

**“I Feel Bad for People Who Don’t Have a Chronic Illness:” Refusing Deviance and
Reframing Illness Through Summer Camp**

by

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Abstract

Scholarship in medical anthropology has a history of characterizing chronic illness as a “deviant” condition. Emerging research problematizes this paradigm, however, and demands its reconsideration. The growing recognition of the significance of shared experiences of illness and community in coping with chronic illness diagnoses also contradicts traditional conceptualizations of illness as disruptive and socially stigmatizing. One example of this phenomenon can be found in pediatric medical summer camps. Stemming from a personal understanding of illness and the summer camp experience, this thesis investigates the transformative nature of these experiences through semi-structured interviews. In doing so, it applies Catherine Tan’s idea of “biographical illumination” to the experience of pediatric medical summer camps, arguing that these camps reframe campers’ understandings of illness through community, shared experiences, and a focus on personal growth. With this new understanding of chronic illness, individuals refuse the label of deviance and come to consider their diagnoses as illuminating.

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Introduction

When I was ten years old, my life changed forever: I was diagnosed with a chronic illness. After months of being sick and not knowing why, I finally had answers, but at the same time, I had never felt so alone. I quickly learned that being diagnosed with a chronic illness is a fundamentally isolating experience. It takes a world that once felt safe and warm and transforms it into something dangerous and often life-threatening. How can a child be expected to understand, let alone cope with that? What supports exist for youth when all the doctors' appointments and tests lead to a diagnosis, but no cure?

A summer camp nestled in Aylesford Nova Scotia called Brigadoon Village, offers one solution. Since opening in 2011, Brigadoon has grown to become the largest pediatric medical camp facility in Canada (*Brigadoon Village*, 2024). In its summer season, the non-profit organization offers week-long summer camp sessions for youth with a variety of different chronic illness diagnoses and life challenges. I started going to camp at Brigadoon in 2012. Before camp, I felt completely alone in my experience. I had never met another person, let alone someone my age, with the same diagnosis as me. In my first summer, I met 30. The next summer I met even more. Over my six years as a camper and working for the organization for the past six summers, cumulating in twelve years of involvement, I have met hundreds of people with the same diagnosis as me. My life was changed for the better because I started going to a week-long summer camp.

Working at Brigadoon opened my eyes to the broader transformation that campers undergo at camp: I have listened to a legion of first-hand accounts that frame Brigadoon as a life-altering experience and watched campers leave camp completely different people from when they first arrived, only six days before. This personal understanding of just how significant a summer camp experience can be fuels this exploration, as I investigate how these

transformations occur over such a short period of time.

Literature Review

My experience has shown me that Brigadoon has the power to change lives, but *how* does this happen? What is it about summer camp that is so transformative? What do campers learn at camp and what do they take with them into the outside world? How can going to summer camp transform someone's understanding of chronic illness? To begin grappling with these questions, I turned to the existing literature on the experience of chronic illness in children and youth and what I could find on the role of pediatric medical summer camps in coping with these diagnoses. In the reviewed literature, pediatric medical summer camps are listed as a potential solution to coping with a youthful chronic illness diagnosis (Dawson & Liddicoat, 2009; Krull, 2023; Singh et al., 2023), however, these investigations dealt with a single type of chronic illness diagnosis, for example cancer (Kearney, 2019) or deafness (Goodwin et al., 2011), I was surprised by the lack of literature concerning the significance of these camps for chronic illness diagnoses more generally. Furthermore, I did not expect to find such a limited amount of writing on *how* pediatric medical summer camps are transformational experiences (Kearney, 2019).

Contextualizing Chronic Illness

In social and anthropological literature, chronic illness is often framed as a form of “deviance,” where individuals who have received these diagnoses stand in stark contrast to the so-called normative society (Goffman, 1963; McRuer, 2006; Thomas, 2012). The idea of chronic illness as deviance is socially constructed through the treatment of individuals with these diagnoses and the way that chronic illness is discussed and reacted to in social discourse (McRuer, 2006). Classic theories of biographical disruption (Bury, 1982), the sick role (Parsons, 1991), and stigma (Goffman, 1963) foundationally depend on the idea of chronic illness as

deviance; describing its construction through diagnosis, social expectations, and negative social reactions. Biographical disruption, conceptualized by Michael Bury (1982) details how chronic illness diagnoses are tumultuous events that make life more difficult because of the changes they cause in one's life (Tan, 2018). Talcott Parsons' (1991) writing on "the sick role" conceptualized the social expectations, obligations and rights of individuals with illness (Kassebaum & Baumann, 1965; Varul, 2010). Finally, stigma, originating from Erving Goffman's work on the *Management of Spoiled Identity* (1963) captures the social consequences of having a chronic illness diagnosis, particularly when received during childhood or youth and how this stigma becomes internalized over time (Millen & Walker, 2001; Saunders, 2014; Scambler & Hopkins, 1986).

Although contemporary explorations of chronic illness problematize and attempt to move past these ideas, "people often draw implicitly on these constructs in responding to chronic disease" (Nowakowski, 2016 p.1621). When someone is considered "deviant," they are expected to do what they can to conceal or overcome that label, it is not something that one is supposed to feel proud of (Goffman, 1963; McRuer, 2006; Thomas, 2012). However, with the turn of the century, there has been a surge of social research critiquing this view of chronic illness; arguing instead that these pressures are harmful and place unrealistic expectations on those who are chronically ill (N. Brown & Leigh, 2018; Nowakowski, 2016; Scambler, 2004). If being diagnosed with a chronic illness turns your whole world upside down (Bury, 1982), why should we be expected to conceal and be ashamed of that disruption? As sociologist Carol Thomas (2012) unequivocally asserts, employing a social deviance framework to analyze chronic illness experiences is no longer "politically or morally appropriate" (p.215). The question then arises: how does one effectively challenge the notion of deviance in this context? How does someone with a chronic illness diagnosis refuse deviance?

Social Isolation

Living with a chronic illness diagnosis can significantly complicate social relationships (Floyd & Gallagher, 1997; Osgood et al., 2010; Scambler & Hopkins, 1986). In social interactions, people tend to “respond to specific performances of sickness as either deviant or normative” (Nowakowski, 2016 p.1621). Medical sociologist Alexandra “Xan” Nowakowski’s autoethnographic exploration of their own experience with a visibly noticeable chronic illness details the double-edged sword of deviance that they face. On the one hand, “the overall framing of illness as deviance [differs] from the usual social expectations I face, both generally as a member of contemporary American society and specifically as a relatively young person who appears female” (p.1621). At the same time, acting in a way that does not align with others’ perceptions of one’s “sick role” is perceived “as deviant, and therefore subject to sanctioning” (Nowakowski, 2016 p.1623). Here, Nowakowski is expressing something that many with chronic illness diagnoses know to be true; there is no “winning” when it comes to these expectations, in part because there is no right way to go about being chronically ill.

When a child receives a chronic illness diagnosis, the social repercussions can be detrimental (Cohen, 2023; Millen & Walker, 2001; Saunders, 2014). Writing in reflection on his diagnosis at thirteen with Crohn’s disease and his now 50-plus years of lived experience with chronic illness, Ed Cohen (2023) expresses that one of the hardest parts of his diagnosis in youth was the consequences it had on his self-esteem and mental well-being:

While at this point in my life [High School] I could discuss the physical manifestations of Crohn’s in exquisite detail, I didn’t have a clue about how to recognize, let alone convey, its psychological implications. If it didn’t exude from my ass, I had no idea how to represent the shit that was happening to me. Moreover, I had no idea about how to address it or to whom to address it. After all, why would I tell a gut doctor that a hollowness had erupted at the center of my existence and that, like an emotional black hole, it had begun to suck away all my newfound vitality? P.82

As is the case for many youths learning to deal with their chronic illness diagnoses, Cohen's earlier memories are peppered with experiences of bullying and social isolation. Unfortunately, these are all too familiar concepts for children and youth living with chronic illnesses (Becker, 1981; Millen & Walker, 2001; Scambler & Hopkins, 1986). The impact that these social repercussions have on youth is severe; for Cohen, "anxiety suffused my way of being. It seemed as familiar as the air I breathed" (p.145). Navigating life with a chronic illness presents significant challenges; how are children and youth expected to manage when their unique circumstances are accentuated by social consequences?

Social Care

In the reviewed literature, ideas of shared experience, social support, and community are offered as ways of learning to manage a chronic illness and coping with the associated social consequences (Goodwin et al., 2011; Josefsson, 2005; Steffen, 1997). Shared experience and community stand out as ways that people have learned to cope effectively with their chronic illness diagnoses (Alper et al., 2023; Barlow et al., 2005; P. Brown et al., 2004; Steffen, 1997).

P. Brown and colleagues (2004) detail a phenomenon they term embodied health movements, where a community of individuals bonded by direct, felt experiences of illness collectively express themselves through activism. Here, the collective identity that emerges from shared experiences of illness serves as a mobilizing force, bringing individuals together to work within existing social institutions and even challenge dominant bio-medical practices (P. Brown et al., 2004). This article comments on only one example of the power that shared experience can have, especially when that experience is a medical one (Nowakowski, 2016). The collective empowerment through shared illness experiences seen in embodied health movements draws

parallels to the sense of unity and support often found in chronic illness summer camp experiences, highlighting the transformative potential of shared narratives and communal action in navigating medical challenges.

Phenomenon like embodied health movements call into question the historical characterization of chronic illness as “disruptive” (Alper et al., 2023; McRuer, 2006; Rasmussen et al., 2020). Through interviews with adults who were diagnosed with autism in their late teens or adulthood, Sociologist Catherine Tan (2018) posits the notion of biographical illumination, where medical diagnoses complement, rather than disrupt personal narratives. Being connected to a community of others sharing their diagnosis was named by many of the people Tan interviewed as one of the reasons they felt as though their lives had been illuminated by their diagnoses (2018 p.166). Since Tan’s original theorization, the idea of biographical illumination has been applied to online communities (Alper et al., 2023) and the way that parents cope with their children’s diagnoses (Legg et al., 2023; Rasmussen et al., 2020), however, it has yet to be applied to chronic diagnoses beyond autism.

Although the investigation at hand does not deal with activist movements or autism diagnoses, there are several overlapping themes at play. The transformative power of shared narratives and collective action, evident in embodied health movements, underscores the profound impact of communal support and solidarity in navigating medical adversities. Considering the empowerment and meaning that members gain from participating in these movements, could it be argued that their experiences of illness were illuminated? In what ways can biographical illumination be applied to other chronic illness diagnoses and experiences?

Contextualizing Summer Camp

Generally, summer camps are characterized as spaces where social norms can be

renegotiated and campers feel a sense of belonging, social support, and empowerment (Baker & Hannant-Minchel, 2022; Harvey, 2017; Tillery, 1992). This is facilitated by the summer camp site's physical removal from society, which instills a sense of freedom in campers (Harvey, 2017; Kearney, 2019). In her Sociology Graduate Thesis, Penny Harvey (2017) describes summer camps as "a fantasy world" (p. 19) where campers feel safe to present different versions of themselves, experience personal growth, and form deep and meaningful connections with others (pp. 19-25). Harvey's thesis also highlights the norms, rituals, and behaviours involved in the typical summer camp experience, arguing that these elements are crucial to the cultural nature of the camp, playing an integral role in facilitating that feeling of belonging (pp. 28-45). These rituals include how campers are welcomed on the first day of camp, all-camp activities such as campfires and talent shows, and the micro-rituals created in individual cabin rooms (Harvey, 2017; Kearney, 2019). Recalling our discussion of the social consequences that many chronically ill youths face, the summer camp's separation from mainstream society lends itself well to this particular population and the unique challenges they face.

Community at Camp

Finding community can help us find meaning in our lives. In the reviewed literature, there was an overwhelming emphasis on the role of the community in pediatric medical summer camp experiences (Dawson & Liddicoat, 2009; Goodwin et al., 2011; Saxton & Govertsen, 2000). In the 1969 publication *The Ritual Process*, Victor Turner explains this phenomenon through his conceptualization of liminality and communitas. Liminality speaks to the social stage of existing both in and out of time, disconnected from typical social structures - a state of in-betweenness - while communitas has something to do with a collective sensation of having one's life gain meaning (E. Turner, 2012; V. Turner, 1969). Communitas is born from liminality (V. Turner, 1969).

Recall Harvey's thesis; summer camps are isolated from mainstream society and spaces where meaning is created through community. In other words, summer camps are liminal spaces that foster experiences of *communitas* in youth (Kearney, 2019). This is the approach taken by Sociologist Peter Kearney in his 2019 book *Healing Rites of Passage*. Based on his experience at an American summer camp for children with cancer diagnoses, Kearney (2019) applied V. Turner's ideas of liminality and *communitas* to the pediatric medical summer camp experience. Here, he describes campers engaging in "joyful recognition of belonging to a fellowship, even if it is in the kingdom of the sick" (p. 39). Emphasizing the transformative power of the summer camp experience and the deeply meaningful community that is formed, Kearney suggests ideas of "magic" and "magical *communitas*" (2019, pp. 18-20). This concept of "magical *communitas*" within pediatric medical summer camps not only features the transformative and communal nature of these experiences but also sets the stage for a deeper exploration of the profound impacts of liminal spaces and communal bonds in the analysis that follows.

In pediatric medical summer camps, we see another example of the power and importance of shared experiences of illness. In the reviewed literature, these camps were credited as spaces of community and meaning-making that helped campers gain a sense of acceptance for their diagnoses and feel empowered (Dawson & Liddicoat, 2009; Kearney, 2019; Singh et al., 2023). In other words, these are illuminating experiences for campers. I thus argue that pediatric medical summer camps, like Brigadoon Village, are experiences in biographical illumination.

Refusing Deviance: Borrowing From Disability Studies

Emerging concepts in the realm of disability studies are relevant to discussions of pediatric medical summer camps. Although disability and chronic illness are not synonymous, "chronic illness is a major cause of disability...therefore, any adequate understanding of

disability must encompass chronic illness” (Wendell, 2001 p.17) and vice versa. In addition to their medical similarities, the two are intimately connected through overlapping experiences of social complexities and injustices (McRuer, 2006; Wendell, 2001). Concepts such as crip theory (McRuer, 2006) and disability culture (Barnes & Mercer, 2001; Ginsburg & Rapp, 2013; Peters, 2000) hold relevance to this investigation. Academics like Susan Wendell (2001) call for a more nuanced understanding of illness and disability:

Illness is not by definition an evil, but people fear and try to avoid illness because of the suffering it causes. Some of that suffering is social and could be eliminated by social justice for people with disabilities, but some of it is not. Solidarity between people with chronic illnesses and people with disabilities depends on acknowledging the existence of the suffering that justice cannot eliminate...[and] on acknowledging that illness is not only suffering. Pp.30-31

In the above quote, Wendell highlights the importance of solidarity between individuals with chronic illnesses and disabilities and encourages us to recognize the shared suffering that social justice can address while simultaneously acknowledging that illness can involve more than just suffering. Wendell’s point aligns with Robert McRuer (2006) conceptualization of crip theory challenges traditional ideas of normalcy and disability by examining how society constructs and values certain bodies over others. Here, the focus is placed on the way that disability is made a social phenomenon, in addition to a medical one. McRuer emphasizes the importance of embracing diversity and difference, advocating for a more inclusive and accepting society that values all individuals regardless of their physical or mental abilities.

Another theme in disability studies literature that relates to the experience of chronic illness is that of disability culture. The idea of considering disability as a cultural identity is often attributed to scholar Lennard Davis (1999), who was particularly interested in the presence of culture in deaf communities. Recently, the idea has been applied to the experiences of pediatric

medical summer camps (Krull, 2023). At these camps, culture is created through collective experiences of meaning-making and discourse surrounding their shared experience of, in this case, disability, but more broadly medical diagnoses and experiences (Goodwin et al., 2011; Saxton & Govertsen, 2000; Singh et al., 2023). Just as disability cultures exist, the pediatric medical summer camp experience facilitates a similar culture for children and youth navigating chronic illness diagnoses.

While crip theory provides a framework for understanding disability as a social construct, ideas of disability culture embody these ideas in practice emphasizing the significance of communities that prioritize inclusivity, accessibility, and empowerment for individuals with disabilities. Both resonate with the experience of pediatric medical summer camps by underscoring the significance of fostering solidarity, understanding, and support among children facing chronic illnesses and disabilities within a communal setting. Here, the importance of acknowledging the multifaceted aspects of their experiences is highlighted; there is more to their diagnosis than the physical and medical challenges they encounter. In other words, the pediatric summer camp experience illuminates campers' experiences of illness.

Reframing Illness

The idea of summer camp as transformative has been mentioned in passing, but what exactly does this mean? How can one week away at camp change someone? According to the reviewed literature, this transformation has something to do with the way that youth who attend pediatric medical summer camps feel about their chronic illnesses (Dawson & Liddicoat, 2009; Kearney, 2019). This is accomplished through meeting other people with the same diagnosis and bonding over shared experiences of illness (Kearney, 2019; Saxton & Govertsen, 2000). Before going to camp, kids' understandings of their conditions were limited to how their doctors,

parents, or guardians had explained it and how their peers responded to their diagnoses, if they even chose to share that part of themselves (Krull, 2023; Singh et al., 2023). Although it has yet to be indicated in the literature, I argue that the transformation that occurs at pediatric medical summer camps is a form of biographical illumination.

Closing the Books

Pediatric medical summer camps serve as unique spaces where community and meaning-making intersect in experiences of *communitas*, providing campers with a sense of empowerment and acceptance for their diagnoses. Based on the reviewed literature and the research I conducted, I apply the principle of biographical illumination to theorize Brigadoon Village as an illuminating experience that fosters a deeper sense of belonging and understanding.

Chronicling Illness: The Research Process

This exploration is qualitative in design, employing semi-structured interviews as its main method of inquiry. The target population for interviews were adults aged 18 and up who attended one of Brigadoon Village's camps for chronic illness diagnoses, and who had not been directly counseled or supervised by me at camp. Although Brigadoon offers programs that cater to a diverse range of lived experiences, due to the time constraints of this project, I have decided to focus solely on those who attended Brigadoon because of a chronic illness diagnosis. To recruit interest, I designed an online poster (see Appendix A) and posted it on an Instagram account that I made specifically for this project. Once interest was indicated, my first step was to distribute my consent form (see Appendix B) to potential interviewees before we scheduled anything. I intended to employ a snowball sample and advertise my project through more venues than a single Instagram post, however, I was graced with an overwhelming amount of support and interest from the Brigadoon community and thus did not need to further advertise.

In January and February of 2024, I hosted eight semi-structured interviews. When interviewing, my goal was to have a conversational flow, as I wanted those I talked with to feel as comfortable as possible, even when we were discussing more sensitive topics like their diagnosis story. The semi-structured design allowed us to go down conversational side alleys and dive into new ideas as they emerged (Kvale, 1996a; Kvale, 1996b).

I decided rather early on that I would audio-record my interviews, as I wanted to be free to take notes on the contextual, bodily, and emotional aspects of the conversations I was having (Luker, 2008 p.175). As Kvale writes: “The ideal interview is to a large extent interpreted throughout the interview...the interviewer attempts to verify his or her interpretations of the subject’s answers in the course of the interview” (1996b p.145). Recording facilitated my ability to conduct in-the-moment interpretations.

The main research instrument topics in my semi-structured interviews were personal histories of chronic illness, the impact of diagnosis, the summer camp experience at Brigadoon Village, and the impacts of those experiences on interviewees and those around them (see Appendix C for my interview guide). After conducting an interview, my first step was to transcribe the recording into a password-protected Microsoft Word document. Following transcription, I hand-coded the collected data according to the literature, emerging concepts and themes, and ones not yet identified (Luker, 2008) before finally accomplishing a thematic analysis of my findings.

Research Population

Two of my participants identified as male, one as non-binary, and the other five as

female. Out of Brigadoon's fifteen summer camp programs, my participants had attended seven,¹ with only two having attended the same camp.

Alex, aged 25, was diagnosed with bilateral retinoblastoma at four months old. They went to Camp Goodtimes² at Brigadoon for five summers; however, they were a Goodtimes camper for twelve years. Debs, aged 19, began experiencing heart episodes at twelve years old. She attended Camp Braveheart³ for four summers. Eliza, aged 24, was diagnosed with psoriatic arthritis at twelve and went to Camp JoinTogether⁴ for five summers. Hank, aged 18, has had oculocutaneous albinism since birth and thus attended Camp See-Ya.⁵ He was a camper for eleven summers. Isabelle, aged 18, was diagnosed with peanut and tree nut anaphylaxis at three. She went to Camp Treasure Chest for eight summers. Mandy, aged 21, received a diagnosis of Crohn's disease at ten and attended Camp Guts & Glory⁶ for five summers. Neil, aged 24, was diagnosed with juvenile idiopathic arthritis at eight and went to Camp JoinTogether for five summers. Finally, Zoey, aged 19, was diagnosed with celiac disease at five. She was a Camp Silly-Yak⁷ camper for 9 summers.

It is worth noting that Alex, Eliza, and Neil also attended Brigadoon's March Break Leadership Camps, however, these camps are beyond the scope of this thesis because they do not occur during Brigadoon's summer season.

Illuminating Illness: Analysis of Findings

¹ It is relevant to note that Brigadoon did not always have fifteen camps, many have been added as the organization continues to grow. Further research in this area might aim to examine the experience of all fifteen of these camps.

² Camp Goodtimes is hosted for youth living with or beyond cancer. Alex has been in remission since before they turned one.

³ Camp Braveheart is hosted for youth with heart conditions.

⁴ Camp JoinTogether is hosted for youth diagnosed with juvenile arthritis.

⁵ Camp See-Ya is hosted for youth who are blind or visually impaired.

⁶ Camp Guts & Glory is hosted for youth diagnosed with irritable bowel syndrome and have ostomies.

⁷ Camp Silly-Yak is hosted for youth diagnosed with celiac disease.

Before Camp

As the reviewed literature suggested, the people I interviewed largely characterized their diagnosis experiences as complicated, disruptive, and overall, a negative time in their childhoods. Before going to camp, interviewees overwhelmingly expressed feelings and experiences of social isolation and stigmatization. Even with familial or community support, all eight of the people I interviewed had examples of the social consequences faced by youth navigating chronic illness diagnoses.

Diagnosis

Previously, I discussed the diagnosis experience and its typical anthropological associations with theories of biographical disruption (Bury, 1982), “the sick role” (Parsons, 1991), and stigma (Goffman, 1963). Neil, Eliza, Debs, and Mandy all remember their diagnosis, while Zoey, Hank, Alex and Isabelle were very young when diagnosed and don’t have those memories. In alignment with Bury’s idea of biographical disruption, those who do remember described their diagnosis as a tumultuous event and something that changed the course of their life forever. For these interviewees, the memories are still fresh:

At twelve you can remember what it’s like to not live with these symptoms, and then all of a sudden, your whole life is different: now it’s about taking medications and you have to remember things like washing your produce because now your immune system is suppressed... (Eliza).

Neil noted something similar, despite being four years younger when he was diagnosed; “I think [that] handling something that is chronic can be very scary at the age of eight. You don’t totally understand the idea of permanence at that point.” However, the other four do not remember what it was like to live any differently. Instead, they were reliant on parents, guardians, and doctors for

information on their own chronic illness experience. Alex described feeling like their neonatal experience with cancer was a fairy tale; a story that they were told as a child, but still feels surreal to have actually happened to them. Regardless of whether interviewees could remember receiving their diagnosis or not, all shared examples of the social consequences of their experience with me.

Stigma

In the earlier discussions of stigma and chronic illness, I highlighted how stigma fundamentally depends on the idea that those who are “ill” are “deviant” (Goffman, 1963). In the interviews I conducted, everyone expressed that their diagnosis has complicated their social relationships to some degree. All eight responded to the question “Has your diagnosis impacted your social life or relationships?” with examples of being stigmatized by close friends, peers, and trusted adults like doctors, friends’ parents, or teachers. Three interviewees said that they were bullied or teased in school because of their diagnoses. Eliza described her high school experience as “a lot of jokes about being a cripple, and then when I started going to camp it was jokes about cripple camp.” Even Isabelle, who made a point to emphasize how much support she had in her home and community, recounted times when she was teased for her anaphylactic allergies and even called “high maintenance” by a friend’s mom.

As the reviewed literature suggested, ideas of chronic illness diagnosis and social isolation came hand in hand in the interviews I conducted. However, these ideas were mostly brought up when the people I interviewed were describing what life was like before camp. In some cases, the exclusion was glaringly obvious: Zoey told me one story about “when I was eight or nine, I didn’t get invited to my best friend’s birthday party because her mom didn’t want to make gluten-free stuff.” For others, feeling isolated was the result of more subtle interactions,

such as disclosing their diagnosis. In our interview, Alex described how they quickly learned that telling others about their experience with cancer often elicited pity and, in more extreme cases, for friends to treat them completely differently. Pity's patronizing connotations tend to cause discomfort for those on its receiving end, as it emphasizes difference and contributes to feelings of social isolation (Nowakowski, 2016 p.1629). Sometimes, the fear of stigma was threat enough: both Neil and Mandy described having an obsession of sorts with keeping their chronic illnesses a secret. As Neil explained:

I refused to tell my teachers that I was in pain, refused to tell my coaches that I had mobility issues. I didn't want to feel different. I didn't want to feel like I wasn't like everybody else, and I think that fear of not being normal was very damaging.

Whether participants chose to disclose their diagnoses or tried to keep them a secret, all eight described feeling isolated at one point or another because of their chronic illness diagnosis.

These shared experiences of isolation highlight the profound impact of social perceptions on the lives of youth learning to live with chronic illnesses.

Available Support

The credit and thanks shown to the families and support systems of the people I interviewed were truly heartwarming. It was evident that those closest to the people I interviewed did the best that they could to help support them in their experiences of chronic illness. Unfortunately, knowing how to support someone living with a chronic condition can be difficult: "My family, for better or for worse, never let vision loss be a barrier for me," said Hank, "But the consequence of that is sometimes they pushed it too far and didn't give space for things that are hard." Hank's family's unwavering support, while well-intentioned, had unintended consequences. In line with Parsons' idea of "the sick role," Hank's family

encouraged him to “manage” his vision loss by going about life like anyone else. However, as Nowakowski pointed out in their discussion of the levels of stigma that chronically ill people are subjected to, the pressure to act normal is just as pervasive and harmful as the pressure to meet others’ expectations of your diagnosis.

When it comes to the support available to the people I interviewed before they found camp, Neil and Mandy had a rather exceptional similarity in their illness experiences. Both named their grandmothers as the only ones who could truly empathize with what they were going through:

My grandma took care of me a lot, that summer that I was first sick, and she was the person that I bonded with over our health and blood tests and trying new medications. And she got it, but she got it as a 75-year-old woman, and I was understanding it at ten years old (Mandy).

Similarly, Neil described one of the hardest parts about his arthritis as being “that one of the only people that understood when I was a young child was my grandmother. And the polarizing difference between talking about yourself when you’re eight to fifteen with a 70-something-year-old woman is very confusing.” Although both Neil and Mandy expressed gratitude for their grandmothers and the support that they provided, the above quotes demonstrate that this relationality further complicated their experience of chronic illness in youth.

Even with those around them putting their best foot forward, the people I interviewed overwhelmingly described life before camp as isolating. Not feeling as though they had adequate support or people who understood what they were going through was a common theme.

The narratives shared throughout the interviews I hosted vividly depict the isolation caused by societal labels of deviance associated with chronic illness. These experiences shed light on a fraction of the challenges faced by people living with chronic illnesses as they navigate

their diagnoses on both a personal and social level. For those I interviewed, there was an urgent need for them to find understanding, empathy, and supportive environments to counteract the stigma and isolation they felt in their everyday lives.

The Brigadoon Experience

In our interviews, camper experiences at Brigadoon Village were described in stark contrast to the complications and stigma that the people I talked with experienced with regard to their diagnoses outside of camp. Instead of facing judgment or isolation, they described finding understanding, acceptance, and a supportive community that empowered them to embrace their chronic illnesses and thrive. From first visits as little kids to senior years as either seventeen- or eighteen-year-olds, interviewees named Brigadoon Village as a significant space for connection, self-acceptance, growth, and the chance to just have fun.

First Visits

Fun was the overarching theme of all eight interviewees' descriptions of their first time at Brigadoon. Four recalled feeling nervous about going to camp for the first time, but everyone described feeling incredibly welcomed and connected once they arrived; “as soon as I walked in, I met [the people] who are now my best friends,” said Debs. When Eliza explained her experience, she said: “I think day one is a bit of apprehension. You’re nervous and settling in, but then by Friday you’re like ‘Oh my goodness, so much time has passed, and these are my best friends, I don’t want to go home without them!’” Connection and shared experience were secondary themes of the significance of interviewees’ first time at camp, whether those pivotal moments occurred during the hustle and bustle of camp or behind closed doors:

It was a really good experience and I remember really liking it. I think I just had fun during the days, it didn’t even feel like sick kid camp. But then you’d go to bed, and then

everyone is whispering “Do you have Crohn’s or Colitis? It was the first time I ever talked about it, so that was really sweet (Mandy).

Mandy was also one of three interviewees who said their parents and guardians noticed a change in them after that first week. When reflecting on his experience, Hank summarized his evolution at camp quite nicely:

As a younger camper, I think it was just a week of a lot of good fun.... but as I became older, it had a lot more to do with understanding what had happened to me and what that diagnosis entailed and meeting a lot of awesome people.

Even in their first encounters with Brigadoon, interviewees were becoming aware of the transformative power of fun, connection, and self-discovery experienced during their time at camp. In these memories, we are made privy to the journey from initial apprehension to profound connections and personal growth, highlighting the significant impact of Brigadoon in fostering a sense of belonging and understanding among individuals navigating chronic illnesses, even in their first week away at camp.

Community

Six of the people I interviewed expressed that they did not know anyone else with the same diagnosis as them before they went to camp that first time, however, all eight said that going to summer camp at Brigadoon Village made them feel less alone in their experience. Everyone I talked with described having a strong sense of community through camp; whether their last year of camp was only the summer before⁸ or 2016, all eight said they still felt

⁸ The summer of 2023.

connected to the community they created at Brigadoon.

Friendships.

At camp “you’re surrounded by really positive friendships,” explained Isabelle, “you see the friendships between campers and then you see the friendships between counsellors.” A similar sentiment to Isabelle’s was expressed by everyone interviewed. All eight expressed how much they valued the connections they made at camp and described how their camp friendships were solidified over only a week. As Zoey explained, “You go and you don’t know anyone when you first get there, but by the end of the week, they’re your best friends.” Emphasizing the latter half of Zoey’s explanation, Debs told me that her camp friends are “definitely going to be my bridesmaids and maid of honour at my wedding.” For Eliza, who found it challenging to connect with peers in high school who could relate to her psoriatic arthritis diagnosis, highlighted the ease of forming bonds at camp:

There was an immediate understanding on a level that we all have the same thing, so you don’t have to talk about it, but if you do everybody gets it. You don’t have to explain yourself, which made it easier to connect with people right off the bat, because you already have something in common with them.

What Eliza is expressing speaks to the bonding nature of shared experience. In all eight of the interviews I hosted, I heard of the impactful and invaluable connections made over the span of just a week. These discussions relate to the ideas of social support as an outcome of these camps brought forth in my literature review (P. Brown et al., 2004; Josefsson, 2005; Tan, 2018). The profound friendships forged at camp emphasize the significance of shared experiences of illness, as these bonds not only provided a sense of belonging but also facilitated personal growth and self-acceptance.

Sharing Circles.

When it came to the community at camp, five out of eight participants brought up a practice that we do at Brigadoon called sharing circles. In these circles, campers are guided through a group conversation about both the bad and the good parts of their chronic illness. They are also prompted to reflect on who they can turn to for support, what around them is good, and what about them as an individual is good. Everyone who brought them up credited sharing circles as a space where they learned about themselves, their condition, and important skills in managing and coping with their chronic lives.

Figure 1

Sharing Circle Quotes

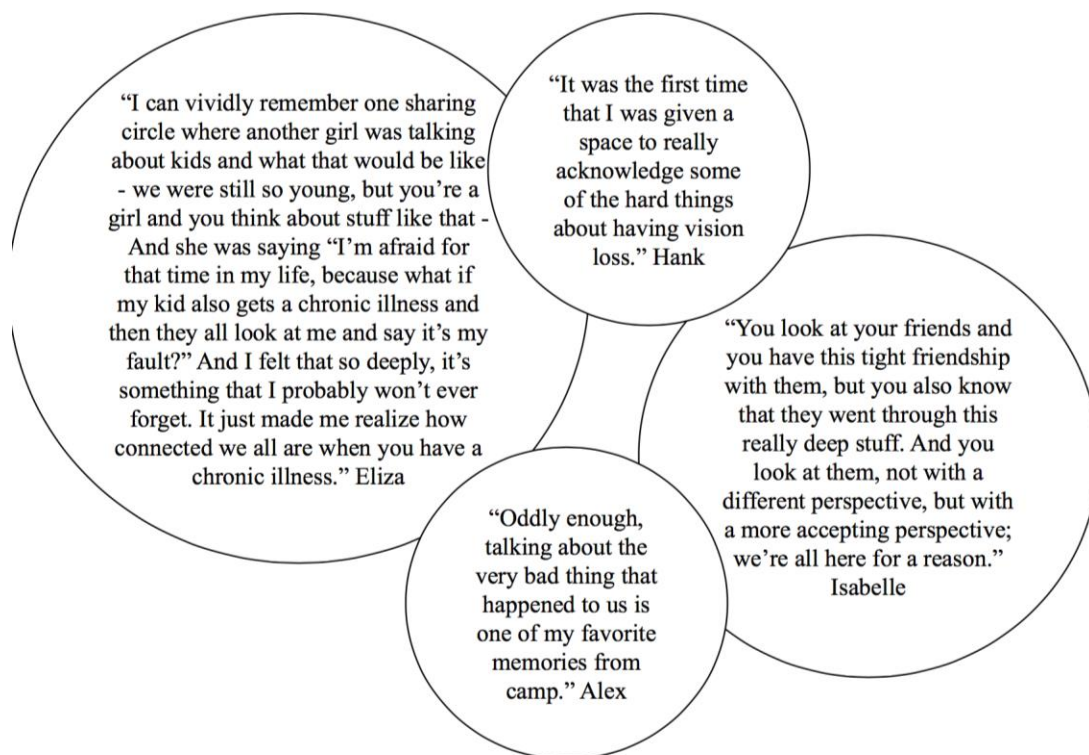


Figure 1 represents only a few examples of the positive things said about sharing circles in the interviews I conducted. These quotes evidence the fact that these circles are an important and

transformative part of the Brigadoon camper experience. I would argue that the sharing circle experience is one of the methods through which *communitas* is cultivated at Brigadoon. Through listening to other's experiences and sharing their own, the people I interviewed described sharing circles as a meaning-making experience. The conversations I had about these circles often reminded me of V. Turner's (1969) writing on *communitas*. If camp is a liminal space, then sharing circles are one of the events through which *communitas* is created, serving as a platform for mutual understanding, meaningful exchanges, and community support. These exchanges of shared experience in illness are also reminiscent of the meaning and community created in embodied health movements (P. Brown et al., 2004).

Stand Out Memories

In our interviews, I asked everyone about their best and worst memories from camp. When asked about their best or favourite memories, all eight described at least one memory that involved the community they formed, with six of those responses having to do with sharing circles. Although the surplus of favourite memories described are impossible to document in their entirety, some more common replies included physical activities such as tubing and Brigadoon's climbing programs, special moments from their senior year at camp, and as Neil said, "the little things where you just get to have fun." He expressed that part of the joy of going to camp is that "it's such a great opportunity for being a kid."

The question that took everyone the longest to answer was the one that asked about their least favourite memories from camp. Although there is certainly a self-selection bias at play in my interview sample, as everyone who expressed interest had a generally positive experience at camp, I want to acknowledge to make sure that I did not give the impression that everything is perfect at camp. Listed by five interviewees, the most common replies were social issues or

minor conflicts, ranging from bullying to simply not getting along with someone. Two brought up COVID-19 consequences, and one brought up ongoing health issues that landed her in the med center throughout her time at camp. One interviewee who spent most of their life at camp wrestled with simultaneously feeling happy for Brigadoon's growth as an organization and feeling as though the camp feels slightly more "corporate" than his first few years. Although the reduction of stigma is named as a benefit of the summer camp experience (Baker & Hannant-Minchel, 2022; Harvey, 2017; Singh et al., 2023), I do not want to give the impression that summer camps are utopias where nothing bad happens and everyone gets along. In any large group of youth, there are going to be social conflicts (Tillery, 1992), and Brigadoon Village is no exception.

Briga See-Ya: Leaving Camp.

Woven throughout interviewees' stories and memories from the camp were those of having to leave at the end of the week. As Neil explained, "You get a week. One week. And it feels so short and so long at the same time. I remember leaving that first week of camp and just thinking, "This is such a bummer.'" Despite never feeling homesick while away at camp, Zoey explained how "I'd cry when it was time to go. I never wanted to go home."

Although Senior Years were often described as some of the best experiences interviewees had at camp, one attempted to put what it feels like to leave camp for the last time into words: "You just age out. And it is a very strange first summer when you do," said Neil, "It's a tradition that is gone, like one year, there's no more Christmas." Although this could perhaps be framed as a critique of the programs Brigadoon offers, I do not see it as such. The camp's purpose is to serve children and youth. Rather than a critique of an organization doing what it can to support a more vulnerable population, I would argue that Neil's experience speaks to a lack of support for

chronically ill adults once they age out of the programs from their youth.

The touching memories of leaving camp at the end of the week that were shared with me encapsulate the bittersweet reality of cherished experiences ending. While Senior Years were often cherished as some of the most memorable moments at camp, Neil's reflection on aging out underscores a significant gap in support for adults managing chronic illness. This transition not only marks the culmination of a transformative chapter but also sheds light on the need for continued support and resources for individuals navigating chronic illnesses beyond their youth.

It Takes a Village: Transforming Illness

Everyone I interviewed appeared eager to discuss their growth at camp and the things they learned. Throughout the interview process, it became evermore clear that Brigadoon has been a transformative experience for all eight participants, especially for their personal growth. Many tied this back to the atmosphere created at camp; “everyone’s growing in the same positive, trusting environment. And I’d say that creates magic” (Isabelle). In direct opposition to classic theorizations of chronic illness as “deviance,” the people I interviewed named themes of chronic acceptance, learning life lessons and reshaping perceptions of illness.

Chronic Acceptance

Learning to accept one’s diagnosis/condition was a pervasive theme when discussing what people took away from their time at Brigadoon. All eight participants learned to accept something about themselves at camp, whether it was their diagnosis or another factor that came with it. Five interviewees credited Brigadoon with helping them accept their chronic illnesses and all that they encompass. Remember Mandy and Neil, who, in my earlier discussion of stigma, described feeling a need to hide their diagnoses? Here’s what Mandy had to say about her transformation through camp:

I spent a lot of time thinking “I’m chronically ill, but I’m in remission so it’s whatever.” But camp taught me it’s not whatever, it’s actually pretty hard and a lot of people get it. It’s not something you have to shy away from or hide about yourself. In a sense, it’s something that you’ve accomplished...it [Brigadoon] definitely gives you a sense of pride for your illness that you don’t get anywhere else.

Here, Mandy sheds light on the way that attending camp at Brigadoon generally re-framed how interviewees considered their chronic illnesses. At camp, campers get to just be kids; a chronic illness diagnosis was the norm, not something that stuck out as odd or “deviant.” For Neil:

Brigadoon kind of sparked the flame of really asking yourself what it means to be a little different forever.... I think it started my understanding of what it means to have arthritis and what it means to have a body that deteriorates with time.

Both Neil and Mandy described how going to Brigadoon helped them come to terms with their respective diagnoses. Both went from seeing their chronic illnesses as something “deviant” and thus a part of their identity to keep secret to avoid stigma, to accepting their chronic illnesses as a part of their identities and even feeling a sense of pride for having their diagnoses.

This sentiment was passionately echoed in other interviews, such as Debs’. “After camp,” she explained, “I realized it doesn’t make me a lesser person to have these issues, I just have different experiences. It’s okay to have medical problems and chronic illnesses, I’m not any less than anyone healthier than me.” The self-acceptance and self-discovery experienced by individuals at Brigadoon encapsulates a transformative shift in perspective toward their chronic illnesses. This collective narrative reflects the empowering impact of Brigadoon in fostering acceptance, resilience, and a positive outlook on living with chronic illness diagnoses.

Life Lessons

Six interviewees said they learned about their chronic illness through their experience at Brigadoon, with four expressing they learned key skills in managing their conditions. Although

the most common reply about growth described an increase in connections, community, and friendships, I have already analyzed this topic in previous sections.

A growth in confidence and self-esteem was the second most common response when it came to growth at camp. Despite experiencing tremendous personal growth over her time at Brigadoon, when asked to consider what camp teaches people, Eliza thinks about her little sister: “I cannot say enough good things about camp and the way that it has really changed her and made her a more confident person. She is just the purest version of herself when she’s there.” Eliza's heartfelt testimony reflects the profound influence that Brigadoon has had in fostering personal growth and self-assurance, creating a space where youth can truly be themselves and flourish. Other themes in the skills that interviewees credited Brigadoon with teaching them were leadership skills, learning how to self-advocate, recognizing their own resilience and strength, and trying new things.

As a Goodtimes camper, Alex had a bit of a different experience in growth from the seven other past campers I interviewed:

Goodtimes being a camp for kids with cancer meant that some of those really awesome people weren't able to come back next year. And suddenly having to learn about grief...because I had met really amazing people who meant a lot to me.

Rather than raising this in reply to being asked about their least favourite memories, as one might expect, Alex brought this up when we were discussing their growth, “it drives me forward, in a way. It makes me think, well, if they’re not here, then at least I can carry on the memory of these people who meant a lot to me.” Alex's perspective reveals a deep sense of resilience and determination, expressing how their loss serves as a driving force, inspiring them to carry forward the legacy of these cherished individuals who had a significant impact on their life. This introspective outlook highlights Alex's ability to find strength and purpose in honouring the

memories of those who have touched their life, reflecting a mature and compassionate response to loss and adversity. According to Alex, Brigadoon and the community created through their camp experience played a pivotal role in realizing this.

In interviews, stories of growth emerged in a multitude of different ways. From the memories and reflections that were shared with me, it became evident that personal and communal growth was present in both the big and small moments of camp, whether it was during the more intentional ones like sharing circles or in the in-between moments:

I always loved making bracelets, and one of my friends could not make them for the life of her. And by the end of camp, she had a whole bunch that she made herself that went from little knots to actual bracelets (Zoey).

From learning to make a bracelet to finding self-confidence, the growth that occurred at camp was undeniable.

Rather than teaching campers how to occupy a role in society that is entirely defined by their diagnosis (Bury, 1982; Goffman, 1963; Parsons, 1991), the testimonies I heard in these interviews demonstrated how Brigadoon encourages campers to grow in ways they would have never thought were possible. The personal growth described in our interviews demonstrated how the people who participated in this exploration learned to accept their diagnoses and gain other important life skills for navigating their chronic lives. In sum, camp helped these individuals to reject the idea of chronic illness as “deviant” through shared experiences of illness, personal growth, and community meaning-making. Recall our discussions of deviance as a social construction; for the eight people I interviewed, Brigadoon facilitated a collective deconstruction of chronic illness as deviance, making way for new conceptualizations of the chronic illness identity.

Illness as Illumination

When Eliza expressed that going to camp “totally flipped my perspective on its head; I went from thinking that this is something awful about me to seeing my chronic illness as something that enriches my life,” I was immediately reminded of Tan’s biographical illumination. In this one sentence, Eliza has outlined the transformation that her understanding of illness underwent at camp, moving from one of biographical disruption to illumination. Although I would not say that interviewees’ initial experiences of diagnosis created a feeling of illumination, as was the case in Tan’s original research, I do argue that the experience of going to camp at Brigadoon Village transformed individual understandings of illness from one of disruption to illumination.

Evidence of this transition was present in all eight interviews. Hank, who is heavily involved in the blind and visually impaired community, recounted many cases where he’s witnessed others redefine their understandings of vision loss through camp. In one, he told me how he once heard from a mother that “her child’s attitude towards vision loss completely changed after going to camp and spending a week with peers at Brigadoon.” When I asked him what he thought about that, he smiled and said, “I’d say it sounded about right.”

Community, in this case characterized by *communitas* and shared experience, plays an integral role in helping someone to shift their view of their diagnosis as disruptive and ultimately negative to a force of illumination in one’s life was illustrated by Debs when she told me how “once you find people going through what you’re going through, it’s really special...it made me see the positive in having my chronic illness.” Through shared experiences of illness, community, and a focus on personal growth, Brigadoon Village offered the people I interviewed a chance to redefine how they think about illness and their respective diagnoses. Before camp,

their narratives were characterized by notions of stigma, social expectations, biographical disruption, and a general feeling of being different, or “deviant.” Going to camp at Brigadoon challenged these ideas, as interviewees became part of a community that encouraged self-acceptance, personal growth, and a view of illness as enrichment. In our interviews, the result of this transformation was described as a refusal to acknowledge oneself as “deviant” and a transformed understanding of illness from biographical disruption to illumination.

Conclusion

Throughout the research process, the experiences shared by interviewees revealed a powerful shift in their perception of their chronic illness. Through shared experiences of illness, personal growth, and community meaning-making, camp served as a catalyst for learning to reject the notion of chronic illness as "deviance." The transformative journey experienced by the people I interviewed reflects a collective deconstruction of chronic illness stereotypes, paving the way for new conceptualizations of the chronic illness identity.

While interviewees’ initial experiences of diagnosis may not have sparked immediate enlightenment, the experience that they had at camp facilitated a profound shift in how they understood their chronic illness diagnoses: from viewing themselves as "deviant" to embracing a narrative of empowerment and illumination. Through community, the idea of chronic illness as deviance is socially deconstructed. These stories demonstrate how spaces like Brigadoon Village encourage the rejection of the chronic illness identity as “deviant” and help youth to understand their diagnoses as something that illuminates their biographies, rather than disrupting them. The more spaces like Brigadoon that exist, the more we have the potential to transform our understanding of what is “normal” to include more accessible and inclusive definitions.

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Appendix A: Recruitment Poster

ATTENTION BRIGADOON VILLAGE GRADUATES!

- ARE YOU ABOVE 18?
- DO YOU HAVE A CHRONIC ILLNESS DIAGNOSIS?
- DID YOU GO TO SUMMER CAMP AT BRIGADOON BECAUSE OF THAT DIAGNOSIS?

If you answered yes to these questions, I'd like to invite you to participate in my Undergraduate research project!

WHAT'S IT ABOUT? I'm studying the effect of the summer camp experience at Brigadoon Village on the lived experience of chronic illness!
WHAT DO I GAVE TO DO? Participation would involve one interview that would take about an hour.

IF YOU'RE INTERESTED, OR IF YOU HAVE ANY QUESTIONS, PLEASE CONTACT ME AT:

SIMONE.SEWELL@DAL.CA

Simone Sewell
simone.sewell@dal.ca

Research Ethics Board Approval: 2023-6961



Appendix B: Ethics Consent Form

Project Title: Summer Camp and Chronic Illness

Lead Researcher: Simone Sewell, Dalhousie University, simone.sewell@dal.ca

Supervisors: Dr. Martha Radice, Dalhousie University, martha.radice@dal.ca and Dr. Karen Foster, karen.foster@dal.ca

Introduction

You are invited to take part in a study being conducted by Simone Sewell, a fifth-year student at Dalhousie University. Choosing whether or not to take part in this research is entirely your choice. The information below tells you about the research, what you will be asked to do and about any benefits, risks, inconvenience or discomfort that you might experience.

If you have any questions about this study, please do not hesitate to email the lead researcher, Simone Sewell, to discuss them.

Purpose of the Study

This study examines the lived experience of chronic illness and the impact that attending a week-long summer camp can have on that experience. I will be interviewing young adults who have attended Brigadoon Village due to a chronic illness diagnosis. In these interviews, I want to find out how individual experiences of chronic illness have been shaped and influenced by attending the camp.

Who Can Take Part?

You may participate in this study if you are 18 or older and have attended summer camp at Brigadoon Village due to a chronic illness diagnosis.

What You Will be Asked to Do

If you decide to participate in this research, you will be asked to complete one interview of approximately an hour in length, during which you will be asked a series of questions. If you are located in Halifax and are comfortable participating in person, interviews can take place in public locations such as a public library or cafe. Alternatively, interviews can take place over a video-calling platform of your choice such as Microsoft Teams or Zoom.

Possible Benefits, Risks, and Discomforts

Participating in this study might not benefit you directly, but we might learn things from this research that will benefit others.

There may be risks or discomfort associated with participating in this study. The interview questions will ask about your experience of chronic illness, which may be sensitive or troubling to discuss. I will mitigate these risks by encouraging you to only give as much information as you feel comfortable giving. We can always take a break, skip questions, or you can withdraw from the study completely.

To help find other study participants, I will invite you to pass on the information about the study to other possible participants. You are welcome to choose not to pass on the information if you prefer. All information from your interview will be kept completely private. All results in the

final paper will be de-identified. I will not share information with participants about who has been interviewed (or not).

Video call interviews will take place on a platform of your choosing. If no preference is indicated, I suggest Microsoft Teams. If choosing a video call, you can choose to do it from a private place where no one will overhear you. If you interview by video call, there is a risk of loss of personal privacy from the use of internet-based communications. The risk is no greater or lesser than when using these applications for other purposes.

Interviews will be recorded using the Voice Memo app on my iPhone.

The information that you provide to me will be kept confidential. Only my supervisors and I will have access to it. The interview will be audio-recorded, and the recording will be stored on a password-protected, encrypted laptop, with a backup saved on Microsoft OneDrive. I will transcribe the interview, and the transcription will be stored on the password-protected, encrypted laptop. Once the interview is transcribed, I will delete the audio. A backup of the transcription will be saved in OneDrive, as well as on an external hard drive. I will keep the de-identified transcription and any associated notes for future research. If you would not like to have your interview data stored long-term, please indicate so below. If you would not like to have your interview data stored, then it will be deleted after my Honours thesis has been submitted and presented.

I consent to having my interview data stored long term

I would not like my interview data stored long-term

Compensation

There will be no compensation for participating in this study.

How Your Information Will Be Protected

Your participation in this research will only be known by me. If you choose to share my study with others for recruitment purposes, you may choose to disclose or not disclose whether you have personally participated - I will not share that information under any circumstances.

Transcripts and the legend of pseudonyms will be kept in password-protected documents on my computer which only I have access to.

If I quote any part of your interview in my thesis, I will remove or alter identifying information to protect your privacy.

If You Decide to Stop Participating

You are free to withdraw from this study at any time until March 1st, 2024. After March 1st, it will be impossible to withdraw your information from the study because I will have integrated it into my analysis. You may withdraw before, during, or after the interview up until that point.

How to Obtain Results

If you wish, I can email you a copy of your transcript and/or the final thesis when it is

completed. You can request this by emailing me or telling me during your interview. My thesis will also be publicly available on the Dalhousie library website after May 1st, 2024.

Questions

I am happy to talk with you about any questions or concerns you may have about participating in this study. You are welcome to contact myself, Simone Sewell, at simone.sewell@dal.ca, or my supervisors, Martha Radice, at martha.radice@dal.ca, and Dr. Karen Foster, at karen.foster@dal.ca, at any time.

If you have any ethical concerns about your participation in this research, you may also contact Research Ethics, Dalhousie University at (902) 494-3423, or email: ethics@dal.ca (REB file # 2023-6961).

Signature Page

Project title: The Impact of Summer Camp on Children and Youth's Experiences of Chronic Illness

Lead researcher: Simone Sewell, Dalhousie University, simone.sewell@dal.ca

I have read the explanation about this study. I have been given the opportunity to discuss it and my questions have been answered to my satisfaction. I understand that I have been asked to participate in one interview of roughly an hour, and that the interview will be audio recorded. I understand that direct quotes may be used from my interview without identifying me. I agree to take part in this study. My participation is voluntary, and I understand that I am free to withdraw from the study at any time until March 1st, 2024.

Name:

Signature:

Date:

Please provide an email address below if you would like to be sent a copy of your transcript and/or a copy of my thesis, and indicate which:

Transcript

Thesis

Email address: _____

Appendix C: Semi-Structured Interview Guide

Introduction: Ask if the participant feels comfortable, interview overview, emphasizing permission to withdraw at any time and relevant dates for withdrawal, and receiving consent to audio record.

- Can you start by telling me about your history with chronic illness? Please only share what you feel comfortable discussing.
- Can you tell me how being diagnosed with a chronic illness has affected your life?
 - Follow up: your social life/relationships?
- Can you tell me how you found out about Brigadoon Village?
- How many years did you attend Brigadoon as a camper?
- What was your first time going to camp like?
- What type of role did Brigadoon play in your life growing up?
- What are your best memories of going to camp at Brigadoon?
 - Follow up: what are your worst memories?
- What did you learn from camp? What were your main takeaways?
- How, if at all, do you think going to camp impacted how you feel about having a chronic illness?
- Do you think that going to camp has impacted your life in the long run?
- Do you think your experiences are typical of other campers at Brigadoon? In what ways?
- Have you observed the impact that Brigadoon Village has had on other campers' lives?

Demographic questions

- How old are you?

- What pronouns do you use?
- (If not yet known) What is your chronic illness diagnosis/what camp did you attend?
- How many years have you been involved with Brigadoon?

Conclusion: consent check-in.

Appendix D: Dalhousie University Ethics Final Report

ANNUAL/FINAL REPORT

Annual report to the Research Ethics Board for the continuing ethical review of research involving humans / Final report to conclude REB oversight

A. ADMINISTRATIVE INFORMATION

This report is (<i>select one</i>): <input type="checkbox"/> An annual report <input checked="" type="checkbox"/> A final report			
REB file number:	2023-6961		
Study title:	Summer Camp and Chronic Illness		
Lead researcher (named on REB submission)	Name	Simone Sewell	
	Email	Simone.Sewell@dal.ca	Phone (902)880-4045
Current status of lead researcher (at Dalhousie University): <input type="checkbox"/> Employee/Academic Appointment <input type="checkbox"/> Former student <input checked="" type="checkbox"/> Current student <input type="checkbox"/> Other (please explain):			
Supervisor (if lead researcher is/was a student/resident/postdoc)	Name	Dr. Martha Radice / Dr. Karen Foster	
	Email	martha.radice@dal.ca / karen.foster@dal.ca	
Contact person for this report (if not lead researcher)	Name		
	Email		Phone

B. RECRUITMENT & DATA COLLECTION STATUS

<p>Instructions: Complete ALL sections relevant to this study</p> <p>Study involves/involved recruiting participants: <input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <i>If yes, complete section B1.</i></p> <p>Study involves/involved secondary use of data: <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No <i>If yes, complete section B2.</i></p> <p>Study involves/involved use of human biological materials: <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No <i>If yes, complete section B2.</i></p>

B1. Recruitment of participants <input type="checkbox"/> Not Applicable	
B1.1 How many participants did the researcher intend to recruit? (provide number approved in the most recent REB application/amendment)	8-10

<p>B1.2 How many participants have been recruited? <i>(if applicable, identify by participant group/method e.g. interviews: 10, focus groups: 25)</i></p> <p>a) In total, since the beginning of the study: 8</p> <p>b) Since the last annual report: N/A</p>
<p>B1.3 Recruitment for this study is:</p> <p><input checked="" type="checkbox"/> complete; or</p> <p><input type="checkbox"/> on-going</p>
<p>B1.4 Data collection from participants for this study is:</p> <p><input checked="" type="checkbox"/> complete; or</p> <p><input type="checkbox"/> on-going</p>
<p>B1.5 Communication with participants related to this study is:</p> <p><input checked="" type="checkbox"/> complete; or</p> <p><input type="checkbox"/> on-going</p>

<p>B2. Use of secondary data and/or biological materials <input checked="" type="checkbox"/> Not Applicable</p>	
<p>B2.1 How many individual records/biological materials did the researcher intend to access? <i>(provide number approved in the most recent REB application/amendment)</i></p>	
<p>B2.2 How many individual participant records/biological materials have been accessed?</p> <p>a) In total, since the beginning of the study:</p> <p>b) Since the last annual report:</p>	

C. PROJECT HISTORY

<p><i>Since your last annual report (or since initial submission if this is your first annual report):</i></p>
<p>C1. Have there been any variations to the original research project that have NOT been approved with an amendment request? This includes changes to the research methods, recruitment material, consent documents, study instruments or research team.</p> <p><input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</p> <p>If yes, please explain:</p>
<p>C2. Have you experienced any challenges or delays recruiting or retaining participants or accessing records or biological materials?</p> <p><input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</p> <p>If yes, please explain:</p>
<p>C3. Have you experienced any problems in carrying out this project?</p> <p><input type="checkbox"/> Yes <input checked="" type="checkbox"/> No</p>

If yes, please explain:
C4. Have any participants experienced any harm as a result of their participation in this study? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No If yes, please explain:
C5. Has any study participant expressed complaints, or experienced any difficulties in relation to their participation in the study? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No If yes, please explain:
C6. Since the original approval, have there been any new reports in the literature that would suggest a change in the nature or likelihood of risks or benefits resulting from participation in this study? <input type="checkbox"/> Yes <input checked="" type="checkbox"/> No If yes, please explain:

D. APPLYING FOR STUDY CLOSURE

Complete this section only if this is a FINAL report as indicated in section A

D1. For studies involving recruitment of participants, a closure may be submitted when: <input checked="" type="checkbox"/> all research-related interventions or interactions with participants have been completed <input type="checkbox"/> N/A (this study did not involve recruitment of participants)
D2. For studies involving secondary use of data and/or human biological materials, a closure may be submitted when: <input type="checkbox"/> all data acquisition is complete, there will be no further access to participant records or collection of biological materials <input checked="" type="checkbox"/> N/A (this study did not involve secondary use of data and/or human biological materials)
D3. Closure Request <input checked="" type="checkbox"/> I am applying for study closure

E. ATTESTATION (both boxes *must* be checked for the report to be accepted by the REB)

I agree that the information provided in this report accurately portrays the status of this project and describes to the Research Ethics Board any new developments related to the study since initial approval or the latest report.

I attest this project was, or will continue to be, completed in accordance with the approved REB application (or most recent approved amendment) and in compliance with the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2).

CONTACT RESEARCH ETHICS

Phone: 902-494-3423

Email: ethics@dal.ca