abundance of 'grey literature' about HIV-specific camps, written by HIV/AIDS service organizations and the camps themselves can be found online. Writing for The Body, an online HIV/AIDS resource, Foster notes that HIV-targeted camps' goals are typically explicitly either medical or non-medical, and typically place heavy emphasis on privacy, confidentiality and anonymity (2000). The National Abandoned Infants Assistance Resource Center (NAIARC) in the United States notes that camps for families with HIV vary in structure, from camps that are part of a time-limited specific therapeutic program and camps that operate as a component of a larger, year-round service for families, to stand-alone summer camps (2003). NAIARC also notes that most HIV camps operate in collaboration between medical and mental health professionals, who often serve in a volunteer capacity.

Swartz (2009) provides a semi-scholarly overview of Camp Sunrise, Camp Dreamcatcher and Camp Laurel, interviewing each camp's director and briefly describing each camp's mandate. Camp Dreamcatcher was founded in 1994 in Pennsylvania by a Gestalt psychotherapist, and underscores the importance of recognizing the "many social inequalities – racism, poverty, lack of access to services, violence and prejudice – that enable the AIDS epidemic to thrive in the first place" (p. 211). Camp Sunrise was founded in 1995 in Connecticut and has a categorically recreational goal of allowing children to enjoy themselves without "the fears and worries they shoulder outside of the camp week" (p. 211). Camp Laurel, founded in

1992 in California, has now expanded to offer camping programs throughout the United States. All three camps now also offer adolescent programs as well as leadership programs for graduated campers.

HIV Camping Programs Offered in North America

Despite the abundance of HIV/AIDS community agencies and recreational programs, there are relatively few camps for individuals and families affected by HIV. To assess the mandate and target populations of available programs, the author has compiled a table of HIV camping programs in Canada and in the United States (see Appendix I). The list was compiled using snowballing, general Internet search engines, and websites targeted to HIV-positive individuals. While there are a variety of "retreat" programs for adults exclusively, these were excluded from the review of existing camps, to maintain a focus on structured, recreational, immersive experiences for children and/or adults affected by HIV. This drew from Henderson, Bialeschki and James' definition of camps as "organized experiences in group living in the outdoors that use trained leaders to accomplish intentional goals" (2007, p. 755).

An analysis of the available camp programs for individuals affected by HIV in Canada suggests several important observations. The first is that there are extremely few HIV camps in Canada: five camps for individuals with HIV were found to be offered in Canada, one of which (Camp Laurel) has its pilot year this summer, 2013. This is compared with thirty-four camps known to be offered in the United States, several of which provide more than one camp session and/or camp location per year. As previously noted, the national prevalence of HIV in Canada is estimated to be roughly 65,000 (PHAC 2010), compared with an estimated prevalence of 1,148,200 persons in the United States (Centers for Disease Control and Prevention 2013). Therefore the discrepancy between the unique number of programs offered in Canada and in the

US appears to be consistent with the HIV prevalence rate; however it is unknown if the total number of camp spaces afforded by these programs is also consistent with each country's prevalence rate.

Second, many of the available camp programs, particularly in the United States, are operated in conjunction with a local Christian church or diocese. This has implications for the nature of the camp experience as well as the accessibility of the camp to campers who are not Christian. It is reminiscent of the early days of social service programs, where the bulk of programs were offered on a charitable basis by churches or religious organizations. This may be indicative of the fact that the need for HIV-oriented programs has existed for a relatively short time – thirty years. This time span for the development of recreational programming is rendered even shorter when one considers that for the bulk of these thirty years, HIV-related programming was focused on palliative care and bereavement, with community-wide devastations caused by AIDS-related deaths.

The third observation is that the case under study in this project, Camp Snowy Owl, is quite unique in the nature of its camp. All other camps, with the exception of Camp Wendake, are eligible only to children and youth, or to families with children. HIV-positive adults who do not have children are eligible only to participate in retreats, which often last for a weekend and are qualitatively different than the camp experience. Camp Wendake and Camp Snowy Owl, however, are accessible to families with children, couples, and single adults. This makes Camp Snowy Owl an especially compelling camp for this case study.

Methods

Theoretical Framework

The theoretical framework chosen for this study is social constructivism, characterized as a view in which "individuals seek understanding of the world in which they live and work" (Creswell, 2013, p. 24). Social constructivism is characterized by the recognition of "multiple realities", the emphasis placed on values, and the inductive process of generating a theory based on the views of those affected by the problem under study (p. 36). It recognizes that the subjective meanings that participants derive from their situations "are formed through interactions with others… and through historical and cultural norms" (p. 25).

In working with a stigmatized social issue such as HIV, the researcher must take extra caution that his or her research does not further stigmatize the problem or misrepresent the population affected by the problem. For example, Link and Phelan (2001) note the problematic dynamic wherein the very definition and understanding of stigma is typically defined by those who do not belong to the stigmatized group under study. The importance of accurately representing a population by directly reporting their views makes social constructivism an especially appropriate theoretical framework for this study. At the same time, it is acknowledged that the very process of research creates a "co-construction" of reality between the researcher and the participants (Creswell, 2013, p. 36), and that attempts to directly report the views of participants will likely be altered by this co-construction. To mitigate this, the author has made efforts to "position" herself (p. 25) within this study, making explicit her role as researcher and her personal biases.

Additionally, the author has made efforts to reflect on her own social location relative to those of the participants. Many campers and volunteers at the camp under study belong to groups that experience forms of oppression: refugees, immigrants and people of colour; individuals and families with low socioeconomic status; sexual minorities; street-involved individuals, etc. As such, the researcher is aware of power dynamics at play. This approach integrates elements of critical theory, in which “researchers need to acknowledge their own power, engage in dialogues, and use theory to interpret or illuminate social action” (Creswell, 2013, p. 30).

In discussion of social location and positionality, it is important to note that the researcher has acted as a volunteer with this camp’s child and youth programming for the past three years. This prior involvement of the researcher required additional caution on her part in the processes of obtaining ethics approval, planning the research design, and collecting the data. Prior to and while conducting research, the researcher engaged in a praxis of reflexivity, or “the role of the researcher’s I”, to assess how to best minimize personal bias (Mauthner, 2000, as cited in Daley, 2010, p. 69). To ensure ethical accountability, the researcher emphasized at numerous points in the study – e.g. recruitment, consent forms – that identifiable information gained from the study would remain confidential and not be relayed to the camp’s team of volunteers.

It is believed that the researcher’s position as an “insider” was invaluable in facilitating access to the camp, in enhancing her integration as a participant-observer, and in mitigating some of the challenges associated with camp research. For example, in their review of camp literature, Henderson, Bialeschki and James note that one significant challenge in camp research is the risk of the alteration of the camp experience by the “intrusiveness” of having an outside researcher participate (2007, p. 757), a risk that is minimized in this study by the researcher’s prior involvement with the camp. Additionally, the following are examples of studies on HIV-related camps where one or more of the researchers has acted as a camp volunteer, suggesting that the social dynamics associated with HIV may make it especially appropriate for participant-observer research: Gillard, Witt and Watts, 2010; Gillard, Witt and Watts, 2011; Hrenko, 2005; and Pearson, Johnson, Simpson and Gallagher, 1997.

The author was acutely aware of the need to separate her perceptions and experiences of the camp as a former volunteer from her perceptions of the camp as a researcher. While this can be considered to be reflexivity, or “reflection in action”, the researcher also took care to build critical reflection, or “reflection on action” into the phases of data analysis and write-up (Daley, 2010, p. 69-70). These two processes are linked and are to be used concurrently, with both emphasizing “a critical stance toward power, knowledge, and self” (Daley, 2010, p. 69). Both reflexivity and critical reflection were facilitated through the use of both field notes.

Methodological Approach

This study uses the case study approach. The objective of this study is to gain an in-depth understanding of the operation and outcomes of the camp described below. The case study approach is characterized by the use of multiple sources of information, the inclusion of a comprehensive case description, and the identification of themes within the case (Creswell, 2013 p. 97). This case represents an intrinsic case, defined as “a case that has unusual interest in and of itself”, due to the relative rarity of such camps in Canada (p. 98). The case study approach is most appropriate for this study due to its singular emphasis on a very detailed analysis of one case.

Objectives of the Study

The main objective of this study is to explore how the camp is experienced by volunteers and campers alike. A secondary objective is to explore the role of three different concepts that may be at play in this camp: stigma, social support, and sense of community.

A commonly cited ethical concern in qualitative research is the lack of reciprocity, or researchers who “use participants by gathering data and leaving the site without giving back” (Creswell, 2013, p. 58). The notion of reciprocity has been built into the design of this study, as a major objective of the study is to undertake an objective consideration of the strengths and areas of improvement for this camp. In the current climate of stringent funding and the need to provide evidence of effectiveness, this research may prove useful for the camp’s application for funding in forthcoming years. In addition, evaluation is an integral aspect of program development and operational planning, with the majority of accredited camps in North America undergoing regular program evaluation (Henderson, Bialeschki and James, 2007).

Overview of the Case

The present study aimed to examine a one-week recreational, residential camp, Camp Snowy Owl, for individuals and families affected by HIV. In 1995, the Anglican Diocese of Huron, Ontario established a one-week residential camp for individuals and families affected by HIV in Ontario: Camp Wendake. This pioneer program was extremely successful, and by 2008, the camp could no longer accommodate all applicants (Camp Wendake, 2012). In 2010, applications were closed to residents of some parts of Ontario. In response, the Snowy Owl AIDS Foundation created Camp Snowy Owl, modeled after the original camp, for individuals living in Ottawa. This one-week camp has occurred in July or August every year so far from 2010-2013 at a camping facility in rural Ontario. The property is on the waterfront, with a small beach on a river, cabins grouped individually and separately, and multiple common areas including a ‘rec hall’, a large screened-in room, and a dining hall.

This camp is attended by a variety of individuals including single men and women with historic or active substance use, GLBTTQ individuals, heterosexual couples with and without children, and African-Caribbean individuals (these groups are, of course, not mutually exclusive). The camp is financed by fundraising initiatives through the Snowy Owl AIDS Foundation and is governed by a steering committee composed of camp volunteers, HIV-positive community members, and professionals involved in HIV-related community organizations in Ottawa. The camp's schedule includes daily time at the waterfront, arts and crafts activities, opening and closing ceremonies, a memorial ceremony, a talent night, and many activities for children and youth.

In accordance with the Ontario Camping Association's regulations, all campers' and volunteers' medications – including over-the-counter medication – are kept in the nurses' cabin, dubbed 'Club Meds' by the camp. 'Club Meds' is overseen by a registered nurse who has been supported by various medical school students over the years. Campers and volunteers are responsible for supervising their own medication regimes and for coming to Club Meds to take their medications, although the medical volunteers will informally remind some campers who require extra support. Club Meds is also responsible for attending to ill and injured campers.

The camp's values include the "uniqueness of each individual", "choice in program participation", "self-directed health management", and "fostering personal growth" (Camp Snowy Owl, 2011). The mission of the camp is

> to provide a safe, welcoming residential camping experience for persons living with HIV as well as their chosen families. We strive to honour diversity in age, gender, race, sexual orientation, ability, culture, spirituality, and economic state. (Camp Snowy Owl, 2013, p. 9)

Participants

The participant population in this study is confined to the campers and volunteers attending the camp in the year under study (2013). Campers are recruited through local HIV/AIDS service organizations, while volunteers are recruited largely informally, through existing networks of HIV advocates, volunteers and community members. As previously discussed, the campers and volunteers are a diverse group; efforts were made to ensure that the interview participants represented this diversity.

Recruitment

Past efforts by the camp to collect post-camp feedback questionnaires proved largely unsuccessful, perhaps due to the somewhat transient nature of some campers' lives. As such, the decision was made to undertake the entirety of the data collection during the week of camp itself. Volunteers arrived a day before campers. The researcher gave an overview of the research process to the volunteers to obtain their consent for the researcher to observe and participate in the preparation activities for the camp. The researcher made a similar speech to the campers when they arrived the next day.

Data Collection

Three sources of data were collected. The first source of data was participant observation. The researcher's pre-existing participative role in camp allowed her to engage in in-depth participation in, and observation of, camp activities. The researcher's observations focused on the structure and activities offered by the camp as well as the organizational processes, such as staff meetings and mealtimes. Field notes were recorded during the camp experience to reflect the observations of the researcher.

The second source of data collected was semi-structured interviews with campers and volunteers. Interviews lasted approximately 45 minutes. Following the recruitment speeches as described above, many volunteers and campers wishing to partake in individual interviews approached the researcher. The level of interest in participating in interviews was overwhelmingly high. Most interview participants were given a $20 Wal-Mart gift card as an honorarium.[1] Twenty-six interviews were conducted, 10 with volunteers and 16 with campers.[2] Within these 16 camper interviews, four were with adolescents. All but two interviews were audio-recorded, with the consent of interview participants. Six interviews were completed in French for the ease of Francophone participants.

The timing and location for the interviews was determined primarily by the participant – within logical constraints of the researcher's schedule – to promote the participant's ability to determine the parameters of research. For the same reason, participants were asked to choose their own pseudonyms. Within the pool of interview participants, efforts were made to ensure representation from campers and volunteers who have attended camp in previous years. In doing so, the goal was to elicit retrospective insights from these campers, and to ensure that the psychosocial benefits are not restricted to the time period in which participants are physically at the camp.

The third source of data collected was an anonymous, self-administered, 10-15 minute questionnaire administered to all interested campers and volunteers on the last day of the camp. All participants who completed the questionnaire received a $10 gift card (either for Wal-Mart or for Tim Horton's) for their time, regardless of whether they had also completed an interview[3]. Forty questionnaires were completed, with 15 completed by volunteers and 25 completed by

---

[1] $1013.00 was received for this project as part of the Tryna Rotholz Award from the McGill School of Social Work (see Appendix II. Budget)

[2] The researcher had prepared to conduct 15 interviews. As there were well over 15 participants expressing strong interest in conveying their thoughts on the camp, an ad-hoc decision was made to extend the number of interviews to all those interested in order to respect the expressed wishes of campers hoping to "give back" to the camp by providing feedback. Those who expressed interest after the initial 15 participants had been signed up were informed that they would be welcome to participate, but that the available honoraria ($20 Wal-Mart gift cards) had been all allotted. All but two participants responded that they wished to provide an interview regardless

[3] After surveys were completed, additional $10 gift cards remained. The researcher made the choice to give two of the leftover $10 gift cards to the interview participants who had not initially received honoraria. In the end, all interview participants did receive the $20 honoraria, with the exception of two volunteers who refused to accept this.

campers. Within these 25 camper surveys, 7 were completed by youth. Ten of the 40 surveys were completed in French.

Response rates for the surveys differ when one compares the number of participants present at the beginning of camp, and those present at the end of camp.[4] Eighty-three percent of all campers and volunteers who began the week of camp completed the survey, while 100% of all campers and volunteers who completed the full week of camp – i.e. who were present on the survey day -- completed the survey. This remarkable response rate may be interpreted as a reflection of the participants' engagement in this research process, and was likely facilitated by the researcher's pre-existing connection to the camp.

Data Analysis

Data was subjected to a "within-case analysis" (Creswell, 2013, p. 101), using a holistic approach to highlight the themes of the case. Surveys were coded for key words and themes that were then tabulated and summarized. Interviews were transcribed, with salient sections transcribed verbatim, and less salient sections transcribed more loosely. Interviews were coded using a coding tree created after transcriptions were completed.[5]

---

[4] 7 campers as well as 1 volunteer left camp before the end of the week (6 of these cases were due to transportation arrangements, with 2 campers electing to leave for other reasons). As such, these 8 participants were not available to complete the survey on the last day of camp.

[5] See Appendix III Coding Tree

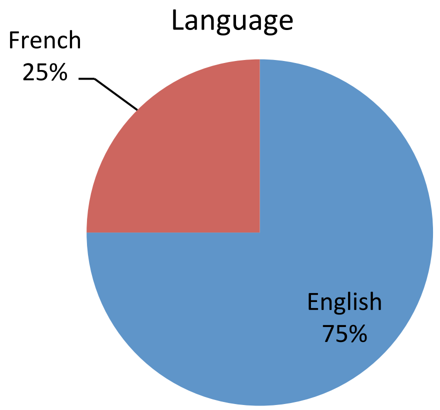
Results

This section outlines five outcomes: the camp as a “family”; the camp as a unique and diverse, yet cohesive community; campers’ and volunteers’ experience of navigating their identity in a setting in which their HIV status is normalized; the psychological continuity of the camp experience beyond the single week that camp is held; and altered family processes while at camp and after the camp session. The sixth result is a series of organizational processes that the researcher recommends that the camp revise. The survey results are presented separately; the second section, main themes, summarizes data from the interviews as well as from the survey.

Survey Results:

The survey results are summarized in a five-page report to the camp, as the survey more specifically targeted program evaluation (see next page).

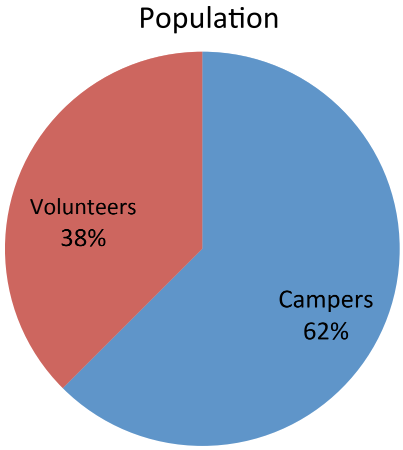
Survey Results



Total number of surveys completed: 40

Language
- 30 in English, 10 in French

Volunteers
- 16 at beginning of week, 15 present on survey day
(One left early due to a previous commitment)
- Number of volunteer surveys received: 15
- Response rate of those who completed the camp: 100%
- Response rate of those who began the camp: 94%

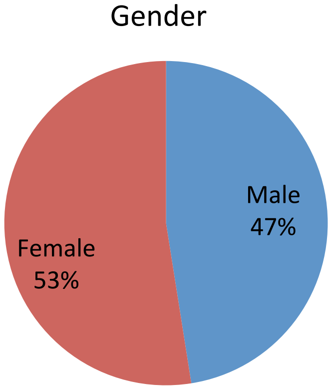


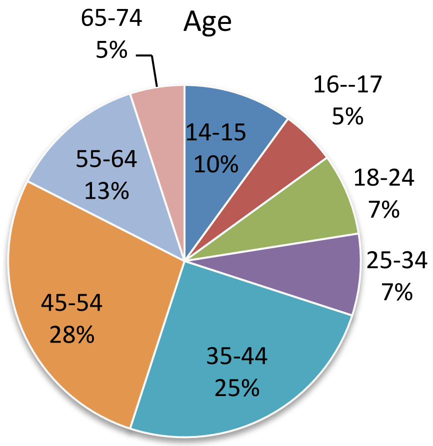
Campers
- 44 at beginning of week, 32 of whom were age 14 and up
- Therefore 32 eligible participants began the camp
- 25 eligible campers completed the camp
(5 left early due to alternate transport, 2 elected to leave)
- Number of camper surveys received: 25 (18 adults plus 7 youth)
- Response rate of those who completed the camp: 100%
(Including 100% of eligible youth)
- Response rate of those who began the camp: 78%

Overall Response Rates (Campers and Volunteers Combined)
- 100% of all participants who completed the full week of camp completed the survey
- 83% of all participants who began the full week of camp complete the survey

Gender
- 19 males
- 21 females

Ages
- Age 14-15: 4
- Age 16-17: 2
- Age 18-24: 3
- Age 25-34: 3
- Age 35-44: 10
- Age 45-54: 11
- Age 55-64: 5
- Age 65-74: 2

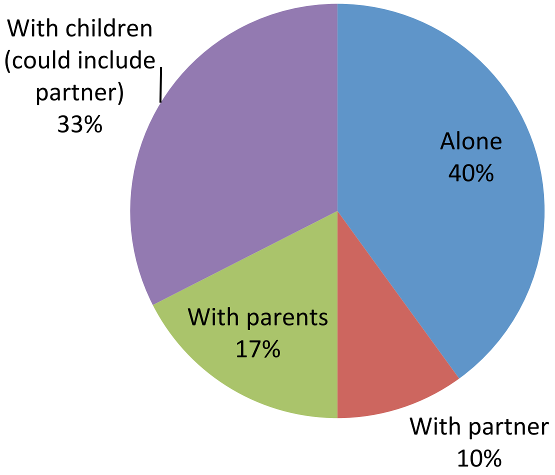




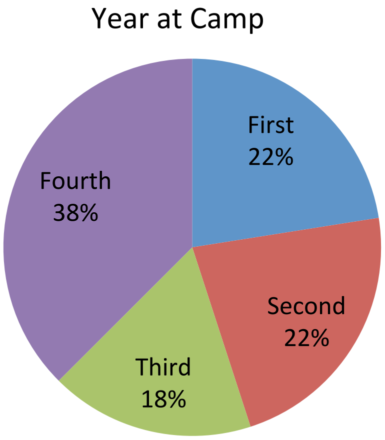
> "I get to meet other individuals who live with HIV and we have formed a community of diverse communities. Otherwise I would not get this back at home" – Camper

Attendance
- Alone: 16
- With partner: 4
- With parents: 7
- With children: 13

> "It is a time and one of the only times in the summer where my HIV community gets to hang and enjoy being in nature" – Camper

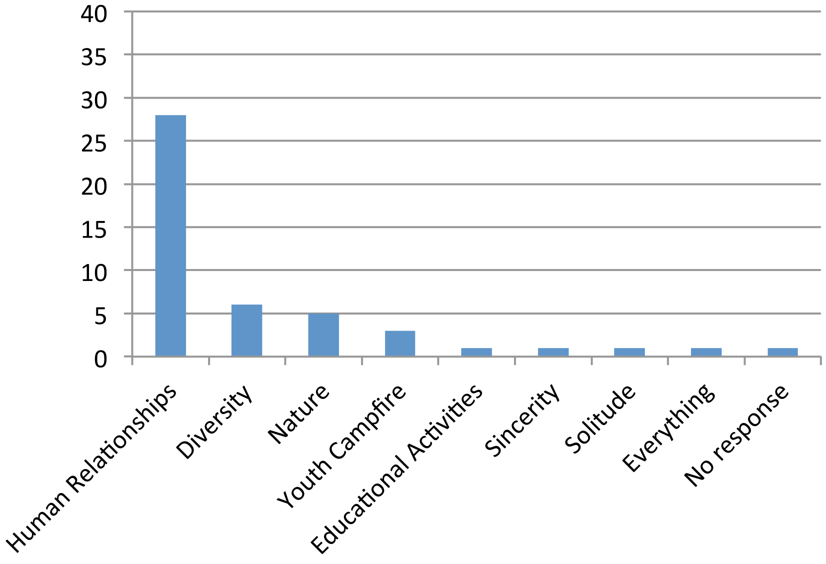


Year at Camp
- First year: 9
- Second year: 9
- Third year: 7
- Fourth year: 15



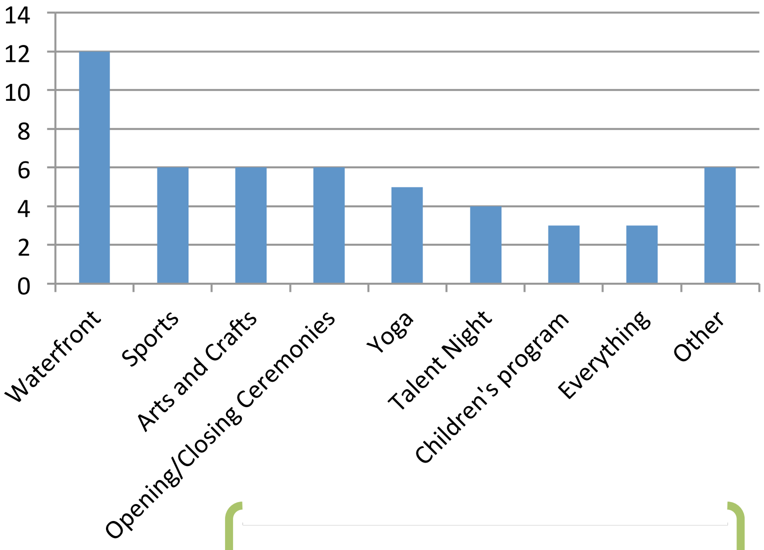
> "Une fois par année, moi aussi je suis sortie de chez moi, une semaine de vacances, trouver une grande famille que j'ai perdue, amour et la joie de vivre" – Camper

Favourite Thing about Camp
(Open-ended question, more than one response allowed)
- Responses specifically including the human relationships (family, friends, campers): 28
- Response including camp's diversity: 6
- Nature: 5
- Youth campfire: 3
- No response: 1
- Educational activities: 1
- Sincerity: 1
- Solitude: 1
- Everything: 1



> "The community of family that withstands a year apart and picks up right where it was left last year" – Volunteer

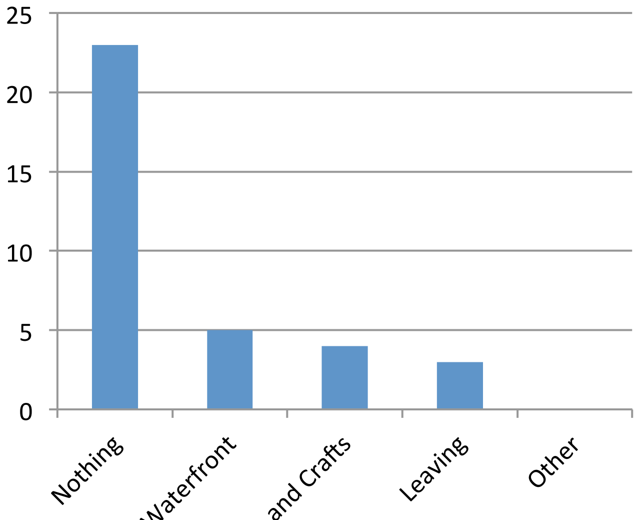
Most-Enjoyed Camp Activities
(Open-ended question)
- Waterfront: 12
- Sports: 6
- Arts and crafts: 6
- Opening/closing ceremonies: 6
- Yoga: 5
- Talent night: 4
- Children’s program: 3
- Everything: 3
-Other: 6



> “The beach – a place of nature and beauty and good conversations” – Volunteer

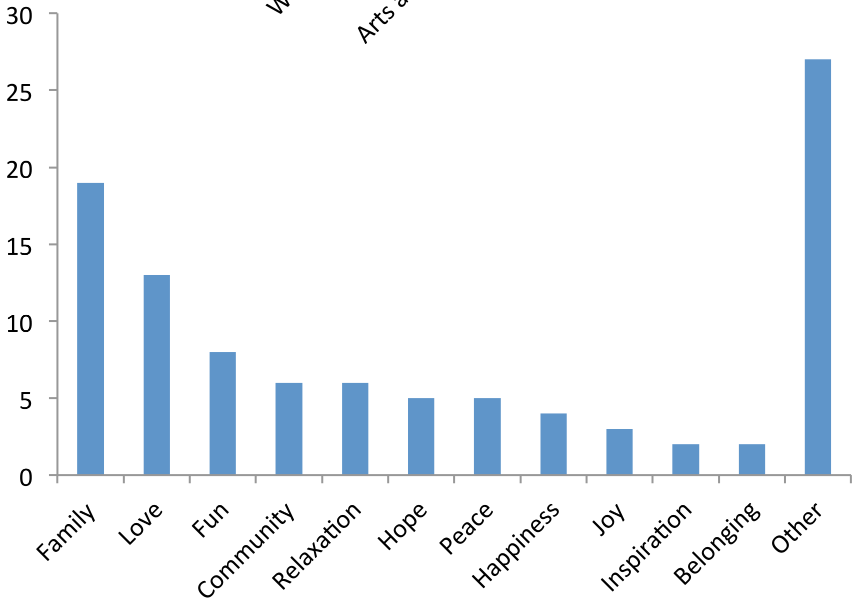
> “I like creating memories with crafts” – Youth Camper

Least-Enjoyed Camp Activities
(Open-ended question)
- Nothing: 23
- Waterfront: 5
- Arts and crafts: 4
- Leaving: 3
- Other: 5



> “HIV women’s night as it appreciates the women living with HIV but fails to recognize everyone else at camp with similar struggles. It also reveals to campers who is positive” – Volunteer

Words to Describe Camp
(Open-ended question, participants asked to list 3 words)
- Family: 19
- Love: 13
- Fun: 8
- Community: 6
- Relaxation: 6
- Hope: 5
- Peace: 5
- Happiness: 4
- Joy: 3
- Inspiration: 2
- Belonging: 2
- Other: 27



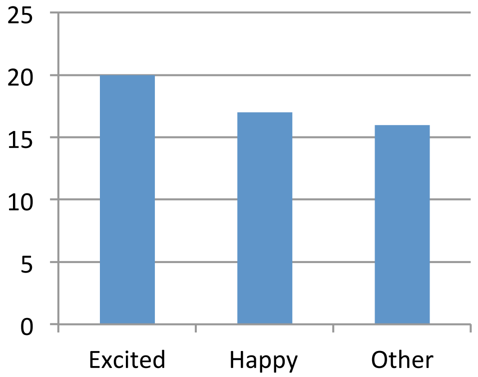
> “There is no judgment and even the loneliest people can have a family here” – Youth Camper

When I Think About Coming to Camp, I Feel

(Open-ended question)

- Excited: 20
- Happy: 17
- Other: 16

"Excité, enthousiaste à l'idée de rencontrer d'autres personnes vivant avec le VIH venant d'autres endroits" – Camper

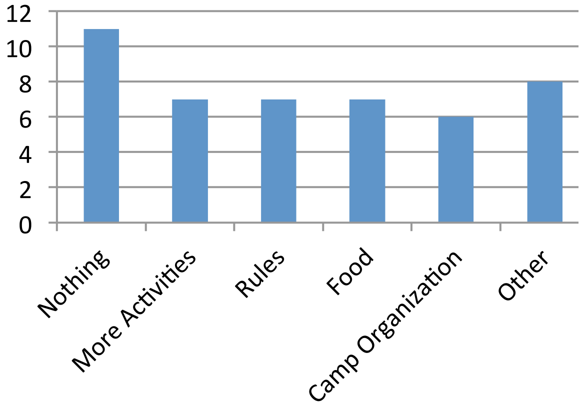


Areas to Improve

(Open-ended question)

- Nothing: 11
- More activities: 7
- Rules: 7
- Food/diversity: 7
- Camp organizational issues: 6
- Other: 8

"Adapter son menu en fonction de la diversité" – Camper



"More outlining of rules and possibly why some rules are there" – Camper

"A little more clarity about *why* rules are in place, more recognition of the campers as adults with the right to choices and individuality, less lumping everyone together with the same rules" – Volunteer

I Want Camp to Know That…

(Open-ended question)

- Expression of gratitude: 21
- Additional suggestions: 7
- Nothing: 8
- Other: 4

"You're locked in for life, man. You've created something beautiful that you will never be able to quit. We could have camp in the middle of a blocked-off street and you'd still see us there. This place is infinite." – Youth Camper

"This camp has created a new family for every camper and volunteer that is here. We have made this place our home." – Youth Camper

Rated Aspects of Camp: Mean Score

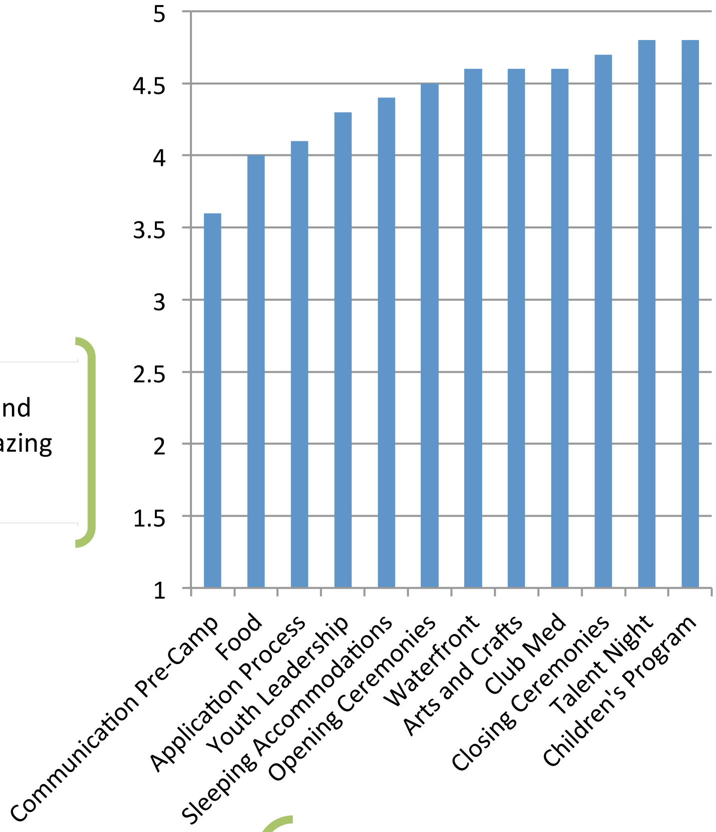
Scale of 1-5 (1= Unsatisfactory, 5 = Excellent)
- Application process: 4.1
- Communication pre-camp: 3.6
- Food: 4.0
- Club Meds: 4.6
- Sleeping accommodations: 4.4
- Waterfront: 4.6
- Opening ceremonies: 4.5
- Talent night: 4.8
- Closing ceremonies: 4.7
- Arts and crafts: 4.6
- Children’s program (as rated by adults): 4.8
- Youth leadership program (as rated by youth): 4.3

“L’équité de traitement, accessibilité, transparence par rapport à ses campeurs est très nécessaire” – Camper

“Did not know where and when the camp was until the day before… no computer. Needs more info for new campers” – Camper

“Peer support and involvement is crucial in developing a culture of respect, individuality, recognition and values of differences and maintaining independence” – Volunteer

“I expected more for the shadowing. They didn’t take it so seriously” – Youth Camper



Club Meds:

“It’s fun to take meds with friends” – Youth Camper

“Always willing to answer my questions” – Youth Camper

“Sitting around the campfire and talking about anything is an amazing therapy” – Youth Camper

“Signed confidential doctor’s forms are needed to see if it is appropriate for campers to attend (listing meds, vitals and allergies, mental health issues, addiction issues)” – Camper

“ The chance to feel part of a group that cares about me and my family” – Camper

“It is a family reunion.” -- Volunteer

“I love it here. Camp is my family and my home. Never stop camp because I will never stop coming back to family.” – Volunteer

Themes: Interviews and Surveys

The initial coding process for the interview transcriptions resulted in fourteen themes, each divided into sub-themes: camp as a family; sense of community; relaxation; gratitude; identity; continuity of camp beyond the week; safety; family processes at camp; culture; peer support; organizational processes; rules; other areas of improvement; and program-specific feedback.These themes were then condensed into thefollowing six findings.

Result #1: Camp as a Family

Sub-Theme #1: Comparison of camp to a family/ family reunion/ 'coming home'

Both campers and volunteers reported having formed supportive relationships at camp that were strong enough in depth and intimacy for most participants to describe camp as a family. As described by one volunteer in the survey, "the most remarkable thing about Snowy Owl is the love, support, caring, respect, openness of a family". When describing this sense of family, participants typically used metaphors. For example, one volunteer, 'Chasen' remarked, "The Snowy Owl community – it gives you lots of brothers, fathers, mothers, sisters, aunts, uncles".

In describing this sense of family, many campers acknowledged that they did not have a supportive family elsewhere. 'Adalène', a camper who was ostracized in her family of origin due to her HIV status commented that, "Une fois par année, moi aussi je suis sortie de chez moi, une semaine de vacances, trouver une grande famille que j'ai perdue, amour et la joie de vivre".

This feeling of family likely also contributed to the fact that several volunteers referred to camp as a "family reunion" or "coming home". As, 'Bethany' described, the camp membership has formed "a family that withstands a year apart and picks up right where it was left last year."

Three of the youth tried to describe the importance of the camp "family" in creating this sense of home:

> I get to be with my family. It's like coming home, you know…. Camp could be anywhere, they could literally block off a road in the middle of downtown, put up tents, you know, and that would still be camp. ('McLane')

> I bet if there was a shade of dust in the air you'd see pink and red, and smileys all over, and you'd see rainbows. Cause that's what this place is, a bunch of laughter and love… camp would be in a cave and I wouldn't care, because it's the people that make the camp. ('Miriam')

> The people… the people really make the camp what it is. They bring, they make an abiotic thing more biotic, like they bring life to it, and they basically make the camp, and they make the personality of the camp. ('Matthew')

Sub-Theme #2: A feeling of unconditional acceptance

Campers and volunteers both linked this sense of family to a feeling of unconditional acceptance at camp. Participants also conceptualized this with the awareness that some of our campers are, in the words of one youth, 'McLane', "pretty eccentric". She commented that at camp, however, "there is no judgment – even the loneliest people can have a family here".

Accompanying this feeling of acceptance was a feeling of protectiveness. As 'Lexi' summarized, "for this one week, we will be a village, so we will be watching each other's backs." Both campers and volunteers referenced their sense of protectiveness of this "second family". One woman linked this to fear and stigma:

> When we do have a picnic at [an AIDS service organization] I always feel that the people at that beach know that we're from [that organization]… Probably not, but that's how I think… and I'm very protective. If another family comes near us, it's like, you're a little too close to our group. I'm always afraid… ('Evelyn')

While not reporting this protectiveness herself, 'Miriam' recognized this in her mother:

> And [my younger sister] saying, 'can I go ride my bike around the block?' and then not having to worry, 'ok, like who's going to watch her?' and here, [my younger sister] saying, 'can I go swimming?' and my mom being ok, because there's like 50 other moms here, and all the volunteers. You're not as protective a momma bear as you are back home.

'McLane' likened the commitment to camp to that of a family. When asked if there was anything she would like the camp to know, she commented that

> You're locked in for life, man. You've created something beautiful that you will never be able to quit. We could have camp in the middle of a blocked-off stress and you'd still see us there. This place is infinite.

Bethany also described this: "I love it here. Camp is my family and my home. Never stop camp because I will never stop coming back to family."

Sub-Theme #3: Youth campers as a family subsystem

The integration of children and youth into the camp structure may also have facilitated this sense of family, with many volunteers and parents describing a sense of shared caretaking of the children and youth, and youth sharing respect and deference to the parents. In an interview prior to the campers' arrival, volunteer 'Bethany' described this closeness to 'Lexi', a new volunteer:

> You'll be surprised – my first year here, one of the kids ran out of the bus, never met her before, right into my arms – she jumped on me. Even if you're brand-new, they're right there, they're ready to be at camp.

As 'Bethany' described later in the week, "all the kids are everybody's kids, all the parents are everybody's parents… it's that everybody feels responsible, they feel like family".

Adults who came without children to camp particularly appreciated the presence of children and youth. As 'Daisy', the mother of a grown-up son described, "a lot of people who are new to their illness, they're thinking about that [HIV]… it gets their mind off it, watching the kids, seeing all the new lives, all the new babies, and every year there's someone new". A gay male camper with no kids, 'Angelo', described that "it makes you realize that it's a new life", describing the sense of hope he had as he watched the children play at camp.

Participants gave multiple examples of family-type interactions during the week. As ‘Erica’ described about her daughter,

> This week, she and one of the girls got together with another parent, not their parent, to just discuss things. And that just gives them the option here to see other parents, because sometimes it is difficult to tell your parent something, right, but you might want an adult’s opinion, somebody that you’re going to trust.

‘Miriam’, described her gratitude for this sense of being cared for

> I just love how the younger volunteers treat us like their younger siblings. And I love how the older volunteers treat us like their kids… I feel in such security because I know they’re fun to be around but they wouldn’t let anything happen to me. I love how they give me kisses on the cheek, how they ask me how my day is, and how I know that I can go to them for anything. And it’s fun having more than one mom, or dad, or older brother or younger sister.

All four youth participants described a particularly strong bond within their subgroup, a bond not found at home or at school.

> C’est pas toujours facile de, comme – À l’école ou à l’extérieur, des fois tu entends les gens discuter de ça [le VIH], et ils disent pas toute, comme, la vérité ou ils sont pas éduqués dans cette domaine. Mais içi, il n’y a pas ce type et je peux, genre, *let loose*. (‘Aadil’)

> We have something really intense to bond over, like… it’s not like our bond is normal, like a normal group of friends. Our bond is something that’s… scary, almost… our bond is over something that only we understand. (‘McLane’)

> We can connect on a level that you can’t connect… with anyone else, knowing that you don’t have to hide, the fact that you’re in a camp with a lot of other people who have what you have. I think that softens people up, it makes them so much more loving... You don’t have to hide anything…. here, trust is not an issue. You can legit walk around and talk to anyone, and that it’ll make someone so happy that *you* want to. Just asking them for help, it makes them so happy, and they’d be more than glad to. They take you and you just sit at the beach or a picnic table and talk to you, for hours on end… You can tell anyone anything, without being afraid of being judged. (‘Miriam’)

> [Camp is] a place where we can gain a better understanding of life and what’s to come, it also shows us that we aren’t always right, and that we still do have a lot to learn. This brings us back to Earth, really. (‘Matthew’)

Youth also expressed gratitude specifically for the youth program volunteers, noting their youth-friendliness and the special relationships they had formed with them.

> [Leur] façon à relier aux ados est extraordinaire. Comme, tu es capable à parler à un ado, mais être capable à rentrer dans sa pensée, penser comme eux pour bien communiquer avec eux, cette personnalité qu'il a et qu'il est capable de bien… Parce que dans notre *youth*, il y a des gens de différentes âges… et ceux de 18, [on] peut communiquer avec eux, et puis changer son attitude pour bien communiquer avec ceux qui ont 13, 14 ans, à leur niveau" ('Aadil')

> I feel like I'm treated as an asset, as like I do carry value within the camp, and I'm also treated with respect… The way they treat me, I find they grew up with me quite well." ('Matthew')

> It's really cool to know people to look up to; I consider them my friends… They're just really admirable people… people you aspire to be, kind of. Just smart, and caring, and they try their best to make people happy, they have people's best interests in mind. You can just tell how much they care ('McLane')

> I want to give back everything that you guys gave for me. I want to be, to those other kids that are going to be coming, what you and the other volunteers gave to us, that brother/sisterhood, and that love and the support and everything, and the fun, and the laughs. I want to give that to, I want to give that back… it gives us the chance to just break out of the bubble we're in when we're at school with all the media, and the magazines, and the girls, and the school, the bigness and everything. I think here, we're advantaged here. I think we see a lot more when we're here. It's hard to explain… ('Miriam')

As 'Miriam' attempted to describe this, the interview was interrupted by 'Matthew' returning a Wal-Mart gift card he had found on the ground, describing to the researcher where he had found it and suggesting who might have dropped it.

'Miriam' then continued:

> Like I think if someone back home, we found, say, a gift card at school, like a $20 gift card, I don't think we'd bring it back to the office and be like, 'hey, I found this'. I think we'd be like, 'Sweet! Wal-Mart, here I come!' I think it helps us see more life as it is. At school they teach us quadratic formula and mathematics and science, but they don't teach us life lessons… There's more to life than just books, you know, and here we have it. That's what we see, that's what we get. We get the life lessons, at the youth fire we talk about what's real, you know. I think that's why we're privileged here.

<u>Result #2: Camp as a Unique Community</u>

Sub-Theme #1: Sense of membership to the community

Campers exhibited a high degree of ownership of their community, viewing themselves as essential members of the camp “family”. This was perhaps best summarized in two women’s answers to the questions of what they bring to the camp: “L’opportunité de me revoir! La diva est là!” (‘Hamda’) and “Je contribue, parce que si je suis pas là, il y a pas le camp!” (‘Virginie’).

Long-term survivors of HIV reported a high degree of pride in being able to share their knowledge with others:

> The looks on people’s faces, I think, whenever, like when I go 23 years [since she was diagnosed with HIV] and you’re like, huh! Oh my God. And even for the new ones, the newly diagnosed, it gives them hope like ok, these are old-timers. I think it just opens everyone’s eyes. (‘Daisy’)

> I have the HIV experience behind me, lots of years of it. If someone’s complaining about their meds, I can say, well I used to take this one that looked like Palmolive anti-bacterial dishwashing liquid, it tasted worse than it, so here are my experiences. So you get a little bit of a headache? Not so bad… [We] meet new people, get new ideas; the dinosaurs that have been around together, they’re going to help out the rookies.” (‘Genesis’)

Sub-Theme #2: A sense of belonging not found elsewhere

One volunteer, ‘Sophie’, who was at a loss for words during much of the interview, came up with this summary of belonging at the end of her interview:

> This is like a family – it offers a sense of belonging. And for me, it just gives me… the love that we share here, you don’t find that anywhere, and it keeps me going all year, it really does.

Some campers compared this sense of membership and belonging to inadequacy of their own support networks and the artificiality of more formal support services:

> It’s just a different kind of atmosphere, ’cause people really understand what you’re going through. At home, maybe people can empathize and sympathize, but they don’t really understand what you’re going through, so here if you have a specific question, you know even if you were to ask your doctor this, this and this, they’ll give you a clinical perspective, and that’s what they know, but they don’t really, really understand what’s going on. (‘Erica’)

This sense of belonging is what the camp director described in her interview as the overarching goal of the camp:

> Camp is an opportunity for people who are either infected or affected by HIV to come together in this very safe environment where they can leave their cares and worries, and daily grind behind, and have an opportunity to share moments with others who are in the same situation, who understand where they're coming from, and they can just be themselves, without having to have their guard up, and just have the respite that they need and deserve, without the stigma and discrimination that is attached to this particular disease.

The director also spoke of the difference between the camp setting and more formal AIDS services:

> Most of the AIDS services are more around the determinants of help, and they offer tangible supports. I think, resources are so tight in most of these organizations… it is all to do with daily life, really, the determinants of health. It doesn't really address the 'let's just go have fun and relax'. Most of these people, when they go to any of these services, it's because they need something from them that is tangible… Here, this is something totally different; I say it's like being at a family reunion, at a cottage.

One camper, 'Anton', echoed this contrast to inner-city AIDS services: "they go there because they need something, or they have a problem, but here… no one's wallowing."

Participants attributed some of the isolation felt outside of camp to their health and HIV, with many long-term survivors noting the constant pre-occupation with health that comes with being an "HIV patient". The camp's medical support staff was considered instrumental in removing the stressors around health. Campers and volunteers were not distressed by having to hand in their medications. Rather, it was appreciated; as camper 'Angelo' noted, "It's nice to know that I have some place I can go, you know, hand in my meds, more or less be taken care of." 'Anton' felt similarly:

> Fabulous idea. It makes sure people take their meds; it makes sure they take it properly, it controls the drug consumption, yah. I was thanking God it was there this afternoon when I was feeling like shit, I was feeling dizzy… they were well-prepared.

The nurse/director of Club Meds summarized:

> The first year people might have been not so comfortable, the second year it had just sort of grown, and now people bring all their stuff in, they know they can have it when they need it, and they know it's safe, they know nothing's gone missing.

Several HIV-positive campers contrasted the peaceful, natural environment of camp with their medically-focused daily routines. As 'Genesis' stated vehemently, "people need to get the fuck out of the city every once in a while." 'Anton', another long-term survivor explained, "We're constantly in and out of medical hospitals, the sterile environment… so just a break from the sterile environment, to get us connected". The environment – in nature and isolated from the city -- was perceived to be important in creating the genuineness of camp:

> It's away from everything that pulls us bound – all the stressors, the immediate stressors in life – city life, all that stuff. Brings us to a serene and yet active environment. It's reminding people to connect even with their own selves, their own inner selves ('Elizabeth')
>
> Once you're here, you have no choice but to embrace it, there's no way out of this, you get solitude and solace. ('Roger')
>
> Look, there's no cars, there's no sirens, there's no police cars buzzing around, there's no motorcycles. All you hear is the birds; you don't hear that in the city… Just being here, and being with all the people that are happy, that are relaxed. To see them relaxed, there's no tension in their face, there's no tension in their body. And just to see… I see three women here that I worry about when I don't see them. But this whole week I'm here with them and I can talk with them… I'm so happy that she [one woman] came, and that we can sit and talk, sit and talk… it's good to see that she's here by herself, and tell me the things that… I had a feeling about why she couldn't talk. I told her, always remember that I'm there… even if it's two o'clock in the morning, come and pound on the door… but she doesn't have to pound this week ('Evelyn')

For one refugee camper, the natural environment was a key element in making her feel at home:

> Moi, ça me ressemble au village. Chez moi, si tu quittes la capitales, tu vas te reposer, tu n'as pas le bruit de la ville, sans les voitures, les autos, si tu viens dans les villages c'est très calme, avec la rivière à côté, c'est comme si c'est mon village… Je me sens comme nouveau-née, pour une semaine je me repose, j'oublie tout. Je me lève, je vais chez les arbres, la rivière, avec la famille qui vit la même chose, comme moi. (Adalène)

In addition to a sense of belonging not found elsewhere, many participants described that they would not be able otherwise to enjoy a vacation. While stigma played a role in this, most campers and volunteers identified financial means, particularly due to living on a fixed income, as the reason for this.

> How do you give your child the life that you want to on thirteen, or fifteen, or seventeen hundred dollars a month when your housing is costing you $1200, and you can't put your kid in the local soccer league because it's $400 a year, and the cleats are $100… camp gives them, I would hope, an escape for 5 days. You know what? We're poorer than dirt– we don't have the wherewithal to go for a vacation… Do we go to camp for a week or do we pay the rent?" ('Lexi')

> A lot of people, they're on disability. So when you have young ones you can't afford to take your kids to camp, and to get subsidies. It's hard to go on a vacation. Or, you're on too many medications that you can't drive. Or, you don't have money to pay for a vehicle or go to camp. So it's one week a year where you get away from all the hustle and bustle, you don't have to worry, you can enjoy, knowing you're not going to put yourself in debt. ('Daisy')

> I'm on EI, which isn't really conducive to paying the rent *and* eating. ('Genesis')

Sub-Theme #3: Freedom from Stigma

Just as the sense of family was contrasted to a lack of a supportive family of origin elsewhere, the strong sense of community was compared to a sense of isolation outside of the camp. This isolation was most often attributed to the stigma of HIV.

> Il y a des gens qui pensent que, à cause de ça, tout le monde s'en fout d'eux et on [ne] les aime plus, alors ils perdent leur confiance, ils [n'] ont plus leurs amis. Alors à cause de ça, ça [le camp] aide les gens qui sont discriminés à se rapprocher, et s'éduquer de façon là. ('Aadil')

> Se sentir en famille, parce qu'on était rejeté par nos familles, nos amis… la culture du VIH, personne ne nous veut plus dans sa famille, sa communauté. Mais içi, on est comme une famille. Moi, je trouve ça. Je me trouve à un endroit où je peux parler du VIH parce que je sais que je ne suis pas la seule qui le vit…" ('Adalène')

> When [you] turn your back on me, then I feel like I'm the dirtiest person who just walked into a room. And I don't want to feel that way. The words, 'Are you clean?', I still hear. Cause that's what people used to ask: 'Are you clean?' And I'm like, 'Yah, I'm clean. I

> take two showers a day, three showers in the summertime, how clean do you want me to be?' And then I found out what the word 'clean' actually meant." ('Evelyn')

One camper's example of her experiences of stigma indicated a sharp contrast between the atmosphere of camp compared and the outside world:

> Ce que ma famille n'accepte pas, eux ils acceptent. Par exemple, ma soeur, quand j'ai accouché [mon enfant] elle est venue me visiter. Avant de venir, elle a amené sa cuillère et fourchette, parce que j'ai le VIH. Et ici, il y a un bénévole qui ramasse toutes les cuillères ensemble, aller les laver. Demain, peut-être qu'ils pourront tomber sur la cuillère que moi j'ai utilisée -- mais ça ne me gêne pas. Même ma soeur, ma propre soeur, elle a apporté sa cuillère. C'est une grande différence. ('Adalène')

'Toumaya', also African, noted a similar contrast:

> Dans la communauté on peut pas parler, on peut pas s'exposer, mais içi… On va à un camp qui sait qu'on a le VIH, et on est accepté – Ça c'est une grande différence! L'avantage aussi, c'est partir avec tes enfants là où tu es accepté, parce que tu es accepté comme tu es, avec ton positif et avec ton négatif.

Many participants referenced the need to "hide" aspects of their HIV, particularly their medication, elsewhere. Other campers felt the effects of stigma compounded by the physical effects of their illness:

> I first moved to Ottawa not so long ago, I was very isolated, alone all the time, all the time. And being very overwhelmed by my disease… I haven't been on meds for a few years, and the numbers are really, really bad, like my body builds immunity to the medications, so I'm going through a lot medically, and dealing with that and being isolated and alone, so this camp was just what I needed. ('Anton')

Some campers were particularly impressed by the HIV-negative volunteers' lack of stigma, and viewed HIV-negative volunteers as adding another value to the camp.

> They know what you have, and they want to come and spend time with you, and it makes you feel good…. A lot of us were positive in the early 90's, so even to touch someone, to shake their hand… they're volunteering, you're more comfortable with that than as to someone who's a staff and being paid cause it's like a job to them. But the volunteers, they choose to come to a camp that's for positive [people]. So they're not going to look at you, or judge you. ('Daisy')

> Par rapport à tout ce qui s'est passé, c'est pas seulement les gens avec le VIH/SIDA qui étaient au premier rang. Il y avait [ces] gens, mais supportés par leurs partenaires, familles,

> qui étaient négatifs. Sans eux, parce que la plupart des gens étaient déjà malades, il faut regarder au début de l'épidémie du VIH/SIDA… les gens étaient vraiment malades… Moi, j'ai tous les deux dans ma famille, positif et négatif, les deux me supportent, mes enfants qui sont positifs comme qu'ils sont négatif, sont un grand support pour moi" ('Toumaya')

One unanticipated theme that arose from the discussion of stigma was the notion of safety – the conceptualization of camp as a "safe haven" where campers and their families felt "protected".

> I hope that Camp Snowy Owl never ceases to exist. That would be a really big loss, a really big loss. I'm hoping that when I'm gone, this camp is still around. Cause I'll come down! I'll come visit every single one of them. I'm looking to have a good place to go, a safe place to go, I really do. Cause this place is safe. Man, this place is safe. ('Evelyn')

> Leur donner une place qui est sécuritaire… dans la sécurité, dans leur *feeling*, être confortable que les personnes soient acceptées. 'Je suis acceptée comme je suis avec ma famille', donc ça, c'est une sécurité qui s'achète pas. ('Toumaya')

Many campers stated that they would be unwilling to attend a "normal" camp due to the stigma around HIV.

> There's a lot of stigma around, like, HIV/AIDS, so I guess if someone was my age, say, and they wanted to go to a camp, they might feel uncomfortable because there's a lot of stuff. There's all this medication that they have to take, that must be weird. I have friends who are never really honest about their medication, so that must be weird, in a position where you have to take your medication. ('McLane')

> The amount of stigma, the amount of misinformation, the amount of stereotypes out there, it's ridiculous. People think you can get HIV from hugging, high fiving someone. It's just absurd. The prejudice is still there, which makes it even harder for those that are looking for the support, looking for the community… I can't even imagine how difficult that is for them. To have an environment that is not only so nurturing and welcoming, but even just for its existence itself… [it's an] indescribable value. I can't imagine if this camp didn't exist, what a lot of the families we have here would do" ('Josh')

> The disease is so overwhelming in their lives they don't think they could find a place that could be so accommodating… at a normal camp you wouldn't find the openness where you could talk about your medical issues, and your past, and your experiences with this disease openly. So [we] wouldn't go to any other camp, because there's a lot of stigma, and judgments of people. ('Anton')

Other campers and volunteers, especially long-term survivors, specifically mentioned the importance of the involvement of younger volunteers:

> Seeing [the younger volunteers] so involved, really does this old queen's heart good… The youth and young people are getting more, realizing that they need to be involved. If we're going to effect change, we can't wait on the next person to start it. And seeing that, it gives my heart reason to rejoice again. ('Lexi')

Long-term survivors and HIV-positive campers similarly felt that they had important knowledge to contribute back to the HIV-negative volunteers:

> If the volunteers are negative, it's a learning experience for them. To see that just ordinary people live with this disease… just like everybody else, we're going to have a good life, and be happy. ('Evelyn')

> I've met a lot of people who when I share my story, say that it's a heavy story, and they're quite amazed of my attitude, because I'm still having a blast, you know. So I think I bring that silver lining in a dark cloud. ('Anton')

Some of the volunteers, such as 'Bethany', voiced their gratitude for learning from the campers:

> It's almost a bit intimidating cause these people are so strong, and they're so amazing, and they've taken such good care of themselves, and they just have a love for life… it kind of teaches me to go through my own life with humour cause I don't have it nearly as hard as they do.

Sub-Theme #4: The role of peer support in community-building

Within this camp, many of the volunteers are HIV-positive themselves, and are members of the HIV community in Ottawa, whether as clients or volunteers at HIV support services, friends of campers, etc. The camp views peer support to be extremely important, and concerted efforts have been made to recruit HIV-positive individuals as volunteers. As one volunteer stated in the survey, "Peer support and involvement is crucial in developing a culture of respect, individuality, recognition and values of differences and maintaining independence."

Some campers felt that the peer support provided by HIV-positive volunteers was invaluable to their experience:

> I find peer support, because we're among peers, helpful too… you don't feel so alone… that's what I like about camp, you're able to meet with other peers that you don't normally meet with. ('Angelo')

> It is comfortable, because a lot of people who come at least know one of them. So if it's their first time and they don't feel comfortable going up to a stranger they can go up to [HIV-positive volunteer] and say look, 'what do I do about that?'… It's good that there's someone that is positive, or that they've known." ('Daisy')

> Avoir des bénévoles qui supportent leurs paires, c'est une très bonne chose… On partage l'histoire similaire, et c'est ça qui est positif, d'utiliser les paires… Ça renforce l'acceptation de l'un et de l'autre par rapport à toute la communauté, et ça donne la valeur au camp aussi… On va mettre en place l'expérience qu'on a vécu déjà pour renforcer la capacité du camp" ('Toumaya')

'Lexi' described the value of his status as both a volunteer at camp and a client at the local AIDS service organization:

> Often, because people with HIV feel that we are told no, a lot, there are some anger issues, or some of us feel like we don't have time… It's the disease's processes speeding our demise, so we, a lot of people with HIV, don't have patience. And so when dealing with a staff – dealing with having service given to them, if things don't happen the way they want them or need them to happen, it can spiral and cause problems… What I see my role as, because I am HIV-positive, I know some of those angers. I'm very lucky in that I'm relatively healthy now, and I've worked through a lot of my anger about it. So talking on a professional level, if you will, and being able to go back and forth… The benefits of that dual role are, people feel more open to talk to me. We have a sense of community or of family, be it right or wrong, because we are bound by an illness… It allows me to be on the inside, where no one can look at me and say, 'Well, how could you possibly understand?'… What's important for HIV-negative volunteers is to not pretend to understand what it is like to live [with HIV].

Almost all HIV-positive volunteers expressed gratitude to be able to "give back" as a volunteer within their own community.

> I just feel like I'm giving back, and that's so important to me. Being a long-term survivor and everything, I've received so many gifts and services over the year. It feels wonderful that I have the health and ability to give back. And helping others, it helps me – it's a bit of a selfish thing in a way, because when I help someone, teach a small child to do something

> for the first time, even crafts, it gives me a joy that it was [me] who showed them how to, specifically – I like that. And they're so very thankful and appreciative here. ('Sophie')

> I always try to give back to a community that has helped me… I'm more of a giver, I give. And sometimes when I *get* things, I feel embarrassed. ('Evelyn')

> It goes both ways – I've given a lot, but I've also taken a lot. This is a way for me to give back to the community, by being involved more with the camp. ('Rob')

> It has given me back a sense of purpose. I had become very lackadaisical and very just, 'why bother'? … For the last year and a half, two years, I've been feeling I haven't been doing as much as I could. And it's really given me a sense of purpose. ('Lexi')

When asked about the dynamic of knowing many volunteers personally as friends, one camper, 'Roger', responded that, "access to the top was never my problem." The problem implied in his statement – that campers who knew volunteers as friends had "access to the top" – was one of a few tensions cited by both volunteers and campers. Although all were asked about this, only three campers recounted specific ways in which this could be problematic:

> We know them, we're comfortable with them, we know they're all respectful people… but the first year they had an issue with them drinking alcohol [an incident the first year with a violation of the no-alcohol rule by both campers and a volunteer]. But if we didn't feel comfortable with the counsellor, we probably wouldn't have tried something like that… so it's a double-edged sword… ('Daniel')

> I think that makes things a little bit weird sometimes, only because I'm assuming that a lot of times at the staff meeting people are getting information about other campers that are also positive, I'm not 100% sure that that's a comfortable feeling. Because you're not really knowing what's being said about you, I think it's just a weird situation… I think it's just a matter of confidentiality, obviously it's a big deal at camp and it's a big deal just in general with HIV, like a lot of people aren't comfortable, I think confidentiality's a big thing." ('Erica')

> Je n'aime pas ça beaucoup… Les bénévoles qui *est* moi, j'ai peur que s'ils vont parler de moi, peut-être il me connait, et je le vois dans la communauté, ils vont parler. [Mais] si une personne est la peau blanche, même si il parle dans la communauté, c'est *leur* communauté, et personne ne me connaît." (Adalène)

A few volunteers expressed that their dual roles occasionally created challenges with rule enforcement:

> People who know you well will try to get away with some shit. (‘David’)

> It speaks to human nature. People tend to blur the lines a lot without even intending to do so… friendships, and ‘I’m your friend, so let me off the hook’, you know things like that… ‘I’m your friend, but don’t speak to me’. (‘Elizabeth’)

The camp director echoed ‘Daniel’s’ statement that peer support is inherently both valuable and difficult:

> I think it becomes difficult for them when we have to make some difficult decisions… this week, when there was a behavioural issue and we had to ask the person to leave. It was a decision, it was a decision made by the team, but it was fairly unanimous… But for the peers, who work with them, live with them, who are their friends, it’s very difficult. It’s very, very difficult. But on the other hand, it also gives us the opportunity to learn more about the community. But it’s difficult for them. It’s a real bridge, they’re a bridge.

Sub-Theme #5: Camp as the intersection of diverse communities

Another crucial aspect of camp that contributes to its uniqueness is the intersection of cultures that meet at this camp, or as described by participants

> L’esprit communautaire, l’entraide, être soi-même, le mélange des cultures, brassage de traditions et personnalités qui font que le camp a un aspect unique à lui-même… les différences sociales, économiques, religion, tout ça ensemble, ca c’est unique… on peut pas trouver ça ailleurs. (‘Toumaya’)

> We used to say, we’re all walks of life, all different colours, but if we didn’t have this disease – if we were walking down the street, we wouldn’t even think twice to say, like, you know… one of them had mohawks, stuff like that, and then you’ve got others who would be in a three-piece suit, but when they come to camp… (‘Daisy’)

> [We] come from all different backgrounds – families, different cultural backgrounds, African-American, Caribbean. You name it, it’s here. Gay, straight, lesbian, transgendered, open doors policy.” (‘Chasen’)

Participants gave extremely divergent opinions on whether or not there were tensions present between these vastly different groups. The volunteers largely perceived that the differences between groups required, at the very least, careful attention and management.

> I’m doing a lot of dancing… this camp represents the face of AIDS. The group that is here is the face of AIDS, and it just shows you how this disease represents all walks of life. As most diseases do. Bringing the groups together in the way we do offers most of the people

> here the opportunity to see the other side of the coin; to experience tolerance, and learn about other cultures, learn about other groups of people. And at the same time they all have, everyone has a common denominator here, and that's the HIV. And yes they are so varied, the needs, the needs of different cultures. From the different cultures, the different communities. And so it is a bit of a dance that we do to try to please everybody that is here, and have other groups understand the needs of other. (Camp director)

> It's a very difficult thing to manage, very very very difficult. It puts a huge strain on the organizers. It's like [we're] doing a perpetual, a continual dance that doesn't stop. And each time we are dancing, the music changes. So finally they don't even know what kind of music they're dancing to. Cause every community is unique and has unique needs and unique requirements, and meeting all of that – which are equally important, meeting ALL of those… People start feeling like, 'oh, we don't matter'. And there's the history of where they're coming from, everyone being together and trying to assert their need and their independence"… 'us and them', that doesn't exist." (Researcher: Does that exist at camp?) "It does, very much. And you hear that in people's language, 'the African ladies'… it's singling people out." ('Elizabeth)

> When you bring any type of community together, whether it be all from the same backgrounds, individuals have individual differences. And there's a lot of times those individuals will have differences of opinion. And that will prompt some sort of a change in your community. So that'll happen, no matter what. Now when you bring this many different people – you've got families here, you've got African families, you've got Caribbean families, you've got single mothers, you've got gay men, you've got straight men. You're bringing everyone together, there's going to be some sort of… ('Chasen')

Among the campers, those who perceived tensions belonged largely to the GLBTTQ community, or were single adults who came with no kids.

> I wonder sometimes if there're issues because of us being gay, I don't know… well, in some African countries it's illegal… ('Angelo')

> It needs to become a little bit more interactive… the group behind you [African-Caribbean], they'll all be together all week, but I think that's just the culture, they'll just communicate with themselves, because they tend to group together, but I could say the same thing for [camper X], [camper Y] and I… and I don't know how to change that ('Genesis')

> The first year we did a drag show, and some of the clients took offense.... It always comes back as, what you did is offensive, or not appropriate. So I'm sorry to say but I've never been in a talent show since... We don't even know what is age-appropriate or not. What's racy? A little one did a striptease one year that I thought was racier than a drag queen… ('Daniel')

> I understand or respect a lot of child friendliness of all of this, but we're also dealing with a lot of adults. We know well that, we try our very best to be respectful, but we're old, and we're gay, we've got our things. It's not a disrespectful thing, it's just, it's our nature" ('Roger')

> C'est difficile de sensibiliser tant que c'est différentes cultures. C'est un choc de cultures. Déjà, quand ils viennent au Canada c'est le choc des cultures avec les Caucasiens, et puis en plus ceux qui sont d'une religion, et puis la culture des gais. ('Alain')

Some members of these communities, as well as all youth participants and many of the African-Caribbean participants, perceived that there was no tension.

> No… I don't know, I don't think so, it makes no sense to have a problem here… everybody is here with the understanding that it should be a no-stress thing, keep your bullshit to yourself, suck it up. This is a gift we're given, shouldn't we at least be appreciative of the fact, you know… and, I really do think though with all the diversity of people, very few fuck up. ('Roger')

> La tension doit exister partout parce que nous sommes des humains. Mais les gens ont tendance à généraliser les choses, à créer des problèmes là ou il n'y a pas des problèmes… Mais moi, ici je ne crois pas qu'il y a des tensions entres les gais et la communauté noire – il y a des gais dans la communauté noire, alors pourquoi cette tension? ('Toumaya')

> I think it just makes us a richer group. I personally love it. I've attended the HIV positive camps in the past, in the early 90's, and it was just families, so having the gay men, and the African Caribbean community too, back then we didn't really have many of them take part, so yah. I think it's great, I love it, I love it. And I always look forward to, and hope, that they will come back, you know. Because they make camp amazing, I love the diversity. ('Sophie')

> I think it's always cool to have a multi-cultural, inter-racial group. You're still treated the same everywhere, then you really feel the love. I remember at my old school, I was the only Black person in my class every year, you know. I didn't see any difference but sometimes I felt like they saw a huge difference with me. Sometimes I felt out of place since I was the only one of my quote-unquote "kind". But here I like how we can teach the "Caucasians" the "African" dance, we can learn from them. There's no Black, White, Asian, or anything, we're just a community and family, we all love each other, and there's no room for that. ('Miriam')

Many participants agreed that the integration of cultures was greatly facilitated by the immersive nature of this experience, and contrasted this to the more divided nature of many local HIV/AIDS services. For example, clients of the local AIDS service organization noted that:

> There's different socials. Like the gay men have their social, the African Caribbean community have their social… Yes, we're together during the day. But when it comes to 5 o'clock then if you're not a gay man and it's not your day, you can't stay. If you're a straight man and it's not your day, you can't stay, stuff like that. ('Rob')

> Just look around… It's like, we're all together. We're like one. You know, like [at the organization] the African Caribbean have their group, the gay men have their group, the mixed social which is straight and gay, which is very rarely done… This is all together, we're mingling, you know ('Evelyn')

One area where culture was particularly salient was food, with some African-Caribbean participants feeling that more accommodation is required.

> Surtout, je baserais beaucoup sur la nourriture, parce que chez nous la nourriture est la clé de toute rassemblement, on peut pas se rassembler sans la nourriture. Et la nourriture qu'on doit manger est très importante. C'est vrai, c'est un camp – [mais] quitter chez toi pour venir dans un camp, il faut que la nourriture que tu manges soit plus ou au moins adaptable à ta nourriture à toi. Et j'ai essayé d'expliquer à mes paires que ici c'est un camp et on doit aussi s'adapter par rapport à ça. Mais la réponse est toujours que, 'le camp sait qu'on est de telle origine, alors le camp doit prendre en considération notre nourriture traditionnelle pour l'impliquer dans le menu' … C'est notre corps, et la nourriture c'est importante… ('Toumaya')

> We're talking about 'all the African people need rice', because the food is not appropriate, there's gotta be rice. And forgetting that when you put out rice, somebody else that needs their potatoes doesn't have their potatoes. It's a little thing but it's a big thing. So how far do you have to go? Do we go from rice to foo foo? So we do now make plantains and make sure we have curried goat? Striking the balance, even for meals, is a nightmare… if we can just accommodate them a little bit, put something that says, 'I see you.' 'I see you, I do see you'. ('Elizabeth)

In discussing food and culture, many participants gave the same example of what they felt to be a "beautiful" illustration of the camp experience: a gay, Christian volunteer waking up each day at 3 AM to prepare food for the Muslim families who were fasting during Ramadan, which began this year during the week of camp.

> In the Muslim culture, having a gay men waking up to serve food for Ramadan – if there's ever anything that broke down barriers, broke down stereotypes, that just smashed it to smithereens… and when he does it, all of us, we're like wow – do you know who went? It was [him]! Oh, my god. It's just so, wow. And that's one of the beauties and the wonders of camp, it really is. Cause nobody would ever have known that [he] would do that, and he

> did not even think, he did not even hesitate, he just does it like he was born for that. ('Elizabeth')

> Avant tout, on est des humains et on est égal… Moi je me fais servie chaque matin d'un chrétien, et c'est lui qui me prépare mon déjeuner chaque matin [pour Ramadan], est-ce qu'il y a quelque chose de plus belle que ça? Est-ce qu'il y a une plus belle exemple? Non… La tension peut être parce qu'on est des individus, pas à cause de la religion… ('Toumaya')

Sub-Theme #5: Camp as a learning opportunity

While there was a divergence of opinion between communities on the subject of cultural tension, there was widespread agreement that nevertheless, the diversity represented a learning opportunity.

> It's almost funny that you could just sit on a bench, and everyone was in front of you, you could sit on a bench and each person you saw interacting would be a completely different experience to each person… it's not until we step outside that comfort zone that we're able to grow, and more possibly learn from this" ('Josh')

> Learning the different views, cultural aspects behind my disease… to see the Africans and Caribbeans, all of us here together, everyone has contracted this disease in a different way and process and it breaks that stereotype of HIV" ('Anton')

> Comme le groupe des gais… je suis africaine-canadienne. Les gais, c'était nouveau pour moi. On entendant, 'ce garçon, il est gai', mais c'était nouveau pour moi. Quand tu viens ici, il n'y a rien à faire – il faut accepter, les gens sont comme ils sont" ('Virginie')

> I think the dynamic is wonderful. Seeing the whole families interacting with single people, or with the men that haven't had children, and just sort of the, the first day, the trepidation of some people – there's spiritual barriers, there's racial barriers, and ethnic barriers – cultural barriers. Seeing that melt away, and having, if it was just a "Christian" camp or "just" a Muslim camp, then we don't have anything to deal with. If it's a Christian camp, you serve bacon every day of the week, ham sandwiches, and you're good to go. So forcing us to blend is a really important way to break down barriers… So it gives us a real inside view –we're getting to go through the front door rather than through the window." ('Lexi')

> [The greatest strength of camp is] smashing stereotypes. Cause any camp that's going to be just for heterosexuals, I probably won't even go. Cause I want my son to see our gay brothers, and just whomever. And know that everybody, as I say in my house, everybody is a people. Everybody is a people, man. ('Elizabeth')

> This camp represents the face of AIDS. The group that is here is the face of AIDS, and it just shows you how this disease represents all walks of life. As most diseases do. Bringing the groups together in the way we do offers most of the people here the opportunity to see the other side of the coin; to experience tolerance, and learn about other cultures, learn about other groups of people. And at the same time they all have, everyone has a common denominator here, and that's the HIV. (Camp director)

'McLane' identified another learning opportunity given to her through camp:

> I feel like it's opened my mind…I used to be afraid of different types of people… I've learned from different people the true meaning of beauty… like X [a camper with extreme facial wasting] is one of the most beautiful people I know… and camp is the only reason I know that. I look at [her] and see nothing but beauty, because someone else could look at her and say "oh, she has HIV"…. people who would normally be perceived as different stereotypes… it's really opened my eyes to things I never would have learned otherwise.

'Lexi' also identified what he felt to be an important learning opportunity:

> I think I certainly this week have learned how important it is to have my ears opened. And being open to criticism, but criticism that's given in a loving and caring way. For example, at one of the meetings it was pointed out to me that I'm rather intimidating. And I don't see myself as intimidating, that six foot-two, two hundred and thirty pound man. I see myself as a little old drag queen. But having heard that from a few people, that they feel I'm a little too out-there, it has forced me to look at my approach to people, and maybe be a little more gentle.

Result #3: Navigation of Identity at Camp

Sub-Theme #1: HIV less present during camp due to normalization

This theme is perhaps best summarized, and certainly most colourfully, by the words of 'Roger'. When asked about the goal of camp, he responded:

> It's probably just to make us acknowledge that we're actually human, human beings, you know. I think a lot of us take a lot of grief and just self-grief, I think, about our status… we're all positive, so it's like, you can't shit on me cause, you know, you have the same problem as I have. This, honey, we both have the same problem.

'Lexi' had the same answer as to the goal of camp: "to allow us to be – and you have to put big quotation marks on this – "normal" for a week. 'Hamda' also commented,

> C'est comme si on était normal – comme si c'était une opportunité, une chance de connaître tous ces gens… Avec ces gens là, tu retrouves la confiance en soi… tu as des problèmes, mais quand tu passes du temps ici, le *self-esteem* reviens, tu deviens normal.

The camp director offered a plausible interpretation:

> It's present [HIV], but it isn't. It is and it isn't. Ok, so I hear the different conversations, the youth – it's so important: some of the youth know their parents are positive, others don't. So there's a lot of education going on between the youth, there's so much exchange of knowledge, exchange of feelings. It's amazing what the kids are talking about, what the adults talk about. It's not as if it's labeled HIV, everyone's talking HIV – but they're free to talk about it, that's the beauty of it. Cause they don't feel they have to hide behind closed doors to talk about what it is, their illness. After all, the damn thing's just a bug. But it's got so much stigma attached to it. HIV is present but the stigma and discrimination is not, how about that.

A surprising result was the degree to which campers and volunteers felt that HIV was "on the back burner" during the week of camp – a sentiment voiced by nearly all participants:

> HIV/AIDS isn't… It's not here… It's never something that's in the atmosphere. It's never something you can really tangibly feel or think about. For example if you walk into a hospital ward you have that sense of sickness, something not right. And that's not the case here. HIV/AIDS isn't here in itself. It's part of us, it's part of the people that are here, but the feeling isn't there… it's not about the HIV/AIDS, it's about the camp, it's about the community, it's about the support…This is about being together. ('Josh')

> Camp is getting out of the city, it's not necessarily about HIV… HIV is a part of my world, it's always going to be a part of my world, but it's not part of my life… I don't need to live, breath, eat it. So for me, that's not what camp is about. It's about being able to hang out with my friends. ('Genesis')

> (Le VIH est) présent seulement lorsque je prends mes médicaments, et je pense pour les autres aussi… même prendre mes médicaments, maintenant c'est un médicament comme tous autres médicaments… C'est pas présent dans mon esprit, que le VIH est là" ('Toumaya')

> On parle jamais du VIH, tu as vu – tout le monde est en bonne santé – on parle pas du VIH souvent. C'est pas ça, l'importance" ('Virginie')

> I would say it's about like 50-50… when you're talking about, like, relationships and how things will work in the future, and when we talk about how, like, it could end good or bad, and then how, like our potential partners, wives or fiancées, could relate and how they would feel about it… HIV is just a microscopic physical being, not an emotional being that should determine how we act and our emotional feelings toward ourselves and others. ('Matthew')

> … to be able to run on the beach, to do the tie-dye, to sit and just chat with people, and the birds flying around you… and it's like, you know, this is a little bit of paradise. I'm never

> going to be not sick again, I'm never not going to have HIV. I would hope they'll find a cure, but realities are there. But for this week I can sort of maybe put it in the back of the closet with the winter clothes." ('Lexi')

> It comes up a few times. I've noticed as a camper/volunteer that it's usually only the first 48 hour that we sort of compare notes, 'how's your health, what meds are you on, how's that working for you'. ('Sophie')

> We are just a group of people getting together for a greater cause… and that cause is to provide a wonderful environment, sense of community, sense of family, sense of love for your fellow human being, and that's pretty much it. ('Chasen')

It is important to note here the role of modern HIV anti-retrovirals (HAART – highly active antiretro-viral therapy) in making HIV less present. Some campers noted the contrast in their relatively stable physical health to the decimation they experienced or witnessed from HIV in the early 90's:

> It's not as scary, where before [at an HIV camp in the early 1990's] we used to wonder every year, well, who's going to be there? Who's gone? It was like, oh god, which ones did we lose this year? We don't think that now. Now we don't see someone and we think, 'Where are they?' We don't think, 'Have they passed away?'… Because in 1995 they came out with the cocktail… before the wasting, it was the cheeks and the legs for the women, and then the butt loss, and the men too. Now it's like, you can't even tell…" (Daisy')

This retrospection prompted both HIV-positive and HIV-negative campers to express gratitude for their own physical health:

> On a tendance à oublier à travers, ce que c'est pour une personne séropositive, c'est un monde complètement étranger… On oublie, mais quand on est présent avec tous ces gens là, on voit qu'il y en a qui sont plus affectés que vous autres, et on sent qu'on a de la chance" ('Alain')

> There's a lot of people who didn't get this. I love the remembering part, I love honouring the people who didn't get to be here… like my mom's best friend, he died a month before the medication that could have saved him… so it's like, remembering all those people who fought so hard, and how lucky we are. Cause it just reminds you, like, a lot of crap can be there in your life, but someone didn't get to experience that crap, which kind of sucks. ('McLane')

Sub-Theme #2: Camp as facilitating the "true self" during camp week

Participants – especially those who are HIV-positive – spoke of being their “real me” during the week of camp. Largely this was perceived to be facilitated through the immersive nature of the experience and the location of the camp in nature, away from the city and their daily routines.

> I come here, this is just me, raw me, no mask, no nothing. No pretences of prejudice, it’s just who I am and I bring all of that here, and it’s one of the few places that I myself can just let that go. I don’t have to think about what someone thinks of me because it doesn’t matter here, a place like this.” (‘Josh’)

> … In my country, we say, if you want to really know somebody go live with them, don’t visit. So we’re living together now, we’re getting to see each other when we just wake up in the morning. If it was just for one day, we could fake it… right now, we bring our selves, because it’s for a long time” (‘Elizabeth’)

> It’s sort like a cleansing session, and you just get more down-to-earth and your mind is more where your body is, instead of my mind being on that person I’m texting in Toronto or that person I’m texting in Ottawa or whatever” (‘Matthew’)

> Some years I have multiple deaths, so it’s a good place as a refuge to sort of, just for that little moment… it’s like you’re a snake and you’re shedding a new skin and then you’re going home… (‘Angelo’)

> Every year when I come back, friends and family say wow, it’s like you’re a new person, cause it really nourishes me spiritually… I’m more positive, I’m happier, and, I don’t know, I just have *hope*, I just feel alive” (‘Sophie’)

Result #4: Year-Long Impacts of Camp

Sub-Theme #1: Relationships formed at camp

While many relationships between campers appeared to have been long-standing, it surprised the researcher that many of these relationships were actually instigated from the week of camp.

> I could be going to [a local AIDS service organization] five, six years, and not know anyone beside their names. So coming here I get to know more people, I think it started here with [camper X], and it was after the first year I actually invited him to my house… so that closeness was because of Camp Snowy Owl… I don’t really have close friends within the HIV community. I guess part of it is your own prejudice, you know… It was after the first camp or so that I really had all of them over to my house one time. (‘Daniel’)

> On a créé hier, avant-hier, avec le groupe des femmes, des africaines-caribéennes, quelque chose qui va s'appeler Tantine. On se rencontre chaque mois, chacune va apporter un montant spécifique, on fait un tirage. Parce qu'on s'est dit, à chaque fois qu'on vient, on est bien ici. Et puis on repart à Ottawa, chacune va à ses occupations… comme on est ici là, il faut qu'on le reprenne en Ottawa… *It's all about Snowy Owl Camp*, c'est ça l'impact. ('Toumaya')

> When we see each other in the city, because we've spent a week together, maybe we have a private little joke… and a sense of closeness, where before coming to camp may have been social graces of 'Oh, hi, how are you, it's nice to see you', and the age-old one 'how are you doing?' 'well, do you really want to know or are you just being polite?' That question doesn't need to be asked anymore because when I ask you how you're doing you know that I'm genuinely concerned" ('Lexi')

Sub-Theme #2: Year-long memories and anticipation for camp

One objective of the interviews was to determine whether the positive impacts of camp were limited to the week of camp itself, or whether campers and volunteers felt impacts from camp throughout the year. Many reported that memories of camp had a positive impact on them year-round.

> Camp is one of the most important things in my life… Camp is such a great place, and a lot of these people have nothing else… You've started something that you can honestly never stop, a lot of these people, all they see is death, there's a lot of death around. And death is depressing, let me tell you. And camp is not. So camp is important, and you can never really get rid of it without having a lot of hell to pay… ('McLane')

> When I'm in a hard spot I try to think of intense conversations I've had here with my friends at camp, and how those conversations can help me get out of those situations, which is a situation that I don't really want to be in" ('Matthew')

> I don't have a very exciting life, so camp is definitely the highlight of my year, every year. I don't think anything beats that… I think about camp most of the year, though. The stuff I learn. Like for example, X [camper] said something really special last night, 'you can accomplish anything'… that, I will carry most of the year, when I feel discouraged about something, I will remember instantly. ('Sophie')

Others reported a significant period of anticipation before the start of camp each year.

> Chaque année, c'est toujours quelque chose de différent, c'est jamais pareil. Alors les semaines avant le camp, je pense à ce qui est arrivé l'année passée, les mémoires, et les

> mémoires sont toujours extraordinaires, donc je suis toujours heureux… C'est toujours quelque chose de bon, qui est positif ('Aadil')
>
> I look forward to my birthday, summer, Christmas, and camp. ('McLane)
>
> As a volunteer, it's nice to see that the work that we do makes a difference for people. And I get emails from X [youth camper] every couple weeks and it's like, 'there's 157 days until camp'. ('Bethany')
>
> Comme mon neveu, tu sais les enfants sont ici au Canada, chaque fois qu'ils sont à côté de leurs parents, c'est de ça qu'ils leur parlent. Tu sais, maintenant que [mon neveu] a 12 ans, il dit 'Je ne veux aller nulle part sauf Snowy Owl, vous allez partir, moi je reste à la maison, là où je vais c'est seulement Camp Snowy Owl'. Là, c'est pour te dire que le camp est vraiment important" ('Virginie')

Sub-Theme #3: Desire to educate others

In the interviews with campers, many of them indicated a strong desire to educate others about HIV. Many campers discussed this spontaneously in response to the last interview question: whether there was anything that had been missed during their interview.

> J'aimerais dire, genre, aux gens qui ne sont pas ici, les autres gens, les gens qui ne sont pas à ce camp: ceux qui sont affectés par le VIH sont des humains aussi. Et qu'on est la même chose que vous… On pense de la même, on est tout de la même, *we're all the same, so* je ne comprends pas pourquoi vous êtes… il y a une grande discrimination. ('Aadil')
>
> I get angry that people still think that it's such a terrible thing to have, you know. And I mean, I want to educate, especially youth, young people. I do it with my grandchildren, I buy my grandchildren condoms and I give it to them. My oldest grandson, when he turned 18 – I didn't do it before – Christmas time, and I wrapped a big box of condoms for him, and he just said, 'Oma!' And I said 'honey, I don't want you to be where I am'. And that's what I want to do. I want to educate. ('Evelyn')
>
> There is still a very big stigma with HIV and AIDS. It's the "taboo cancer", the cancer that we don't talk about. Whereas as myself and the coordinator have said, "it's just another bug". It's like a common cold that you treat, and you live with, and it's there… It's not being educated well enough in the system, that it's increasing. The number of cases in young people – you go to a high school, and there's people teaching about HIV and AIDS that still think that it's found on a toilet seat. ('Chasen')

Some participants directly linked this desire to educate others to their experiences at camp.

> I have two friends from school that I can talk to it about, but they're my two best friends on the planet… like, 'oh I'm going to camp', they're like, 'what camp?' I'm like, 'oh it's a family camp for people infected and affected by HIV', cause I'm not embarrassed to know people who have it" ('McLane)

> I was spending time with a friend's sister in Grade 9 and it got into the topic of my volunteer work and she turned to me and she said, 'It's great that you do all this AIDS stuff, but why bother? It's just in Africa'. And I was like, 'What? OK, no, let's just stop here. What did you just say?' … When I tell people that I'm going to the camp I don't pretend like it's not an HIV camp, I'm very upfront about that's what this is and that's where I'm going… People do make comments – actually for a while in my school there was a rumour that I had HIV… It's just a bug. And HIV may not be as sexy as cancer or the other diseases that get funding and walks, and stuff like that. But I think it's definitely an issue and something I feel really strongly about and that's definitely worth all the time I can give it. ('Bethany')

Result #5: Family Processes at Camp

Sub-Theme #1: Parental appreciation for respite

The parents interviewed expressed gratitude for the children's programming, where they largely perceived volunteers to be genuinely invested in their children's happiness.

> Ma famille, ils sont tellement excités… ils comptent les jours, quand est-ce le camp va être ouvert… Parce que quand on vient, on est une communauté, tout le monde relaxe, tout le monde est respectueux… Ils adorent les bénévoles, surtout. En tout cas, mes enfants adorent les bénévoles. ('Toumaya')

> Retrouver les personnes, les amis qui s'occupent de lui [son fils]… c'est pas quelque chose qu'on retrouve tout le temps" ('Hamda')

Sub-Theme #2: Youth appreciation for parental respite

This was an unanticipated theme. The four youth who were interviewed demonstrated what the researcher felt to be a remarkable level of insight and awareness in general, as well as specifically about the effects of HIV on individuals both infected and affected, and the role of HIV in their own and their families' lives. Perhaps due to this level of awareness, all four youth expressed a sense of relief at the respite they perceived their parents to have while at camp.

> I feel like camp, for my mom, is a place where she doesn't have to work as hard to take care of me, and she can just socialize with her friends, and then I feel like she's more

> relaxed and comforted to know that there's counsellors taking care of me, especially after all the work she's put into taking care of me. So I like that I have that feeling that my mom is more at ease and not working so hard to take care of me. ('Matthew')

> I can tell my mom loves it, because she talks about how much she loves it… she loves these people with all of her heart, and she loves that I love these people, and that these people trust her and love her and love me… My mom's seen a lot of sadness in her life, and a lot of death, and a lot of just bad things… and I guess this is her place, she gets to be happy. ('McLane)

> Mon père… il est pas le type de beaucoup socialiser autant, mais au camp je le vois s'amuser, jouer les tambours, parler… Ma mère, elle est toujours en train de travailler… Quand elle vient ici, c'est sa semaine de relaxation. Alors pour elle c'est vraiment bon, et pour mon père aussi… Comme en ville on a plus de distractions, les parents travaillent, mon frère est en université, tout le monde est plus dispersé. Mais au camp, il y a rien qui nous retient de se rapprocher. Et comme ça, je le trouve très relaxant… comme un *youth*, je m'implique aux activités qui se passent, mais quand je trouve ces petits 10, 15 minutes avec mon père ou ma mère, c'est juste comme, *relieving*, genre." ('Aadil')

> I think it is a place to get away… like back home, the phone rings constantly, and my dad is going through, like, a lot right now. And I think just coming here and not having a worry in the world, feels nice. ('Miriam')

Sub-Theme #3: Improved family relationships during/after camp week

A few parents described that during the week at camp, as well as directly afterwards, they enjoyed relationships with their children that were less conflictual or more intimate than the rest of the year.

> We went out a few mornings on the kayak, her and I, we got to spend some q-t [quality] time together cause, you know, she's married, so we see each other sporadically… ('Genesis')

> It's different here… At home she's always involved with her activities… Here, she has her time where she does her activities, and we'll still eat together sometimes… It's not necessarily that camp is really different, like the other day she still had a bit of a like, 'she wasn't talking to me face', so it's not necessarily totally different. It's not like she becomes a perfect little child. But it's just different. I think she feels more independent here, she can come from one activity to the other. She has to monitor her own time and what she wants to do. ('Erica')

> It [positive effect from camp] would last for several months, and then the preparation for coming to camp too, and the excitement of it, too. I benefited from when we would come

> to camp. Because we were connected, so therefore when we would go back home, he would respect me more, sometimes… Maybe because recognizing the realities of HIV, with the illnesses, and seeing campers weaker than others, I think it just kind of reminded him, a gentle reminder that I'm battling a virus – it's not visible. And so he would be like, 'Do you need anything, Mom?' That kind of thing. ('Sophie')

Sub-Theme #4: The Role of Disclosure at Camp

Within the group of families who attend camp, some children are aware of that their parent(s) is/are HIV-positive, while in other families, the children are not. As previously discussed, HIV itself is not a main topic of conversation or programming at camp. However, in the words of 'Genesis', "at some point, the letters [HIV] are going to come out." The philosophy of the camp has been to allow those who wish to discuss HIV publicly to do so, while trying to respect the parents who do not want their children to overhear these discussions. At opening and closing ceremonies, there have been multiple references to, and discussions about, HIV. It is perhaps for this reason that 'Genesis' theorized that:

> If they want to stay that closed to their status then they wouldn't be bringing their kids here. They know it's an HIV camp… It's a line, it's up to each individual parent whether they want to disclose to their child or not, but you come to a camp – every kid has access to the Internet, I mean, you're going to look up Camp Snowy Owl.

One camper navigated her non-disclosure to her child by telling her child that she was a volunteer:

> …because I wanted to be able to come, but of course I didn't want to tell her at that point… You have to know that there's some kind of risk involved, that someone could say something. Because knowing that there's other kids here and knowing some of the kids as well could be positive, a lot of them are open. I don't know if all of them know their own status. I don't know if their kid's going to say, 'Well, everybody here is and so are you', or 'your parent is'… It's always on my mind, even on a daily basis, regardless of camp. You know I have meds at home and some of my friends are positive -- That's something that's always on my mind, not just with my child but with work and friends are stuff… I think sometimes you have to, not lie, but just kind of go around the situation if it's something that you're not comfortable telling your child – for me, anyway ('Erica')

Other HIV-positive parents firmly believed that disclosure to their children was essential, and viewed the camp experience as an opportunity for more education.

> C'est bon que les enfants connaissent le VIH… Parler du VIH comme ça, ils vont grandir en savant c'est quoi le VIH, c'est normal... Le jour que les enfants vont décider de parler de leurs statuts, ça va pas être nouveau pour eux" ('Virginie')

> Le dévoilement, c'est l'éducation… J'ai pris le temps de dévoiler à un jeune âge. Lorsqu'ils sont jeunes, c'est plus facile à dévoiler… et puis ça devient normal… J'ai pas honte de ce que je suis, parce que le VIH fait partie de moi, ça identifie pas à ma personnalité, mais ça fait partie de mon identité… de faire comprendre aux enfants que j'ai le VIH, on l'achète pas au marché! Je l'ai, et j'ai besoin de votre support… On peut pas leur dire, parlez pas du VIH. L'enfant va parler du VIH! Le parent doit préparer l'enfant – là ou tu vas, c'est le VIH, et toi tu es affecté du VIH, parce que moi je suis ta mère et je suis positive. C'est pour ça que tu vas à ce camp." ('Toumaya')

Result #6: Organizational Processes to be Considered

Sub-Theme #1: Enforcement of rules

The complaint that was, by far, most-often cited by participants was the enforcement of rules at camp. This was seen as not having been a problem in past years. Some campers perceived that this year, however, there were more rules, or stricter enforcement of the rules. In the interviews, this opinion was voiced by gay male participants.

> This year, it's all about don't, don't, don't. All the restrictions, it's bugging you, you can't even be yourself… the restrictions are a bit more, every year it's getting more rigorous as opposed to more laid-back… Maybe we need a whole new venue where they will tolerate us more… This year it seems a bit off, right off the bat, all this don't-don't-don't. And no no no… I don't think it has to do with the volunteers. Maybe numbers, that there's more of us? But it seemed to start off so negatively this year… I mean, it's better now. ('Daniel)

> Faire la différence entre nous et les enfants, et expliquer. Expliquer, c'est ça. On n'est pas des enfants d'abord. ('Alain')

Participants seemed to feel that it was more the enforcement of the camp rules, as opposed to the rules themselves.

> Sometimes I feel, I don't know exactly how to put it, some people give you that high school marm type, no no no no no, and I just… no you can't do this and no you can't do

> that… I feel watched all the time, especially with the new folk here, I feel watched” (‘Angelo’)

> Could be both, it’s almost the strict enforcement, it’s too broad and too non-specific, you’ve got a catch-all for everything, they watch… (‘Roger’)

Some volunteers also felt this concern. On the survey, one volunteer asked for “more clarity about *why* rules are in place, more recognition of the campers as adults with the right to choices and individuality, less lumping everyone together with the same rules, etc.” Other volunteers felt that the rules and enforcement of the rules were appropriate, yet were concerned by the campers’ reactions to them.

> I think they’re feeling like the new rules that we have put in place, they’re having trouble with it, and it’s taking them a little bit back from the support system. Like they’re reserving themselves a little bit, so it’s not only reserving themselves from the people, they’re reserving themselves from the support. (‘Bethany’)

Other campers felt strongly that the rules and their enforcement were appropriate.

> It’s never an issue, I think we’re all grown ups. I think there have to be rules in some issues… If they weren’t, I’d feel frustrated. They’re lenient rules, very lenient, and the nice thing is, they all abide by them. There’s nobody who says, “Why can’t I do this?” (‘Evelyn’)

> I never usually think, oh I hate that rule. Cause all the rules are put there from experience… It’s kind of common sense, things that people have to follow cause if they don’t, camp won’t be as good as it can be. Everything is done with love, kind of. Every rule is instilled because there’s a reason, not because anyone’s trying to be malicious. (‘McLane’)

> I personally don’t have an issue with the rules. Most of them I think are there for our benefit. I can understand that the smokers are finding it a little bit more difficult. But I don’t really think that the camp is so huge that it’s such a big deal to go from the waterfront to the smoking area… (‘Erica’)

> On essaie d’être au milieu, on apprend chaque jour, on apprend chaque année à faire mieux… Plus de règles, c’est pas bon, moins de règles, c’est pas bon… Les gens viennent ici parce que leur vie est déjà gérée par des règlements alors [quand] je viens ici, je veux pas être géré par les règlements (Toumaya)

A few of the gay male participants specifically discussed the owner of the campground on which the camp takes place. Not affiliated with the camp itself, the campground is owned by a Christian couple with limited experience interacting with many of the groups represented by campers. Two examples were given of interactions between the camp owner and campers in which they felt they were judged based on their sexual orientation:

> I have no idea if it's because I'm a gay man, because I'm a pothead, or what the situation is… but for the most part people are okay with each other. So I just thought it was funny that, OK, I wasn't in skimpy clothes like I was the first year, I had the music at a low level. Right off the bat, I'd just gotten there and I thought, whoa! OK, well, then fine. I'll move over here… ('Angelo', speaking about feeling watched by the campground owner)

> It's just cultural tensions. Like with my shirt [a t-shirt he had cropped into a belly top]. She [the owner of the campground] said 'This is a Christian camp. It would be better if you didn't wear any shirt at all…' It also may be because I'm gay… the homophobia… It's obvious we have our differences. She's Christian, I'm a wild gay guy…" ('Anton')

Campers also expressed concerns with the location of the smoking area – a picnic table in a field near the dining hall and arts and crafts cabin, with some smokers feeling that it was too segregated.

> Being stuck out here in the woods to smoke, I don't feel comfortable with it… The bugs out here, and those of us with open sores, HIV people, should not be stuck in the bugs… You should make that note, seriously. Open sores are the most dangerous thing for someone who's HIV… And it's very dark, we're out here at night, you don't feel safe. And we want to feel safe here. ('Anton')

> I can't smoke at the beach. And for me yesterday that would have been really nice if I could have sat at the beach. Because of my leg, walking back and forth to have a cigarette… It almost makes me feel that the non-smokers have more control than the smokers, and I think it should be half and half…. That's the only thing… I feel isolated. I feel that we're isolated, that we're not welcome to be where we want to be… It's almost like, when you're first diagnosed, you're shunned. And being a smoker, you're shunned, and I don't like that feeling. That's the only thing, I'm feeling shunned. And I don't want to be shunned anymore. ('Evelyn')

Campers and volunteers who have medical marijuana licenses may bring marijuana to camp, store it in Club Meds, and use it in the designated area. The decision had been made this year to have the smoking area also serve as the medical marijuana area. Nearly all medical marijuana users felt that this location was too public, causing them to feel self-conscious. Non-medical marijuana users also disagreed with this decision.

> To have us smoke and medicate (at the same spot), it kind of makes no sense. And it does centre us out. It's like 'We know what you're doing'. Not that we care, but really. ('Roger')

> I do feel, as a person that's got a medical marijuana card and I'm able to smoke, I feel really put on the spot. I'm worried about the children… I went to do my medical marijuana thing, I came back and went to fill up the water bottles to bring back to the beach, and I know X [volunteer] didn't mean to put me on the spot, but she said 'God, you smell skunky.' And it was like, 'Oh my god, all the kids were around'… I know she didn't mean anything by it, but it was like 'Oh my god, put me on the spot. I'm the pothead' ('Angelo')

> I don't agree with it (medical marijuana) being the same area as the smoking area because there are people who don't smoke marijuana, and we should respect them. ('Anton')

Despite the difficulties with the management of medical marijuana and the designated smoking area, the rule of no alcohol or illicit drugs was unequivocally endorsed. Campers particularly felt that this contributed to the atmosphere of safety at camp.

> I like that there's no alcohol here… This is really a family camp, and if you are a dedicated parent to your children, why drink? And I think some of the single people have to learn to respect the families with children. It's ok that you're smoking your pot, and I know that nobody gets overly buzzed, which is good, really, really good, but if people were drinking as they were smoking, it would be out of control. And I know for myself, I wouldn't show up here. Because I'm afraid of alcoholics who get rowdy, terrified, terrified. ('Evelyn')

> I love it, honestly… We have to remember that a lot of HIV patients are addicts, you know. I have been one… So I know that people really go overboard, and we don't have the means to be able to care for those people…I don't think I would want a lot of people out of control around me if I'm trying to connect spiritually back to myself. ('Anton')

> I think it helps people to see why they need to help themselves to come away from the lifestyle… It may stop some people [from coming], however, it points people to a need to come away from a lifestyle that is detrimental. ('Elizabeth')

> I believe it's a good way for us to look at some of our addictions and dependency… What it does force us to do is reevaluate what our priorities and needs are, at any given time. And I don't think it's a bad idea to, once a year, take stock of that sort of thing. ('Lexi')

Sub-Theme #2: Volunteer teamwork and teambuilding

Generally, campers reported being grateful for volunteers' efforts and attitudes; and, as described previously, volunteers reported many positive impacts from their efforts at camp. However, volunteer teamwork and teambuilding was identified by volunteers as an area for improvement. In the surveys, two volunteers' answers for areas for improvement were "rules explained better and stronger chain of command and communication" (there were ten total volunteer surveys).

The most common suggestion given by volunteers for how to improve the teamwork and cohesion was for the camp to enhance clarity around volunteer roles.

> Last year, I wasn't ever entirely sure what my responsibility was, and for me that made it really difficult to do what I thought I needed to do best. If I can't deal with my responsibility first then I can't then make it even better outside of the box, if I don't know where the box is. … We need at least a foundation that people with expectations can then work around it. Everyone needs here – 'OK, here's a set of what we want and need to do'. When we have at least those boundaries, everyone else can do what they want and work around within it. ('Josh')

> I think we work well, but I find as a new person that maybe there needs to be a better way of incorporating new people… I don't know if it's human nature, I don't know what it is, but there seems to be – there seems to be some kind of power tussle, 'I was here before you, so what I say is what matters… It shows up in creepy little places… Many things are not spoken clearly. For instance, maybe we need to have one person that does announcements… instead of, you give the impression that anyone can give the announcements. Then you get pissed off when people take the liberty and make the announcements… There's a lot of fluidity… We need clarity on who is doing what and whose position… Let it be clear, "This is what you do, and this is the scope"… Let there not be assumed authority, or assumptions of superiority. ('Elizabeth)

> It's very hard to do teambuilding when it's only going to be one week in a year… I hate things written in stone, but I'm going to say, more things written in stone. More clearly defined. Not our roles, because I think our roles were clearly defined, but the parameters of said roles… What I would like to see, and they're working on it, is volunteer guidelines. What I would like to see is that sent out maybe a month before camp, so every volunteer has a chance to go through it, read it, really understand it, and then get back to the powers that be if there are things that we don't understand. ('Lexi')

> There were a couple of times that I had an issue – and whether it was or wasn't, I felt it was important. And I got the 'Well, I don't want to hear it right now', and that shouldn't happen. Now, I am fairly resilient and the outcome wasn't really a big deal. My concern would be, and I can think of a couple of volunteers, one in particular, that if you said to this volunteer 'I can't deal with it right now', or 'no', then it is going to cause this person a great deal of anxiety. So that sort of 'I don't have time right now' or 'in a minute', that can't really happen… The volunteer should be given a direction of 'Right now, I can't deal with it, you need to speak to – and then give the volunteer a name'. ('Lexi')

When asked, most campers reported that the volunteers appeared to work well as a team. However, two campers also perceived a lack of cohesion among the team of volunteers.

> The organizing factor… you get different info about rules and activities when you go to different volunteers. It's frustrating. ('McLane')

> It's like… there's a volunteer trying to make an announcement during a mealtime and another volunteer who's louder and bigger, is able to command the room's attention … Almost like, 'I'm a better volunteer because I'm louder and bigger… it's like they need affirmation in the position… I don't know, these could just be my perceptions… It's just they don't feel very unified. Like, I've seen two volunteers pass each other on the road, like just kind of in walking, and not really acknowledge each other… If you'd had time to bond as a team, 'OK, we're in this together, guys, we're going to give the campers the best week they've ever had', and even teambuilding exercises before the campers come… It doesn't even necessarily have to be here… It's just not a whole lot of camaraderie. It's like, "OK, you guys are volunteering, figure out each other's names, give each other nicknames", stuff like that. ('Genesis')

Sub-Theme #3: Program-Specific Feedback to be Considered

Most areas of programming – the waterfront, Club Meds, children's programming, and arts and crafts – received almost uniformly positive feedback. Two areas of programming – the youth leadership program, and the opening/closing ceremonies – received mixed feedback, and as such were examined for areas of improvement.

Youth Leadership Program

All four youth interviewed felt that the youth leadership program as implemented this year lacked structure. The intent for the program was explained by one youth programming volunteer:

> This year, the youth program will be a little different. Last year we had more of a formal leadership training type thing, but I think this year it will be more of actual hands-on work, so the youth will be shadowing different program leaders around the camp, and actually helping out, and helping with the programs… I think the youth will actually be really happy to do something different than we did last year, and I think we're still going to have some informal talks and stuff, but I think with the shadowing thing, it'll really prepare the youth well for next year if they want to be volunteers.

However, the youth felt that this was not implemented with enough structure and investment, and as such reported not having fully participated in this shadowing program.

> C'est pas si fort. On fait le *shadowing* des autres bénévoles, mais comme, il y a des gens qui ont pas envi de le faire, même si au temps ils font quelque chose d'autre, ça devrait être plus valorisé... Plus de rendez-vous entre les ados et les adultes pour plus comprendre pourquoi… Il y a des gens qui ont oublié, des gens qui sont trop fatigués donc quelqu'un remplace l'autre, mais puis l'autre est pas remplacé… Plus d'accords entre les ados et les adultes pour dire, 'Tu vas venir, et si tu viens pas, au moins de dire en avance que tu seras pas là.' ('Aadil')

> It's not *bad*, it's fun, but I think that we should have been put in a much more volunteer-y position, because now it's very loose, it's very step-by-step, kind of… it's too basic. I just didn't learn anything… it would have been easier if you instilled us with a certain thing that we wanted to keep doing… We're not going to be volunteers if we can't voluntate (laughs)… I thought that it would be a good idea to have, every day … a meeting that's kind of just to say, like, 'How is your day? What do you think?'… Cause we're the young leaders, right, we could say, 'This should be thought of to change, and that could be brought to the staff meeting'… Just so we have more learning to lead… The leadership program seems kind of hasty. ('McLane')

> I find that would be fun… I did part of it, sort of, but I found it was too loosely regulated, so then I didn't really hear of many people being formal about it, but that doesn't necessarily mean they didn't do it. But I found it could have been enforced a bit more. ('Matthew')

> I guess I didn't take it seriously cause I didn't feel that they were taking it seriously… It's not necessarily their job to remind us, but they weren't talking about it at all…The way to improve, if you're going to do a program, *assume-la à 100%,* you guys have to be 110% in that. If you want to start a program or whatever, and you don't give all you have in it, it's not going to work. And that's what happened here, like none of the youth really showed up to the shadowing. ('Miriam')

Youth also reported that they missed the youth leadership retreat, which had been a special opportunity for "bonding" in other years.

> Je pense que, à cause qu'on est autour des adultes, on devient plus poli. Ben, c'est pas qu'on devient impoli quand on est au *retreat*, mais à cause qu'on est loin des adultes, on peut plus se relâcher, être avec nous, pas avoir peur de faire quelque chose de irrespectueuse à un adulte ('Aadil')

> I find that it could have been better, like I would have appreciated having a place where we camped overnight… I liked the experience of not being particularly in a cabin with lights and all that stuff. I also liked the scary stories, the jokes we would have out there in the woods. ('Miriam')

Opening and Closing Ceremonies

Opening ceremonies, held at the campfire on the first night of camp, holds the intent to welcome campers and integrate them as a group. Typically, the director tells the story of the creation of camp, and volunteers pass out a beaded necklace to each camper. Following this, some campers or volunteers choose to say a short welcoming statement, and some years this has been followed by dancing around the campfire. Closing ceremonies, held at the campfire on the last night of camp, has the intent of summarizing the camp experience. In previous years it has been themed "Remembering Our Losses", with campers invited to honour and remember their AIDS-related losses. This year it served more as expressions of gratitude, with campers sharing favourite moments from their week, and the impact that camp has had on them.

Feedback on opening and closing ceremonies was largely positive. Out of 40 surveys, the average rating on a scale of 1-5 was 4.5 for opening ceremonies, and 4.7 for closing ceremonies; yet 6 out of 40 participants listed this as the camp activity they enjoyed the most. However, some campers suggested that opening/closing ceremonies were overly emotional.

> They tend to be a little maudlin… a little sad… I could see the closing ceremonies being a little sad, everybody's going home… The opening ceremonies should be like, welcome to camp, you're going to have a great week! I think the necklace thing should be kept to the end of the week… You want everybody going home with them." ('Genesis')

> I think my thing about closing ceremonies is - there's always like the acknowledgements of losses… I don't have to acknowledge all of my friends once a year, to the sky. It's like

> they know, all the time, there's no nonsense there. They've been well-mourned and they're well-loved, so you move on from there. This is just how I work now. ('Roger')

> …Les gens, peut être ils ont refoulé. Ils peuvent s'exprimer, remercier les pertinents, une façon de décharger un petit peu de quoi… Un peu comme une thérapie de groupe si on se trouvait chez un psychologue… Ça sent moins, je ne sais pas, ça peut être dur pour certains… Je suis un peu étranger à ça, je dis pas que… ça m'a pas dérangé, mais c'est quand même lourd, il y a beaucoup d'émotions. ('Alain')

Other campers and volunteers suggested that the emotionality of the ceremonies was a key factor in their impact. A few campers who wanted more spiritual programming from camp cited opening and closing ceremonies as an example of what to have *more* of. Opening and closing ceremonies are perhaps a fitting example of the difficulty in preparing programming that suits the needs and tastes of such a large and diverse group of individuals.

Discussion

Perhaps the most important and surprising finding from this study is that HIV was very minimally present during the week of camp, superseded in importance by the sense of family and community that participants felt had been created. In Hrenko's article about her experiences as an art therapist at a camp for children with HIV, she describes:

> I entered the lodge to find 141 campers laughing and talking as they enjoyed breakfast. It brought back memories of when I had once been a camper. I met my first cabin – a group of boys who greeted me with waves and smiles. What struck me initially was how healthy and happy everyone appeared. Then as children received their morning meds, the truth was evident in the form of individual plastic bags filled with many pills of various shapes and sizes (2011, p. 41).

In other studies of HIV-targeted camps, HIV seems to remain front-and-centre during camp activities and throughout the participants' and authors' discussions about the camps. Pearson, Johnson, Simpson and Gallagher's description of the 'Hole in the Wall Gang Camp' for children with vertically transmitted HIV/AIDS (1997) focused almost exclusively medical management of the illness, symptoms and medication at camp. Similarly, in Bergman et al.'s study of a camp for children with hemophilia, HIV, and other immunodeficiencies (2005), the central aim was to determine the safety level and medical feasibility of such a camp. In Kmita, Baranska and Niemiec's comparison of a medical intervention and a camp intervention for families with HIV-positive children (2002), the camp relied heavily on educational and therapeutic programming, and the camp was studied only in terms of its clinical outcomes on the children's and families' ability to cope with HIV and its impacts on their lives.

In the most relevant study to this case – Gillard, Witt and Watts' 2011 case study of a camp for youth with HIV – the three major outcomes of the camp were "caring connections" (p. 1514), "reprieve and recreation" (p. 1517) and "increasing knowledge, skills, and attitudes" (p. 1518). The first outcome, caring connections, was divided into the subthemes of commonalities and lack of isolation. This is very similar to the findings of home and community from the present study, with Gillard, Witt and Watts also noting that the commonalities and lack of isolation “fostered feelings of camp as a home” (p. 1514). The authors also compare the feeling of closeness at camp to the feelings of loneliness experienced by many campers in their lives outside. Disclosure of HIV, and the openness to discuss HIV at camp, was found to be as crucial in this case as it was in the present study, which the authors described as there being “no need to hide because everybody knew each other’s most closely held secret” (p. 1516). The second major finding by Gillard, Witt and Watts – reprieve and recreation – was also primarily linked to HIV, with the authors noting that reprieve and recreation were facilitated largely through the openness and non-discrimination about HIV. Therefore, it would seem that in their study as well, HIV was not normalized and as such minimized to the degree found in this present study.

In Swartz’ semi-scholarly article on three camps for children affected by HIV, one participant notes “even though camp is a place where HIV is okay, it’s also the only place where HIV doesn’t make a difference one way or another” (p. 211). Swartz also notes that “to an onlooker, the only tangible sign that these camps are different is the medical staff on hand to administer antiretroviral medicines and a host of other drugs” (p. 211). While the normalization of HIV status is similarly hinted at in a few articles, it is not explicitly identified as a goal or outcome. Therefore, the degree to which HIV is, in the words of “Lexi”, “put in the closet with the winter clothes” at Camp Snowy Owl appears to be unique. There are several possible explanations for this: the health of campers due to the advent of HAART; the fact that many campers were affected, and not infected, by HIV; and the diversity of campers, which may have promoted sharing and education about important subjects other than HIV: culture, ethnicity, religion, sexual orientation, etc.

Like Gillard, Witt and Watts (2011), Kmita, Baranska and Niemiec also found that the relationships formed at the camp represented an important part of the benefits that families derived from the experience, noting that “the most powerful intervention turned out to be group activities” (2010, p. 283). This supports the present study’s finding that the relationships at camp, and the sense of family/community that this created, were the most salient aspect of camp for both campers and volunteers.

In the HIV camps reviewed in the literature, there are a variety of systems by which camp staff operate. In the camps reviewed by Bergman et al. (2005), Hrenko (2011), and Pearson, Johnson, Simpson and Gallagher (1997), the camps are run entirely, or almost entirely, by volunteers. Hrenko notes the importance of volunteer dedication, and how the volunteer aspect of the job seemed to contribute much: “the many unpaid doctors, nurses and counsellors, through simple acts of kindness and caring, were able to give much to children who often have so little” (p. 43). Gillard, Witt and Watts (2010) reviewed the organizational culture at a camp for youth with HIV that was staffed by volunteers who were present at the campground specifically for the week targeted to HIV, as well as by camp counsellors who worked at the accessible facility all summer long. The authors noted a marked contrast between the HIV camp-specific volunteers and the general camp counsellors in terms of their understanding and empathy for HIV, and their ability to promote more therapeutic outcomes by relating to campers. However, the authors conclude that, “camp may be such a powerful process in itself that meaningful youth outcomes can still occur even in the presence of high levels of stakeholder role differentiation and low levels of role integration” (p. 61). This supports the finding of the present study that although volunteers did not always perceive themselves to be an entirely cohesive team, this was rarely perceived by campers and did not serve to the detriment of the positive outcomes of the camp.

Several findings of the present study link to available literature on other forms of medical camps. For example, Dawson and Liddicoat's study of a camp for adults with cerebral palsy held 'sense of community' as its primary theme, noting that participants felt that "camp is home", and that in this setting uniquely, they felt like "respected members of a community" (p. 16). The authors conclude therefore that the primary benefit of camp is the "therapeutic use of community". This is similar to Goodwin and Staple's analysis of meaning-making in a summer camp for youth with disabilities, in which the authors concluded that camp represents an important "therapeutic landscape" (p. 173) – a finding that is certainly supported by the present study as well. Themes of reducing isolation and promoting normalization of the illness were also found in other studies of medical camps (Nicholas, Williams & MacLusky, 2009; Ashton-Shaeffer, Gibson, Autry & Hanson, 2001; Dawson & Liddicoat, 2009).

Goodwin and Staples' two other major themes – "not alone" and "a chance to discover" - are replicated by the present study's themes of sense of community, a stigma-free environment, normalization of the illness, and camp as a learning opportunity (p. 160). Goodwin and Staples compared the "disability isolation" (p. 168) experienced by many participants in their daily lives to a strong sense of community and "social belonging" experienced at camp (p. 168). The authors noted that this allowed adolescents to re-examine their disability identity in a setting "where disability was the norm and not the exception" (p. 168). Similarly, Hill and Sibthorp's analysis of autonomy support at a camp for adolescents with diabetes (2006) found that "perceptions of relatedness" greatly increased for adolescent campers at camp, aided by an organizational approach that emphasized acceptance and independence (p. 118). The authors note that, "as individuals began to feel more supported by a social environment, they were more likely to internalize behaviours and act responsibly" (p. 118-119).

This discussion of self-competence in illness management is similar to the finding of Gillard, Witt and Watts (2011) that camp attendance promoted adolescents' adherence to HIV medications. Adherence to medication was not examined in the present study, and would be a valuable area for future research, especially in consideration of evidence that adherence to medication is impeded by perceived experiences of stigma (Bogart, 2008). However, the more general finding that attendance at camp promoted self-competence (Dawson & Liddicoat, 2009; Hill & Sibthorp, 2006, Thomas & Gaslin 2001) may be linked to the present study's finding that camp attendance promoted the normalization of HIV status, which led participants to express feeling "normal" and that "la confiance en soi revient".

The finding of autonomy promotion, or independence, was found in Goodwin and Staples' (2005) study; Nicholas, William and MacLusky's evaluation of a summer camp for children and youth with asthma (2009); and Thomas and Gaslin's study of a camp for children with hemophilia (2001). It is interesting that independence and autonomy were mentioned only once by participants – by a mother who found that her daughter felt more autonomous at camp, which was positive for their relationship. One possible reason that HIV was not discussed more could be that HIV has become such a manageable disease that participants did not feel that they lacked autonomy in their daily lives. Another reason could be that much of this literature on medical camp focuses largely on the experience of children and youth – not adults – where growth of independence and autonomy may be more developmentally relevant.

Ashton-Shaeffer, Gibson, Autry and Hanson's study of a sports camp for adults with physical disabilities (2001) provides an interesting perspective on the comments of this study's participants about enforcement of rules. They discuss the notion of surveillance: that participants perceived their identity as dominated by their disability, and as such "faced surveillance in their everyday interactions with the able-bodied", resulting in feelings of exclusion (p. 103). This may partially explain the comments of the camper who reported feeling "watched", and other campers – in particular, gay male long-term survivors of HIV – who reported feeling restricted by the enforcement of rules.

Ashton-Shaeffer, Gibson, Autry and Hanson's second theme, resistance, also shed lights on the finding of this study that camp attendance seemed to be linked to participants' desire to educate others about HIV. The authors note that by participating in group activities that shattered stereotypes about physical disabilities, participants were encouraged to "challenge the able-bodied" (p. 107). It is possible that this form of resistance and desire for social change may also be linked to the feelings of increased self-competence reported in other studies.

Looking beyond structured camp experiences, the findings of the present study can also be linked to the wider body of literature available on recreational programs in general – including drop-in centres and therapeutic group activities – for individuals affected by HIV. A major theme from Caroleo's (2001) exploration of a recreation program for individuals with HIV was extremely similar to that of this study: that the program "provided participants with a sense of community and family from whom support developed" (p. 162). Caroleo emphasizes that the strength of the social support found through the recreational program rivals that of a family, a finding supported by the present study.

The present study's finding that HIV proved to be a sufficient bond to unite campers and volunteers despite considerable diversity is well supported by the literature on HIV and group programming (Kelly, 2010; Caroleo, 2001). This was also found by Sausser, Dattilo and Kivel in their study of leisure and HIV (2000). In this study, the authors also found that participants navigated their self-perception and identity in recreational activities. This theme, replicated as well in the more general literature on medical camps, supports the present study's finding that camp was a setting in which participants were able to navigate their identities, facilitated in part through the normalization of their HIV status.

In the present study, camp was found to promote a sense of community and social support, with campers reporting having developed strong, supportive friendships from the camping experience. This finding is significant, as numerous studies have linked social support to physical health and management of HIV. For example, Friedland, Renwick and McColl (1996) found that emotional support was a statistically significant factor in determining quality of life for individuals living with HIV, and note that support services that "bridge the gap between informal and formal" (e.g. a camp experience) may be particularly beneficial (p. 28). Numerous authors have reported correlations between social support and health-related quality of life. Ashton et al. reported that satisfaction with social support was linked to a lower level of progression of HIV-related health symptoms (2005); Bekele et al. (2013) found that perceived social support directly affected both physical and mental health, as well as mediating depressive symptoms; and Clingerman (2010) found that social support provided by friends was positively linked to health-related quality of life. Extrapolating these findings, it is therefore theoretically possible that attending a camp – which has proven in this study to act as a significant form of social support – may have some affects on health-related quality of life. This would prove to be another interesting future area of research.

In linking the findings of the present study to the findings in the relevant body of literature, it is again important to emphasize the unique nature of the case under study (and, therefore, the unique nature of this study itself). For example, the present study suggested several findings about HIV and family processes: that youth were acutely aware of the strain that HIV places on their parents; that youth and parents both enjoyed improved family relationships during an HIV-targeted week of camp; and that youth were particularly grateful for the support their parents received during the week of camp. It is difficult to link this to literature, as most literature about HIV camps focuses on camps for children and youth only. However, the findings of the present study about youth and family processes at camp *are* supported by the more general literature on HIV and family processes.

The finding of a remarkable bond between the youth at camp – a bond reported by youth to be not replicated elsewhere in their lives – is supported by Kang et al.'s article on a youth clinic in Harlem (2008). HIV-infected youth were found to have an "unspoken and powerful source of affiliation" (p. 231); due to the commonality of being HIV positive, youth were able to broach topics and support in a way that they were unable to in other relationships. This was also replicated in Di Risio, Ballantyne, Read and Bendayan's study of HIV-positive adolescents (2011). The authors found that having a support network of other HIV-positive adolescents was crucial in normalizing the experience of being HIV positive. As a result, HIV was perceived by the youth as barely affecting their lives, to the extent that the authors titled their study 'HIV isn't me…'.

The finding of improved parent-child relationships during the week of camp may be supported by literature in other fields examining the role of child or parental respite for other medical conditions. The author has been unable to find literature examining any long-term effects of a camping experience for families affected by HIV. This certainly is a compelling area for more research, considering the importance of parent-child relationships in families affected by HIV. Rotheram-Borus et al., Stein and Lester (2006) found that HIV-affected youth who had more positive parental relationships experienced less emotional distress, less sexual risk-taking, and more positive expectations for the future.

In this study, disclosure of parental HIV status was not a subject in the interview guide, nor was it an anticipated theme. However, many participants – in particular parents and youth – spontaneously discussed parental disclosure of HIV, often in the context of the effects of stigma or the need for the supportive community found at camp. This can be understood by the literature on disclosure among families that describes disclosure as a difficult process, with the result that some parents choose not to disclosure their HIV status to their children (Sherman, Bonanno, Wiener & Battles, 2000; Fielden, Chapman & Cadell, 2011).

A finding that cannot be supported by the literature, owing to this case's unique integration of children and adults with no children, was the tentative finding that adults who attended camp without children reported benefits from being around children, such as renewed hope and the sense that "it's a new life". Likewise, the theme of camp as the intersection of diverse cultures and lifestyles was difficult to compare to the literature, as the majority of camps for HIV are exclusively for children and youth and therefore do not have the same diversity of family types and sociodemographics.

Ethical Considerations

Participants' spontaneous comments on the participatory role of the researcher confirmed that in this study, the value of the researcher's role as 'insider' outweighed the ethical tensions arising from this dual role. For example, the researcher was surprised by the eagerness of campers from the African-Caribbean community to take part in this study, considering the heightened anxiety that some campers from this community seem to experience around fear of disclosure and confidentiality. The African-Caribbean support worker explained to the researcher that their willingness to participate could be attributed to the relationship between the researcher and this community, and the trust that had been built over several years. She explained, “Même si cette année tu es ici comme chercheur, tu n’es pas bénévole, *whatever* – tu es encore notre, tu es la nôtre”.

The team of volunteers expressed similar sentiments and demonstrated a remarkable openness in their interviews, with no participants expressing concerns around confidentiality or anonymity. The camp director commented several times to the researcher that she felt that the depth of information gathered was attributable to the researcher’s pre-existing relationship with the camp – “otherwise, it wouldn’t have been the same – you wouldn’t have gotten anything”. Therefore, the researcher strongly believes that this study demonstrates the value of participatory research in which members of the affected community are directly involved in the research process.

Limitations

This study has several important limitations. The first is that, in spite of the above discussion, it remains possible that the dual roles of the researcher prompted participants to express more positive feedback about the camp, or to overly focus on positive aspects in the hopes of ‘pleasing’ the researcher. The second limitation is that all data was collected during the week itself, so that participants had not had time for reflection after this year’s camp experience. It is also possible that the positive impacts that they described were amplified by being in the actual camp setting and time frame during the interview. The third caveat is that this is a case study, examining only one camp during only one year of operation of the camp. Generalizability was not an aim of the study, and results should not be interpreted as generalizable.

Conclusion

The preliminary data as presented in this report suggests that a recreational camping experience for individuals and families affected by HIV may promote significant positive outcomes for these individuals and families. In this study, benefits were found to include a sense of family and sense of community; membership to the community and a sense of belonging; a sense of safety from stigma; and the normalization of HIV status. This in turn allowed participants' HIV status to become less present during camp. Another important outcome for those who attended camp with their families was improved family relationships during the week of camp, as well as appreciation for the perceived respite for other family members. These outcomes were facilitated through the setting of the camp in nature and away from the city; the immersive/residential nature of the experience; and the non-judgmental, dedicated team of volunteers that included HIV-positive community members in key roles.

This study contributes to the scant body of literature on camps for individuals affected by HIV. The results suggested by this study highlight the need for more research on this type of recreational programming as a viable modality of psycho-social support for individuals affected by HIV across the spectrum of age, gender and sexual orientation, ethnicity and religion, and other social groups. In addition, the changing nature of the medical aspects of HIV, as reflected in the literature as well as by the participants in this study, highlights the need for continuing and up-to-date research. Similarly, the unfortunate stability of the stigma and discrimination associated with HIV supports the need for continued and renewed efforts for education and advocacy around this illness.

References

AIDS Foundation Houston. (2013). *Camp Hope.* Retrieved May 20th, 2013 from http://www.aidshelp.org/index.cfm?fuseaction=cms.page&id=1027

AIDS Outreach Center. (2007). *Client services and programs.* Retrieved May 20th, 2013 from http://www.aoc.org/services.asp

Alamo Area Resource Centre. (2010). *Jennifer's Camp – Information, application and news*. Retrieved May 20th, 2013 from http://www.aarcsa.com/jennifers_camp/

American Camping Association. (2013). *Jameson Camp – Tatayo Mato: Program Description*. Retrieved May 20th, 2013 from http://find.acacamps.org/program_profile.php?-back=camp_profile&program_id=3252

Angels Unaware. (2008). *Welcome to Camp Ray-Ray!* Retrieved May 20th, 2013 from http://www.angelsunaware.net/Camp_Ray_Ray.htm

Ashton, E., Vosvick, M., Chesney, M., Gore-Felton, C., Koopman, C., O'Shea, K., . . . Spiegel, D. (2005). Social support and maladaptive coping as predictors of the change in physical health symptoms among persons living with HIV/AIDS. *AIDS Patient Care and STDs, 19* (9), 587-598.

Ashton-Shaeffer, C., Gibson, H.J., Autry, C.E., & Hanson, C. (2001). Meaning of sport to adults with physical disabilities: A disability sports camp experience. *Sociology of Sports Journal, 18,* 95-114.

Balen, R. Fielding, D., & Lewis, I. (1996). Activity Camps for Children with Cancer. *Children & Society, 10*, 317-323.

Barrera, J. (1986). Distinctions between social support concepts, measures and models. *American Journal of Community Psychology, 14* (4), 413-445.

Bekele, T., Rourke, S., Tucker, R., Greene, S., Sobota, M., Koornstra, J., Monette, L., Rueda, S., Bacon, J., Watson, J., Hwang, S., Dunn, B., Guenter, D. & The Positive Spaces Healthy Places Team (2013). Direct and indirect effects of perceived social support on health-related quality of life in persons living with HIV/AIDS. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV, 25* (3), 337-346.

Bergman, J., Kinsella, E., Kenny, J., Barbor, P. & Zeltzer, P. (2005). Medical Utilization by Immunodeficient, Hemophiliac, and HIV Positive Children During Summer Camp: Evidence for a Safe Camper Experience. *Pediatric Blood Cancer, 45,* 826-830.

Betancourt, T., Meyers-Ohki, S., Charrow, A. & Hansen, N. (2013). Annual Research Review: Mental health and resilience in HIV/AIDS-affected children – a review of the literature and recommendations for future research. *Journal of Child Psychology and Psychiatry, 54* (4),423–444.

Block, J. (2013). For kids affected by HIV, Camp Starlight is a ray of hope. *EDGE on the Net.* Retrieved May 20th, 2013 from http://www.edgeonthenet.com/news/aids/features//-143191/for_kids_affected_by_hiv,_camp_starlight_is_a_ray_of_hope_

Bogart, L., Cowgill, B., Kennedy, D., Ryan, G., Murphy, D., Elijah, J. & Schuster, M. (2008). HIV-Related stigma among people with HIV and their families: A qualitative analysis. *AIDS and Behaviour, 12,* 244-254.

Brown, K. & DeMaio, D.M. (2008). The impact of secrets in hemophilia and HIV disorders. *Journal of Psychosocial Oncology, 10* (3), 91-101.

Camp Amerikids. (2013). Summer Camp Program. Retrieved June 1st, 2013 from http://www.campamerikids.org/

Camp Benedict. (2013). *What is Camp Benedict?* Retrieved May 20th, 2013 from https://www.campbenedict.org/

Camp Bright Feathers. (2013). *Camp Bright Feathers: A fun place where children can enjoy a week-long recreational experience for free.* Retrieved June 1st, 2013 from www.camp brightfeathers.com/

Camp Corazones. (2012). *Camp Corazones: Serving New Mexico families since 1995.* Retrieved June 1st, 2013 from http://www.kids-camp.org/

Camp Dreamcatcher. (2004). *Year-round programs for children whose lives have been touched by HIV/AIDS.* Retrieved April 1st, 2013 from http://www.campdream-catcher.org/about.htm

Camp Heart to Heart. (2013). *Camp Heart to Heart: July 8-12, 2013.* Retrieved May 20th, 2013 from http://camphearttoheart.com/

Camp Kindle. (n.d.) *About us: History.* Retrieved May 20th, 2013 from http://www.campkindle.org/about_us.html

Camp Sunburst. (n.d.). *Camp programs.* Retrieved May 20th, 2013 from http://www.sunburstprojects.org/programs.shtml

Camp Sunrise. (n.d.) *Empowering children and families impacted by HIV/AIDS since 1994.* Retrieved May 20th, 2013 from http://www.sunrisekids.org/

Camp Wendake. (2013). *Camp Wendake: A place set apart.* Retrieved May 1st, 2013 from http://campwendake.org/about.html

Canadian AIDS Society (n.d.) *CAS Members.* Retrieved June 26th, 2013 from http://www.cdnaids.ca/members.nsf/members!Openview&language=english

Caroleo, O. (2001). An ethnographic study examining the impact of a therapeutic recreation program on people with AIDS: In their own words. *Therapeutic Recreation Journal, 35*(2), 155-169. doi:20013140679

Centers for Disease Control and Prevention (2013). *HIV/AIDS Statistics Overview.* Retrieved June 28th, 2013 from http://www.cdc.gov/hiv/statistics/basics/

Clingerman, E. (2010). Physical activity, social support, and health-related quality of life among persons with HIV disease. *Journal of Community Health Nursing, 21* (3), 179-197

Catholic Community Services of Montreal. (2013). *Services & activities.* Retrieved May 20th, 2013 from http://ccs-montreal.org/services-actvities/

Clairborne, J. R. (1995). Escaping worries: Camp provides HIV-AIDS families a weekend of good memories. *The Arizona Republic.* Retrieved May 20th, 2013 from http://www.landmarkeducation.com/The_Landmark_Forum/What_People_Say/Grads_in_the_News/The_Arizona_Republic_-_Escaping_Worries_Camp_Provides_HIV-Aids_Families.aspx

Creswell, J. (2013). *Qualitative Inquiry and Research Design: Choosing among five approaches*, 3rd edition. London: Sage

Daley, A. (2010). Reflections on reflexivity and critical reflection as critical research practices. *Affilia, 25*, 68-2.

Dawson, S., Liddicoat, K. (2009). “Camp gives me hope”: Exploring the therapeutic use of community for adults with cerebral palsy. *Therapeutic Recreation Journal, 43* (4), 9-24.

Di Risio, M. , Ballantyne , P., Read, S. & Bendayan, R. (2011). “HIV isn't me…”: HIV+ adolescents' experiences in a positive context of support and treatment. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV, 23,* (6), 694-699

Douglas, D. (2001). *Camp Oasis replaces stigma with laughter.* Retrieved May 20th, 2013 from http://www.donnadouglas.com/columns/barrie-advance/camp-oasis-replaces-stigma-with-laughter.html

Duke, D. (2003). Camp Hope provides respite for families struggling with HIV. *Washington University in St. Louis Newsroom.* Retrieved May 20th, 2013 from http://wupa.wustl.edu/record_archive/1997/09-04-97/5007.html

Egan, M. (2011). *From the front line: family matters.* Retrieved May 20th, 2013 from http://www.catie.ca/en/positiveside/summer-2011/front-lines-family-matters

Falco, R. (n.d.). An Affirmation of Life: HIV Kids and Summer Camp. *Witness: an online magazine.* Retrieved May 29th, 2013 from http://www.visionproject.org/images-/img_magazine/pdfs/hiv_kids_summercamp.pdf

Families & Children's AIDS Network. (n.d.) *Red Ribbon Trails.* Retrieved May 20th, 2013 from http://www.familiesandchildrensnetwork.org/programs-services/red-ribbon-trails

Family Services of Winchester. (2011). *Camp Viva.* Retrieved June 1st, 2013 from http://www.fsw.org/our-programs/hivaids-services-partnership-for-care/camp-viva

Fielden, S., Chapman, G. & Cadell, S. (2011). Managing stigma in adolescent HIV: silence, secrets and sanctioned spaces. *Culture, Health & Sexuality: An International Journal for Research, Intervention and Care, 13* (3), 267-281.

First Congregational Church. (2013). *Camp Totokett: July 15-19, 2013.* Retrieved May 20th, 2013 from http://www.firstcongregationalbranford.org/CampTotokett.html

Foster, B. (2000). *Camps with heart and soul.* Retrieved May 20th, 2013 from http://www.thebody.com/content/art31281.html

Friedland, J., Renwick, R., & McColl, M. (2010). Coping and social support as determinants of quality of life in HIV/AIDS. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV.* 8 (1), 15-32.

Gillard, A., Witt, P.A. & Watts, C.E. (2010). An examination of staff-level stakeholders and organizational culture at a camp for youth with HIV/AIDS. *Journal of Park and Recreation Administration, 28* (3), 61-78.

Gillard, A., Witt, P.A. Watts, C.E. (2011). Outcomes and Processes at a Camp for Youth with HIV/AIDS. *Qualitative Health Research, 21* (11) 1508-1526

Goodwin, D.L. & Staples, K. (2005). The meaning of summer camp experiences to youths with disabilities. *Adapted Physical Activity Quarterly, 22,* 160-178.

Henderson, K. A., Bialeschki, M. D., & James, P. A. (2007). Overview of camp research. Child and *Adolescent Psychiatric Clinics of North America, 16*(4), 755-767. doi:10.1016/j.chc.2007.05.010

H.E.R.O. for Children. (2013). *Camp High Five.* Retrieved May 20th, 2013 from http://www.heroforchildren.org/camphighfive.php

Hill, E. & Sibthorp, J. (2006). Autonomy support at a diabetes camp: A self determination theory approach to therapeutic recreation. *Therapeutic Recreation Journal, 40* (2), 107-125.

Hrenko, K. (2005). Remembering camp dreamcatcher: Art therapy with children whose lives have been touched by HIV/AIDS. *Art Therapy, 22*(1), 39-43.

Hispanos Unidos, Inc. (2013). *Camp Meechimuk: The only sleep-away summer camp for children affected by HIV/AIDS in Connecticut.* Retrieved May 20th, 2013 from http://www.hispanos-unidos.org/camp-meechimuk.aspx

Kang, E., Mellins, C. A., Yiu Kee Ng, W., Robinson, L.-G., & Abrams, E. J. (2008). Standing between two worlds in Harlem: A developmental psychopathology perspective of perinatally acquired human immunodeficiency virus and adolescence. *Journal of Applied Developmental Psychology, 29*(3), 227-237. doi:10.1016/j.appdev.2008.02.001

Kelly, T. (2010). Group Work for People Touched by HIV/AIDS Yesterday and Today. *Social Work with Groups, 33,* 282-287.

Kmita, G., Baranska, M., & Niemiec, T. (2002). Psychosocial intervention in the process of empowering families with children living with HIV/AIDS: A descriptive study. *AIDS Care, Special Issue: Women (2*), 279-284. doi:10.1080/09540120120076959

Link, B. G. & Phelan, J. C. (2001). Conceptualizing Stigma. *Annual Review of Sociology, 27,* 33-385.

Lutheran Social Services of Illinois. (2007). *News Release: LSSI offers week-long Camp Getaway for families affected by HIV/AIDS.* Retrieved May 20th, 2013 from NewsLSSICampGetaway20070830

Lutheran Social Services National Capital Area. (n.d.) *Youth Haven camps.* Retrieved June 1st, 2013 from http://www.lssnca.org/lss/wwd_youth

Malee, K., Tassiopoubs, K., Huo, Y., Siberry, G., Williams, P., Hazra, R., Smith, R., Allison, S., Garvie, P., Kammerer, B., Kapetanovic, S., Nichols, S., Van Dyke, R., Seage, G., Mellis, C. (2011). Mental health functioning among children and adolescents with perinatal HIV infection and perinatal HIV exposure. *AIDS Care: Psychological and Socio-medical Aspects of AIDS/HIV, 23* (12), 1533- 1544.

Mavandadi, S., Zanjani, F., Ten Have, T.R., & Oslin, D. (2009). Psychological well-being among individuals aging with HIV: The value of social relationships. *Acquired Immune Deficiency Syndrome, 51* (1), 91-98.

Marhefka, S. L., Lyon, M., Koenig, L. J., Orban, L., Stein, R., Lewis, J., & Tepper, V. J. (2009). Emotional and behavioral problems and mental health service utilization of youth living with HIV acquired perinatally or later in life. *AIDS Care, 21*(11), 1447-1454. doi:10.1080/09540120902883085

McMillan, D. & Chavis, D. (1986). Sense of community: A definition and theory. *Journal of Community Psychology, 14, 6*-23.

Michigan Thespians. (n.d.) *Camp Rainbear.* Retrieved May 20th, 2013 from http://www.michiganthespians.com/events-1/camp-rainbear

National Abandoned Infants Assistance Resource Center. (2003). *Recreational programs for HIV-affected children and families.* Retrieved May 20th, 2013 from http://special-needs.adoption.com/children/recreational-programs-for-hiv-affected-children-and-families.html

Newbery, L. (2004). *Letting kids be kids: Camps offer children with serious illnesses the chance to let loose.* Retrieved May 20th, 2013 from http://www.ourkids.net/camp/learn-more-article.php?id=37

Nicholas, D., Williams, M. & MacLusky, I. (2009). Evaluating group work within a summer camp intervention for children and adolescents with asthma. *Social Work with Groups, 32* (3), 209-221.

Norbeck, J. (1981). Social support: A model for clinical research and application. *Advances in Nursing Science*, July 1981, 43-59.

One Heartland. (2013). *Our Mission.* Retrieved June 1st, 2013 from http://oneheartland.org/-about-us/our-mission.html

Parker, R. & Aggelton, P. (2003). HIV and AIDS-related stigma and discrimination: A conceptual framework and implications for action. *Social Science & Medecine, 57*, 13-24.

Parkes, J. (2002). *Kids live the darndest lives: AIDS Camp provided a strange experience*. Retrieved May 20th, 2013 from http://archives.xtra.ca/Story.aspx?s=14671207

Project Ark. (n.d.) *Camp Hope.* Retrieved June 3rd, 2013 from http://projectark.wustl.edu/SupportUs/CampHope/tabid/804/Default.aspx

Pearson, H., Johnson, S., Simpson, B., Gallagher, M. (1997). A residential summer camp for children with vertically transmitted HIV/AIDS: A six-year experience at the Hole in the Wall Gang Camp. *Pediatrics, 100* (4), 709 -713.

PLWHA. (2003). *HIV travel restrictions and retreats.* Retrieved June 1st, 2013 from http://plwha.org/retreats/

Public Health Agency of Canada. (2006). *HIV/AIDS Treatment and Care.* Retrieved on May 19th, 2012 from < http://www.phac-aspc.gc.ca/aids-sida/info/5-eng.php#antiretroviral>

Public Health Agency of Canada. (2010). *HIV Epi Updates – July 2010.* Retrieved on May 19th, 2012 from < http://www.phac-aspc.gc.ca/aids-sida/publication/epi/2010/7-eng.php>

REACH Ministries. (2005). *Programs.* Retrieved May 20th, 2013 from http://www.reachministries.org/programs.php#camp

Rotheram-Borus, M. J., Stein, J. A. & Lester, P. (2006). Adolescent adjustment over six years in HIV-affected families. *Journal of Adolescent Health, 39,* 174-182.

Safe Haven Project. (2013). *Camp Safe Haven Martha's Vineyard, MA.* Retrieved May 20th, 2013 from http://safehavenproject.org/programs/

Sawin, K., Lannon, S., & Austin, J. (2001). Camp experiences and attitudes toward epilepsy: A pilot study. *Journal of Neuroscience Nursing, 33* (1), 57-64.

Sausser, C. E., Dattilo, J., & Kivel, B. D. (2000). Leisure in the lives of people with HIV and AIDS: Implications for leisure services. *Journal of Park and Recreation Administration, 18*(4), 38-56. Retrieved from http://journals.sagamorepub.com/ebooks/

Sherman, B.F., Bonanno, G. A., Wiener, L., & Battles, H. B. (2000). When children tell their friends they have AIDS: Possible consequences for psychological well-being and disease progression. *Psychosomatic Medecine, 62,* 238-247.

Steele, R., Nelson, T. & Cole, B. (2007). Psychosocial functioning of children with AIDS and HIV infection: Review of the literature from a socioecological framework. *Journal of Developmental and Behavioural Pediatrics, 28,* 58-69.

Swartz, A. (2009). The strongest prescription of all: A week in the woods. *American Journal of Public Health, 99* (2), 210-215.

Swartz, A. (2012). *HIV R&R. Real Health: Your Guide to Black Wellness.* Retrieved May 20th, 2013 from http://www.realhealthmag.com/articles/HIV_Summer _Camp_2703-_22045.shtml

Teresa Group. (2013). *Camp Laurel Canada.* Retrieved June 1st, 2013 from http://www.teresagroup.ca/camp.html

The Laurel Foundation. (2011). *About.* Retrieved June 1st, 2013 from http://www.laurel-foundation.org/about/

The Seattle Foundation. (n.d.) *Rise N' Shine Foundation.* Retrieved June 1st, 2013 from http://www.seattlefoundation.org/npos/Pages/RisenShineFoundation.aspx

Thomas, D. & Gaslin, T. (2001). "Camping up" self esteem in children with hemophilia. *Issues in Comprehensive Pediatric Nursing, 24,* 253-263.

Thomas-Laury, L. (2012). NJ camp helps youngsters deal with HIV and AIDS. *abc Action News.* Retrieved May 20th, 2013 from http://abclocal.go.com/wpvi/story?section=-news/special_reports&id=8785941

Western Canadian Pediatric AIDS Society. (2013). Camp Moomba: about. Retrieved May 20th, 2013 from http://campmoomba.com/about/

Wiener, L., Mellins, C. A., Marhefka, S., & Battles, H. B. (2007).Disclosure of an HIV diagnosis to children: History, current research, and future directions. *Journal of Developmental and Behavioral Pediatrics, 28*(2), 155-166. doi:10.1097/01.DBP.0000267570.87564.cd

Appendix I HIV/AIDS Camping Programs in North America

Despite the abundance of HIV/AIDS community agencies and recreational programs, there are relatively few camps for individuals and families affected by HIV. To assess the mandates and target populations of available programs, the author has compiled this table of HIV camping programs in Canada and in the United States. The list was compiled using snowballing, general Internet search engines, and drew from the following websites: the Canadian AIDS Society[6], special-needs.adoption.com[7], NeedyMeds[8] and The Body[9]. The author also made use of older lists compiled in research articles[10,11]. While there exist a variety of "retreat" programs for adults exclusively, these were excluded from the review of existing camps, to maintain a focus on structured, recreational, immersive experiences for children and/or adults affected by HIV. This drew from Henderson, Bialeschki and James' definition of camps as "organized experiences in group living in the outdoors that use trained leaders to accomplish intentional goals" (2007, p. 755). Camps are divided by those for families (appearing first) and those for children (appearing second); within these categories, camps are arranged alphabetically.

CANADA

Camp Name	Target Population	Brief Summary	Website
Camp Positive Quebec	- Individuals from throughout Quebec	- Established by Catholic Community Service Montreal in 1992 - Primary goal is to "break the isolation" associated with HIV - Supported by 90 volunteers - Costs $50 to attend	http://ccs-montreal.org/services-actvities/
Camp Snowy Owl	- Families residing in Ottawa with at least one member who is infected with HIV	- Established in 2010 through the Snowy Owl AIDS Foundation after Camp Wendake was forced to narrow its catchment region, excluding Ottawa	http://www.snowyowl.org/en/specialevents/campsnowyowl.spy http://ottawa.ctvnews.ca/free-

---

[6] http://www.catie.ca/en/positiveside/summer-2011/front-lines-family-matters

[7] http://special-needs.adoption.com/children/recreational-programs-for-hiv-affected-children-and-families.html

[8] http://www.needymeds.org/camps.taf?_function=list_disease&disease_id=106&disease=HIV/AIDS

[9] http://www.thebody.com/index/treat/camps.html

[10] Swartz, A. (2009). The strongest prescription of all: A week in the woods. *American Journal of Public Health, 99* (2), 210-215.

[11] Falco, R. (n.d.). An Affirmation of Life: HIV Kids and Summer Camp. *Witness: an online magazine.* Retrieved May 29th, 2013 from http://www.visionproject.org/images/img_magazine/pdfs/hiv_kids_summercamp.pdf

Appendix I HIV/AIDS Camping Programs in North America

	- Includes individuals, couples, and families with children (children/youth must be accompanied by their parents) - Currently accommodates 50 campers	- Modeled after Camp Wendake (See below)	spirits-combatting-sadness-at-camp-snowy-owl-1.544281
Camp Wendake	- Families residing in South Western Ontario with at least one member who is infected with HIV - Includes individuals, couples, and families with children (children/youth must be accompanied by their parents) - Accommodates 65 campers	- Established in 1995 by the AIDS Committee of the Diocese of Huron but is explicitly a "non-religious camp" - Focus is on those affected as well as infected: "a camp for people living with HIV/AIDS and their care-givers, loved ones, and traditional/non-traditional families"	http://campwendake.org/about.html http://www.diohuron.org/what/camps/wendake.php
Camp Laurel	- 40 children from the Greater Toronto Area (GTA)	- 2013 will be the first year - In collaboration with The Teresa Group, an organization that works with children, youth and families affected by HIV - The Laurel Foundation is an international foundation based in the US that aims to improve the lives of children affected with HIV through recreational and camping programs	http://www.teresagroup.ca/camp.html http://www.laurel-foundation.org/
Camp Moomba	- Children across Canada, ages 6-17, affected or infected with HIV	- Established in 1997 through the Western Canadian Pediatric AIDS Society - Children across Canada are flown, free of charge, to the camp's location in BC - "Moomba" is an Australia Aboriginal word that describes the camp's motto: "friends together having fun" - Does not provide a number of attendees but notes that the number of applications has grown from "a couple dozen" to 200 children	http://campmoomba.com/
Camp Oasis (now closed)**	- 50-60 children across Canada, age 7-16, affected or infected by HIV	- *Appears to have closed in 2004 –* little information available - Explicitly a "non-medical" camp with the goals of respite and recreation - Took place at a YMCA waterfront in Muskoka, with the support of medical	http://www.donnadouglas.com/columns/barrie-advance/camp-oasis-replaces-stigma-with-laughter.html http://www.thebody.com/index/tr

		staff from the Sick Kids Hospital in Toronto	eat/camps.html http://archives.xtra.ca/Story.aspx?s=14671207

UNITED STATES

Camp Name	Target Population	Brief Summary	Website
Camp Benedict	- Families from across Minnesota in which at least one family member is affected	- "Educational/recreational family camp" - Offers typical camp activities as well as workshops with themes such as HIV 101, grief and loss, and how to deal with stigma - Free of charge, funded entirely through fundraising events	https://www.campbenedict.org/
Camp Birch	- For "mostly inner-city families from low socioeconomic, underserved areas in New York" with at least one HIV-positive family member - Families must have children to be eligible - Accommodated 100 families in 2012	- Children's programming similar to a "traditional summer camp", while parents' programming focuses on life skills and mutual support - Overseen by One Heartland, an umbrella nation-wide organization whose mission is to "improve the lives of children, youth, and families facing significant health challenges or social isolation" (also oversees Camp Heartland and Camp Hollywood Heart as well as non-HIV camps)	http://www.visionproject.org/images/img_magazine/pdfs/hiv_kids_summercamp.pdf http://oneheartland.org/programs-a-services/camping-a-care-programs.html
Camp Care	- Families in Fresno, California - Unclear if it only accepts families with children (little information available)	- Began in 1996 through All About Care, a "one-woman social service agency" established in 1990 by a woman whose husband died of AIDS - Staffed by 60 volunteers, including medical professional - Camp operates in partnership with the Seventh-day Adventist Church	http://allaboutcare.org/camp-care/
Camp Corazones	Families **with children aged 5-13 years old** in New Mexico	- Free of charge - Established in 1997 - Staffed entirely by volunteers - Recreational activities for children, HIV-related parenting workshops for parents	http://www.kids-camp.org/

Appendix I HIV/AIDS Camping Programs in North America

Camp Getaway	- Families with at least one HIV-positive family member in Illinois - Seems to require families to have children to be eligible (unclear) - Accommodated 97 campers in 2012	- Run through Lutheran Social Services of Illinois - Two “independent contractors” (camp directors) oversee the team of 40 volunteer - Adult programming is intended to be therapeutic, with art therapy workshops and sobriety meetings	http://www.lssi.org/News/NewsLSSICampGetaway20070830.pdf
Camp Hakuna Matata)	- Families **with children** in Arizona	- A” weeklong "no worries" summer camp for children infected/affected with/by HIV/AIDS in the forests of Prescott, Arizona” (little information available) - Run through the Arizona AIDS Project	http://www.azfoundation.org/catalog/org.shtml?org_id=11249 http://www.landmarkeducation.com/The_Landmark_Forum/What_People_Say/Grads_in_the_News/The_Arizona_Republic_-_Escaping_Worries_Camp_Provides_HIV-Aids_Families.aspx
Camp Hope	- Families **with children** with at least one HIV-positive family member in St. Louis, Missouri	- A weekend retreat - A *“nondisclosure camp”:* focus is on recreation and *HIV is not discussed* - Affiliated with Washington University in St. Louis - Not affiliated with Camp Hope in Texas	http://projectark.wustl.edu/SupportUs/CampHope/tabid/804/Default.aspx http://www.stlouischildrens.org/health-resources/support-groups/hivaids-hey-health-and-education/camp-hope
Camp Rainbear	- Families **with children** with at least one HIV-positive family member in Southeastern Michigan - Accommodates 60 campers	- Staffed entirely by volunteers from the associated organization, Rainbow Alliance - Recreation focus - Also supported by the Michigan Thespians, a theatre troupe whose members act as camp counselors and assist with fundraising	http://www.razoo.com/story/Camp-Rainbear
Camp Ray-Ray	- Families **with children** with at least one HIV-positive family member in the Rocky Mountain Region and the Midwest	- Operated through Angels Unaware, an organization in Colorado that serves families affected by HIV, mainly through support groups - Focus appears to be recreational (little information available)	http://www.angelsunaware.net/Camp_Ray_Ray.htm
Camp REACH	- Families **with children** with at least one HIV-positive family	- Run by REACH ministries, a Christian organization offering various support programs to families affected by HIV - Camp has an explicitly religious focus,	http://www.reachministries.org/programs.php#camp

Appendix I HIV/AIDS Camping Programs in North America

	member in the Southwest and Pacific Northwestern states	e.g. volunteers must be "followers of Christ" - Supported by medical professionals from the Seattle Children's Hospital and Regional Medical Center - REACH also offers after-school, school-based and mentorship programs	
Camp Sunburst	- Families with **children aged 6-11** with at least one HIV-positive family member California	- 2:1 or 1:1 counselor: camper ratio - Recreational focus - Also offers a weeklong 'Teen Camp' for HIV-positive youth aged 13-18 as well as their siblings	http://www.sunburstprojects.org/programs.shtml
Camp Viva	- Families **with children** with at least one HIV-positive family member in the Westchester County area (New York state) - Children must be bathroom-trained and must be at least 4 years old	- Weeklong sleepaway camp is complemented by a yearlong 'follow up program' including reunions, respite care and "informal gatherings" - Recreational focus - Staffed entirely by volunteers - Overseen by Family Services of Winchester	http://www.fsw.org/our-programs/hivaids-services-partnership-for-care/camp-viva
Red Ribbon Trails	- Families with at least one HIV-positive family member who also have children between the ages of 2 and 17	- In collaboration with Families & Children's AIDS Network (FCAN) - Offers a three-day spring retreat and a four-day summer retreat - Focus is both recreational and educational (e.g. grief counseling, parenting education and support)	http://www.familiesandchildrensnetwork.org/programs-services/red-ribbon-trails
Camp Amerikids	- 250 "inner-city" children from NYC with sickle cell or infected with HIV - Ages 7-15	- Offers two one-week long sessions per summer - Medical staff and a "Wellness Team" overseen by a clinical social worker - Founded in 1995 - Focus is on recreation and structured camp activities, including a Leader-in-Training program for graduated campers aged 16 and 17	http://www.campamerikids.org/
Camp Brightfeathers	- Children aged 7-16 from New Jersey and Philadelphia who are either affected or infected - Served 97 children in 2012	- Now in its 22nd year of operation, has served over 2500 campers - Held at a YMCA campground in New Jersey - Staffed entirely by volunteers - Focus is on recreation and entertainment - Program for graduated campers to become counselors	http://www.campbrightfeathers.com/ http://abclocal.go.com/wpvi/story?section=news/special_reports&id=8785941

Appendix I HIV/AIDS Camping Programs in North America

Camp Courage	- Children aged 6-17 in Las Vegas - Accommodated 17 children in 2012	- Run through Aid for AIDS in Nevada - Recreational focus - Also offers one cost-free recreational activity for children per month through their 'Kids Campus' program	http://www.examiner.com/article/afan-sends-kids-affected-by-hiv-aids-to-camp-courage
Camp Dreamcatcher	- 130 children aged 5-17 in Pennsylvania affected or infected by HIV	- Founded in 1996 by a gestalt psychotherapist - Focus is not purely recreational: workshops with yoga instructors, psychotherapists, art therapists - Staffed by 260 volunteers - Also offers year-round weekend retreats for youth and holiday/reunion events	http://www.campdreamcatcher.org/about.htm
Camp Firelight	- Youth affected/infected by HIV in Tarrant County, Texas	- Run through the local AIDS Outreach Center (little information available)	http://www.aoc.org/services.asp
Camp Heart to Heart	- Children aged 5-12 in Kentucky, affected or infected by HIV	- Founded in 1999 - Run through Lions Camp Crescendo (a local youth camping organization) in partnership with local HIV/AIDS services - Staffed by volunteers, with a camper: counselor ratio of 3:1 - Recreational focus	http://www.camphearttoheart.com/
Camp Heartland	- Children in Minnesota infected or affected by HIV - 75% of participants live in poverty	- Overseen by One Heartland, an umbrella nation-wide organization whose mission is to "improve the lives of children, youth, and families facing significant health challenges or social isolation" (also oversees Camp Birch and Camp Hollywood Heart, as well as non-HIV camps)	http://oneheartland.org/programs-a-services/camping-a-care-programs.html http://www.thebody.com/content/art31281.html
Camp High Five	- Children and youth aged 6-16 in Georgia who are affected or infected by HIV - 90% of campers' families have an annual income of $10, 000 or below	- Run through H.E.R.O. for Children, a Georgia organization serving children affected by HIV - Recreational focus	http://www.heroforchildren.org/camphighfive.php
Camp Hollywood Heart	- Youth aged 15-20 in California who are either affected by HIV or are otherwise "at-risk" (is not clearly defined)	- Overseen by One Heartland, an umbrella nation-wide organization whose mission is to "improve the lives of children, youth, and families facing significant health challenges or social isolation" (also oversees Camp Birch and Camp Heartland as well as non-HIV camps) - Camp is a "week-long interactive arts	http://hollywoodheart.org/mission/ http://oneheartland.org/programs-a-services/camping-a-care-programs.html

Appendix I HIV/AIDS Camping Programs in North America

		experience" for young adults - Staffed by artists and mentors, focus is on developing art skills (visual art, music, dance, etc.) - Supported by "Hollywood professionals" and occasionally celebrities	
Camp Hope	- Children aged 7-15 in Texas	- Not affiliated with Camp Hope in St. Louis - Focus is on recreation - Run through AIDS Foundation Houston - Also offers 'Universal Teens', a weeklong "overnight workshop" for HIV-positive teens aged 16-19 - Also offers 'Camp HUG', a weekend camp retreat for the children of Camp Hope as well as their families	http://www.aidshelp.org/index.cfm?fuseaction=cms.page&id=1027 http://www.futurecamping.com/blog/2008/12/camping-with-hivaids-children-to-build.html
Camp Kindle	- Children and youth aged 7-15 affected by HIV in the Central and Western United States	- Established by two college students - Since 1999, has served over 1500 children - Now two locations: one week-long camp in Nebraska, and the second in Southern California - Leaders-in-Training program for youth aged 13-15 - Has also established scholarship and advocacy programs	http://www.campkindle.org/about_us.html http://www.iknowhiv.org/what-is-kindle/ http://www.thebody.com/content/art58026.html
Camp Laurel	- Children and youth infected or affected by HIV in California - Serves over 500 children and youth a year	- Founded in 1992 - Also offers a 'Teen Adventure Camp' for campers aged 13-17 to build leadership - Also offers a 'Winter Family Camp' for children and their guardians - The Laurel Foundation funds/sponsors, but does not oversee, HIV camps elsewhere (e.g. the Teresa Group in Toronto, Canada)	http://www.laurel-foundation.org/about/
Camp Meechimuk	- Children aged 6-15 affected by HIV in Connecticut - Unclear if camp is open to non-Hispanic HIV-affected children	- Operated through Hispanos Unidos, a local Hispanic social services agency - Recreation focus: it is "not a therapeutic camp"; the aim is "for our children to have plain fun"	http://www.hispanos-unidos.org/camp-meechimuk.aspx
Camp Rise n Shine	- Children and youth affected by HIV in Western Washington (Puget Sound area)	- Offers year-round programming including mentorship, support groups, and holiday events - Recreational focus but includes an annual camp memorial service to remember family members who have	http://www.seattlefoundation.org/npos/Pages/RisenShineFoundation.aspx

Appendix I HIV/AIDS Camping Programs in North America

		died due to HIV	
Camp Safe Haven	- Multiple camps offered to children and youth affected by HIV	- Martha's Vineyard location offered annual camp from 1994 until 2012; the reason for closing is unclear - Unclear whether other locations are still operating (web links are non-functional)	http://safehavenproject.org/programs/
Camp Starlight	- Children and youth affected by HIV in Oregon and Southwest Washington	- Founded in 1999 by a clinical social worker - Is now in its fourth location - Accommodates over sixty children, with a 1:1 counselor: camper ratio	http://www.edgeonthenet.com/news/aids/features//143191/for_kids_affected_by_hiv,_camp_starlight_is_a_ray_of_hope_
Camp Sunrise	- Children aged 6-17 affected by HIV in Ohio - Accommodates 100 children	- Founded in 1994 with a palliative focus Includes a leadership program for the 'Sundogs' (youth aged 16-17) - Focus is on recreation and "traditional summer camp activities"	http://www.sunrisekids.org/ http://www.realhealthmag.com/articles/HIV_Summer_Camp_2703_22045.shtml
Camp Tataya Mato	- Children aged 7-18 affected by HIV across Indiana and surrounding states	- Focus is on recreation and is "just that, a camp" - 'Youth Leadership Track' program for youth aged 15-18 - Free for all children and youth	http://find.acacamps.org/program_profile.php?back=camp_profile&program_id=3252
Camp Totokett	- Children affected by HIV, "while not infected themselves", in Connecticut	- Founded in 1996 by the First Congregational Church of Branford - Explicitly religious - Staffed by volunteers including high school students - Recreational focus	http://www.firstcongregationalbranford.org/CampTotokett.html http://www.realhealthmag.com/articles/HIV_Summer_Camp_2703_22045.shtml
Imani Village	- Children and youth - Infected OR affected by HIV - Boston	- *Departure from traditional one-week residential model*: runs for five weeks a summer and is a day camp - Fully subsidized for low-income families - Operated in collaboration with the Boston University School of Medicine	http://bmc.org/pediatrics-sparkcenter/services/afterschoolsummerprogram.htm
Jennifer's Camp	- Children affected by HIV in the Texas Hill County	- Run through the Alamo Area Resource Centre - Has served 1000 children since it was founded in 1996 - Website states that it was the "first summer camp for children with HIV and their primary caregivers" - Unclear if the camp is still in operation (little information available)	http://www.aarcsa.com/jennifers_camp/
The Sue Kuhlen Camp for Kids	- 110 children affected or infected by HIV in South Carolina	- Named after a nurse who died of AIDS in 1993 - Founded in 1995 by a woman whose son died of AIDS - Unclear if the camp is still in operation (very little information available)	http://www.volunteermatch.org/search/org7912.jsp http://www.thebody.com/content/art31281.html

Appendix I HIV/AIDS Camping Programs in North America

Youth Haven Camps	- Camp Kids Haven: children aged 7-13 affected by HIV in Washington, DC and Baltimore - Teen Haven retreats: youth aged 14-18 affected by HIV	- Located on a campsite in Jefferson, MD - Run through Lutheran Social Services National Capital Area - Focus is primarily recreational	https://www.lssnca.org/lss/wwd_youth

Appendix II Budget

$1013.000 was awarded to this research project in February 2013 as part of the Tryna Rotholz Group Work Award, through the McGill School of Social Work.

Proposed Budget

Budget Item		**Total Cost**
Transportation to/from camp		$78.00
Photocopying, purchasing of supplies for questionnaires and interviews (pens, cassette tapes)		$35.00
$10 honorarium for campers and volunteers who complete the written questionnaire	$10 x 45 (anticipated # of questionnaires)	$450
$25 honorarium for campers and volunteers who participated in interviews	$ 25 x 15 (anticipated # of interview participants)	$375
Honorarium to the camp for their staff's time		$75
Total expenses:		$1013.00
Total funds received:		**$1013.00**

Actual Budget

Budget Item		**Total Cost**
Photocopying of materials	- Surveys: adult and youth, both in French and English - Interview guides - Consent forms (surveys and interviews) - Materials for camp	$87.00
Batteries for audio recorders		$6.00
$10 honorarium for campers and volunteers who completed the written questionnaire	$10 x 60 (anticipated # of questionnaires)	$600
$20 honorarium for campers and volunteers who participated in interviews	$ 20 x 15 (anticipated # of interview participants) **More than 15 interviews were completed, but less than 60 questionnaires were completed, therefore the extra $10 gift cards for questionnaires were used to compensate the additional interview participants*	$300
$10 for gas money contribution to volunteer driving to and from Ottawa	2 x $10 **Researcher's transportation to/from Ottawa not included*	$20
Total expenses:		$1013.00
Total funds:		**$1013.00**

Appendix III Coding Tree

Coding Tree

Theme	Sub-Themes
1. Camp as a family	1.1 Campers/volunteers compared to family members
	1.2 Camp as 'home'
	1.3 Camp as a family reunion
2. Sense of community	2. 1 Camp as a unique community
	2.2 Sense of membership/ being an essential member of the community
	2.3 Sense of belonging not found elsewhere
3. Relaxation	3.1 Due to non-stigma and normalization of HIV
	3.2 Facilitated by nature
	3.3 Facilitated by camp structure
	3.4 Comparison to cottage life
4.Gratitude	4.1 Gratitude for volunteers
	4.2 Gratitude for campers
	4.3 Youth gratitude for mentorship
	4.4 Gratitude for health
	4.5 Gratitude for a free camping week
5. Identity	5.1 HIV less present during camp
	5.2 HIV identity normalized during camp
	5.3 New/true identity during camp week
	5.4 New identity after camp week
6. Continuity of camp beyond the week	6.1 Memories of camp throughout year
	6.2 Anticipation/excitement for camp session
	6.3 Relationships formed from the camp experience
	6.4 Desire to educate others
7. Safety	7.1 Safety unique to this experience
	7. 2 Safety from stigma
	7.3 Safety due to no rule of drugs/no alcohol
8. Family processes at camp	8.1 Parental appreciation for child respite
	8.2 Youth appreciation for parental respite
	8.3 Improved parent-child relationship during/ after camp week
	8.4 Role of disclosure during camp week
9. Culture	9.1 Camp as the intersection of cultures
	9.2 Tensions between different communities
	9.3 Lack of tensions observed elsewhere
	9.4 Food requiring more cultural accommodation
10. Peer Support	10.1 Value of peer support
	10.2 Difficulties associated with peer support
	10.3 Dual roles of volunteers
11. Organizational processes	11.1 Camper application process
	11.2 Volunteer teamwork commended
	11.3 Volunteer teamwork to be improved
	11.4 Volunteer dedication
12. Rules	12.1 Need more transparency

Appendix III Coding Tree

	12.2 More respectful enforcement of rules
	12.3Appreciated as they are
	12.4 Smoking/Medical Marijuana Management
13. Other areas of improvement	13.1 Food
	13.2 More programming (general)
	13.3 More educational programming
14. Program-specific feedback	14.1 Club Meds
	14.2 Yoga/meditation program
	14.6 Youth program
	14.7 Opening/closing ceremonies
	14.8 Talent show