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# "HIV/AIDS Isn't Here"

A Case Study of a One-Week Recreational Camp for Individuals Affected by HIV

# Naomi Hyba

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Dans la présente étude, nous avons examiné l'expérience de campeurs et de bénévoles à un camp d'une semaine pour personnes et familles affectées par le VIH au Canada. Les données ont été recueillies durant le camp de juillet 2013 au moyen de 26 entretiens avec des campeurs et des bénévoles et de 40 questionnaires autoadministrés. Ces données font ressortir cinq thèmes : le camp vu comme une « famille » ayant un fort esprit de solidarité; le sentiment d'appartenance qui ne se ressent pas ailleurs à cause de la stigmatisation; le rôle crucial du soutien social entre pairs; le camp vu comme la rencontre de divers groupes culturels et sociaux; et la diminution de l'importance de la séropositivité de la personne au camp. L'étude recommande que les travailleurs sociaux dont la charge comprend des personnes ou des familles affectées par le VIH tirent davantage profit de tels camps – par exemple, en adressant systématiquement ces personnes à ce genre de camp pour qu'elles profitent d'une dose accrue de soutien social. L'article invite aussi les travailleurs sociaux à s'investir dans ce type de programmes communautaires afin d'améliorer la qualité et la quantité des services qu'ils offrent.

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# "HIV/AIDS ISN'T HERE" A Case Study of a One-Week Recreational Camp for Individuals Affected by HIV

# Naomi Hyba

**Abstract:** In this case study we examine the experiences of campers and volunteers at a one-week residential camp for individuals and families affected by HIV in Canada. The data presented was gathered during the camp session held in July 2013, and was derived from 26 interviews with campers and volunteers and from 40 self-administered surveys. This data highlights five themes: the camp as a "family" with a strong sense of community; a sense of belonging not experienced elsewhere due to stigma; the crucial role of peer social support; the camp as the intersection of diverse cultural and social groups; and reduced significance of one's HIV status in the camp environment. This study recommends that social workers, whose caseloads include HIV-affected individuals or families, make greater use of such camps – for example, systematic referrals, to boost social support. This article also calls on social workers to invest themselves in this type of community programming in order to enhance the quality and quantity of services offered.

**Keywords:** HIV, camp, sense of community, sense of belonging, stigma, social support

**Abrégé :** Dans la présente étude, nous avons examiné l'expérience de campeurs et de bénévoles à un camp d'une semaine pour personnes et familles affectées par le VIH au Canada. Les données ont été recueillies durant le camp de juillet 2013 au moyen de 26 entretiens avec des campeurs et des bénévoles et de 40 questionnaires autoadministrés. Ces

Naomi Hyba is a MSW graduate of the School of Social Work, at McGill University.

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données font ressortir cinq thèmes : le camp vu comme une « famille » ayant un fort esprit de solidarité; le sentiment d'appartenance qui ne se ressent pas ailleurs à cause de la stigmatisation; le rôle crucial du soutien social entre pairs; le camp vu comme la rencontre de divers groupes culturels et sociaux; et la diminution de l'importance de la séropositivité de la personne au camp. L'étude recommande que les travailleurs sociaux dont la charge comprend des personnes ou des familles affectées par le VIH tirent davantage profit de tels camps – par exemple, en adressant systématiquement ces personnes à ce genre de camp pour qu'elles profitent d'une dose accrue de soutien social. L'article invite aussi les travailleurs sociaux à s'investir dans ce type de programmes communautaires afin d'améliorer la qualité et la quantité des services qu'ils offrent.

**Mots clés :** VIH, camp, esprit de solidarité, sentiment d'appartenance, stigmatisation, soutien social

#### 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 (PHAC, 2010). With strong cultural taboos, stigma, and secrecy, HIV has a unique social context that adds to the complexity of social work interventions with affected populations. In fact, HIV has been described by many researchers as a "social disease" (e.g., Mavandadi, Zanjani, Ten Have, & Oslin, 2009; Friedland, Renwick, & McColl, 1996) due to the stigma and marginalization of affected individuals. These two factors can make accessing traditional forms of social support particularly difficult for individuals and families living with, or affected by, HIV (Caroleo, 2001; Sausser, Dattilo, & Kivel, 2000; Kelly, 2010).

This article presents a mixed-method case study of Camp Snowy Owl, a camp that brings together a diverse group of people living with the effects of HIV and AIDS. Aiming to provide a positive recreational experience tailored to the unique social needs of these individuals, the one-week residential camp offers a relaxed, outdoor experience to people who find such settings difficult to access due to the stigma so often associated with the illness. The article begins with a literature review on recreational programs – in particular camps – as a tool to boost social support and the well-being of individuals living with HIV. Next, the case under study will be presented: a case overview, review of the methodology, and results. The article will conclude with a discussion linking these findings to the existing scholarly literature.

The article contributes to this under-developed area of scholarship in both its subject – at the time of submission, it is the only known Canadian study on a camp for people with HIV, and the only known study to explore a camp that welcomes families, couples, and individuals alike – and its approach, highly valuing the stories, knowledge and words as expressed by the participants themselves. This article argues that a recreational camp experience is a particularly effective mode of intervention for individuals and families infected or affected by HIV, and is recommended to social workers whose caseloads include these populations.

## Literature Review

This section examines the existing literature on recreational programming for HIV-positive individuals and families. As affirmed by Gillard, Witt, and Watts (2011) and Hrenko (2005), the body of literature on HIV camps is extremely scant. As such, the literature review was then widened to include non-camp recreation programming, focusing on impacts and benefits derived from the programming that would also be applicable to a camp setting.

## HIV Recreational, Stigma and Social Support

One intervention that is often proposed for stigmatized populations who lack social support is group recreational activities. However, authors such as Caroleo (2001) contend 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 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 they may simply make recreation less enjoyable (Sausser et al., 2000). These factors may be: physical, such as loss of strength, endurance, and fatigue; mental, such as loss of short-term memory or concentration, and depression; and/or structural, such as job loss, decrease in income, and complicated medication regimes (Sausser et al., 2000).

Despite these barriers, Caroleo (2001) posits that recreational activities offered by community social work services or AIDS service organizations may 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). In their qualitative study of eight HIV-positive individuals engaging in a variety of leisure activities in a therapeutic recreation program, Sausser et al. found similar benefits to those listed by Caroleo, with an added benefit of the negotiation of "perception of self" through leisure activities (Sausser et al., p. 48). 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 by Kelly in his retrospective article on social work group practice with individuals affected or infected by HIV (2010). Kelly writes 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). Kelly also contends that group work remains the most powerful "antidote" to the stigma surrounding HIV/AIDS (p. 286).

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 (1992) 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. Additionally, the authors note that secrecy and stigma surrounding HIV often prevented family members from accessing HIV-related social support from outside the family.

#### HIV, Social Support, and Well-Being

The previous sections have discussed the relationship between HIV recreational programming, stigma and social support. This section will explore the relationship between social support and general wellbeing for individuals affected by HIV in order to understand a possible relationship between HIV recreational programming and general wellbeing. Numerous authors have specifically examined the role of social support in the well-being of individuals living with HIV. Mavandadi et al. (2009) studied the role of social relationships in determining the psychosocial well-being of 109 adults in Philadelphia who are aging with HIV. The authors found that compared to younger adults, older adults reported greater perceived social support and more "vigor," which was linked to more positive effects and fewer 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 (Mavandadi et al., 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 et al., (1996) studied the roles of social support and coping in determining the quality of life for 120 HIV-positive individuals in Toronto. 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 et al., 1996). While the participants perceived the emotional support they received was of sufficient quality, they wished for a 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, et al., (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., 2005 p. 28).

Less research is available on the impact of HIV-related stigma and social support in the well-being of children. In the available research, study of 64 caregiver-child dyads, Sherman, Bonanno, Wiener, and Battles (2000) 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. 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. Sherman et al., 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). 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 that promoted well-being in children affected by HIV: individual, family, and community. Community resilience factors include access to education, information sharing, participation in mental health interventions, and social and peer support (2013).

#### HIV-Specific Camps

The scholarly literature on camps for individuals affected by HIV is scant, with very few recent studies available. 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 an informative but anecdotal article. Pearson, Johnson, Simpson, and Gallagher (1997) provide a detailed description of the Hole in the Wall Gang Camp, a camp for hemophiliacs with a special session for children with HIV. Written in 1997 by a pediatric HIV/AIDS team, 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 1990s. In 2005, a similar article by Bergman, Kinsella, Kenny, Barbor and Zeltzer examined primarily the issue of medical safety at summer camp for immunodeficient, HIV-positive, and hemophiliac children.

Apart from these articles, only three studies were found in which the authors studied camps for individuals affected by HIV from a psychosocial or social work approach. Gillard et al. (2011) undertook a study of a recreational camp program for youth with HIV in the Southern United States, noting the relevance of "nonclinical therapeutic intervention outside the formal medical setting" – and the lack of nonmedical research on this subject (p. 1508). 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 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 same authors had previously completed a study on the camp focusing on staff-camper relationships and organizational processes (Gillard, Witt, & Watts, 2010, p. 63). The authors suggest that medical and social work practitioners refer youth affected or infected by HIV for camp and nonclinical interventions as part of a "holistic" approach that considers the development of youth overall, countering the tendency of practitioners to "narrowly focus on the medical aspects of illness and neglect other parts of youth's lives." (2011, p. 1521).

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, run by social workers and various (arts, play) therapists. The camp offered therapeutic sessions with parents and children separately; group sessions for the 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 the group experiences facilitated by the 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" (2002 p. 283). The authors find that psychosocial interventions outside of standard social work or medical settings - e.g., hospitals and clinics - can be particularly effective for more vulnerable families. The authors conclude that medical and clinical interventions 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 popular literature and grey media about HIVspecific camps, often written by HIV/AIDS service organizations, and the camps themselves, can be found online. Some relevant sources include the websites for specific camps or the larger organizations that operate them; Egan (2011), Newbery (2004), Duke (2003), National Abandoned Infants Assistance Resource Center (2003), Parkes (2002), Foster (2000), Clairborne (1995). 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) notes that most HIV camps operate in collaboration with 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.

# HIV Camping Programs Offered in North America

I researched the available camp programs for individuals affected by HIV in Canada and the United States, with the disappointing conclusion that very few programs are offered in Canada. At the time of publication, five camps were found in Canada, one of which (the Canadian branch of Camp Laurel) had its pilot year in 2013. The United States offers significantly more camp programs for individuals affected by HIV, however the majority are operated in conjunction with a local church or diocese and operate with a charity model of service. Presently, the differences in HIV camps operating with a charity model are not documented, due to the aforementioned lack of research in this area; however, one could hypothesize that there could be differences in the camp culture, camp population, and camper experience for camps operating under a religious or charity model of service. Significantly, all camps in Canada and the United States other than Snowy Owl and its model, Camp Wendake, are open only to children and youth, or to families with children. This makes Camp Snowy Owl an especially compelling camp for this case study because of its inclusion of campers across the lifespan, whether as individuals or as families.

## Methods

The main objective of this study was to explore how volunteers and campers experience Camp Snowy Owl. A secondary objective was to explore the role of three different concepts that may be at play in this camp: stigma, social support, and sense of community.

## Theoretical Framework

The theoretical framework chosen for this study is social constructivism, defined as a view whereby, "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, I have made efforts to "position" myself (p. 25) within this study, making explicit my role as researcher and my personal biases.

Additionally, I have made efforts to reflect on my 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, I am 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, it is important to note that I have acted as a volunteer with this camp's child and youth programming for three years prior to undertaking the study. This prior involvement required additional caution on my part in the processes of obtaining ethics approval, planning the research design, and collecting the data. Prior to and while conducting research, I 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, I 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 my position as an "insider" was invaluable in facilitating access to the camp, in enhancing my 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 my prior involvement with the camp. Additionally, the following are examples of studies on HIV-related camps where one or more of the researchers 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, 2011; Hrenko, 2005; and Pearson, Johnson, Simpson, and Gallagher, 1997.

I was acutely aware of the need to separate my perceptions and experiences of the camp as a former volunteer from my perceptions of the camp as a researcher. While this can be considered to be reflexivity, or "reflection in action", I 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 field notes.

#### Methodological Approach

The objective of this study is to gain an in-depth understanding of the operation and outcomes of the camp described below. This study uses the case study approach, which 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 by Creswell as "a case that has unusual interest in and of itself," as camps for HIV positive individuals are extremely rare in Canada, and this camp's inclusion of individuals and families of all ages makes it unusual and unique (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 both 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, and 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 et al., 2007).

#### Overview of the Case

Camp Snowy Owl is a one-week recreational, residential camp for adult 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: Camp Wendake. This pioneer program was extremely successful, and by 2008, the camp could no longer accommodate all applicants (Camp Wendake, 2013). In 2010, applications were restricted to residents of specific parts of Ontario. In response, the Snowy Owl AIDS Foundation created Camp Snowy Owl. This camp has occurred in July or August every year since 2010, at a camping facility in rural Ontario.

This camp is attended by a variety of individuals including single men and women with historic or active substance use, LGBTTQ individuals and couples, heterosexual couples with and without children, and immigrants from Africa and the Caribbean (these groups are not, of course, mutually exclusive). Campers are recruited through local HIV/AIDS service organizations, while volunteers are recruited more informally through existing networks of HIV advocates, volunteers and community members. 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 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)

The camp's schedule includes shared meals, 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.

#### Data Collection

This mixed-method case study included three sources of data: participant observation, a survey (n = 40) and semi-structured interviews (n = 26). 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. (See "Limitations" section for discussion on the potential impact of this decision.) The participant population in this study was confined to the 25 campers (aged 13 years and older) and 15 volunteers attending the camp in the year under study. Efforts were made to ensure the participants

represented both the diversity of campers and volunteers as well as a representation from campers and volunteers who had attended camp in previous years.

I began data collection as a participant observer in daily camp activities such as mealtimes, craft times, waterfront time, the opening and closing ceremonies, the talent show, etc. This data provided the context and the background information necessary to understand the survey and the interview responses.

The second source of data was 26 semi-structured interviews with campers (n = 16) and volunteers (n = 10), each approximately 45 minutes long. Within the 16 camper interviews, four were with adolescents. Six interviews were completed in French. The timing and location for the interviews were determined primarily by the participant, as were their pseudonyms. Most interview participants were given a \$20 gift card as an honorarium.

The third source of data collected was an anonymous, selfadministered questionnaire, which took about 10 to 15 minutes to complete and was administered to all interested campers and volunteers on the last day of the camp. This questionnaire asked respondents to rate a variety of camp aspects (programming, food, etc.) on a scale of 1-5, and asked six open-ended questions. Forty questionnaires were completed, with 15 completed by volunteers and 25 completed by campers. Ten of the 40 surveys were completed in French; 19 were completed by men, and 21 by women. Survey respondents ranged in age from 14 to 74 years old, with the most common age groups reported as 35-44, and 45-54. Sixteen participants attended camp alone; four attended with a partner; and 20 attended either with their children, or their parents in the case of adolescent respondents. Nine participants indicated it was their first year of camp; nine indicated it was their second; seven indicated it was their third; and 15 indicated it was their fourth. Ethnicity was not included as a survey question, I felt that in the context of a very small pool of participants, it would compromise confidentiality as age and gender were already asked. Within the 25 camper surveys, seven were completed by youth.

All participants who completed the questionnaire received a \$10 gift card. 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 my 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. Survey

responses were tabulated using Excel to calculate the mean for each camp aspect as rated by the respondent on a scale of 1-5, while openended questions were coded for the frequencies of keywords and themes. The results of the survey rating questions are not here, as the questions targeted program evaluation to be used by the camp. Interviews were transcribed, with sections perceived as particularly salient transcribed verbatim. Interviews were coded using a coding tree created after transcriptions were completed.

# Results

This section outlines five themes that emerged from the data: camp as a family, with campers reporting ownership of and membership to the community; sense of belonging; the role of peer support; and camp as the intersection of diverse communities.

# Theme #1: "Coming Home": Camp as a Family Reunion

Both campers and volunteers reported having formed supportive relationships at camp that were strong enough in depth and intimacy for most participants to talk about 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"<sup>1</sup> remarked, "The Snowy Owl community – it gives you lots of brothers, fathers, mothers, sisters, aunts, and uncles." The sense of family, described as strong enough to "withstand a year apart and pick up right where it was left last year," was a particularly central theme in all four youth interviews. As described by "McLane":

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... This place is infinite.

Campers exhibited a high degree of ownership of their community, viewing themselves as essential members of the camp. In the words of two women who were asked what they bring to the camp: "I contribute, because if I am not here, it's not camp!" (translated from French, "Virginie") and "The chance to see me! The diva is here!" (translated from French, "Hamda").

<sup>&</sup>lt;sup>1</sup> Research participants were invited to choose a pseudonym that would be used in any reporting of the results. These are the names used in this article.

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

For me, it's like a village. At home [my country], if you leave the capital, you'll rest, you don't have the noise of the city. Without the cars, if you go the village it's very calm. Beside the river, it's like it's my village... I feel like a newborn. For one week I rest, I forget everything. I get up, I go to the trees, to the river, with a family that is going through the same thing, like me (translated from French, "Adalène").

### Theme #2: A Unique Sense of Belonging at Camp

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")

Some campers compared their sense of membership and belonging to inadequacy of their own social support networks and the artificiality of more formal support services. Participants attributed a large part of the isolation felt outside of camp to their health and HIV status, 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, as were the HIV-positive volunteers in removing the stigma around HIV status:

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")

The sense of community that participants described was often contrasted with a sense of isolation elsewhere, including within their extended families, most often attributed to the stigma of HIV:

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What my family won't accept, they [volunteers] accept. For example, my sister, when I gave birth, she came to visit me. Before coming, she brought her spoon and fork, because I have HIV. And here, there's a volunteer who gathers all the spoons together, and goes to wash them. So, maybe they could come across the spoon that I used — but that doesn't embarrass me. Even my sister, my own sister, she brought her spoon. ("Adalène")

"Toumaya" noted a similar contrast between camp and her ethnic community:

In the community we can't speak, we can't reveal ourselves, but here... We go to a camp that knows that we have HIV, and we're accepted — it's a huge difference! The other advantage is going with your children to where you are accepted, because you are accepted as you are, positive and negative.

When "Roger" was 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.

Many participants referenced the need to "hide" aspects of their HIV elsewhere, particularly their medication, as we hear from this youth participant:

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")

Many campers stated they would be unwilling to attend a "normal" camp due to the stigma around HIV. Some felt the effects of stigma were 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")

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 government assistance, as the reason for this. Financial difficulties could be amplified when people with the illness were responsible for children:

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?... 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. ("Lexi")

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."

# Theme #3: Peer Support: A "Bridge"

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. With peer support highly valued by the camp, concerted efforts have been made to recruit HIV-positive individuals as volunteers. Some campers felt the peer support provided by HIV-positive volunteers was invaluable to their experience: "To have volunteers who support their peers, that's a very good thing. We share a similar history... It reinforces the acceptance of each other in this whole community, and it adds value to camp too." ("Toumaya")

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

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 joy... ("Sophie")

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 special privileges – was one of a few tensions cited by both volunteers and campers. Other tensions included the ambiguity of confidentiality considering the dual roles of peer volunteers, and the difficulties that these dual roles created with rule enforcement: "People who know you well will try to get away with some shit" ("David"). As one camper described:

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")

Some campers were particularly impressed by the lack of stigmatization they felt from HIV-negative volunteers 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 90s, 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")

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

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")

# Theme #4: "We're All Walks of Life": Camp as the Intersection of Diverse Communities

One characteristic that seems to be unique to the camp under study is the intersection of cultures that meet at this camp. As participants described, "[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 divergent opinions on whether or not there were tensions between these vastly different groups. The volunteers tended to believe that the differences between groups required, at the very least, careful attention and management. Among the campers, those who perceived tensions belonged largely to the Gay, Lesbian, Bisexual, Trans, Two-Spirit, and Queer (GLBTTQ) community, or were single adults who came with no kids. For example, "Angelo" wondered sometimes "if there are issues because of us being gay.... in some African countries it's illegal." And "Daniel" related this story:

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...

Others perceived that there was no tension:

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... With all the diversity of people, very few fuck up ("Roger").

"Elizabeth" expressed it this way:

The greatest strength of camp is] smashing stereotypes... 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.

Many participants agreed 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. A few 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 man 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 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")

# Theme #5: "HIV/AIDS Isn't Here": Minimal Importance of HIV Status While at Camp

Perhaps the most surprising finding from this study is that HIV was perceived to be minimally present during the week of camp, superseded in importance by the sense of family and community that participants felt had been created.

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"Lexi" had a similar answer when asked what he perceived as the goal of camp: "to allow us to be – and you have to put big quotation marks on this – "normal" for a week." The concept of "normal" and the link to HIV status was also explained by the other campers; "Hamda," for example:

It's like here we're normal – it's like an opportunity, a chance to get to know a lot of people... With the people here, you can rebuild your self-confidence... you have problems, but when you spend time here, your self esteem comes back, you become normal. (translated from French)

The camp director offered a plausible interpretation:

It's present [HIV], but it isn't. It is and it isn't... 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, breathe, eat it. So for me, that's not what camp is about. It's about being able to hang out with my friends. ("Genesis")

(HIV) is there only when I take my medication, for others too I think... even taking my medication, here it's just a medication like any other... it doesn't live in my being here, HIV. (translated from French, "Toumaya")

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")

We never talk about HIV, you've seen what I mean – everyone here is in good health – we don't talk a lot about HIV. That's not what's important. (Translated from French, "Virginie")

It is important to note here the role of modern HIV anti-retrovirals (HAART – highly active antiretroviral 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 90s:

It's not as scary, where before [at an HIV camp in the early 1990s] 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")

#### Discussion

In the three other studies of HIV-targeted camps, HIV seems to remain front and centre during camp activities as well as throughout the participants' and authors' discussions about the camps; this could be partly explained by the earlier publication dates of the studies, in the early days of highly active antiretroviral therapies. 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 on 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 et al.'s (2002) comparison of a medical intervention and a camp intervention for families with HIV-positive children, the findings focused exclusively on HIV: clinical outcomes on the children's and families' ability to cope with HIV and its impacts on their lives.

Closely related to the finding of a minimized presence of HIV is the finding of the normalization of HIV at camp. In Swartz' 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" (2009, p. 211). While the normalization of HIV status is similarly hinted at in a few other articles, it is not explicitly identified as a central outcome of camp. Therefore, the degree to which HIV is, in the words of "Lexi" from Camp Snowy Owl, "put in the closet with the winter clothes" appears to be unique.

This study's findings of a sense of family, home, and community replicate the first of three central findings in the most relevant study to this case, Gillard et al.'s 2011 case study of a camp for youth with HIV that described the outcome of "caring connections" as the presence of commonalities and a lack of isolation. Similar to the present study, Gillard et al. found that this feeling of "camp as a home" was enhanced by the contrast of the commonalities among campers with isolation felt elsewhere, as well as the contrast of closeness at camp with loneliness elsewhere in campers' lives (2011, p. 1514). Disclosure of HIV and the openness to discuss HIV at camp was found by Gillard et al. to be as crucial to the positive impact of camp as in the present study. The authors summarized there was "no need to hide because everybody knew each other's most closely held secret" (p. 1516).

The centrality of staff-camper relationships, as well as camper-camper relationships, found in this study mirrors what Gillard et al. noted in 2011: that staff-camper relationships were more significantly associated to the outcomes than were any camp activities themselves. This follows the results of Gillard et al.'s 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 et al, 2010, p. 63). Kmita et al., also found the relationships formed at 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" (2002, p. 283). This supports the present study's finding that the relationships at camp, and the sense of family and community this created, were perhaps the most salient aspect of camp for both campers and volunteers.

Looking beyond the literature on structured camp experiences, the findings of the present study can also be linked to the wider body of literature available on recreational programs 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.

A recurring theme in the results of this study is the bond that campers and volunteers alike felt they shared, regardless of race, religion, social class, etc. Participants also expressed appreciating the diversity of ages, for example with some campers particularly appreciating the younger volunteers' energy. The 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) when they documented how 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 et al., (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). Similarly, 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 (2004) 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 effects on health-related quality of life. This would prove to be another interesting future area of research.

Considering that camp attendance reduces the sense of stigma, which is considered to be a major impediment to HIV medication adherence (Bogart et al., 2008), a second valuable area for future research would be the impact of camp attendance on adherence to medication.

#### 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, I 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 me that their willingness to participate could be attributed to the relationship between me and this community, and the trust that had been built over several years. She explained, ""Even if you are here with us this year as a researcher, we don't see you as a volunteer or whatever. You are still part of our group – you are one of us."

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 that she felt the depth of information gathered was attributable to my pre-existing relationship with the camp – "otherwise, it wouldn't have been the same – you wouldn't have gotten anything." Therefore, I strongly believe 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 my dual roles (that of researcher and volunteer) prompted participants to express more positive feedback about the camp, or to overly focus on positive aspects in the hopes of "pleasing" me. The second limitation is that all data was collected during the week itself, so participants had not had time for reflection after their camp experience. It is also possible that the positive impacts they described were amplified by being in the actual camp setting and time frame during the interview. The third limitation is that this is a case study, in which I examined only one camp during only one year of operation. Generalizability was not an aim of the study, and results should not be interpreted as generalizable.

#### Conclusion

The research findings presented in this article suggest that a recreational camping experience for individuals and families affected by HIV promotes significant positive outcomes for these individuals and families. In this study, benefits were found to include a sense of family and community, including membership to and ownership of the community; 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. 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.

The primary conclusion from this study is that camp is a highly effective social intervention for individuals and families affected by HIV. As such, social work and medical practitioners are highly encouraged to supplement the clinical services offered to these individuals and families with references to camp or other nonclinical interventions. As shown by the results of this study, a camp intervention may prove particularly pertinent to reduce stigma associated with a diagnosis of HIV; create a sense of belonging and community; and, somewhat ironically, minimize Revue canadienne de service social, volume 33, numéro 2

the importance and impact of HIV on these individuals' lives for the duration of the camp.

This study contributes to the scant body of literature on camps for individuals affected by HIV. It is the only known study of a camp for individuals with HIV that welcomes families with children, couples, and individuals of all ages. The findings of this study highlight the need for more research specifically on camp and nonclinical recreation experiences as a viable modality of psychosocial support for individuals affected by HIV from a wide variety of demographic groups. The hope would be that more research and documented findings would in turn pave the way for more funding allotted to camps and programs of this type, which would allow more individuals and families to access this unique support. Lastly, I hope more Canadian social workers will involve themselves in this type of community programming. The skills possessed by social workers – community-building, empowerment of affected populations, and the fostering of mutual support networks – would prove invaluable to the success of community-driven initiatives such as Camp Snowy Owl.

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