THE EFFECT OF ATTENDING A VIRTUAL ONCOLOGY CAMP ON CHILDHOOD CANCER PATIENT’S PYSHCOSOCIAL FUNCTIONING AND PARENTAL STRESS – A PILOT STUDY

A Thesis Submitted to the Committee of Graduate Studies in Partial Fulfillment of the Requirements for the Degree of Master of Science in the Faculty of Arts and Science

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Abstract

The effect of attending a virtual oncology camp on childhood cancer patient's psychosocial functioning and parental stress – a pilot study

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Objectives/purpose:
The current study examined whether attending a 1-month virtual oncology camp (VOC) improved resilience and hope in childhood cancer patients and parental/caregiver stress.

Methods:
Childhood cancer patients/survivors and their parent/caregivers enrolled for VOC, participated in an online anonymous survey: before, after and 3-months after VOC. The survey included the Child and Youth Resilience Measure (CYRM) and the Snyder's Children's Hope Scale (CHS) for the childhood cancer patients/survivors and the Pediatric Inventory for Parents (PIP) for parent/caregivers.

Results:
CYRM scores increased from T1 to T2 (*d*=0.86). Compared to T1, at T2 CHS scores also increased (*d*=1.33). Both CHS and CYRM scores remained higher at T3 compared with T1 (*d*=1.34; *d*=0.86). There were no changes in PIP scores between any time points.

Conclusion and significance:
Our study demonstrated that participation in a VOC improved children's resilience and hope but did not change parental stress. Highlighting the clinical significance of these VOCs and the impacts they have on childhood cancer patients/survivors.

Keywords: Children, cancer, virtual oncology camp, resilience, hope, parental stress, psychosocial functioning

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List of Abbreviations

Oncology camp: OC

Recreational oncology camp: ROC

Virtual oncology camp: VOC

Child and Youth Resilience Measure: CYRM

Children’s Hope Scale: CHS

Pediatric Inventory for Parents: PIP

Analysis of Variance: ANOVA

Glossary

Late effects: secondary effects from cancer treatment that appear after the acute phase of the cancer treatment is complete

Psychosocial late effects: psychological or emotional responses that can occur after treatment but persist for at least five years post-treatment

Social functioning: is as an individual's interactions with their environment and the ability to fulfill their role within such environments as work, social activities, and relationships with partners and family members

Resilience: as an individual's ability to maintain or restore relatively stable psychological and physical functioning when confronted with stressful life events and adversity

Hope: involves the belief in one's capabilities to produce efficient routes to goals and a self-related belief that they can sustain momentum towards achieving that goal

Parental stress: the stress experienced and linked within a parenting role

1.0 Introduction

Childhood cancer is a common pediatric disease; it is third only to childhood asthma and diabetes[1], and is the second leading cause of death in Canadian children[1]. In 2021 alone, there was roughly 1000 new cases of cancer diagnosed in children aged 0 to 14 years in Canada[2]. While treatment for childhood cancer includes extensive and demanding therapy regimes (such as chemotherapy and radiation), recent medical advancements have resulted in treatments that lead to good survival outcomes[3]. However, despite reduced mortality, childhood cancer patients still experience both short-term and long-term direct and indirect effects of cancer treatment[4]. Direct effects of cancer treatment include toxicity from radiation and chemotherapy resulting in stalled growth and development, deficits in neurocognition, cardiopulmonary complications, hormonal imbalances and secondary malignancies[3]. Furthermore, many negative outcomes may be due to the indirect consequences of cancer treatment[5], in particular, from extensive time in-hospital receiving treatment, leading to exclusion from key developmental opportunities[6]. Childhood is a crucial time for both physical and psychosocial growth. The disruptions of developmental opportunities can result in reduced physical literacy, diminished social connection, negative self-perceptions, altered psychosocial functioning, academic delays and parental distress[7–9]. These adverse psychosocial effects are referred to as psychosocial late effects of childhood cancer treatment[10–14].

The experience of a cancer diagnosis is not simply confined to the ill-child themselves but is shared by the whole family[15]. Therefore, a pediatric cancer diagnosis and the subsequent treatment regimens and associated challenges may be one of the most severe stressors that a parent or caregiver will encounter. Increased parental stress is associated with adverse outcomes in children's behavioural adjustment[16,17]. In fact, the ability for parents/caregivers to cope and be resilient through the course of their child's treatment may be an important predictor of the patients' psychosocial outcomes. For example, a study published in 2018 stated that while most childhood cancer patients (140 out of 209) exhibited long-term resilience as a result of their cancer experience, patients who's parents experienced higher distress at baseline were predicted to not adapt well (defined as self-reported internalizing and attention problems) to their cancer treatment[18]. A 3-year investigative study that followed both healthy and chronically ill children also indicated that parental distress was the best predictor of child behavioural problems, outweighing child health, child temperament and parent-child relationship[19]. This underscores the importance of introducing experiences to foster developmental growth for pediatric cancer patients, which may ultimately improve physical and psychosocial well-being in both the child and their parents[20] and importantly, reduce parental distress[21].

Recreational oncology camp (ROC) is one example of an opportunity for children with cancer to engage in social interaction and physical activity in a medically safe and inclusive environment. ROCs are similar to regular camp experiences, where campers are immersed in nature and get to participate in outdoor activities (such as hikes, canoeing, campfires and scavenger hunts), however, ROCs have the medical support that allow for pediatric cancer patients going through treatments to safely attend. Some ROCs provide overnight stay, while providing intravenous chemotherapy and blood transfusions onsite. ROCs provide pediatric oncology patients a chance to meet other children, families and counselors who are experiencing similar illnesses and treatments. However, there are very few ROCs in Canada, and only one that can provide onsite intravenous chemotherapy and blood transfusion: Campfire Circle (formerly Camp Oochigeas and Camp Trillium). Published research on the impact of ROCs in childhood cancer patients have shown positive effects on patient mood[22], increased ability to interact and identify with others[20,23], improved quality of life[24], and a better attitude toward their illness[22]. While there is published research on the impact of ROCs in childhood cancer patients, there is, to our knowledge no published research on the impact of virtual oncology camps (VOC) on psychosocial outcomes in childhood cancer patients.

COVID-19 is the name of the disease caused by the virus SARS-CoV-2. On March 11, 2020, the World Health Organization declared COVID-19 to be a global pandemic[25]. Pandemic-related restrictions have further highlighted the important role of social interaction in the development and well-being of youth worldwide[26]. For example, mandated social distancing orders, school closures, and repeated lockdowns have had a negative impact on childhood social development[26]. While the direct psychosocial impact of COVID-19 related social isolation may not be apparent for some time, it is likely that those with chronic illnesses have been disproportionately negatively affected[26]. For example, during the summers of 2020 and 2021, there were COVID-19 related safety concerns in attending in-person and overnight oncology camps (OC), especially for children with cancer and who may already be immune-compromised[27]. In response, childhood OCs including Campfire Circle shifted their camp programming to a virtual “camp-in-a-box” style, providing an opportunity to continue participating in camp programming in some capacity. While VOC experience is much different than an in-person overnight camp experience, VOC still provides an opportunity for children to work through creative activities, interact socially with other attendees and build meaningful relationships with children who have similar medical challenges. Thus, the COVID-19 pandemic introduced a unique landscape highlighting a lack of high-quality quantitative and qualitative research that examines the impact of VOCs on childhood cancer patient's psychosocial functioning. To our knowledge, there have been no published studies that have explored the impact of a VOC on childhood cancer patient's psychosocial health, and/or parental/caregiver stress. Thus, the current research sought to assess the impact of a 4-week VOC on childhood cancer patient's psychosocial health and parental stress. In addition to filling an important knowledge gap in the research literature, the information obtained may also support the importance of VOCs and thus inform an evidence-based strategy for OCs to implement continued VOC access beyond the COVID-19 pandemic.

1.1 Objectives

VOC is an opportunity for children to socialize, interact with other children, interact with camp counselors, and participate in fun activities. Research on in-person OC demonstrates that OCs in childhood cancer patients have positive effects on mood[22], increased ability to interact and identify with others[20,23], improved quality of life[24], and a better attitude toward their illness[22]. Thus, a VOC experience may also positively impact psychosocial health in childhood cancer patients; however, there is no published research assessing the impact of a VOC on childhood cancer patient's psychosocial health. As well, OC may offer an opportunity for a parent/caregiver to gain some respite from day to day stressors because they feel that their child is engaging in a "normal" activity[28,29]. However, there are no studies that examine the impact of either in-person or VOCs on parental or caregiver stress[30]. Therefore, the current study aimed to inform an important knowledge gap: evaluating the impact of a VOC on childhood cancer patient's psychosocial health, as well as parental/caregiver stress in the immediate and longer-term. Thus, the primary objectives of this study were to:

1. Evaluate the impact of a 1-month virtual oncology camp (Campfire Circle) on resilience in pediatric cancer patients and survivors.
2. Evaluate the impact of a 1-month virtual oncology camp (Campfire Circle) on hope in pediatric cancer patients and survivors.
3. Evaluate the impact of 1-month virtual oncology camp (Campfire Circle) on stress in parents and/or caregivers of pediatric cancer patients and survivors.

1.2 Research Questions:

The purpose of this study was to examine the impact of a 1-month virtual oncology camp (Campfire Circle) on resilience and hope outcomes in pediatric cancer patients and survivors, and on stress in parents/caregivers. Thus, this study looked to answer three research questions:

1. Is resilience improved by 1-month of virtual oncology camp in children who have or had cancer of any kind?
2. Is hope improved by 1-month of virtual oncology camp in children who have or had cancer of any kind?
3. Is parental/caregiver stress improved by their child attending 1-month of virtual oncology camp?

1.3 Research Hypotheses:

OC is an environment where oncology patients and survivors can build new relationships, reduce stress, minimize feelings of isolation[31] and provide respite, social support, and improve psychological health in parents/caregivers (e.g., depression, anxiety and stress)[29]. When in-person OC is not feasible (such as due to health concerns related to COVID-19), VOCs may provide an opportunity to allow childhood cancer patients to connect with peers who are also working through similar experiences thus potentially improving the psychosocial health of pediatric oncology patients and parental/caregiver stress. Thus, we hypothesize:

1. That resilience is improved by 1-month of virtual oncology camp in children who have or had cancer of any kind as measured by Child and Youth Resilience Measure (CYRM).
2. That hope is improved by 1-month of virtual oncology camp in children who have or had cancer of any kind, as measured by the Children Hope Scale (CHS).
3. That parental/caregiver stress is improved by their child attending 1-month of virtual oncology camp as measured by the Pediatric Inventory for Stress[32].

1.4 Significance

This study is the first to evaluate the impact of VOCs on the psychosocial outcomes in pediatric cancer patients and their parent / caregiver. VOCs may be advantageous over in-person OCs in some respects, such as removing barriers of attendance[33] while providing a low stress environment for participants to get socially and actively involved[34]. More specifically, VOCs remove barriers that may otherwise withhold some patients from participating (e.g., geographical location, lack of resources, physically unable to attend)[26]. Even after COVID-19 restrictions are reduced, and in-person camps are operating again, there may be a continued and justified need for VOCs. Therefore, considering the potential for virtual camp programming to transform the way psychosocial interventions are delivered and are available to childhood cancer patients, the need for research supporting the impact of VOCs is critical. The current research may also initiate an evidence-based strategy and on-going research program that is supported by both research institutions (University) and partnerships with recreational oncology camps (Campfire Circle).

2.0 Literature Review

2.1 Pediatric Cancer Patients

2.1.1 What are physical and psychosocial late effects?

Childhood cancer survival rates are increasing with advances in medical care[35,36]. More specifically, while the incidence rates of childhood cancer have remained relatively stable since 1992, mortality rates have decreased over this same period[36]. For example, survival rates in children diagnosed with acute lymphoblastic leukemia (ALL) in the 1960’s was 10%, whereas in 2009 children diagnosed with ALL were estimated to have a 90% chance of survival[1,37]. These advances have much to do with an increased understanding of pediatric biology from high-quality and multi-institutional clinical trials[36] which have also lead to successful aggressive and multimodal therapies[38]. While increasingly high survival rates in pediatric oncology have been among the great successes in medicine in recent years, this also presents new challenges with cancer survivors aging into adulthood. These new challenges come in the form of both physical and psychosocial late effects[10].

We introduce these two terms in hopes of distinguishing them, as physical and psychosocial late effects are often discussed without discussing differences between them. Late effects can be broadly defined as secondary effects from cancer treatment that appear after the acute phase of the cancer treatment is complete[39]. While late effects can occur in patients undergoing any type of medical treatment, late effects are particularly problematic in pediatric oncology patients due to the high degree of intensive medical treatment which occurs during vital childhood developmental periods[40]. This can cause profound long-term physical and/or psychosocial damage to the child lasting into adulthood[39]. Physical late effects include increased risk in harm to particular tissues and organs[41], which result in a decrease in physical functional ability[40], and in extreme cases of damage to tissue appendage amputations may be required[42]. Physical late effects can, themselves, lead to psychosocial late effects caused by negative self-image, lack of autonomy, and poor well-being[43,44].

Psychosocial late effects refer to psychological or emotional responses that can occur after treatment but persist for at least five years post-treatment[40]. It is well documented that childhood cancer treatment can lead to an increased risk of depression and anxiety[45,46]. For some individuals, symptoms may be characterized as post-traumatic stress symptoms[46] or in more extreme cases post-traumatic stress disorders[47]. Psychosocial late effects can also include social and relationship difficulties. For example, childhood cancer survivors are significantly more likely to report poor social support or lack of close friendships as compared to healthy controls[48]. Predictors for worse psychosocial late effects include earlier age of diagnosis, later stage of diagnosis, treatment with chemotherapies and radiation, diagnosis or treatment of central nervous system tumors and low socioeconomic status[13,48,49].

More than half of childhood cancer patients display at least one significant ongoing psychosocial late effect that requires ongoing care[50]. Childhood cancer survivors have also been demonstrated to have lower academic and occupational attainment compared to healthy controls[51]. This may further exacerbate one's ability to reintegrate back into what one may consider a "normal" lifestyle, causing a potential positive feedback loop. For example, pediatric cancer patients may experience deficits in academic achievement, while also faced with potential neurocognitive deficits[52], memory, attention[7], and physical limitations[40]. If deficits in these critical functional domains are not addressed, pediatric cancer survivors may not be able to adjust and then recover without being left behind (psychologically) by age-related peers. This underscores the importance of addressing issues in psychological health of childhood cancer survivors.

While it was important to distinguish physical late effects from psychosocial late effects, they are not the topic of this thesis. The current thesis provides more insight into one possible intervention (VOC) to improve psychosocial functioning in childhood cancer patients. Next, social functioning in pediatric oncology patients will be discussed, followed by resilience and hope in pediatric oncology patients.

2.1.2 Social Functioning:

Broadly defined, social functioning is as an individual's interactions with their environment and the ability to fulfill their role within such environments as work, social activities, and relationships with partners and family members[53]. Key deficits in social functioning in pediatric oncology patients may be a result of the low quantity and potentially quality of interactions during treatment. Over the course of typically long treatment regimes, this can result in overall reduced social functioning, quality of interactions, lack of close friendships, relationship problems, peer rejection and isolation[53]. Social support may be an important mediator in childhood cancer patient's and survivor's resilience and hope[54], which is why we briefly touch on social isolation, social interventions below and frequently discuss the topic of social support within this thesis.

Childhood cancer patients may miss out on important social interactive opportunities due to lengthy hospital visits and school absences[55] which can lead to increased social isolation[56]. Although some childhood cancer patients report feelings of social isolation[57], studies have shown that the degree of social isolation may depend on the type of cancer treatment[11]. For example, aggressive medical treatments directed at the brain are associated with reduced attention, processing speeds, working memory and ability to learn causing academic delays[52] and increased social anxiety due to lack of peer acceptance[11]. Evidence suggests that frequent hospitalizations increase the risk that childhood cancer patients feel socially isolated from peers, resulting in feelings of loneliness, confusion and exclusion[58].

Social support is thought to indirectly assist with alleviating negative life stressors[59,60] and is positively associated with cancer patient well-being and psychological adjustment after diagnosis[61]. For example, a cross sectional study in Brazil examining 144 patients with mean age of 56.9±11.4, assessed whether social support was associated with quality of life in colorectal patients undergoing chemotherapy[62]. Social support was associated with increased resilience, reduced perception of stress and greater quality of life in this cohort of colorectal cancer patients. There is however limited research assessing the impact of social support in childhood cancer populations, we suggest that social support plays a similar role in improving resilience, hope, stress and quality of life in childhood oncology patients as it does in adult cancer populations[59,63].

Interventions to improve social functioning should be included in treatment plans for pediatric oncology patients. While social functioning is not directly measured in this study, Campfire Circle's VOC programming utilizes social interactions and works toward providing a social support network as camp progresses[64]. The inclusion of social support within interventions may also indirectly lead to improvements in stress, hope and resilience in childhood cancer patients[59–61,63,65]. However, little is known about the effects of VOC on social functioning in childhood cancer patients.

2.1.3 Resilience in Pediatric Cancer Patients and Survivors

Resilience is a complex and multidimensional concept that is considered a successor to other positive health outcomes[66]. Thus, decades of research has highlighted the importance of targeting positive health outcomes such as coping[67], hope[66,68], social support[69] and sense of coherence[70] in interventions aimed at increasing resilience in pediatric oncology patients. In the context of cancer and other related chronic illnesses in children, the development of positive health characteristics is defined as the process of building the child's 'tool kit' of resources that allows flexible management of stressors which points to increases in self-confidence, self-esteem and a sense of independence[71].

Resilience can be defined as an individual's ability to maintain or restore relatively stable psychological and physical functioning when confronted with stressful life events and adversity[72]. In pediatric cancer patients, resilience refers to the person's flexible individual attributes and characteristics that promote positive adaptation to cancer such as: sense of purpose, self-esteem, self-efficacy, self-determination[73], coping, social support, self-coherence[66] and cognitive flexibility[74,75]. Resilience can also change during the course of a person's life and is thus also heterogenous[75]. Clinically this means that a variety of potential solutions to increase a person's resilience are available and interventions should not be considered a one-size-fits-all model. Aside from a person's biological factors and individual characteristics mentioned above, environmental circumstances (e.g., social support, disease severity, treatment experience) can manipulate the level of resilience a patient shows and thus illustrates its fluidity[68].

While the implications of a cancer diagnosis are often thought to be only negative (i.e, distress), cancer patients who display high levels of resilience can experience positive life changes (i.e, grow from their diagnosis, or "become stronger") [68,76–78]. However, this phenomenon has only been reported in adult cancer patients, including breast and prostate cancers[76–78]. Which brings an important point, what are factors that both facilitate or reduce resilience in pediatric cancer patients?

Uncertainty of illness in pediatric oncology patients is associated with increased levels of psychological distress and lower levels of social support and has negative effects on resilience[66,79]. Illness uncertainty is greatest when patients do not understand information from healthcare providers, or when treatment events are unfamiliar, confusing or unpredictable[79]. Increasing levels of uncertainty strains psychosocial adjustment and its mediators such as quality of life[79], social support, psychological well-being and resilience[66,80]. For example, a study in 2012 assessed the impact that illness uncertainty degree had on pediatric cancer patients resilience[81]. The resilience of cancer patients showed a significant relationship with the degree and appraisal of uncertainty, which explained 26.5% of the variance using multiple linear regression[81]. These results, and other studies report that illness uncertainty is associated with poor quality of life and negative influences on resilience[73,74,79]. Illness uncertainty, is negatively associated with social support, indicating that as social support increases, illness uncertainty decreases[82].

Social support is the social connection provided by a person close to you (e.g., parents, siblings, health care providers) and is highly associated with resilience in pediatric cancer patients[62,68,81,83,84]. Social support can include the presence of someone who loves you, someone who shows you empathy, someone who shows that they value your presence and the sense of belonging to a larger community[60,83]. The absence of social support is associated with detrimental effects to life expectancy, similar to other risk factors such as obesity, cigarette smoking, hypertension or low levels of physical activity[60]. A study in 2017 found that social support was a predictor of lower stress and high quality of life in colorectal cancer patients in Southern Brazil[62]. Study findings from the 2017 paper are consistent with an American paper from 2014 that showed resilience correlated with increased quality of life, higher physical, emotional, and social functioning in patients with leukemia, lymphoma, myeloma, and aplastic anemia after allogenic stem cell transplantation[85]. Benefits in areas such as illness uncertainty and resilience indicate that interventions should include social support as a major theme to help improve these psychosocial domains in all cancer patients.

The absence of social support and the resulting reductions in mental health, resilience and quality of life are likely due to neurobiological effects[60]. Studies have shown that low social support is associated with increased stress reactivity (increased and prolonged hypothalamus-pituitary-adrenal (HPA) response[60]) elevated heart rate, increased blood pressure and magnified cardiovascular and neuroendocrine responses to stressors within controlled studies[86]. Thus, high levels of social support appear to allow for resilience to stress in terms of dampening the HPA axis by mediating release of dehydroepiandrosterone (DHEA) which has been associated with low levels of posttraumatic stress disorder (PTSD) and increased resilience to stress[87].

There are many other factors that may influence a cancer patients' resilience over the course of their diagnosis, treatment, and survivorship. These can include things such as demographic factors[68], personality related factors[88], coping strategies utilized[67], and hope[89]. While results are inconclusive in studies that look at demographic characteristics, generally, increased resilience is associated with cancer patients who are younger, have high levels of education, higher income and are Caucasian[90–92]. Personality traits become particularly important when controlling mental and emotional states in the situation of a life-threatening stressor. Personality related factors such as high self-concept, self-esteem, self-control, optimism, positive emotions are discussed widely in the literature to aid in building resilience[76,88,93]. In terms of coping strategies, those who use adaptive coping strategies including positive reappraisal, social support seeking behavior, problem focused coping and religious coping report increased quality of life and lower stress levels compared to cancer patients who use nonadaptive coping strategies[66,94–97]. Studies demonstrate that adaptive coping strategies influence resilience and thus increase quality of life in cancer patients[94,95]. Lastly, hope can be one of the most powerful tools for cancer patients[89]. Various practices have been shown to provide psychosocial adjustment and hope through cancer treatment including: religious practices, spiritual well-being and spiritual awareness[98]. These practices are existential ways that cancer patients can foster hope to help get a sense of meaning of their cancer diagnosis, the cancer experience, and help to maintain, improve wellbeing and to look toward survival[68].

Psychosocial care in cancer patient populations is quickly becoming a vital part of the treatment and rehabilitation plan[99]. Research that includes resilience and hope as their main outcome measures are becoming more prevalent, but studies are still limited and research that incorporates more cancer diagnoses, gender and age ranges is needed[100,101]. Studies that look to enhance resilience in cancer patients work to promote this resilience to a specific stressor on an individual level[100]. These interventions can be applied both acutely (newly diagnosed patient) or long-term (enduring, chronic cancer patients), as they look to strengthen pertinent resilience factors such as psychosocial resources patients can use to maximize their resilience, including: problem solving skills, self-efficacy, optimism and acceptance of their situation and related emotional feelings[100].

A narrative review published in 2019 was the first to assess resilience based interventions in cancer patients[100]. In this review they reported that studies with large sample sizes primarily found effect sizes ranging from small to large (Hedges' g=0.2-0.8) when looking at increases in resilience in cancer patients after participating in an intervention targeting resilience. Variation within the review arose from studies that lacked sample size (under 50 participants), in addition all but one study showed positive effect on resilience[102]. Mediators that showed increased benefit of resilience-based interventions were those that were applied acutely after cancer diagnosis and longer duration of the intervention (>12 sessions or 24 hours of accumulative intervention duration). Studies that had longer interventions also showed lasting effects on resilience in those cancer patients (stable resilience outcomes for up to one year). Conclusions from this review indicate that resilience-based interventions should be offered to every cancer patient that is willing to participate, and should be applied as soon as possible after diagnosis and over a long duration[100]. However, it is important to note that when looking at the literature on resilience-based outcomes in cancer patients, there are no studies assessing resilience in pediatric cancer patients. The review paper discussed excluded pediatric oncology patients and the youngest participant was 30 years of age[100]. To our knowledge, there is currently no intervention-based study in pediatric oncology patients that includes resilience as a primary outcome measure. However, many correlational studies link resilience with positive health outcomes in adult oncology patients[18,66,68], highlighting the need for intervention research on resilience outcome measures in pediatric oncology patients.

Resilience as shown by previous research is highly influenced by the individual's surroundings. Social support plays a major role in increasing resilience by reducing the level of illness uncertainty and allows a cancer patient to adjust to their cancer diagnosis, increasing quality of life[79]. Social support has also been tied to psychological well-being and resilience in cancer patients[66,80]. There are many other factors that may influence a cancer patients' resilience, which include demographic factors[68], personality related factors[88], coping strategies utilized[67], and hope[89]. There is however a lack of research driven questions on resilience in pediatric cancer patients and the impact of interventions on resilience in this population. Thus, there needs to be more research assessing the impact of interventions on resilience in pediatric cancer patients and survivors.

2.1.4 Hope in Pediatric Cancer Patients and Survivors

Children's hope involves the belief in one's capabilities to produce efficient routes to goals and a self-related belief that they can sustain momentum towards achieving that goal[103]. Snyder et al., indicate that there are two components to this definition of hope: 1) pathways and 2) agency. The pathway component is defined as children being able to envision a variety of means to achieve their desired goal related outcomes. The agency component includes the ability to initiate those goals and allow for sustained efforts towards their goals[103]. Children who are recently diagnosed with cancer must focus on new goals, learn new treatment regimens and cope with new unfamiliar disease symptoms. As healthcare providers, the task is not just to treat the child's physical illness but also to balance hope with honesty[104]. This can instill hope in the childhood patient while maintaining patient autonomy allowing the child to maximize health outcomes. Thus, hopeful thinking in childhood cancer patients aids ongoing medical treatment[103].

Strategies that were identified in a 2001 paper to facilitate hope in nine cancer patients aged 21-76 years, undergoing bone marrow transplantation included: building and maintaining meaningful relationships, staying positive, living in the present moment, promoting accomplishments, feeling a spiritual connection, and anticipating survival[105]. A study in 2016 found that hope in 365 bladder cancer patient changed over time and was manipulated by internal and external factors including patients resilience and social support[63]. Hope provided patients the ability to adapt, give meaning to their diagnosis, and maintain higher levels of well-being and motivation for survivorship[63]. Hope is also positively correlated with treatment efficacy in adult patients with breast cancer[106]. Another study found that pediatric and adult cancer patients who had higher hope were able to tolerate more pain[107]. In summary, both hope and resilience have been found to play a significant role in overall quality of life, psychological well-being and physical well-being in cancer patients[63]. There is however, a lack of information specifically on pediatric cancer patients in hope based findings.

Similarly to resilience based interventions, there is also a lack of published literature on hope-based interventions in pediatric oncology patients. Intervention based studies that target hope are mainly nurse led[108–110] in pediatric oncology wards, and are thus different than a real world intervention, but may offer some insight into VOC interventions. A nurse-led interview based study in 2021 including twenty children aged 6-12 years with various cancer diagnoses, examined major themes that should be used in pediatric oncology interventions to improve hope[109]. From this thematic analysis, six major themes were identified: emotional connectedness with nursing staff, playrooms to facilitate play in hospital settings, presence of parents in hospital settings, symbols of recovery, presence of nature, and escaping the "hospital cage"[109]. These results indicate that hope can be facilitated through many different circumstances in the hospital environment, and thus staff within hospitals need to be equipped with an understanding of how to foster hope in this population. This also highlights that virtual based interventions held within hospital settings could have some efficacy.

A meta-analysis published in 2018 summarized studies that evaluated hope in adult cancer patients through nursing interventions (individual and group based programs focused on solution, forgiveness and learning to live with cancer focused interventions) and found that nursing interventions contributed to a significant enhancement in hope when compared to control groups[110] Inclusion criteria for this meta-analysis was ages >18 years and thus did not include pediatric oncology patients. Similarly, another review found that in adult cancer patients, hope targeted interventions, such as; “Forgiveness therapy”, “Living with hope Program” and “Learning to Live with Cancer”, showed efficacy in increasing hope in this population of patients[101]. Psychological interventions with education can increase expectations in patients with cancer providing cognitive, emotional and social support[111]. Several studies have discussed the benefits of interventions that include psychoeducation in adult cancer patients on based outcomes (e.g., pressure on cancer, anxiety on relapse, ways of coping, importance of physical activity, making goals, positive thinking and planning)[112–114]. Overall, the results from these review articles indicate that hope based interventions are feasible for increasing hope in adult cancer patients[101,110]. Interventions that were found to increase hope were those that included psychological and spiritual elements including face to face sessions as well as group sessions[109]. Still, there is a need for these types of interventions to be analyzed in pediatric oncology patients to see how hope differs for older and younger cancer patients[110]. This will be crucial in the development of future interventions for pediatric oncology patients.

2.1.5 Non-virtual Interventions for Childhood Cancer Patients

There are many types of interventions offered to pediatric cancer patients to improve psychosocial outcomes after diagnosis and into survivorship[115]. A systematic review published in 2018 included studies that evaluated psychosocial interventions in settings such as outpatient group settings, inpatient rehabilitation programs, outpatient individual setting, camp setting, computer-based and home-based[115]. The primary outcome of the studies reviewed varied from reduction of psychological burden, reduction of both physical and psychological burden, improvement of social skills[116], increase in social support and psychoeducation. From the 15 studies that looked at the impact of outpatient group setting interventions, many reported positive impact on social skills[116], anxiety scores[117], quality of life[118], global self-worth, social acceptance, and positive thinking[119,120]. Family oriented rehabilitation programs resulted in positive impacts on patients' physical and psychological scores, however outpatient individual interventions and home-based interventions did not lead to improvements in psychosocial outcomes[115]. While computer-based interventions were included in this systematic review, they only examined the psychosocial outcome of parents. Although, the results were mixed from the three computer-based interventions, one study found a decrease in maternal depression and paternal anxiety and stress[121]. However, an e-mental health intervention did not improve psychological functioning in parents and or family functioning[122]. While data is still limited, the variety of interventions discussed in the noted review paper[68,123–128] is indicative that research on interventions to improve psychosocial outcomes in pediatric cancer patients is increasing.

Oncology camp experience can offer an inclusive environment where childhood cancer patients can interact and share common experiences and is as an intervention that may improve psychosocial health. Adolescence is a time when children rely heavily on social comparison to evaluate their own emotions and abilities[126]. One study including 34 adolescents with cancer reported that social engagement at a childhood OC led to self-reported increases in self-competence related to physical appearance, social acceptance, and global self-worth as these children were able to relate to their peers[126]. In addition, other overnight camp experiences for pediatric cancer patients resulted in improvements in self-esteem[124], and social support[127]. A publication from Yale Child Study Center in collaboration with SeriousFun Children's Network reported changes in children attending OCs such as increased interest in social activities, increases in self-esteem, increased sense of belonging, increased medication adherence, increases in psychosocial functioning and improved relationship skills in children with chronic illness[125]. However many of these changes have not been measured in the longer-term (all less than 3 months post-camp), thus existing studies are still limited by their experimental design.

The idea of using recreation to help reduce the adverse effects of acute and long-term stress on psychosocial health in cancer patients is not new; however, there have been very few published studies examining the impact of overnight childhood OCs[47]. In pediatric cancer patients, camps may reduce stress through exposure to nature[129], increased physical activity[130], respite from stressors at home[123] and/or improved emotional reactivity to stressors[131]. The relationship between stress regulation through these behaviours is likely bidirectional[132], in which lower stress can support engagement in pro-social and healthful activities during camp, which helps reinforce social behaviours beyond camp.

While in-person OCs have had a positive impact on psychosocial outcomes in pediatric oncology patients[123–125,127], they may not always be practical. For example, increased overhead costs, medical and non-medical staffing and the magnitude of space required may be some of the challenges associated with in-person OCs. The practical advantages of a VOC was highlighted by the COVID-19 pandemic. VOCs were quickly put into place during the pandemic as a way for interventions to remain available to pediatric oncology patients. VOCs are able to remove multiple barriers that may have kept some children from attending an in-person camp[33]. More specifically VOC can reduce geographical barriers, socioeconomical barriers, provide a hygienic space, as well as mitigate fears of attending an in-person camp during a pandemic[33,34]. Members of a virtual support group at SickKids hospital in Toronto, Ontario, Canada stated that previously (before COVID-19) they were unable to attend the in-person support group sessions, but with the addition of virtual sessions they were now able to join from their home or hospital beds[33]. Anxiety or fear of in-person gatherings may be heightened in families as sending pediatric cancer patients to attend in-person camp may be seen as a unreasonable risk to the physical health[34]. VOCs may be more practical when trying to offer psychosocial interventions acutely after childhood cancer diagnoses[100]. However, evidenced based findings on VOCs are significantly understudied[50,128,133–135].

2.1.6 Virtual Interventions for Childhood Cancer Patients

The COVID-19 pandemic has necessitated that many psychosocial treatment options be offered online, including OCs such as Campfire Circle. These camp programs have transitioned to online programming with very little high quality research studies to inform the efficacy of virtual camp programming[50,128,133]. To our knowledge, there are no published research studies that examine the efficacy of VOC interventions on improving psychosocial late effects in pediatric oncology patients. Virtual intervention studies on mental and psychosocial health outcomes in pediatric cancer patients that exist tend to focus on other interventions, such as mobile (wireless applications, text messaging, apps, wearable devices, and social media platforms) and computer online interventions (digital gaming, virtual reality, robotics, online support groups, social networks and computerized cognitive rehabilitation)[50,128,133].

There is an increase in the use of mobile and electronic devices in adolescent and youth globally, which makes the idea of VOC programming appealing. For example, 95% of teens report having access to mobile devices such as smartphones, while access to home computers is at 87%[136]. In addition, childhood and adult cancer survivors report being interested in receiving online or mobile interventions both during and post treatment[137]. Lastly, there is marked feasibility and efficacy of mobile interventions demonstrating improvements in adherence among adolescents living with chronic health conditions[138], adherence to preventative behaviours in adolescents[139], and patient-centered interventions for those with anemia[140]. While there is an upward trend in how many interventions are assessing online delivery and their efficacy in reducing adverse psychosocial late effects, it’s important to note that many of the interventions being studied are not virtual camp programming which is being explored in the current study[50,128,133].

A systematic review in 2019 looked to: (a) summarize the current evidence of electronic health (eHealth) and mobile health (mHealth) interventions in pediatric cancer patients and (b) critically audit the current scientific evidence and efficacy of these e/mHealth interventions on emotional distress, health behaviours, health related outcomes, neurocognitive functioning and perceptions attitudes and concerns[133]. mHealth is the use of mobile and wireless applications, such as text messages, apps, wearable devices, and other mobile platforms to deliver health services[141]. eHealth refers to the use of information technology to promote, prevent, treat and maintain health, which could be delivered on platforms such as virtual games, virtual reality and on the internet[141]. This 2019 review found mixed evidence from use of virtual interventions across domains such as; emotional distress, health behaviour change, health outcomes, and neurocognitive functioning[133]. Interventions that they found most efficacious where those that engaged youth the most (e.g., virtual games, robotics, cognitive behaviour therapy groups), targeted specific emotional distress (e.g., depression and anxiety), incorporated a highly personalized user experience, and used active self-monitoring frequently.

Similarly, there are three other relevant reviews, including two narrative reviews that examined the use of technology based interventions on psychosocial outcomes, involving children and adolescent and young adult cancer patients[128,135]. The third was a meta-analysis of four studies that assessed the efficacy of distance based physical activity interventions[134]. The findings of these narrative reviews and meta-analysis support the findings in the review from 2019, that digital health interventions (including mHealth and eHealth interventions) demonstrate efficacy within multiple different modalities for improving overall health and emotional well-being[128,133–135]. While no individual studies discussed in the three relevant reviews used a virtual camp program, overall, there is strong evidence suggesting the use of technology-assisted interventions can help distract child/young adult cancer patients and survivors from the tribulations of a cancer diagnosis and improve psychosocial and emotional well-being. While these forms of online based interventions have shown efficacy in some cases with interventions targeting emotional distress, health behaviours, health outcomes, and neurocognitive functioning, the external validity of those studies is another question entirely.

2.2 Parental Stress from Pediatric Cancer Treatment and Survivorship

The diagnosis of childhood chronic illness often impacts the entire family and is a significant stressor for parents and/or caregivers[142]. While childhood cancer is associated with extensive and demanding therapy regimes that lead to good survival outcomes, there are still many stressors including the child’s potential for a shortened life, reduced quality of life, treatment and unknown responsibilities included in caring for their child’s chronic illness and siblings[143,144]. Therefore, it is important to consider parental/caregiver stress in addition to the wellbeing of the child diagnosed with cancer.

Parental stress can be defined as the stress experienced and linked within a parenting role[32]. Parents who have a child with a chronic illness such as cancer will suffer from additional stresses above and beyond that of a typical parent[32]. These additional stresses can include communicational stresses (e.g., arguing with family members, communication with health care team), emotional stresses (e.g., family difficulties, upsetting news about child), medical care (e.g., new medical procedures, making decisions on treatment), and role function (e.g., attending to other aspects of important life factors, work/life balance)[32]. There is also immediate stressors about the health and wellbeing of their child and thus stress about what the future will hold for their child[145].

Not only is distress a negative symptom for the parent/caregiver themselves, there is a growing body of evidence that indicates unfavorable health outcomes in children are associated with increases in parental stress[16,17,144,146–148]. For example a study in 2014 including 50 child-parent dyads highlighted that parental stress was a more significant predictor of functional impairments in their children than neurocognitive deficits (e.g., neurocognitive functioning, attention and memory)[146]. These results support another study that used maternal reported data for children with cancer (N = 65, mean age = 8.3 years) that higher maternal distress at three time points (2-5 weeks, 12-14 weeks and 22-24 weeks post-pediatric cancer diagnosis) resulted in higher child emotional distress[148]. In addition, a study from Sawyer and colleagues that assessed children aged two to five years with cancer and their families (N = 38) found a significant relationship between parental stress related symptoms (e.g., somatic complaints, anxiety, insomnia, social dysfunction, and depression) immediately after a pediatric cancer diagnosis and child's psychological adjustment 2 years post-diagnosis[149]. They found that increased maternal stress symptoms (e.g., anxiety, insomnia, depression and somatic symptoms) correlated with increased levels of child internalizing and externalizing behaviours[149]. Thus, therapeutic strategies should be proposed and studied for a better understanding of how we can reduce stressors in parents and caregivers of pediatric oncology patients and in turn improve the development and maintenance of stress symptoms in this population[150,151].

Increases in parental stress is associated with negative parenting behaviours, which may include harsh child discipline[152] and hostility[153], which have been linked to worse psychological outcomes in youth[154]. Providing interventions for parents/caregivers to help cope and manage their stress should be a priority when children are diagnosed with chronic illnesses. One systematic review published in 2019 highlighted the benefit of providing mindfulness interventions, such as (mindfulness training in group format including Mindfulness-based Cognitive Therapy and Mindfulness-based Stress Reduction programs) for parents[151]. There was a small within-group reduction in parental stress immediately after the intervention (g=0.34), however this rose to a moderate reduction 2 months afterward (g=0.53). This indicates that the impact the intervention had lasted even after the intervention ended and improved over-time. Also, this systematic review showed that improvements in parental stress were associated with improvement in youth cognitive and psychosocial outcomes. Youth outcome measures showed small, within-group improvements in internalizing (g=0.29), externalizing (g=0.26), cognitive (g=0.27), and social (g=0.28) domains[151]. Internalizing (g=0.33), externalizing (g=0.39), and cognitive (g=0.40) domains were maintained 2 months post intervention in youth. This systematic review demonstrated benefits in child psychosocial outcomes when parents attended interventions to help cope and manage their stress. It is important to note that, this systematic review did not include studies that provided the child with any intervention, thus the change in youth outcomes could be attributed to the parental intervention[151]. The results of the 2019 systematic review are supported by two other meta-analyses that highlighted improved psychological distress including depression, anxiety[155] and stress symptoms[155,156] after parents attended a intervention to reduce stress. While research has demonstrated that interventions that target improving parental/caregiver stress also improve psychosocial outcomes of their child, what is not clear is whether interventions aimed at improving child psychosocial outcomes could work the other way, meaning reduction in parental/caregiver stress. Understanding this relationship, and identifying if it is indeed bidirectional, is an important future direction.

VOC may offer the parents/caregivers of childhood cancer patients some respite from day-to-day routines and treatment regimes. One study suggests that a prominent cause of parental stress is activity limitations that children experience as a result of cancer and on-treatment status[157]. VOC programming includes daily activities for camp participants, ensuring parents/caregivers that their children are actively engaged in important social, physical activity and learning experiences, potentially mediating those stressors[158]. Camp may also increase family intra- and inter-communication as childhood cancer participants begin to build relationships with camp staff, volunteers and other campers[20]. This network of individuals can allow parents/caregivers to have more conversations, including: learning more about their child’s illness, how to improve coping mechanisms, sharing their stories and the ability to have positive conversations with their child[159]. Importantly, improved family functioning (e.g., positive communication and cohesiveness) was found to be associated with less parenting stress among caregivers of children with cancer[143]. Thus, parental/caregiver stress may be improved by their child attending a VOC, however, there are currently no research studies that examine this area.

The present thesis looks to provide more insight into one possible intervention to improve psychosocial late effects in childhood cancer patients and the effect on parental stress. The literature review summarized and highlighted important themes in social functioning, resilience and hope in pediatric oncology patients as well as summarized non-virtual and virtual interventions that have already been assessed and finally stress in parents and caregivers. These concepts are widely seen as psychosocial outcomes that are hindered after a pediatric cancer diagnosis, however, have also improved after attending psychosocial interventions as we have summarized[66,109,123–127]. There is a lack of quantitative data within the literature on the impact of in-person OC but also no published data on the impact of VOC pediatric oncology patient’s psychosocial outcomes and parent/caregiver’s stress.

3.1 Methods

3.1.1 Ethics Approval

This study was approved by the Trent Research Ethic Board on June 24th, 2021 (File 26663).

3.1.2 Study Design, Participant Recruitment, and Informed Consent

This thesis was a pilot, prospective research study. The study was conducted on two different groups: 1) childhood cancer patients who were enrolled to participate in the VOC program in the summer of 2021 with Campfire Circle (formerly Camp Ooch and Camp Trillium); and 2) the parents/caregivers of children who attended the VOC program in the summer of 2021 with Campfire Circle. Children ages 7 to 18 years and their parents and/or caregivers were contacted on July 6th, 2021 via email from the VOC registration lists provided by Campfire Circle. Children with all cancer diagnoses and stages of treatments were included. All parents/caregivers were invited to participate as well. Included in the information letter (Appendix 5.6) was a description of the study for both the parents and pediatric cancer patients/survivors who were attending camp (i.e., campers). Links to the online survey were provided for both parent/caregiver and camper as parent assent could be provided for the camper if consent of the child could not be given alone.

Campers followed the regular camp programming provided (see section 3.2 below). Study testing occurred at 3 time points: one-week before camp (T1), immediately post-camp (T2), and 3-months post-camp (T3). This was an entirely virtual study, thus, all study testing (i.e., questionnaires) were completed through the Qualtrics survey program via Trent University. This is a secured online software that allows study participants to complete questionnaires and surveys online. Informed consent was obtained prior to completion of questionnaires by providing participants with a detailed information/letter of consent, which included the study's title, purpose, methods, duration, use/storage of data, confidentiality and researcher contact information (see Appendix 5.4 and 5.5).

Participants were made aware that participation in the study was voluntary, that could choose not to complete the survey or withdraw from the study at any time without it impacting their participation in the Campfire Circle camping program. A letter of consent tailored to each of the two groups (children/adolescents campers, and parents/caregivers) was provided at the beginning of the Qualtrics survey (top of the first page), and participants selected "YES" on the survey if they chose to participate in the study. As per the TCPS-2[160], children were invited to consent if they had the capacity to decide for themselves (i.e., not based in age alone). There were options for parents to provide consent for their child, if the consent form was deemed too difficult for the child to read and decide themselves. The Qualtrics survey consent for campers included questions such as: “Did your parent/caregiver help you with this form?” with a yes or no response provided. If the camper did have help with the consent form they were also asked “If your parent/caregiver helped you with this form, does your parent/caregiver agree for you to take part in this study?” Afterward the survey resumed and the camper could continue the survey with or without the help of their parent/caregiver.

All participation in the study was anonymous. As such we were not able to determine or track if each person who completed T1 also completed T2 or T3. We provided an option for participants to record a randomly generated participant ID that they were provided with at the end of their survey (T1), however, it was not mandatory to provide this participant ID for T2 and or T3. If the participant did happen to forget their ID, they could select an option that read “I did not remember my participant ID”, and then could carry on with T2 or T3.

3.1.3 Intervention

Campfire Circle is a privately funded charity that provides support to families coping with pediatric cancer. Camp Ooch and Camp Trillium were established in 1983 and 1984 respectively, merged into one camp in 2020, and then rebranded as Campfire Circle in 2021. In the summer of 2021, which is the camp season the current study focuses on, Campfire Circle offered a VOC experience. Specifically, the virtual camp was a summer “Camp in a Box” program had kids spending time outside away from screens, with flexible schedules that kept kids both physically and socially active taking activities from both camps. Campers who participated in the virtual camp programming were sent a virtual camp kit that included materials that would be used for various activities during camp (See Appendix 5.7 for material list). The VOC that was assessed in the current study ran from July 12th, 2021, to August 6th, 2021. VOC sessions included three hours a week of camp for 4 weeks with an additional 90 minutes for closing ceremonies.

Examples of VOC sessions for children ages 5-13 included “Cabin Time”, where attendees spent time with their cabin groups via zoom which were allocated at the start of camp. Cabin groups and counselors met for three hours each week to play games and try new camp activities which were included in the “Camp in a Box” delivery. Activities included comic book creation, puppetry and circus skills. For ages 14-18 camp activities included leadership development sessions, where campers would listen to guest speakers and participate in group activities which would allow members to grow leadership skills and learn how to positively impact their community. There were also activities like skill-building workshops and social clubs during these sessions. Both groups finished with closing campfire ceremonies (live, online), where songs were sung, stories were shared, and highlights from the camp were brought up[64].

3.1.4 Measures

The study timeline can be found in Figure 1 below, and a summary of the measures as they related to the current study objectives are found in Table 1.

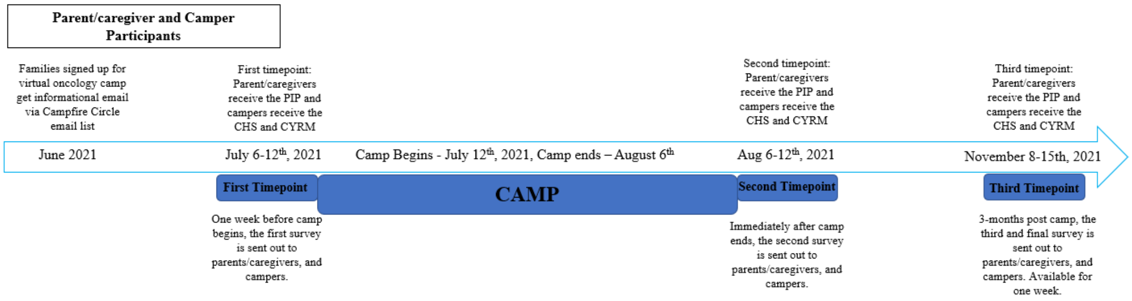

Figure 1: Method timeline including all three timepoints, before camp (one week), immediately post-camp, and 3-months post-camp. Children and Youth Resilience Measure-17 (CYRM); Children's Hope Scale (CHS); Pediatric Inventory for Parents (PIP).

Table 1: Research study questions, time-points, and outcome measures

Research Question	**Time points**	**Questionnaire**	**Dependent Variables**	**Time required to complete**
Children/Adolescent participants				
Is resilience improved by 1month of VOC in children who have had cancer?	T1 = Baseline (~1 week before camp) T2 = post-camp (immediately after camp) T3 = 3 months post-camp	Children and Youth Resilience Measure-17	Resilience	15 items - 8 minutes per time point **Total= ~11 minutes per time point**
Is hope improved by 1-month of VOC in children who have had cancer?	T1 = Baseline (~1 week before camp) T2 = post-camp (immediately after camp) T3 = 3 months post-camp	Children's Hope Scale	Hope	6 items - 3 minutes per time point **Total= ~11 minutes per time point**
Parent/caregiver participants				
Is parental/family stress improved by their child attending 1-month of VOC?	T1 = Baseline (~1 week before camp) T2 = post-camp (immediately after camp) T3 = 3 months post-camp	Pediatric Inventory for Parents	Parental Stress	42 items - 15 minutes per time point **Total=~15 minutes per time point**

Three research questions were addressed, 1) Is resilience improved by 1-month of virtual oncology camp in children who have or had cancer of any kind? 2) Is hope improved by 1-month of virtual oncology camp in children who have or had cancer of any kind? And 3) is parental/caregiver stress improved by their child attending 1-month of virtual oncology camp?

3.1.5 Resilience

The Child and Youth Resilience Measure-17 (CYRM-17) will be used to measure resilience at three time points in all virtual camp participants at 3 points: baseline (T1), post-camp (T2), and 3 months post-camp (T3). The CYRM-17 is a 17-item scale, that was developed to have flexibility in how questions are phrased or the selection of applicable questions. Thus, the CYRM is dynamic and can be adapted to fit needs of the study population. The goal of measuring resilience with the CYRM would be to address: both internal and external resources children are using to adapt to major sources of stress or trauma[161]. The CYRM also includes questions related to social interaction or function. See Appendix 5.2.

The CYRM-17 was reduced to 15 items for the purpose of this study. Two of the items were deemed inappropriate for our study population and were thus removed from the 17 items. These two items included 1) Item 6: “Is there enough to eat in your home when you are hungry?” and 2) Item 17: “Do you like the way your family/caregiver(s) celebrates things (like holidays or learning about your culture)?”. In addition to the removal of these two items, there were very minor changes to two of the items. In both items 11 and 12 on the original CYRM, there is a phrase as follows, “(for example, if you are sick or have done something wrong)?”. We changed the wording to (“for example if you are not feeling well or have done something wrong)?”.

The items within the measures can be directly summed to gain a total score of this population’s individual resilience. The CYRM is typically 17 items long but for the purpose of this study was cut down to 15 items, thus the minimum score achievable on this score is 15 and the highest score achievable is 75. As the CYRM is highly adaptable and resilience changes from one context to the next, there are not cut-offs provided with this scale[162], the authors suggest that low and high scores are investigating potential reasoning for these changes (See Appendix 5.2). The CYRM has been validated for these age ranges[161]. A Cronbach's alpha of 0.863 confirmed the internal consistency of the CYRM[161].

3.1.6 Hope

The Children's Hope Scale (CHS) was used to measure hope at three time points in all VOC participants: baseline (T1), post-camp (T2), and 3 months post-camp (T3). The CHS is a 6-item scale that encompasses two major conceptualizations of goal orientation: agency and pathways[163]. Children who score high on the CHS will show both a high sense of agency in initiating and sustaining action toward a goal and be able to produce the necessary means to achieve these goals[163]. The CHS has been validated for the use in all age ranges and is appropriate for the study population[103,161,164]. Internal consistency estimates (alpha) from Snyder et al., 1997 ranged from 0.72-0.86. Test-retest reliability estimates (over a one-month interval) ranged from 0.71 to 0.73[103].

The CHS has six questions on it. Three of them measure pathways and three that measure agency. The CHS uses a six-point response scale with "none of the time" equating to the lowest value of one and "all of the time" equating to the highest value of six. Thus, for the pathways or agency the scores can range from 3-18, or if you take the overall hope score of the CHS which scores can range from 6-36. Scores from 6-12 indicate no to very low hope, 13-18 indicate slightly hopeful, 19-24 indicate moderately hopeful and 25-36 indicates highly hopeful[103] (Appendix 5.1). Thus, the CHS will have three separate scores, the pathways and agency subscales and the total score from the CHS (See Appendix 5.5).

3.1.7 Parental Stress

Parental stress was measured at baseline (T1), post-camp (T2) and 3 months post-camp (T3) using the Pediatric Inventory for Parents (PIP)[32]. The PIP is a 42-item survey which is a commonly used measure of disease related parental stress (see Appendix 5.3). The PIP asks parents to indicate the frequency of disease-related parenting stressors occurs and the difficulty level of each stressor[32]. Thus the 42-item survey results in 84 responses, for each item there are two responses (frequency and difficulty). There are 4-subscales: communication, emotional distress, medical care and role function. Parental stress may be an important measure for this type of study as many studies have found that parental stress can have adverse effects on child psychological outcomes[144]. The PIP has been validated specifically for parents with children diagnosed with cancer[32]. The internal consistency of the PIP (alpha) is high at 0.80-0.96[32].

The PIP is scored separately for each of the 4 domains (Communication, Emotional Distress, Medical Care, Role Function) across 2 scales Frequency (F) and Difficulty (D). There is also a total score comprised of a sum for each other 4 domains, yielding total F and total D scores. The minimum score achievable for the total is 84 and the highest score achievable is 420, (See Appendix 5.3).

3.1.8 Demographic Measures

Demographic questions included age, gender, and race of the participants. For age, participants self-reported their age in years, or could stated they did not want to answer the question. Participants self-reported their gender or had the option to not answer. Lastly, participants self-reported their race or had the opportunity to not answer if they preferred not to (See Appendix).

3.1.9 Statistical Analysis

The current study design (anonymous survey) allowed for individuals to complete the survey any or all of T1, T2, and/or T3. Therefore, participants could join the study during the second and third timepoint without having completed the first survey. This resulted in each timepoint consisting of different participants and thus the timepoints were not repeated. Therefore, we had three potentially independent groups to assess at each time point. One-way ANOVAs were conducted to test if there were differences between the three timepoints independently (pre-camp, post-camp and 3 months post-camp). As this was a pilot study with small sample sizes, we also used Cohen's d used to assess effect size between timepoints one and two, one and three and two and three, in both pediatric cancer patients and parents. Cohen's d is independent of sample size unlike other significance testing such as the one-way ANOVA[165]. In Cohen's d an effect size of 0.20 is considered small, 0.50 is considered medium and 0.80 considered large[165].

Thus, to answer our first research question a one-way ANOVA was used to assess changes between the three timepoints in the pediatric cancer patient's CYRM scale, also Cohen's d was used to measure effect size between each timepoint. To answer our second research question a one-way ANOVA was used to assess changes between the three timepoints in the pediatric cancer patient's CHS (both agency and pathways subscales were analyzed), also Cohen's d was used to measure effect size between each timepoint (T1 vs. T2, T1 vs. T3 and T2 vs. T3). To answer our third research question a one-way

ANOVA was used to assess changes between the three timepoints in the parent/caregiver PIP scores, also Cohen's d was used to measure effect size between each timepoint. All data was tested to meet assumption of normality and homogeneity of variances for one-way ANOVA testing. Tukey's Post Hoc test was used to test for differences between each timepoint in both pediatric cancer patients and parents.

3.2 Results

3.2.1 Incomplete Surveys

For the pediatric cancer patient/survivor (i.e., campers) there was a total of 13 incomplete surveys over the three timepoints. Incomplete surveys meant that the participant gave consent to begin the study but did not complete any other part of the surveys. Four out nine surveys in T1 were incomplete, five out of nine in T2 were incomplete and four out of eight were incomplete in T3. Therefore, we present data on five surveys at T1, four surveys at T2, and four surveys at T3. There were 343 campers total who participated in the virtual camp programming, thus 4% of campers participated in the virtual oncology camp study.

For the parent/caregiver participants there was a total of 46 incomplete surveys. Incomplete surveys meant that the parent or caregiver gave consent to begin the study but did not provide any other information past that point. Ten out of twenty-two surveys were incomplete in T1, six out of twenty in T2 and ten out of thirty-five in T3. Therefore we present data on twelve surveys at T1, fourteen surveys at T2, and fifteen surveys at T3.

3.2.2 Pediatric Cancer Patients

Demographic characteristics are summarized in Table 2. As indicated above, five responses were recorded at T1, including three female participants and two males. Mean age of T1 was 12.25 ± 4.65 years with one missing entry for age out of the five participants. Out of the five participants in T1 four self-identified as Caucasian and one as Asian. At this timepoint three out of the five had parent/caregiver help with filling out CHS and CYRM scales.

As discussed above, five responses were recorded at T2, including two female participants and two males with one missing entry point. Mean age of T2 was 13.75 ± 5.51 years with one missing entry for age out of the five participants. Out of the five participants, at T2 two self-identified as Caucasian, one as Muslim, one as Islam and one missing entry point. At this timepoint one out of the five had parent help with filling out CHS and CYRM scales. Three out of the five indicated that they were returning participants (i.e., they stated that they completed the questionnaires at T1).

Four responses were recorded at T3, including two female participants and two males. Mean age of the participants at T3 was 13.75 ± 4.27 years. At this timepoint two out of the four had parent help with filling out CHS and CYRM scales. Two out of the four were returning participants however two participants stated that they did not participate in the first or second timepoint.

Table 2: Descriptive statistics of camper participants

Timepoint Variable	T1	T2	T3
N	5	5	4
Age (SD)	12.25(4.65)	13.75(5.51)	13.75(4.27)
Gender (%)			
Male	40%	40%	50%
Female	60%	40%	50%
Missing entry	0.%	20%	0%
Race (%)			
Caucasian	80%	40%	50%
Asian	20%	0%	25%
Muslim	0%	40%	0%
Prefer not to say	0%	0%	25%
Missing	0%	20%	0%
Parent Help? (%)			
Yes	60%	20%	50%
No	40%	80%	50%

3.2.3 Pediatric Cancer Patient/Survivor (Camper) Resilience

One-way ANOVA found no differences between T1 (57.20±7.82), T2 (65.40±8.39), and T3 (64.25±8.66), in the CYRM scores in campers ($F_{2,11}$=1.41, P = 0.284). However, when effect size was examined using Cohen’s d, CYRM scores were higher (high effect size) after attending a 1-month virtual oncology camp compared to pre-camp, T1 vs. T2 (57.20±7.8 vs. 65.40±8.4; P=0.15, d=0.86). CYRM score decreased 3-months post-camp compared to immediately post-camp, T2 vs. T3 (65.40±8.4 vs. 64.25±8.7; d=-0.14). However at 3-months post-camp CYRM scores remained higher compared to pre-camp, T1 vs. T3 (57.2±7.8 vs. 64.25 ±8.7; d=0.86).

3.2.4 Pediatric Cancer Patient/Survivor (Camper) Hope

One-way ANOVA found no differences between T1 (20.80 ± 4.7), T2 (28.60 ± 6.7), and T3 (26.00 ± 2.16), in the total CHS scores in pediatric cancer patients

($F_{2,11}$=2.99, p = 0.091). No significant differences were found between T1(10.40 ± 3.0), T2 (13.60 ± 4.2), and T3 (12.75 ± 1.0) on the Pathways subscale within the CHS ($F_{2,11}$=1.39, p = 0.29). However, significant differences were found between T1(10.40±2.4), T2 (15.00 ± 3.0), and T3 (13.25 ± 1.7) on the Agency subscale within the CHS ($F_{2,11}$=4.35, p = 0.041). Tukey's Post Hoc revealed that T2 was significantly higher than T1 (10.40 ± 2.4 vs. 15.00 ± 3.0, p = 0.034), but T3 was not significantly higher than T1 (10.40 ± 2.4 vs. 13.25±1.71, p = 0.245) and T3 slightly decreased from T2 but was not significant (15.00±3.00 vs. 13.25±1.71P = 0.563), Figure 2.

Scores from 6-12 indicate no to very low hope, 13-18 indicate slightly hopeful, 19-24 indicate moderately hopeful and 25-36 indicates highly hopeful[103]. Thus, this cohort started camp with a mean group average of 20.80 ± 4.7 (moderately hopeful), immediately after camp mean group hope levels were 28.60 ± 6.7 (highly hopeful) and the camper scores stayed highly hopeful 3-months post-camp (26.00 ± 2.2).

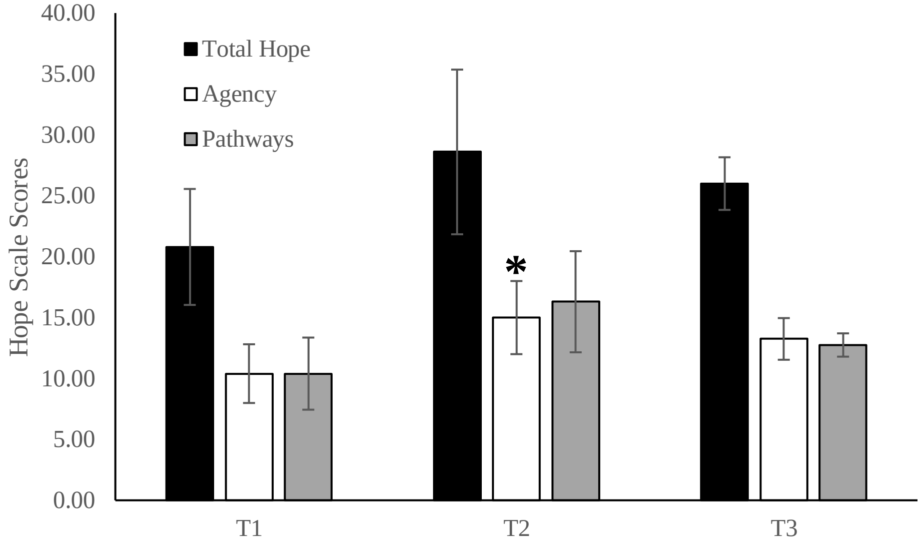

Figure 2: Mean Total Hope scores with subscale scores from the CHS, Agency and Pathways, with SD. * denotes significant difference between T1 Agency scores vs. T2 (p = 0.041).

Due to the small sample size, Cohen’s d was also used to examine the magnitude of effect. The total CHS score was higher after attending a 1-month virtual oncology camp at T1 vs. T2 (20.80 ± 4.8 vs. 28.60 ± 6.8; *d*=1.33). Hope decreased slightly from immediately after camp to 3-months post-camp (T2, 28.60 ± 6.8 vs. T3, 26.00 ± 2.2; *d*=0.49). However, hope remained higher 3-months post-camp compared to baseline (T1, 20.80 ± 4.76 vs. T3, 26.00 ± 2.2; *d*=1.34).

The agency score (subscale of the CHS) was higher in campers after attending a 1-month virtual oncology camp at T1 vs. T2 (10.40 ± 2.4 vs. 15.00 ±3 .0; *d*=1.69). Camper’s agency score decreased from immediately after camp compared to 3-months post-camp, T2 vs. T3 (15.00 ± 3.0 vs. 13.2 5 ± 1.7; *d*=-0.69). However the agency score remainder higher 3-months post-camp compared to pre-camp, T1 vs. T3 (10.40±2.4 vs. 13.25±1.7; *d*=1.33).

The ability to form pathways score (subscale of the CHS) was higher in campers after attending a 1-month virtual oncology camp at T1 vs. T2 (10.40 ± 3.0 vs. 13.60 ± 4.2; *d*=0.89). The pathways score decreased from immediately after camp compared to 3-months post-camp, T2 vs. T3 (13.60 ± 4.2 vs. 12.75 ± 1.0; *d*=0.69). However, the pathways score also remained higher compared at 3-months post-camp compared to pre-camp, T1 vs. T3 (10.40 ± 3.0 vs. 12.75 ± 1.0; *d*=1.01).

3.2.5 Parent/Caregiver

As discussed in section 3.11 above, twelve responses were recorded at T1, including eleven female participants with one missing entry. Mean age of T1 was 40.58 ±5 .42 years. Out of the twelve participants in T1 nine were Caucasian and two were Asian and one preferred not to answer.

Fourteen responses were recorded at T2, including twelve female participants and two males. Mean age of T2 was 42.21 ± 5.74 years. Out of the fourteen participants in T2 nine were Caucasian, one was Asian, and the remaining participants preferred not to answer. Twelve participants were returning from T1 and two did not complete the first timepoint.

Fifteen responses were recorded at T3, including fourteen female participants and one male. Mean age of T3 was 42.67 ± 5.53 years. Out of the fifteen participants at T3, eight self-reported as Caucasian, four as Asian, one as Indian, one as Armenian and one preferred not to answer. Eleven out of the fifteen were returning participants and the remaining four stated that they did not participate in the first or second timepoint.

Overall, there was 41 PIP surveys completed over 3 timepoints, with a mean age of 41.90 ± 5.50 yrs. Descriptive statistics are presented in Table 3 below.

Table 3: Descriptive statistics of parent/caregiver participants.

Variable	**Timepoint**	**T1**	**T2**	**T3**	**Overall**
N		12	14	15	
Age (SD)		40.58(5.42)	42.21(5.74)	42.67(5.53)	41.90(5.50)
Gender (%)					
	Male	0.00%	14.28%	6.67%	7.32%
	Female	91.67%	85.71%	93.33%	90.24%
	Missing Entry	8.33%	0.00%	0.00%	2.44%
Race (%)					
	Caucasian	75.00%	64.29%	53.33%	63.40%
	Asian	17.00%	7.14%	26.67%	17.10%
	Armenian	0.00%	0.00%	6.67%	2.40%
	Indian	0.00%	0.00%	6.67%	2.40%
	Prefer not to say	8.30%	29.00%	6.67%	14.60%
	Missing	0.00%	0.00%	0.00%	0.00%

3.2.6 Pediatric Inventory for Parents

One-way ANOVA found no significant differences between T1 (219.5 ± 81.0), T2 (228.7 ± 92.5), and T3 (227.0 ± 79.1), in the parent/caregiver PIP scores ($F_{2,38}$=0.43, P = 0.958). Cohen’s d also revealed no differences in parental stress as measured by the PIP between any time points measured (all effect sizes categorized as low), T1 vs. T2 (219.5±81.0 vs. 228.7±92.5; P=0.79, d=0.11), T2 vs. T3 (228.7±92.5 vs. 227.0±79.1; P=0.98, d=-0.02), and T1 vs. T3 (219.5±81.0 vs. 227.0±79.1; P=0.81, d=0.09). One way ANOVA found no significant differences between the Frequency (F) subscale between T1 (113.0 ± 36.8), T2 (112.14 ± 45.3), and T3 (110.9 ± 41.3) ($F_{2,38}$=0.008, P = 0.992). Finally, one way ANOVA found no significant differences between the Difficulty (D) subscale between T1 (106.5 ± 50.7), T2 (116.6 ± 48.7), and T3 (116.1 ± 39.1) ($F_{2,38}$=0.19, P = 0.825).

3.3 Discussion

The current study examined the impact of a 1-month VOC (Campfire Circle) on resilience and hope outcomes in pediatric cancer patients and survivors, and on stress in parents/caregivers. Compared to pre-camp, resilience was higher immediately post-camp (T1 vs. T2 (57.2±7.82 vs. 65.4±8.35; P=0.15, d=0.86)), as well as 3-months post-camp as measured by Cohen's d (T1 vs. T3 (57.2±7.82 vs. 64.3 ±8.66; P=0.24, d=0.86)). Moreover, compared to pre-camp, we found that total hope scores, as measured by the CHS, was higher immediately post-camp (T1 vs. T2) (20.8±4.76 vs. 28.6±6.77; P=0.07, d=1.34) and higher 3-months post-camp (T1 vs. T3), as measured by Cohen's d (20.8±4.76 vs. 26.0±2.16; P=0.09, d=1.33, respectively). Therefore, our findings satisfied our hypothesis that attending a 1-month VOC would improve resilience and hope in children who have or had cancer.

The final component of our study was to examine if parental/caregiver stress improved by their child attending 1-month of virtual oncology camp. We did not find any difference in mean parental/caregiver stress as measured by the PIP, pre-camp vs. immediately post-camp (T1 vs. T2; 219.5±81.0 vs. 228.7±92.5; P=0.79, d=0.11), pre-camp vs. 3 months post-camp (T1 vs. T3 (219.5±81.0 vs. 227.0±79.1; P=0.81, d=0.09), or immediately post-camp vs. 3 months post-camp (T2 vs. T3 (228.7±92.5 vs. 227.0±79.1; P=0.98, d=-0.02). Thus, our findings did not satisfy our hypothesis that parental or caregiver stress would be reduced by children attending a 1-month VOC.

3.3.1 Resilience in Pediatric Oncology Patients

Resilience is the ability to use internal and external resources to maintain or restore psychological functioning when faced with adversity or trauma and continue his or her normal development or functioning[103,162]. We used the Child and Youth Resilience Measure-17 (CYRM-17) to measure resilience at three time points in all virtual camp participants: baseline, post-camp, and 3 months post-camp. The CYRM uses individual, relational, communal, and cultural resources available to the individual to assess the level of resilience and how these aspects may bolster their resilience[166]. Thus, this shifts our typical understanding of resilience as purely individual to a more social-ecological framework. This suggests that as an individual you are a part of larger community and have supports around you to help bolster your resilience. Thus, to have high resilience there must be two things: 1) individuals must have resources of value in place from families, communities, and/or governments, and 2) individuals must be able to navigate toward these resources that are meaningful to them that will enhance their well-being[73].

With our observed improvements in resilience in the camp participants, and considering the social-ecological definition of resilience above, we suggest that VOC was successful at instilling "community" resources to bolster camper's resilience while also supporting their skills in navigating what resources are meaningful for them individually. As mentioned above, resilience is a social-ecological framework, which requires the availability of resources (in the form of family support, community support, and other protective factors) before an individual can navigate these resources and access them[63,162]. Social connection, expression of feelings and hope were prominent aspects of Campfire Circle's camp programming[64] and could be one of the reasons we observed an increase in resilience both immediately and long-term in this group of cancer patients and survivor's resilience.

Studies have found that coping and facing pain with resiliency can be in the form of positive self-talk, relaxation and respite (in the form of games)[167]. Also strategies that can help to promote resilience within interventions include optimism, self-confidence, altruism, hope and the expression of feelings[167]. While it is the child who carries the diagnosis of cancer in the family, family and community functioning play a major role in the child's ability to be resilient. We suggest that even in a virtual setting, camp played a major role in providing these pediatric oncology patient's with a social support network, coping strategies, respite from their illness and social connection that are all correlated highly with resilience[167]. Another study describes multisystem factors (social, cultural, family, community, and individual aspects) correlate highly with levels of resilience in children and adolescents without chronic illnesses, after analyzing 25 studies[168]. The higher the level of support around the child or adolescent led to increased resilience, and this social support came from a number of different avenues, including family, neighbours, teachers and clinicians[168]. Another study investigated negative life events (e.g., violence from grown-up, catastrophes, death of someone close to them), depressive symptoms and resilience in 9,546 adolescents[169] and found that adolescents who had illustrated more resilient factors (goal orientation, self-confidence, social competence, social support and family cohesion) were less likely to show depressive symptoms, and resilience increased in these individuals. In addition, protective effects against depressive symptoms were found when adolescents displayed goal orientation and self-confidence[168]. The theme among these studies is the use of social support and social connection, and building self-confidence through games and other activities that can lead to improvements in resiliency[167,168].

The VOC programming offered by Campfire Circle includes the use of social support, hope building exercises and coping mechanisms in camp participants, which are all major attributes that can improve resilience in this population[66,68,69]. Social support is a mediating factor in both hope and resilience[63] and is highly utilized in Campfire Circle's programming[64]. Social interactions at camp included "cabin time" where each online session was spent with the same persons each time allowing relationship building. Other interactions included craft time, games, sing along and skill building activities. While we did not measure social support directly in the current study, increases in both resilience and hope indicates that social support was a major theme in Campfire Circle's programming[63], and in turn lead to an increase in camper resilience.

While there are no normative ranges indicating, low, medium or high resilience for the CYRM, based on other studies that have used the CYRM version or scores that are equivalent of the 15-item version that we used in the present study, include a pre CYRM resilience score of, 55.7 out of 75[170–172]. The reasoning behind averaging pre-intervention resilience scores as measured by the CYRM in other populations, meant that we could compare baseline resilience scores with our childhood cancer population baseline scores. Children within these studies were children of military family[172], school children without any chronic illness[171], and Spanish at-risk youth[170] The pre-camp mean resilience score as measured by the CYRM in this study was 57.2, a similar group average score of resilience compared to the group average from multiple other studies that have used the CYRM[166]. Post-camp resilience scores (T1 and T2) averaged at 65.4 and 64.3 respectively, indicating an increase, but not significantly different than T1 ($F_{2,11}$=1.41, P = 0.284). At T1, 60% of participants were below 55.7 CYRM score average from studies including military children, healthy school aged and Spanish at-risk youth[170–172]. At T2, 100% of participants were above the 55.7 CYMR score averaged from other studies and at T3 75% were above 55.7. Thus, this population of childhood cancer patients and survivors began the study with high resilience scores and only improved their resilience scores further after the VOC intervention, even when compared to otherwise healthy children.

3.3.2 Hope in Pediatric Cancer Patients

The results of the current study indicate that hope scores were increased both immediately after 1-month of virtual oncology camp, and were sustained 3-months post-camp. This gives some insight in the ability for a VOC to instill some sustained agency and pathways thinking into pediatric oncology patients and survivors. This might be due to strengthened self-confidence through many social interactions that occurred via the regular zoom sessions, and through skill building workshops where the children were able to build on their own self-belief.

The Children's Hope Scale (CHS) measures hope through agency ways of thinking and pathway ways of thinking[103]. Agency ways of thinking means that children are able to initiate and sustain action toward a goal whereas pathways is the second component reflects the child's ability to produce routes toward their goals[164].

An integrative review published in 2016 highlighted ten papers that measured hope in chronically ill children using the CHS[173]. Their main objective was to determine how hope influences a child with chronic illness, and the impact of hope on several different outcomes. Hope, as measured by the CHS, correlated highly with medication adherence in children with chronic disease and type 1 diabetes[174,175], had positive correlations with family functioning in children with juvenile rheumatoid arthritis[176], positively correlated with active family coping strategies in children with sickle cell disease[177], and positive correlation with physical activity in obese children[178]. Additionally, one study used the CHS to measure hope and health related quality of life in children with chronic medical conditions attending a summer camp[179]. Camp in this cohort, increased hope and goal directed activities, while participants learned new skills, and socialized with similarly afflicted peers. Woods et al., 2013 suggested that the reason hope scores were improved at camp was because children were able to improve their coping skills, strengthened their self-confidence, and were able to reinforce their confidence in their own abilities to work through barriers[179]. Similar to the present study, Woods et al., found that differences in overall levels of hope were heavily influenced by increases in agency scores. This could indicate that changes in overall hope scores were predominantly associated with the children's capacity to identify and to develop specific goals (agency) compared to the ability to produce routes to attain goals (pathways)[179]. These findings are similar to those observed in the present study as total hope scores were more predominantly related to increases in agency scores.

While total hope scores as measured by CHS were not significantly different between T1 vs. T2 and T1 vs. T3 ($p = 0.082$ and $p = 0.322$ respectively), agency, one of two subscales within the CHS was significantly different between T1 and T2 ($p = 0.034$) as determined by ANOVA. Children who have high agency are said to be able to initiate and sustain action toward goals, whereas children who can identify the means they need to carry out specific goals will score high on the pathways subscale[103]. Children who have agency thinking will have high self-efficacy and motivation when trying to reach specific goals. On the other hand, children with high pathways thinking will have belief in their own capacity to find multiple ways to reach their goals. The results of our study may indicate that Campfire Circle's VOC prepared kids to have more positive thoughts when comparing themselves to others their age, and/or VOC was able to make children feel confident about their future regardless of their current hardships and overall feel good about how they are coping with daily challenges that come with being a pediatric cancer patient. This could have been because VOC included many opportunities for the campers to be themselves, have respite from daily stressors, and learn new skills which could enable them to feel more worthy of positive self-comparisons to closely aged peers and thus feel motivated for the future.

VOC was less effective at improving the pathways subscale from the CHS ($F_{2,11}$=1.39, p = 0.29). Pathway-type thoughts include the ability to identify ways to get things in life that are most important to them, or situations when these children have a problem, they can independently come up with ways to solve them, and the ability to stay motivated even when others around them want to quit[103]. Pathways implies a more independent nature of thinking, meaning the child has the capacity and ability to complete tasks on their own. Our results suggest that VOC could increase ways of incorporating independent skill development, to foster the pathways component of hope in children. Also Campfire Circle should continue to build on their successes in children who participated in VOC to feel high self-efficacy, positively compare themselves to those around them and be confident (agency ways of thinking). Overall, hope, (especially agency) and pathways all showed large differences (as determined by effect size) when comparing pre-camp to immediately after camp (T1 vs. T2) and 3-months post-camp (T1 vs. T3), indicating success within the VOC programming for instilling hope in pediatric cancer patience and survivors.

Our study is the first to assess hope as an outcome before and after a VOC. Up until now, there has been no researched findings assessing the effects of a VOC on hope in pediatric cancer patients or survivors and very minimal findings on in-person OCs on improving hope[101]. Our observation of higher hope following participation in a VOC might suggest that that a virtual platform (vs. in-person camp) is sufficient in instilling change in the hope outcome in pediatric cancer patients and survivors. In previous studies, successful hope based interventions incorporated many social activities, active coping based strategies and camp objectives that clearly encouraged participants to set personal and group goals[179]. Considering the wide-reaching benefits of hope with increases in medication adherence[174,175], positive coping strategies[177], increases in physical activity[178] and increases in family functioning[176], hope based interventions should be utilized within camp programming.

This is an important consideration as there are many benefits to virtual camp programming. First of all, VOC has the potential to have a larger outreach due to accessibility. VOC may be set-up wherever the camper is, and participation is not restricted to one geographical location. It also allows participants who are physically unable, whether if it is from severity of disease, or treatment to be present at camp in some form or another. VOC camp can be held within a hospital setting, at home, or on-the-go depending on an individual’s circumstances. In addition, there are less upfront and overhead costs associated with running a VOC compared to an in person OC. As a result, VOC requires less external funding. The findings of the current study suggest that

Campfire Circle’s VOC may incorporate the use of strategies such as building and maintaining meaningful relationships, staying positive, living in the present moment, promoting accomplishments, feeling a spiritual connection, and anticipating survival, which were all highlighted in a 2001 paper as top strategies utilized in hope based interventions for stem-cell transplantation pediatric cancer patients[105]. Social support is also an important component of any hope based intervention in pediatric cancer patients[63], and these findings may also indicate an effectiveness of VOC in their ability to instill social support in Campfire Circle’s VOC programming.

3.3.3 Parental Stress

Parental stress can be defined as the stress experienced and linked within a parenting role[32]. Parents who have a child with a chronic illness such as cancer will suffer from additional stresses above and beyond that of a typical parent[32]. These additional stresses can include communicational stresses (e.g., arguing with family members, communication with health care team), emotional stresses (e.g., family difficulties, upsetting news about child), medical care (e.g., new medical procedures, making decisions on treatment), and role function (e.g., attending to other aspects of important life factors, work/life balance)[32]. There is also immediate stressors about the health and wellbeing of their child and thus stress about what the future will hold for their child[145]. We used the PIP to measure stress in parents. The PIP is a 42-item survey which is a commonly used measure of disease related parental stress. The PIP asks parents to indicate the frequency of disease-related parenting stressors occurs and the difficulty level of each stressor[32]. The PIP addresses four common indicators of stress in parents, communication, emotional distress, medical care and role function.

Stress in parents and caregivers of pediatric cancer patients or survivors who attended camp was not different when comparing pre and post intervention stress. Our observation that there was no change in parent or caregiver's stress following the 1-month VOC may indicate that while a virtual platform may improve hope and resilience outcomes of the camper participants themselves, it may not alleviate parental or caregiver stress. This may be because a virtual intervention was insufficient in giving the parent/caregiver respite from day-to-day stressors, as the parent/caregivers may still feel pressure to facilitate the VOC via computer difficulties, the children are still home and away from friends physically, it may be hard for the parent to notice changes in their children from day to day check ins and there was no direct interventions for the parents themselves.

A more direct, in-person intervention may be required to mark any change in parental stress levels. A direct intervention for parents could include online interventions like the CASCAdE (Cope, Adapt, Survive: Life after Cancer)[122], group mindfulness programs[151], coping support[155] or in-person family camps alongside their child[29]. These types of direct interventions could offer more respite for parents from day to stressors, and initiate socialization with others in their position[29,180]. Direct interventions for parents can teach positive coping mechanisms[94], how to be hopeful, and mindfulness training[153] and an in-person family camp would allow parents to see their children play, be social and have fun in a positive envrionment[29] . VOC likely did not fulfill this requirement as children were still either still in their hospital beds, "stuck" at home and not outdoors playing with friends. This type of indirect intervention as mentioned above may not give the parents enough respite from their day-to-day stressors to make a significant difference in stress.

While other studies found indirect improvements in youth cognitive and psychosocial outcomes when parental or caregiver stress was improved by a direct intervention[151], the present did not observe indirect reductions in parental stress levels when it was the child who attended a direct intervention. This suggests that there was no improvement in parental stress, even though VOC resulted in improved camper resilience and hope. As mentioned above this may be because a virtual intervention was insufficient in giving the parent/caregiver respite from day-to-day stressors or it was the lack of a direct intervention for parents. VOC interventions may have a larger impact in the future by offering group sessions for parent or caregivers in conjunction with child programming. Past virtual interventions for parents were successful in improving maternal depression, paternal anxiety and stress[121] but unsuccessful at improving paternal quality of life, psychological functioning and family functioning[122]. Thus, the importance of health outcomes in parent or caregivers in pediatric cancer diagnoses should not be overlooked as negative parental and caregiver health outcomes can negatively impact the child's psychosocial health[151]. In addition, future studies should put emphasis on assessing bidirectional relationships between parental or caregiver stress and child psychosocial outcomes.

While there are no clinical normative ranges for low, medium or high stress as determined by the scores from the PIP by the original authors[143], other studies that have looked at parental/caregiver stress in guardians looking after children with cancer showed stress level PIP scores of 217.1[181]. In the present study, the stress level at T1 was 219.50±81.0, at T2 was 228.7±92.5 and at T3 was 227.0±79.1. Thus, when comparing stress scores from the present study to other studies that used the PIP to examine parental/caregivers of children with cancer, diabetes and inflammatory bowel disease, the scores are reasonably close[142,181]. Interestingly, in another study, Monaghan et al., reported PIP scores in parents of children with Type I diabetes. They found difficulty scores of 77.63±23.61, which was much lower than each of the pre- and post-camp difficulty scores reported in the present study (T1 (106.5 ± 50.7), T2 (116.6 ± 48.7), and T3 (116.1 ± 39.1))[182]. In another study that assessed the quality of life of children with sickle cell disease, the authors reported that parents had an mean difficulty score on the PIP of 97.87±33.1[183], which is still lower than what we report in the current study. Although we are not statistically comparing the means of the difficulty subscale scores in the current study with other studies[182,183], we observed that parents/caregivers who participated in the present study reported higher difficulty scores than parents of children with type 1 diabetes and sickle cell disease. Thus, this may mean that a cancer diagnosis comes with more illness-related stress as compared to sickle cell disease and type-1 diabetes, based off of the higher difficulty subscale scores found within the PIP. A cancer diagnosis in our society may come with heightened fear that death is soon to follow. While we are not downplaying the severity of sickle cell disease and type-1 diabetes in children, there may be a misconception that those diseases have a higher chance of survival as compared to cancer. If this assumption is correct, this would reduce the perceived stress from parents or caregivers whose children have type-1 diabetes or sickle cell disease.

3.3.4 Limitations

It is important to note the current study had several limitations. First of all, we had a very small sample size. The present study statistics including the one-way ANOVA was not appropriately powered before completing participant intake, also camper and parent participant uptake was minimal. This led to the study having low statistical power, meaning that even if there was a chance that there were differences between pre, immediate and 3-month post-camp, the difference would likely not have been seen. For example, a post hoc power analysis was completed for the total resilience (CYRM) scores, total hope (CHS) scores, and total parental/caregiver stress (PIP) scores. The statistical power for each study outcome respectively was 0.241, 0.465 and 0.056. Thus, for the total hope score, even if there was a difference between the pre, immediate post and 3-months post hope scores as measured by the CHS, we would only have a 46.5% chance of finding a significant difference. The chance of finding a significant difference for the CYRM and the PIP were even lower. This meant that the present study relied heavily on Cohen's d, which does not rely on sample size[165] to support study findings. This also allowed us to estimate the magnitude of the difference between the time points. Also using both analyses, allows us to report both substantive significance (effect size) and statistical significance (P value)[165]. While we are confident in reported effect sizes in the present study, caution should be used when making conclusions from the statistical significance testing as the study was not statistically powered.

Our small sample size was due to the low response rate. Out of the 343 campers who participated only five participated in any one of the timepoints during the study, indicating a 1.45% response rate/timepoint. While we did not have information on if children had both parents, biological parents present or caregivers, the parent/caregiver response rate was also very low 2.2%-4.4% response rate/timepoint. Invitation emails were sent to camp registrants and their parents on July 6th, 2021, by the Campfire Circle team. There was also a suggestion from the Campfire Circle team that study invitations could get lost within the other camp programming emails. As well, the current study had no additional compensation offered for participants. Lack of compensations within a study can also lead to biases toward families who have more positive perceptions of camp to participate in the study as compared to families that have negative perceptions; previous research has found that families who have more positive perceptions of camp are more likely to participate in a study which can help camp improve future programming[123].

Another important limitation is that we did not assign a study ID to individuals who completed the surveys, therefore different individuals completed surveys at T1, T2, and T3. This limited our ability to look at someone's individual change in resilience, hope, or stress. We could not measure direct changes in participants but only group differences between timepoints. Giving the campers or parents the option to be an anonymous participant was a priority of the research team alongside Campfire Circle, thus this was the reasoning behind not tracking participants. However, this limited our ability to track participants and thus we could not use specific statistical tests (repeated measures ANOVA) that we could have used otherwise, limiting our analysis. We tried to reduce the effects of this limitation by giving participants a random number identification that was generated after their completion of the first timepoint. However, this resulted in many participants forgetting their random number identification. Based on the study's limited participation numbers we were also not in the position to restrict access to the second and third timepoint if participants did not have their random number ID equipped.

Another limitation of our study was the lack of sociodemographic data collected. To help preserve anonymity of the study's participants we collected very minimal sociodemographic data. Not collecting demographic and socioeconomical data means that we were unable to build linear models of the data and thus could not make health outcome predictions based on socioeconomic status, race, age of diagnosis, type of cancer diagnosis and other family characteristics. These types of analyses can be an important indicator of limitations in programming, for example, not reaching certain demographics, improvement of one gender over the other, or if there is a significant relationship between time from diagnosis to inclusion in the VOC programming and positive health outcomes in pediatric oncology patients. These are all areas of our methods that should be improved upon in future studies. As well, our results may not be generalizable to the large population of pediatric oncology patients, survivors, and parents, due to lack of diversity within our sample. The sample population was largely Caucasian (50% in campers, 63.4% in parent/caregivers), with little representation from other communities (Asian, Indian, Muslim, Armenian). Thus, the external validity of this study may be low, and study results should be examined with this in mind.

The present study was completed entirely online. Thus, only participants who felt comfortable navigating online surveys, filling out personal information online and had easy access to internet and electronic devices could participate in the study.

Additional methodological pitfalls of the present study include having no comparison control group, such as, an oncology children cohort who are not attending camp due to their choice alone. Having no comparison group leaves questions about the interpretation of our intervention and whether time alone led to improvements in camper hope and resilience. Including multiple experimental groups, with varied camp duration, would also be beneficial to develop a dose response relationship. This could indicate the duration of camp necessary for improvements in psychosocial outcomes and or reductions in parental stress. While there are several limitations within the present study, we suggest that it has served its purpose in beginning the discussion on VOC programming for pediatric oncology patients and survivor's resilience and hope and parents or caregiver's stress.

4.0 Conclusions

This study found that a 1-month VOC improved residence and hope in pediatric oncology patients and survivors who attended a 1-month VOC yet did not change stress in parental or caregivers. Overall, even though a small sized study, our results suggest that VOC may be an effective intervention for improving these outcomes in oncology patients/survivors. This study indicates that VOC programming was not just important amidst the COVID-19 pandemic but should also be utilized going forward. There will always geographical, socioeconomic and physical barriers to in-person camp. VOC programming may be one of the best ways at reducing these barriers and allowing all pediatric oncology patients and survivors to attend some form of camp. Computer technology continues to improve and become more accessible thus allowing far reaching inclusion[133]. This therefore supports the continuation and perhaps further development of VOC programming for pediatric oncology patients and survivors. Future studies should evaluate the impact of a VOC on additional psychosocial outcomes, such as social functioning and stress, as well as targeted interventions for parent or caregivers. In addition, more sociodemographic data should be collected in the future to make sure we can target more at-risk genders, races and socioeconomic statuses. While quantitative data allowed us to measure large improvements in hope and resilience in pediatric oncology patients or survivors, inclusion of qualitative measures may also be beneficial to support quantitative findings while also enhancing VOC programming for future participants.

Although this study had many limitations, its timing and clinical significance should be considered. The hope and resilience pf pediatric oncology patients increased greatly both immediately after camp and 3-months post-camp, indicating efficacy in Campfire Circle's VOC programming. Although, parent or caregiver stress did not decrease after their child attended a 1-month VOC, this gave us insight that a more direct intervention for parents is likely needed to address additional stressors a childhood cancer diagnosis brings. This study is also, to our knowledge the first of its kind to measure any psychosocial outcomes in pediatric oncology patients and parental or caregiver stress after the pediatric oncology patient or survivors attended a 1-month virtual oncology camp. This study can be used as a guide for further development in pediatric oncology psychosocial interventions in the future. Based on the results of the study the following suggestions can be made: 1) VOC should be utilized whenever any potential camp participant cannot attend in-person camp for any reason (geographical, socioeconomical, physical); and 2) VOC itself may not impact parental/caregiver stress, therefore direct interventions for parent/caregivers should be integrated as parental stressors can negatively impact pediatric oncology patient and survivors' psychosocial health outcomes[29,149,151]; and 3) While social functioning was not directly measured within this study, social activities were a major component of the VOC programming offered by

Campfire Circle[64] and social functioning is positively correlated with increases in both hope and resilience in pediatric oncology patients[63,184]. Thus, we suggest that the use of social activities continue be central in future VOC programming.

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5.0 Appendix

5.1 Children and Youth Resilience Measure

Resilience Research Centre DALHOUSIE UNIVERSITY

Child & Youth Resilience Measure-Revised (CYRM-R)

CYRM-R (child)

Please choose one answer for each question. There are no right or wrong answers.		Not at all [1]	A little [2]	Somewhat [3]	Quite a bit [4]	A lot [5]
1	Do you share with people around you?	☺	☺	☺	☺	☺
2	Is doing well in school important to you?	☺	☺	☺	☺	☺
3	Do you know how to behave/act in different situations (such as school, home, holy places)?	☺	☺	☺	☺	☺
4	Do you feel that your parent(s)/caregiver(s) know where you are and what you are doing all of the time?	☺	☺	☺	☺	☺
5	Do you feel that your parent(s)/caregiver(s) know a lot about you (for example, what makes you happy, what makes you scared)?	☺	☺	☺	☺	☺
6	Is there enough to eat in your home when you are hungry?	☺	☺	☺	☺	☺
7	Do other children like to play with you?	☺	☺	☺	☺	☺
8	Do you talk to your family/caregiver(s) about how you feel (for example when you are hurt or feeling scared)?	☺	☺	☺	☺	☺
9	Do you have friends that care about you?	☺	☺	☺	☺	☺
10	Do you feel you fit in with other children?	☺	☺	☺	☺	☺
11	Do you think your family/caregiver(s) cares about you when times are hard (for example, if you are sick or have done something wrong)?	☺	☺	☺	☺	☺
12	Do you think your friends care about you when times are hard (for example if you are sick or have done something wrong)?	☺	☺	☺	☺	☺
13	Are you treated fairly?	☺	☺	☺	☺	☺
14	Do you have chances to show others that you are growing up and can do things by yourself?	☺	☺	☺	☺	☺
15	Do you feel safe when you are with your family/caregiver(s)?	☺	☺	☺	☺	☺
16	Do you have chances to learn things that will be useful when you are older (like cooking, working, and helping others)?	☺	☺	☺	☺	☺
17	Do you like the way your family/caregiver(s) celebrates things (like holidays or learning about your culture)?	☺	☺	☺	☺	☺

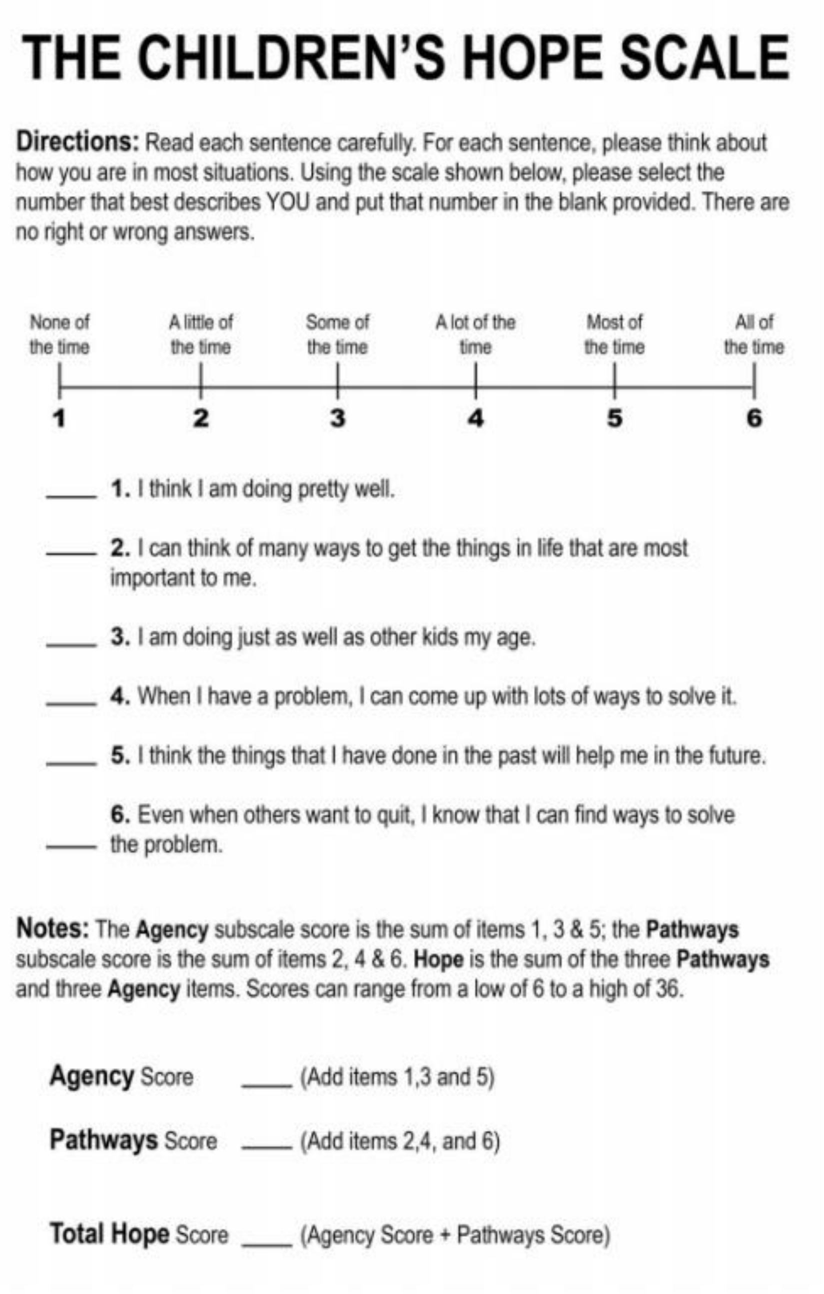
For administration instructions and scoring, please refer to the accompanying manual.

When using the measure, please cite the following:

Resilience Research Centre. (2018). CYRM and ARM user manual. Halifax, NS: Resilience Research Centre, Dalhousie University. Retrieved from http://www.resilienceresearch.org/

Jefferies, P., McGarrigle, L., & Ungar, M. (2018). The CYRM-R: a Rasch-validated revision of the Child and Youth Resilience Measure. *Journal of Evidence-Informed Social Work*, 1-24. https://doi.org/10.1080/23761407.2018.1548403

5.2 Child Hope Scale



THE CHILDREN'S HOPE SCALE

Directions: Read each sentence carefully. For each sentence, please think about how you are in most situations. Using the scale shown below, please select the number that best describes YOU and put that number in the blank provided. There are no right or wrong answers.

None of the time	A little of the time	Some of the time	A lot of the time	Most of the time	All of the time
1	**2**	**3**	**4**	**5**	**6**

____ **1.** I think I am doing pretty well.

____ **2.** I can think of many ways to get the things in life that are most important to me.

____ **3.** I am doing just as well as other kids my age.

____ **4.** When I have a problem, I can come up with lots of ways to solve it.

____ **5.** I think the things that I have done in the past will help me in the future.

____ **6.** Even when others want to quit, I know that I can find ways to solve the problem.

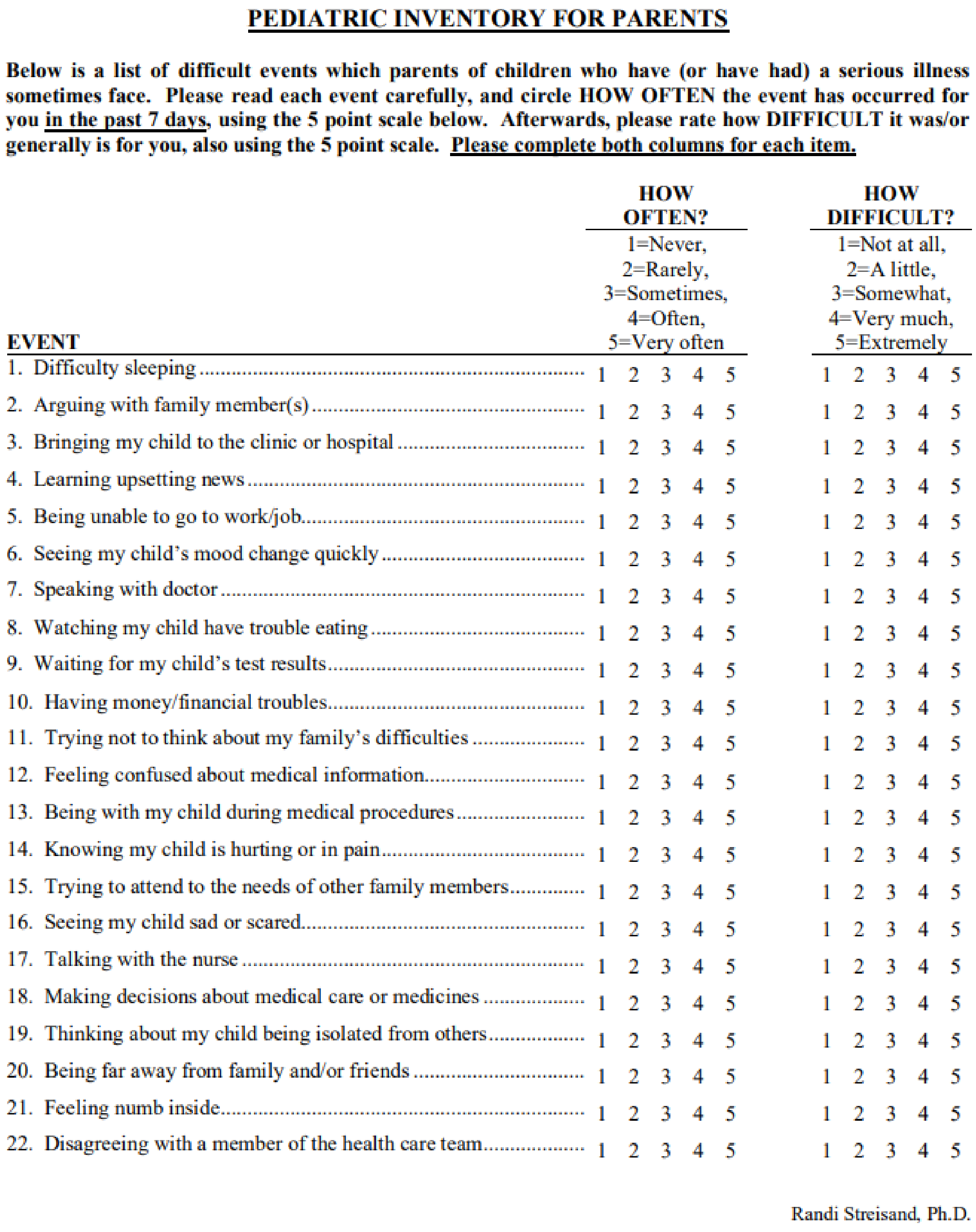
Notes: The **Agency** subscale score is the sum of items 1, 3 & 5; the **Pathways** subscale score is the sum of items 2, 4 & 6. **Hope** is the sum of the three **Pathways** and three **Agency** items. Scores can range from a low of 6 to a high of 36.

Agency Score ____ (Add items 1,3 and 5)

Pathways Score ____ (Add items 2,4, and 6)

Total Hope Score ____ (Agency Score + Pathways Score)

5.3 Parent/Caregiver Questionnaire



PEDIATRIC INVENTORY FOR PARENTS

Below is a list of difficult events which parents of children who have (or have had) a serious illness sometimes face. Please read each event carefully, and circle HOW OFTEN the event has occurred for you in the past 7 days, using the 5 point scale below. Afterwards, please rate how DIFFICULT it was/or generally is for you, also using the 5 point scale. Please complete both columns for each item.

EVENT	**HOW OFTEN?** 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often	**HOW DIFFICULT?** 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely
1. Difficulty sleeping	1 2 3 4 5	1 2 3 4 5
2. Arguing with family member(s)	1 2 3 4 5	1 2 3 4 5
3. Bringing my child to the clinic or hospital	1 2 3 4 5	1 2 3 4 5
4. Learning upsetting news	1 2 3 4 5	1 2 3 4 5
5. Being unable to go to work/job	1 2 3 4 5	1 2 3 4 5
6. Seeing my child's mood change quickly	1 2 3 4 5	1 2 3 4 5
7. Speaking with doctor	1 2 3 4 5	1 2 3 4 5
8. Watching my child have trouble eating	1 2 3 4 5	1 2 3 4 5
9. Waiting for my child's test results	1 2 3 4 5	1 2 3 4 5
10. Having money/financial troubles	1 2 3 4 5	1 2 3 4 5
11. Trying not to think about my family's difficulties	1 2 3 4 5	1 2 3 4 5
12. Feeling confused about medical information	1 2 3 4 5	1 2 3 4 5
13. Being with my child during medical procedures	1 2 3 4 5	1 2 3 4 5
14. Knowing my child is hurting or in pain	1 2 3 4 5	1 2 3 4 5
15. Trying to attend to the needs of other family members	1 2 3 4 5	1 2 3 4 5
16. Seeing my child sad or scared	1 2 3 4 5	1 2 3 4 5
17. Talking with the nurse	1 2 3 4 5	1 2 3 4 5
18. Making decisions about medical care or medicines	1 2 3 4 5	1 2 3 4 5
19. Thinking about my child being isolated from others	1 2 3 4 5	1 2 3 4 5
20. Being far away from family and/or friends	1 2 3 4 5	1 2 3 4 5
21. Feeling numb inside	1 2 3 4 5	1 2 3 4 5
22. Disagreeing with a member of the health care team	1 2 3 4 5	1 2 3 4 5

Randi Streisand, Ph.D.

EVENT	HOW OFTEN? 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often	HOW DIFFICULT? 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely
23. Helping my child with his/her hygiene needs	1 2 3 4 5	1 2 3 4 5
24. Worrying about the long term impact of the illness	1 2 3 4 5	1 2 3 4 5
25. Having little time to take care of my own needs	1 2 3 4 5	1 2 3 4 5
26. Feeling helpless over my child's condition	1 2 3 4 5	1 2 3 4 5
27. Feeling misunderstood by family/friends as to the severity of my child's illness	1 2 3 4 5	1 2 3 4 5
28. Handling changes in my child's daily medical routines	1 2 3 4 5	1 2 3 4 5
29. Feeling uncertain about the future	1 2 3 4 5	1 2 3 4 5
30. Being in the hospital over weekends/holidays	1 2 3 4 5	1 2 3 4 5
31. Thinking about other children who have been seriously ill	1 2 3 4 5	1 2 3 4 5
32. Speaking with my child about his/her illness	1 2 3 4 5	1 2 3 4 5
33. Helping my child with medical procedures (e.g. giving shots, swallowing medicine, changing dressing)	1 2 3 4 5	1 2 3 4 5
34. Having my heart beat fast, sweating, or feeling tingly	1 2 3 4 5	1 2 3 4 5
35. Feeling uncertain about disciplining my child	1 2 3 4 5	1 2 3 4 5
36. Feeling scared that my child could get very sick or die	1 2 3 4 5	1 2 3 4 5
37. Speaking with family members about my child's illness	1 2 3 4 5	1 2 3 4 5
38. Watching my child during medical visits/procedures	1 2 3 4 5	1 2 3 4 5
39. Missing important events in the lives of other family members.	1 2 3 4 5	1 2 3 4 5
40. Worrying about how friends and relatives interact with my child	1 2 3 4 5	1 2 3 4 5
41. Noticing a change in my relationship with my partner	1 2 3 4 5	1 2 3 4 5
42. Spending a great deal of time in unfamiliar settings	1 2 3 4 5	1 2 3 4 5

Randi Streisand, Ph.D.

PEDIATRIC INVENTORY FOR PARENTS
SCORING SHEET

PIP item number and brief description of event within each domain
(F = Frequency, D = Difficulty)

COMMUNICATION (CM: 9 items)	**F**	**D**
2. Arguing		
7. Speaking with doctor		
12. Feeling confused		
17. Talking with the nurse		
22. Disagreeing		
27. Feeling misunderstood		
32. Speaking with child		
37. Speaking with family		
40. Worrying		
CM TOTAL		

MEDICAL CARE (MC: 8 items)	**F**	**D**
3. Bringing my child to the clinic		
8. Watching/eating		
13. Being with my child		
18. Making decisions		
23. Helping/hygiene needs		
28. Handling changes		
33. Helping/procedures		
38. Watching/procedures		
MC TOTAL		

EMOTIONAL DIST. (ED: 15 items)	**F**	**D**
1. Difficulty sleeping		
4. Learning upsetting news		
6. Seeing mood change		
9. Waiting for test results		
11. Trying not to think/difficulties		
14. Knowing/hurting		
16. Seeing child sad		
19. Thinking about/isolated		
21. Feeling numb inside		
24. Worrying about/impact		
26. Feeling helpless		
29. Feeling uncertain		
31. Thinking about/other ill		
34. Having my heart beat fast		
36. Feeling scared		
ED TOTAL		

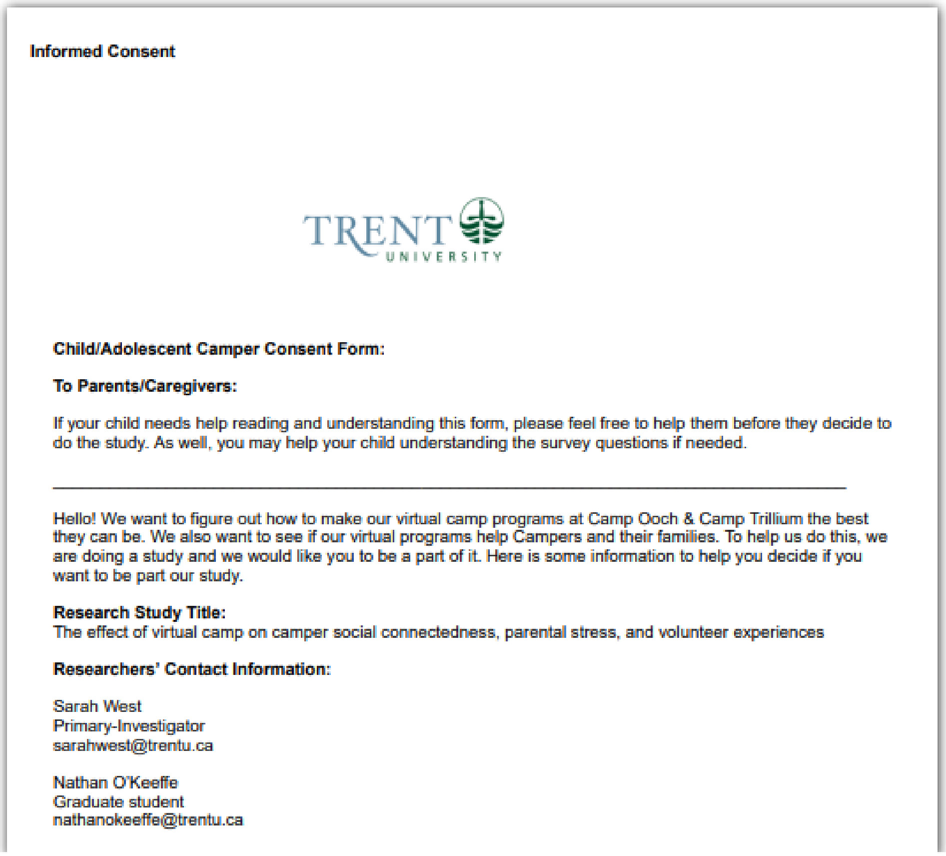
ROLE FUNCTION (RF: 10 items)	**F**	**D**
5. Being unable to go to work		
10. Having money		
15. Trying to attend/other		
20. Being far away from family		
25. Having little time		
30. Being in the hospital		
35. Feeling uncertain		
39. Missing important events		
41. Noticing a change		
42. Spending a great deal of time		
RF TOTAL		

CM+ED+MC+RF TOTAL:F ☐

CM+ED+MC+RF TOTAL:D ☐

Randi Streisand, Ph.D.

5.4 Qualtrics Survey: Campers



Informed Consent

TRENT UNIVERSITY

Child/Adolescent Camper Consent Form:

To Parents/Caregivers:

If your child needs help reading and understanding this form, please feel free to help them before they decide to do the study. As well, you may help your child understanding the survey questions if needed.

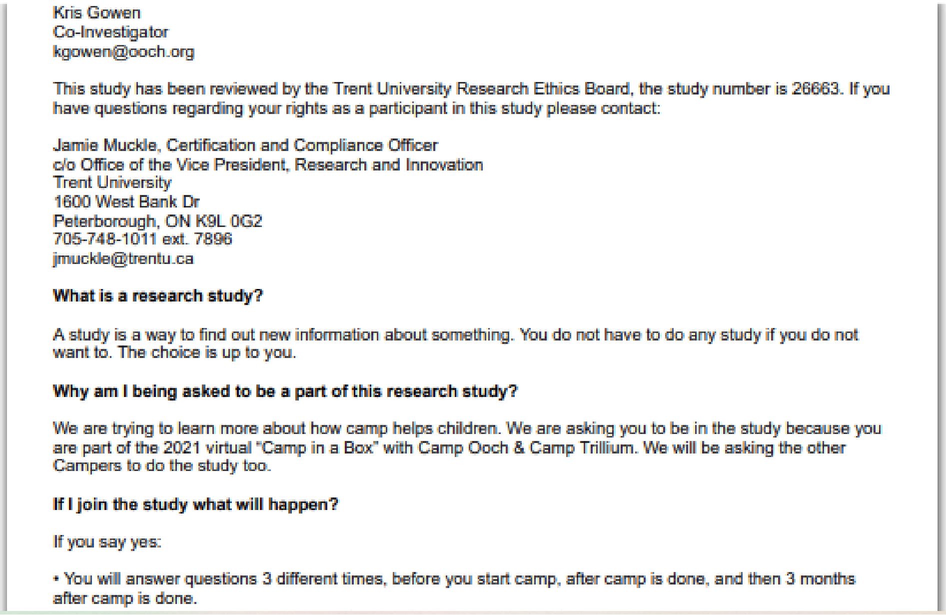
Hello! We want to figure out how to make our virtual camp programs at Camp Ooch & Camp Trillium the best they can be. We also want to see if our virtual programs help Campers and their families. To help us do this, we are doing a study and we would like you to be a part of it. Here is some information to help you decide if you want to be part our study.

Research Study Title:
The effect of virtual camp on camper social connectedness, parental stress, and volunteer experiences

Researchers' Contact Information:

Sarah West
Primary-Investigator
sarahwest@trentu.ca

Nathan O'Keeffe
Graduate student
nathanokeeffe@trentu.ca



Kris Gowen
Co-Investigator
kgowen@ooch.org

This study has been reviewed by the Trent University Research Ethics Board, the study number is 26663. If you have questions regarding your rights as a participant in this study please contact:

Jamie Muckle, Certification and Compliance Officer
c/o Office of the Vice President, Research and Innovation
Trent University
1600 West Bank Dr
Peterborough, ON K9L 0G2
705-748-1011 ext. 7896
jmuckle@trentu.ca

What is a research study?

A study is a way to find out new information about something. You do not have to do any study if you do not want to. The choice is up to you.

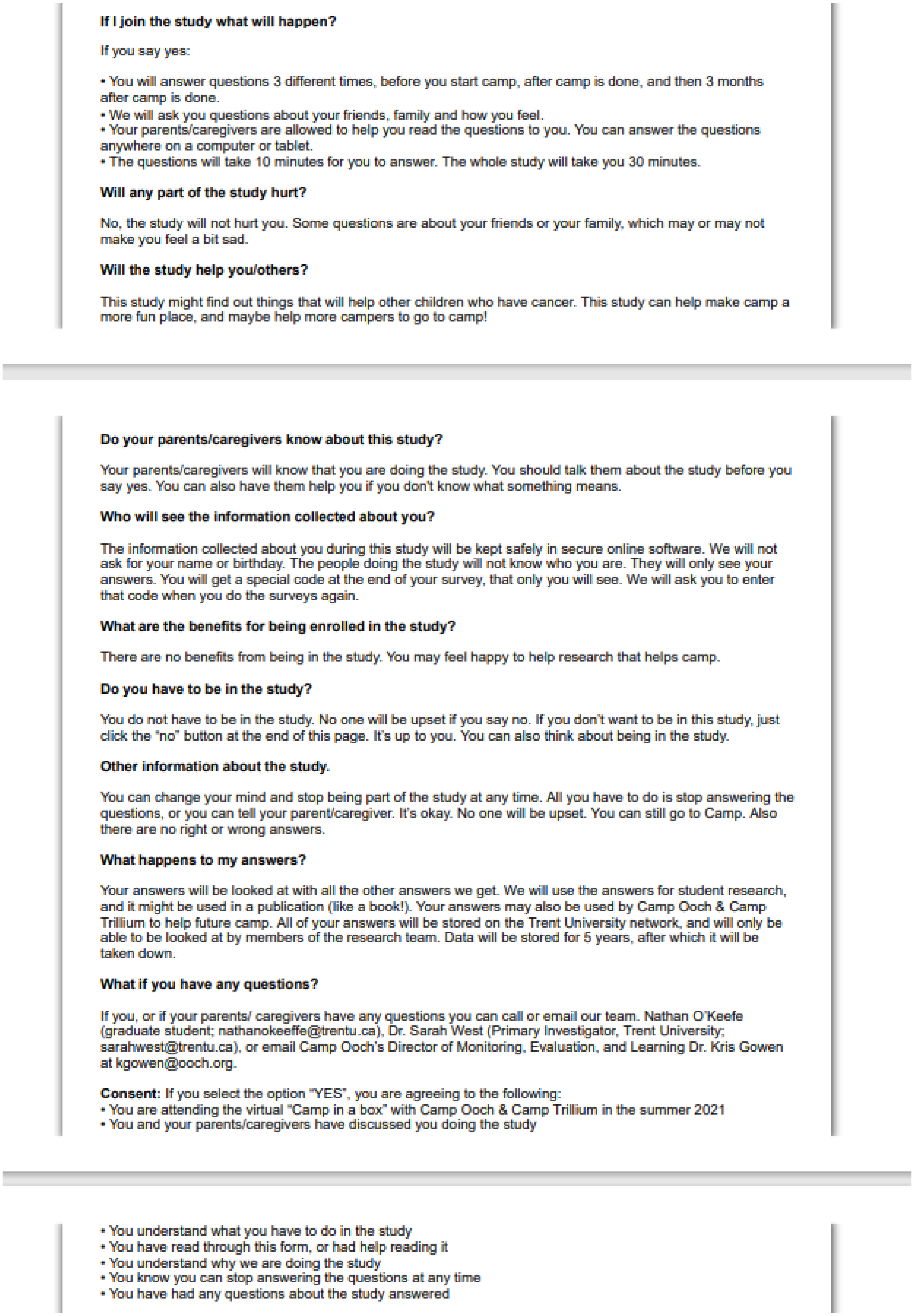
Why am I being asked to be a part of this research study?

We are trying to learn more about how camp helps children. We are asking you to be in the study because you are part of the 2021 virtual "Camp in a Box" with Camp Ooch & Camp Trillium. We will be asking the other Campers to do the study too.

If I join the study what will happen?

If you say yes:

- You will answer questions 3 different times, before you start camp, after camp is done, and then 3 months after camp is done.



If I join the study what will happen?

If you say yes:

- You will answer questions 3 different times, before you start camp, after camp is done, and then 3 months after camp is done.
- We will ask you questions about your friends, family and how you feel.
- Your parents/caregivers are allowed to help you read the questions to you. You can answer the questions anywhere on a computer or tablet.
- The questions will take 10 minutes for you to answer. The whole study will take you 30 minutes.

Will any part of the study hurt?

No, the study will not hurt you. Some questions are about your friends or your family, which may or may not make you feel a bit sad.

Will the study help you/others?

This study might find out things that will help other children who have cancer. This study can help make camp a more fun place, and maybe help more campers to go to camp!

Do your parents/caregivers know about this study?

Your parents/caregivers will know that you are doing the study. You should talk them about the study before you say yes. You can also have them help you if you don't know what something means.

Who will see the information collected about you?

The information collected about you during this study will be kept safely in secure online software. We will not ask for your name or birthday. The people doing the study will not know who you are. They will only see your answers. You will get a special code at the end of your survey, that only you will see. We will ask you to enter that code when you do the surveys again.

What are the benefits for being enrolled in the study?

There are no benefits from being in the study. You may feel happy to help research that helps camp.

Do you have to be in the study?

You do not have to be in the study. No one will be upset if you say no. If you don't want to be in this study, just click the "no" button at the end of this page. It's up to you. You can also think about being in the study.

Other information about the study.

You can change your mind and stop being part of the study at any time. All you have to do is stop answering the questions, or you can tell your parent/caregiver. It's okay. No one will be upset. You can still go to Camp. Also there are no right or wrong answers.

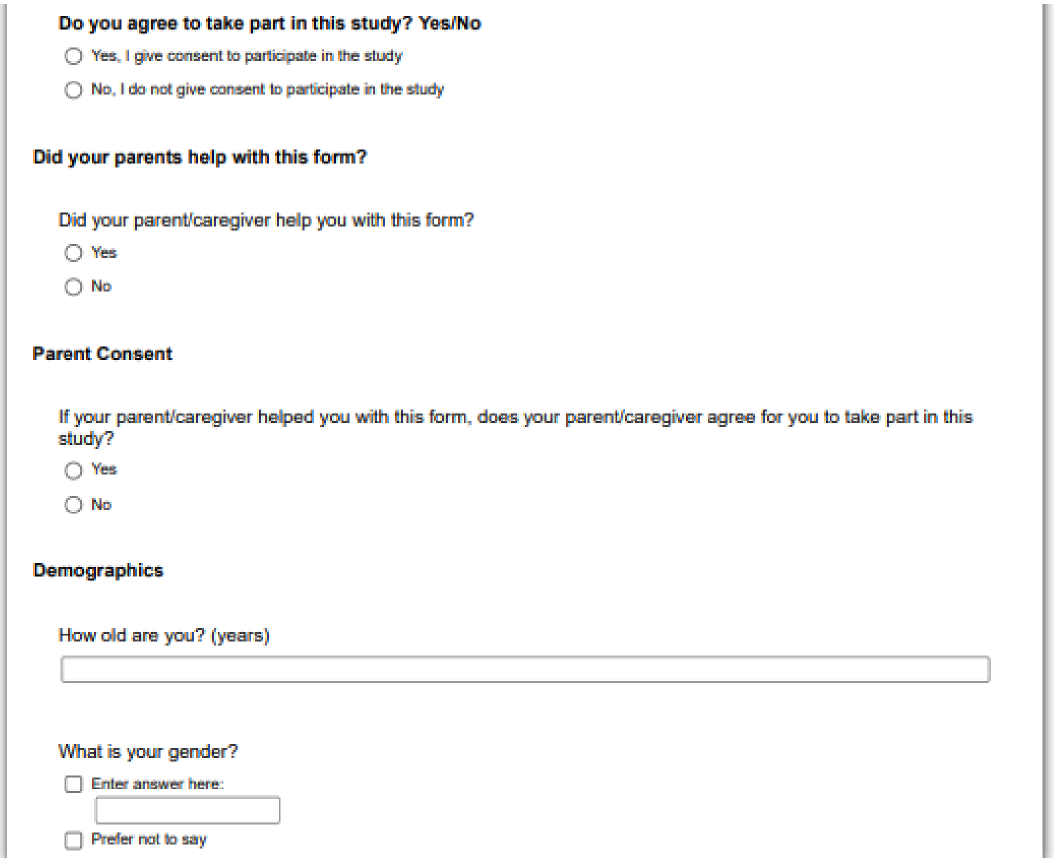
What happens to my answers?

Your answers will be looked at with all the other answers we get. We will use the answers for student research, and it might be used in a publication (like a book!). Your answers may also be used by Camp Ooch & Camp Trillium to help future camp. All of your answers will be stored on the Trent University network, and will only be able to be looked at by members of the research team. Data will be stored for 5 years, after which it will be taken down.

What if you have any questions?

If you, or if your parents/ caregivers have any questions you can call or email our team. Nathan O'Keefe (graduate student; nathanokeeffe@trentu.ca), Dr. Sarah West (Primary Investigator, Trent University; sarahwest@trentu.ca), or email Camp Ooch's Director of Monitoring, Evaluation, and Learning Dr. Kris Gowen at kgowen@ooch.org.

Consent: If you select the option "YES", you are agreeing to the following:
- You are attending the virtual "Camp in a box" with Camp Ooch & Camp Trillium in the summer 2021
- You and your parents/caregivers have discussed you doing the study
- You understand what you have to do in the study
- You have read through this form, or had help reading it
- You understand why we are doing the study
- You know you can stop answering the questions at any time
- You have had any questions about the study answered



Do you agree to take part in this study? Yes/No

○ Yes, I give consent to participate in the study

○ No, I do not give consent to participate in the study

Did your parents help with this form?

Did your parent/caregiver help you with this form?

○ Yes

○ No

Parent Consent

If your parent/caregiver helped you with this form, does your parent/caregiver agree for you to take part in this study?

○ Yes

○ No

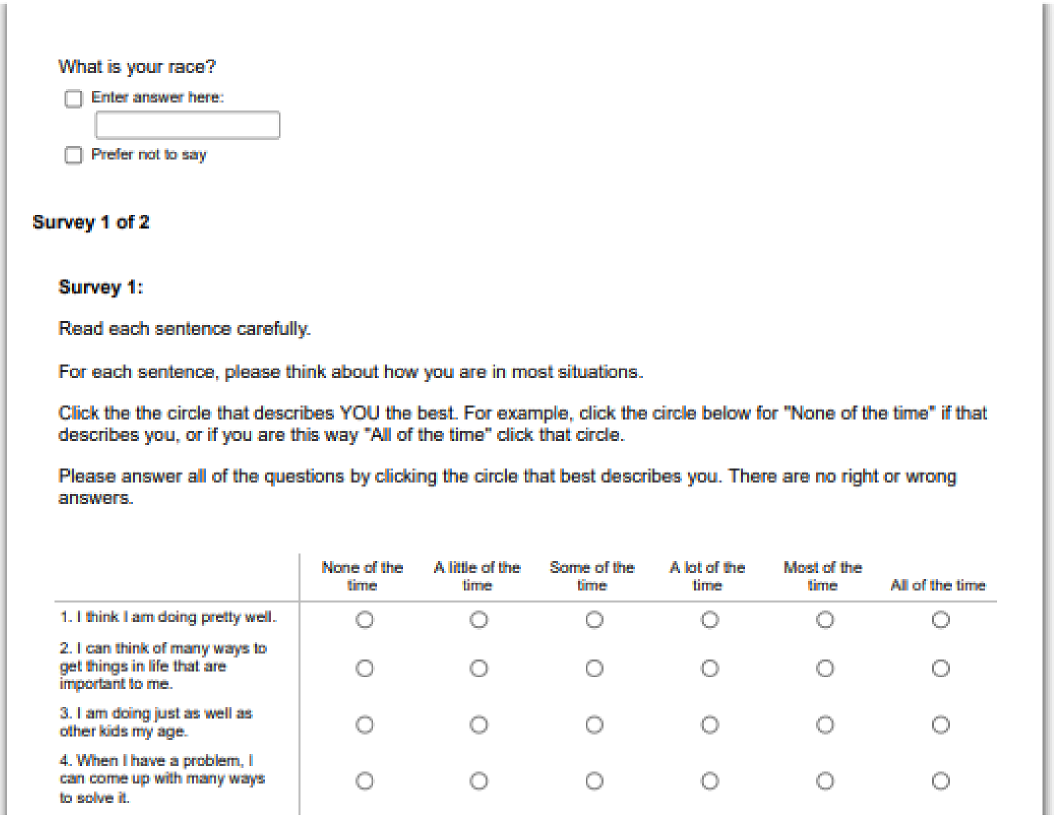
Demographics

How old are you? (years)

What is your gender?

☐ Enter answer here:

☐ Prefer not to say



What is your race?

☐ Enter answer here:

☐ Prefer not to say

Survey 1 of 2

Survey 1:

Read each sentence carefully.

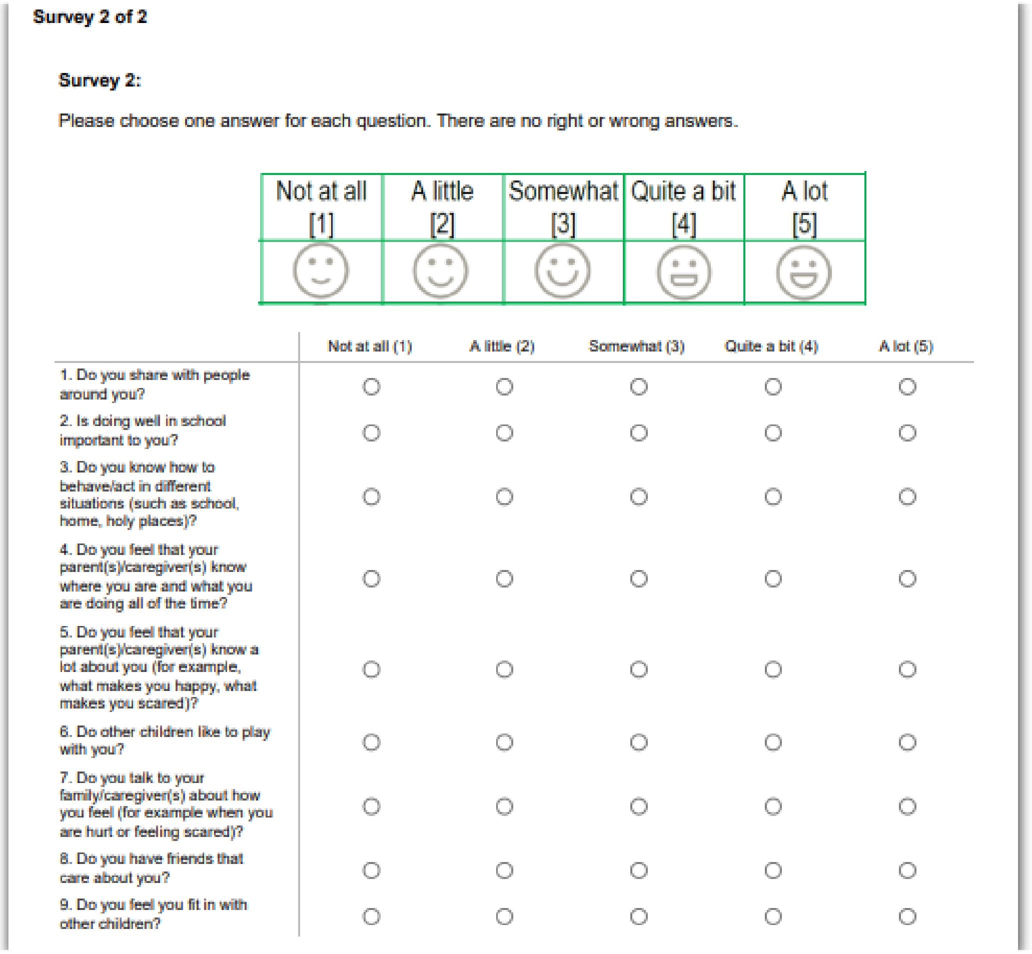
For each sentence, please think about how you are in most situations.

Click the the circle that describes YOU the best. For example, click the circle below for "None of the time" if that describes you, or if you are this way "All of the time" click that circle.

Please answer all of the questions by clicking the circle that best describes you. There are no right or wrong answers.

	None of the time	A little of the time	Some of the time	A lot of the time	Most of the time	All of the time
1. I think I am doing pretty well.	○	○	○	○	○	○
2. I can think of many ways to get things in life that are important to me.	○	○	○	○	○	○
3. I am doing just as well as other kids my age.	○	○	○	○	○	○
4. When I have a problem, I can come up with many ways to solve it.	○	○	○	○	○	○

5. I think things that I have done in the past will help me in the future.	○	○	○	○	○	○
6. Even when others want to quit, I know I can find ways to solve a problem.	○	○	○	○	○	○



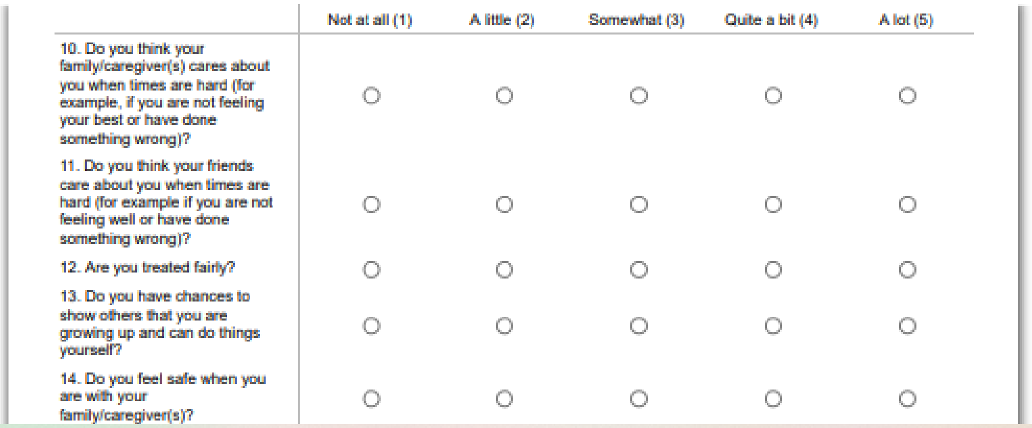
Survey 2 of 2

Survey 2:

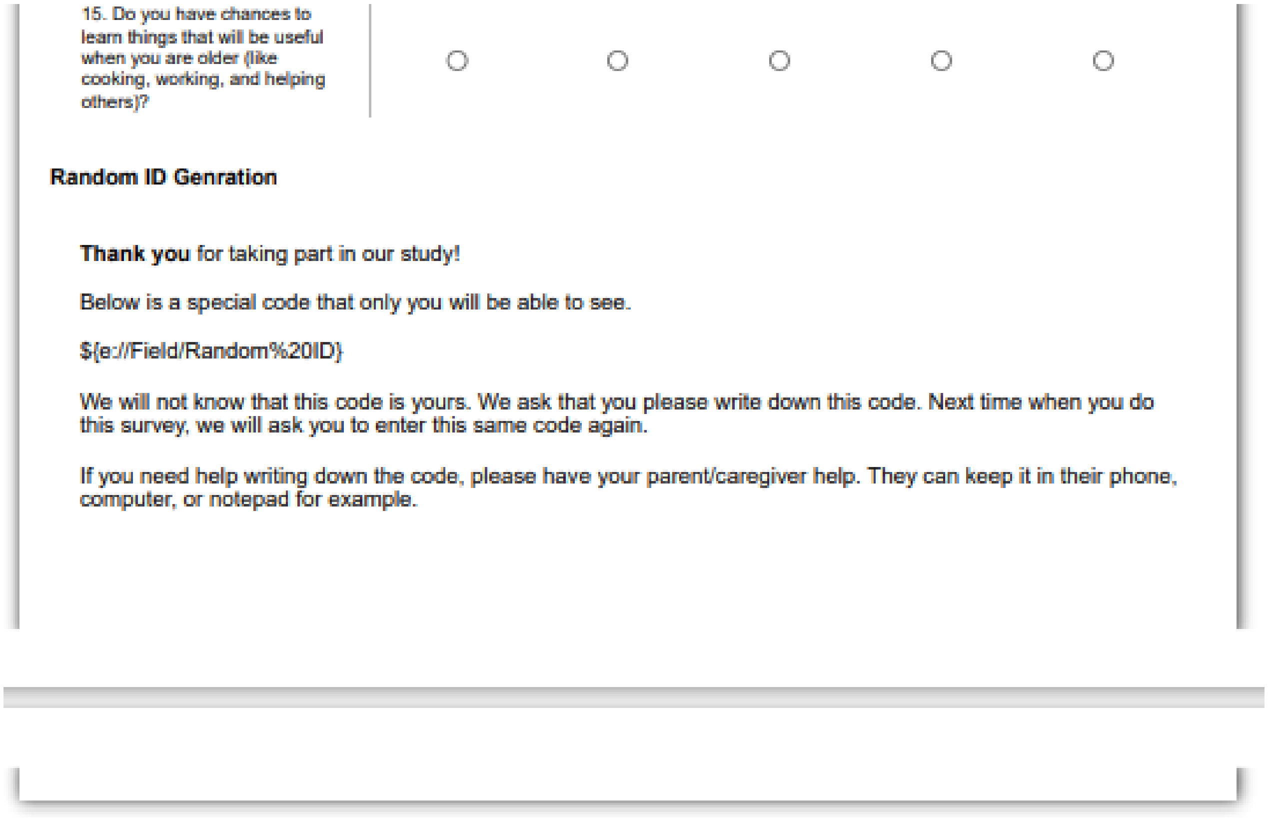
Please choose one answer for each question. There are no right or wrong answers.

Not at all [1]	A little [2]	Somewhat [3]	Quite a bit [4]	A lot [5]
☺	☺	☺	😃	😃

	Not at all (1)	A little (2)	Somewhat (3)	Quite a bit (4)	A lot (5)
1. Do you share with people around you?	○	○	○	○	○
2. Is doing well in school important to you?	○	○	○	○	○
3. Do you know how to behave/act in different situations (such as school, home, holy places)?	○	○	○	○	○
4. Do you feel that your parent(s)/caregiver(s) know where you are and what you are doing all of the time?	○	○	○	○	○
5. Do you feel that your parent(s)/caregiver(s) know a lot about you (for example, what makes you happy, what makes you scared)?	○	○	○	○	○
6. Do other children like to play with you?	○	○	○	○	○
7. Do you talk to your family/caregiver(s) about how you feel (for example when you are hurt or feeling scared)?	○	○	○	○	○
8. Do you have friends that care about you?	○	○	○	○	○
9. Do you feel you fit in with other children?	○	○	○	○	○



	Not at all (1)	A little (2)	Somewhat (3)	Quite a bit (4)	A lot (5)
10. Do you think your family/caregiver(s) cares about you when times are hard (for example, if you are not feeling your best or have done something wrong)?	○	○	○	○	○
11. Do you think your friends care about you when times are hard (for example if you are not feeling well or have done something wrong)?	○	○	○	○	○
12. Are you treated fairly?	○	○	○	○	○
13. Do you have chances to show others that you are growing up and can do things yourself?	○	○	○	○	○
14. Do you feel safe when you are with your family/caregiver(s)?	○	○	○	○	○



15. Do you have chances to learn things that will be useful when you are older (like cooking, working, and helping others)?	○	○	○	○	○

Random ID Genration

Thank you for taking part in our study!

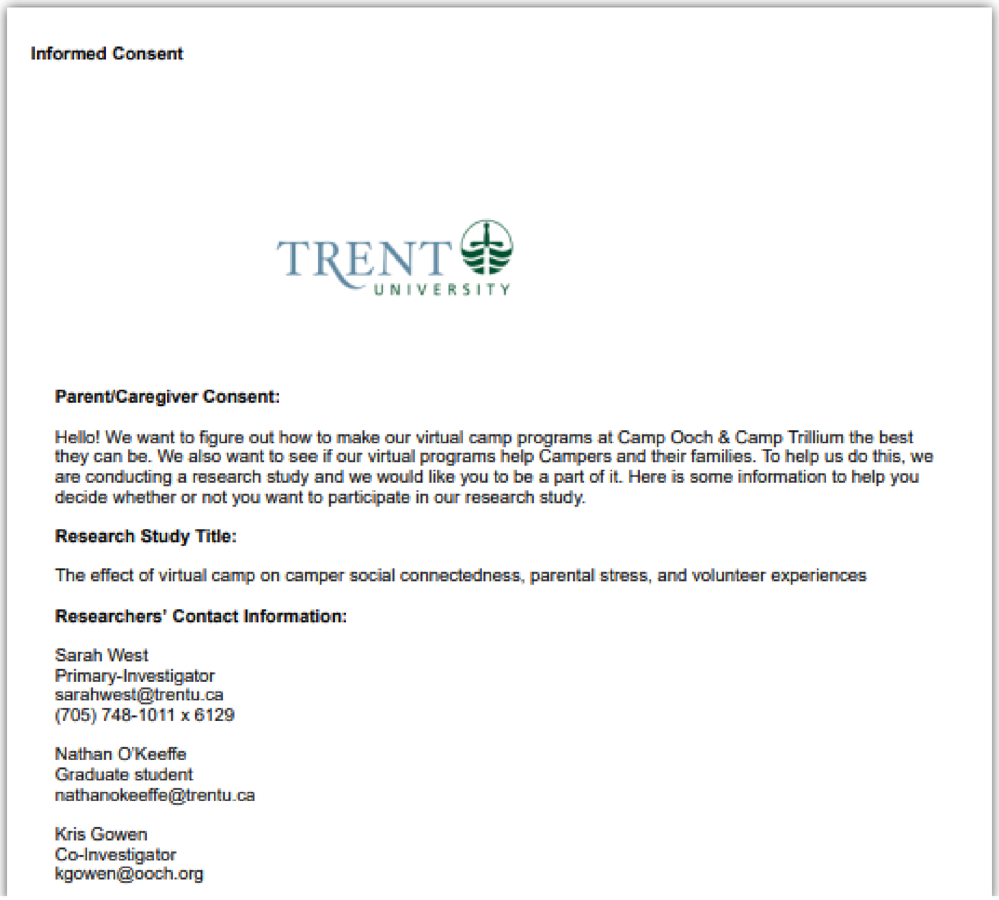
Below is a special code that only you will be able to see.

${e://Field/Random%20ID}

We will not know that this code is yours. We ask that you please write down this code. Next time when you do this survey, we will ask you to enter this same code again.

If you need help writing down the code, please have your parent/caregiver help. They can keep it in their phone, computer, or notepad for example.

5.5 Qualtrics Survey: Parent/Caregivers



Informed Consent

Parent/Caregiver Consent:

Hello! We want to figure out how to make our virtual camp programs at Camp Ooch & Camp Trillium the best they can be. We also want to see if our virtual programs help Campers and their families. To help us do this, we are conducting a research study and we would like you to be a part of it. Here is some information to help you decide whether or not you want to participate in our research study.

Research Study Title:

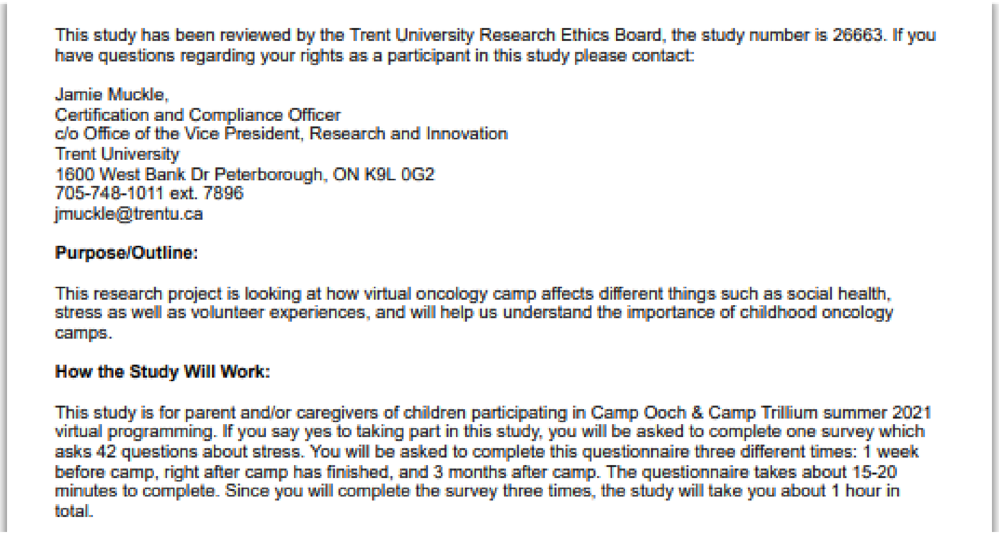
The effect of virtual camp on camper social connectedness, parental stress, and volunteer experiences

Researchers' Contact Information:

Sarah West
Primary-Investigator
sarahwest@trentu.ca
(705) 748-1011 x 6129

Nathan O'Keeffe
Graduate student
nathanokeeffe@trentu.ca

Kris Gowen
Co-Investigator
kgowen@ooch.org



This study has been reviewed by the Trent University Research Ethics Board, the study number is 26663. If you have questions regarding your rights as a participant in this study please contact:

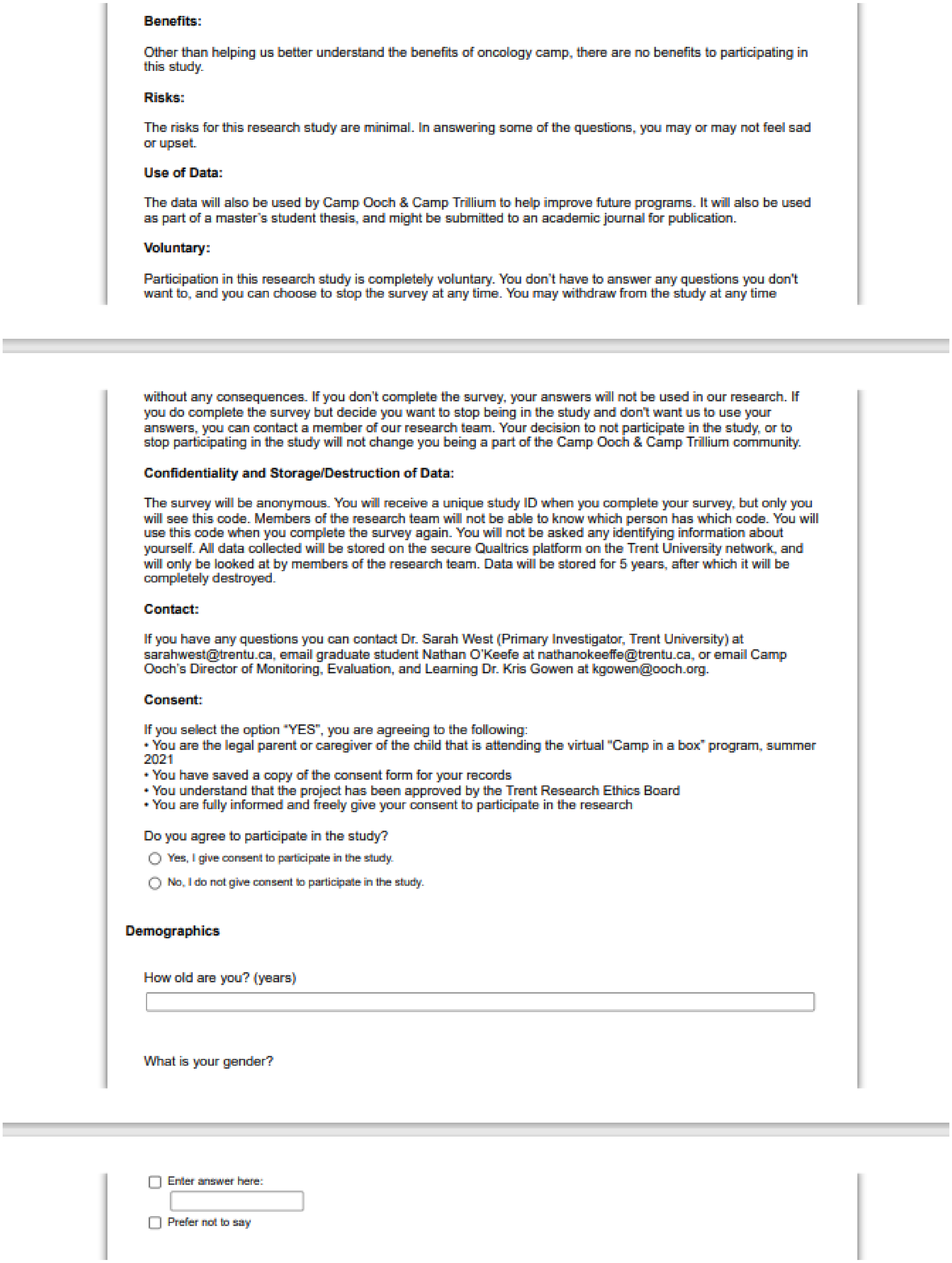
Jamie Muckle,
Certification and Compliance Officer
c/o Office of the Vice President, Research and Innovation
Trent University
1600 West Bank Dr Peterborough, ON K9L 0G2
705-748-1011 ext. 7896
jmuckle@trentu.ca

Purpose/Outline:

This research project is looking at how virtual oncology camp affects different things such as social health, stress as well as volunteer experiences, and will help us understand the importance of childhood oncology camps.

How the Study Will Work:

This study is for parent and/or caregivers of children participating in Camp Ooch & Camp Trillium summer 2021 virtual programming. If you say yes to taking part in this study, you will be asked to complete one survey which asks 42 questions about stress. You will be asked to complete this questionnaire three different times: 1 week before camp, right after camp has finished, and 3 months after camp. The questionnaire takes about 15-20 minutes to complete. Since you will complete the survey three times, the study will take you about 1 hour in total.



Benefits:

Other than helping us better understand the benefits of oncology camp, there are no benefits to participating in this study.

Risks:

The risks for this research study are minimal. In answering some of the questions, you may or may not feel sad or upset.

Use of Data:

The data will also be used by Camp Ooch & Camp Trillium to help improve future programs. It will also be used as part of a master's student thesis, and might be submitted to an academic journal for publication.

Voluntary:

Participation in this research study is completely voluntary. You don't have to answer any questions you don't want to, and you can choose to stop the survey at any time. You may withdraw from the study at any time without any consequences. If you don't complete the survey, your answers will not be used in our research. If you do complete the survey but decide you want to stop being in the study and don't want us to use your answers, you can contact a member of our research team. Your decision to not participate in the study, or to stop participating in the study will not change you being a part of the Camp Ooch & Camp Trillium community.

Confidentiality and Storage/Destruction of Data:

The survey will be anonymous. You will receive a unique study ID when you complete your survey, but only you will see this code. Members of the research team will not be able to know which person has which code. You will use this code when you complete the survey again. You will not be asked any identifying information about yourself. All data collected will be stored on the secure Qualtrics platform on the Trent University network, and will only be looked at by members of the research team. Data will be stored for 5 years, after which it will be completely destroyed.

Contact:

If you have any questions you can contact Dr. Sarah West (Primary Investigator, Trent University) at sarahwest@trentu.ca, email graduate student Nathan O'Keefe at nathanokeeffe@trentu.ca, or email Camp Ooch's Director of Monitoring, Evaluation, and Learning Dr. Kris Gowen at kgowen@ooch.org.

Consent:

If you select the option "YES", you are agreeing to the following:
- You are the legal parent or caregiver of the child that is attending the virtual "Camp in a box" program, summer 2021
- You have saved a copy of the consent form for your records
- You understand that the project has been approved by the Trent Research Ethics Board
- You are fully informed and freely give your consent to participate in the research

Do you agree to participate in the study?

○ Yes, I give consent to participate in the study.

○ No, I do not give consent to participate in the study.

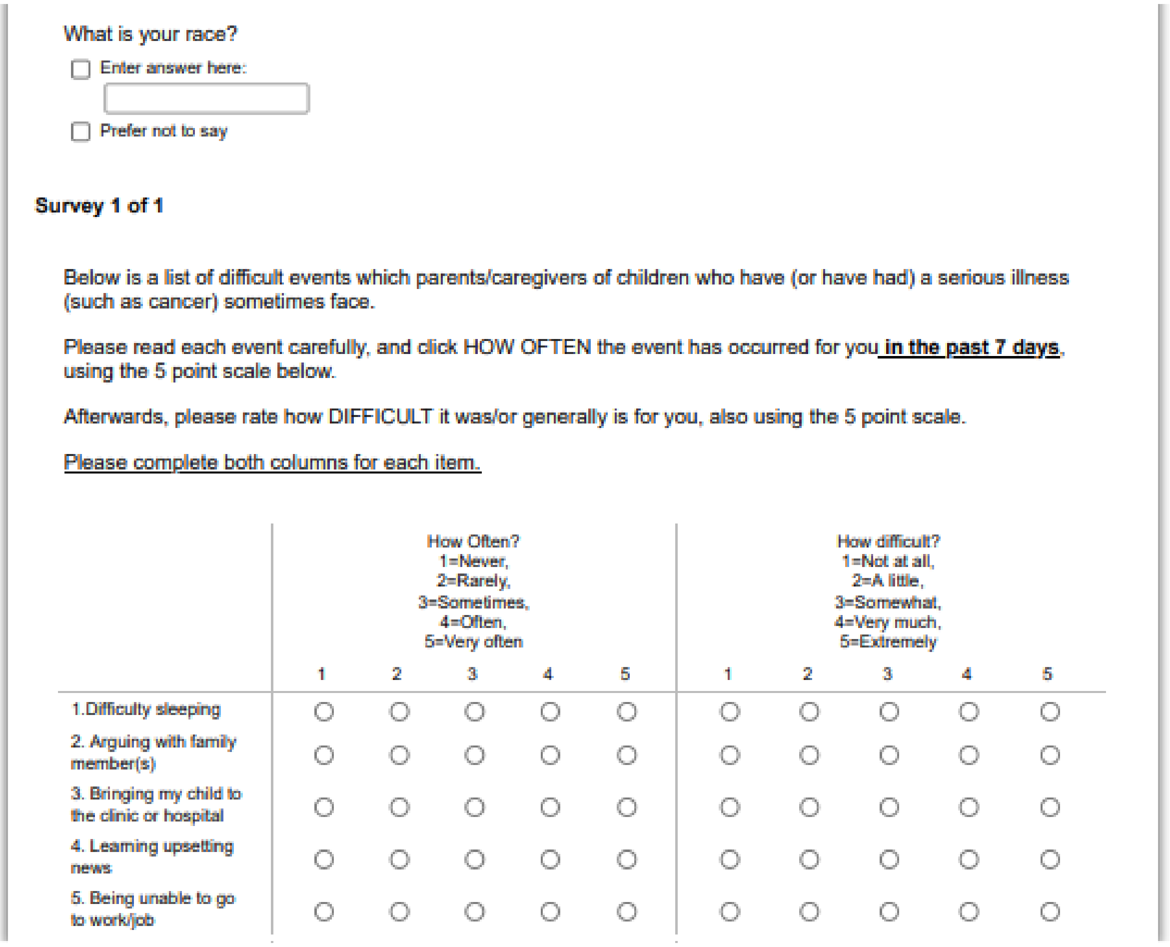
Demographics

How old are you? (years)

What is your gender?

☐ Enter answer here:

☐ Prefer not to say



What is your race?

☐ Enter answer here:

☐ Prefer not to say

Survey 1 of 1

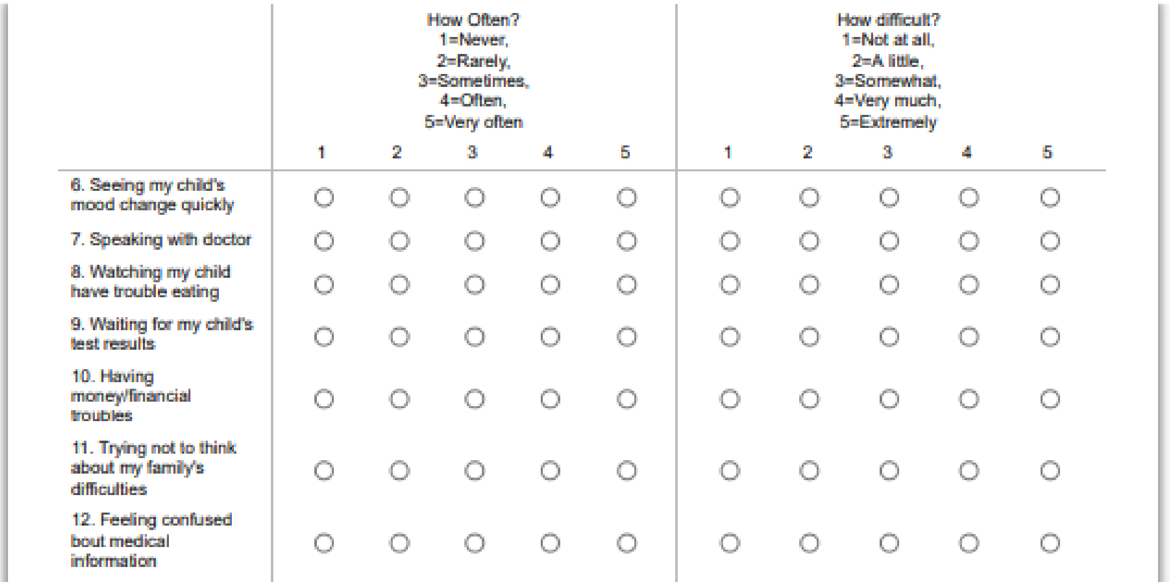
Below is a list of difficult events which parents/caregivers of children who have (or have had) a serious illness (such as cancer) sometimes face.

Please read each event carefully, and click HOW OFTEN the event has occurred for you <u>**in the past 7 days**</u>, using the 5 point scale below.

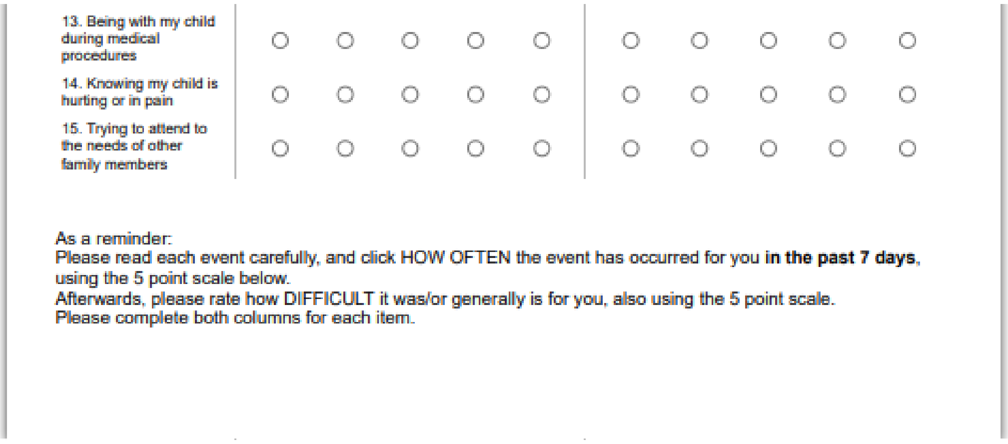
Afterwards, please rate how DIFFICULT it was/or generally is for you, also using the 5 point scale.

<u>Please complete both columns for each item.</u>

	How Often? 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often					How difficult? 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely				
	1	2	3	4	5	1	2	3	4	5
1.Difficulty sleeping	○	○	○	○	○	○	○	○	○	○
2. Arguing with family member(s)	○	○	○	○	○	○	○	○	○	○
3. Bringing my child to the clinic or hospital	○	○	○	○	○	○	○	○	○	○
4. Learning upsetting news	○	○	○	○	○	○	○	○	○	○
5. Being unable to go to work/job	○	○	○	○	○	○	○	○	○	○

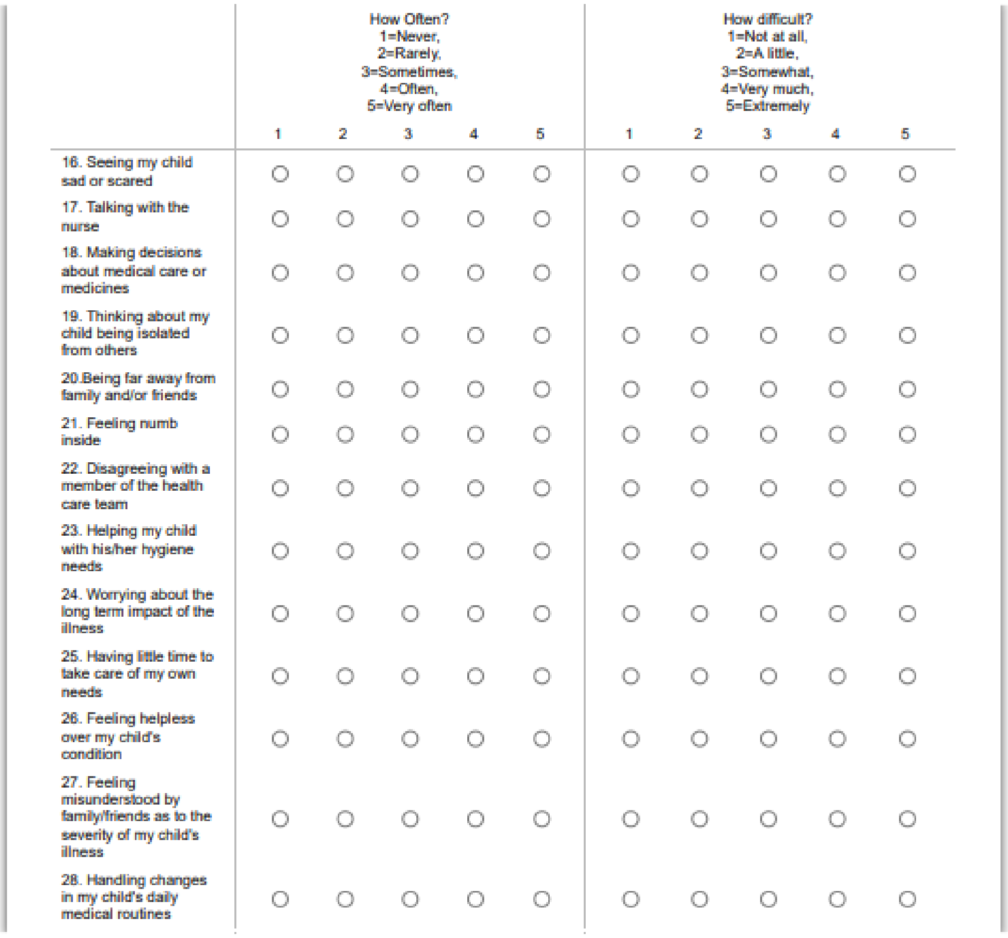


	How Often? 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often					How difficult? 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely				
	1	2	3	4	5	1	2	3	4	5
6. Seeing my child's mood change quickly	○	○	○	○	○	○	○	○	○	○
7. Speaking with doctor	○	○	○	○	○	○	○	○	○	○
8. Watching my child have trouble eating	○	○	○	○	○	○	○	○	○	○
9. Waiting for my child's test results	○	○	○	○	○	○	○	○	○	○
10. Having money/financial troubles	○	○	○	○	○	○	○	○	○	○
11. Trying not to think about my family's difficulties	○	○	○	○	○	○	○	○	○	○
12. Feeling confused bout medical information	○	○	○	○	○	○	○	○	○	○

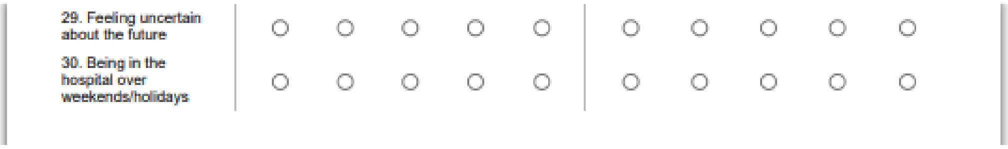


13. Being with my child during medical procedures	○	○	○	○	○	○	○	○	○	○
14. Knowing my child is hurting or in pain	○	○	○	○	○	○	○	○	○	○
15. Trying to attend to the needs of other family members	○	○	○	○	○	○	○	○	○	○

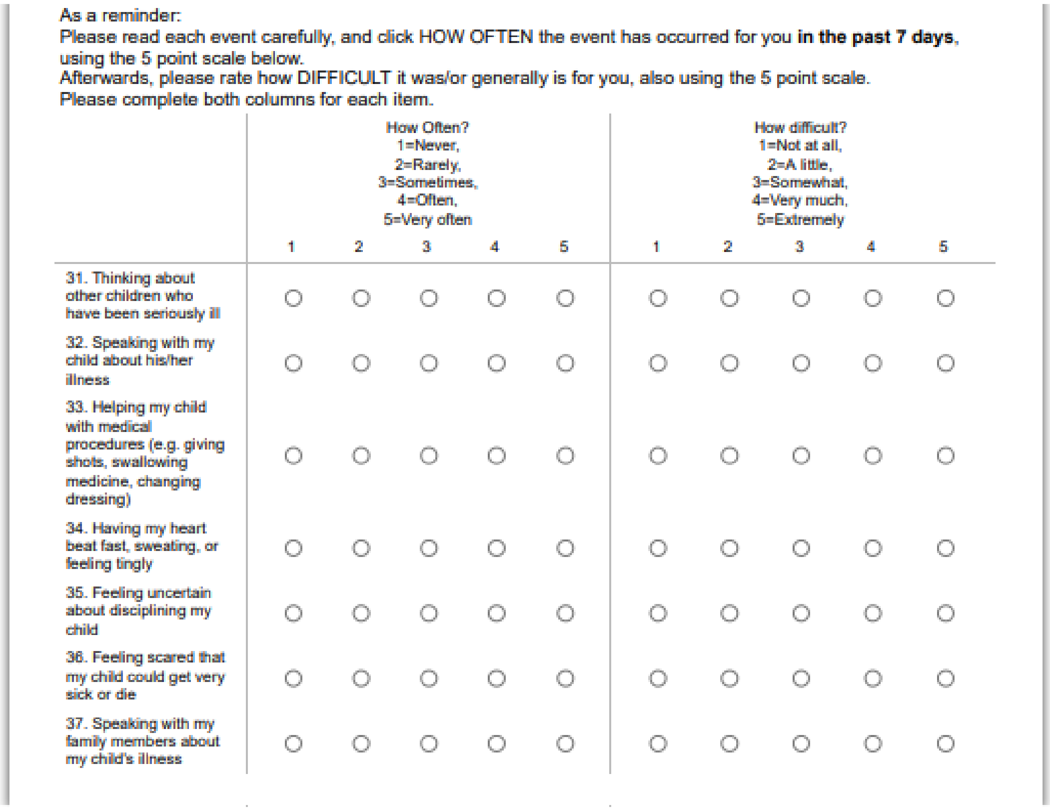
As a reminder:
Please read each event carefully, and click HOW OFTEN the event has occurred for you **in the past 7 days**, using the 5 point scale below.
Afterwards, please rate how DIFFICULT it was/or generally is for you, also using the 5 point scale.
Please complete both columns for each item.



	How Often? 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often					How difficult? 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely				
	1	2	3	4	5	1	2	3	4	5
16. Seeing my child sad or scared	○	○	○	○	○	○	○	○	○	○
17. Talking with the nurse	○	○	○	○	○	○	○	○	○	○
18. Making decisions about medical care or medicines	○	○	○	○	○	○	○	○	○	○
19. Thinking about my child being isolated from others	○	○	○	○	○	○	○	○	○	○
20.Being far away from family and/or friends	○	○	○	○	○	○	○	○	○	○
21. Feeling numb inside	○	○	○	○	○	○	○	○	○	○
22. Disagreeing with a member of the health care team	○	○	○	○	○	○	○	○	○	○
23. Helping my child with his/her hygiene needs	○	○	○	○	○	○	○	○	○	○
24. Worrying about the long term impact of the illness	○	○	○	○	○	○	○	○	○	○
25. Having little time to take care of my own needs	○	○	○	○	○	○	○	○	○	○
26. Feeling helpless over my child's condition	○	○	○	○	○	○	○	○	○	○
27. Feeling misunderstood by family/friends as to the severity of my child's illness	○	○	○	○	○	○	○	○	○	○
28. Handling changes in my child's daily medical routines	○	○	○	○	○	○	○	○	○	○

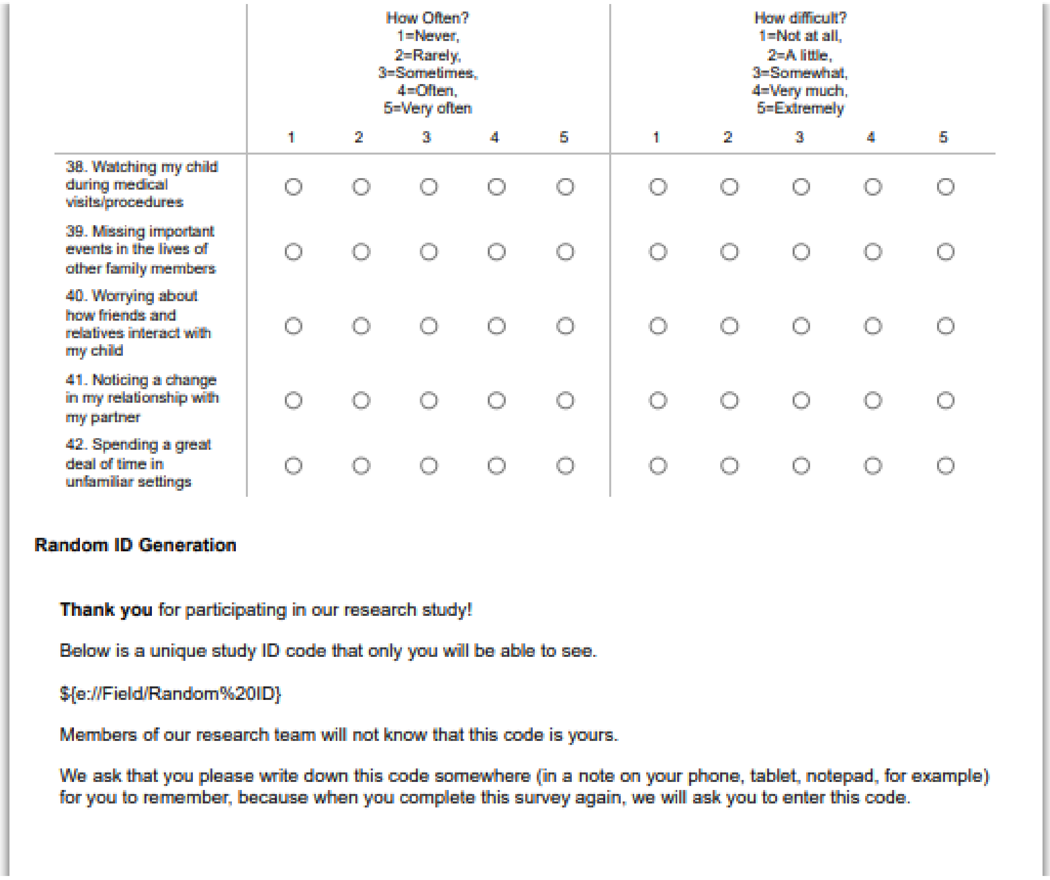


29. Feeling uncertain about the future	○	○	○	○	○	○	○	○	○	○
30. Being in the hospital over weekends/holidays	○	○	○	○	○	○	○	○	○	○



As a reminder:
Please read each event carefully, and click HOW OFTEN the event has occurred for you **in the past 7 days**, using the 5 point scale below.
Afterwards, please rate how DIFFICULT it was/or generally is for you, also using the 5 point scale.
Please complete both columns for each item.

	How Often? 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often					How difficult? 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely				
	1	2	3	4	5	1	2	3	4	5
31. Thinking about other children who have been seriously ill	○	○	○	○	○	○	○	○	○	○
32. Speaking with my child about his/her illness	○	○	○	○	○	○	○	○	○	○
33. Helping my child with medical procedures (e.g. giving shots, swallowing medicine, changing dressing)	○	○	○	○	○	○	○	○	○	○
34. Having my heart beat fast, sweating, or feeling tingly	○	○	○	○	○	○	○	○	○	○
35. Feeling uncertain about disciplining my child	○	○	○	○	○	○	○	○	○	○
36. Feeling scared that my child could get very sick or die	○	○	○	○	○	○	○	○	○	○
37. Speaking with my family members about my child's illness	○	○	○	○	○	○	○	○	○	○



	How Often? 1=Never, 2=Rarely, 3=Sometimes, 4=Often, 5=Very often					How difficult? 1=Not at all, 2=A little, 3=Somewhat, 4=Very much, 5=Extremely				
	1	2	3	4	5	1	2	3	4	5
38. Watching my child during medical visits/procedures	○	○	○	○	○	○	○	○	○	○
39. Missing important events in the lives of other family members	○	○	○	○	○	○	○	○	○	○
40. Worrying about how friends and relatives interact with my child	○	○	○	○	○	○	○	○	○	○
41. Noticing a change in my relationship with my partner	○	○	○	○	○	○	○	○	○	○
42. Spending a great deal of time in unfamiliar settings	○	○	○	○	○	○	○	○	○	○

Random ID Generation

Thank you for participating in our research study!

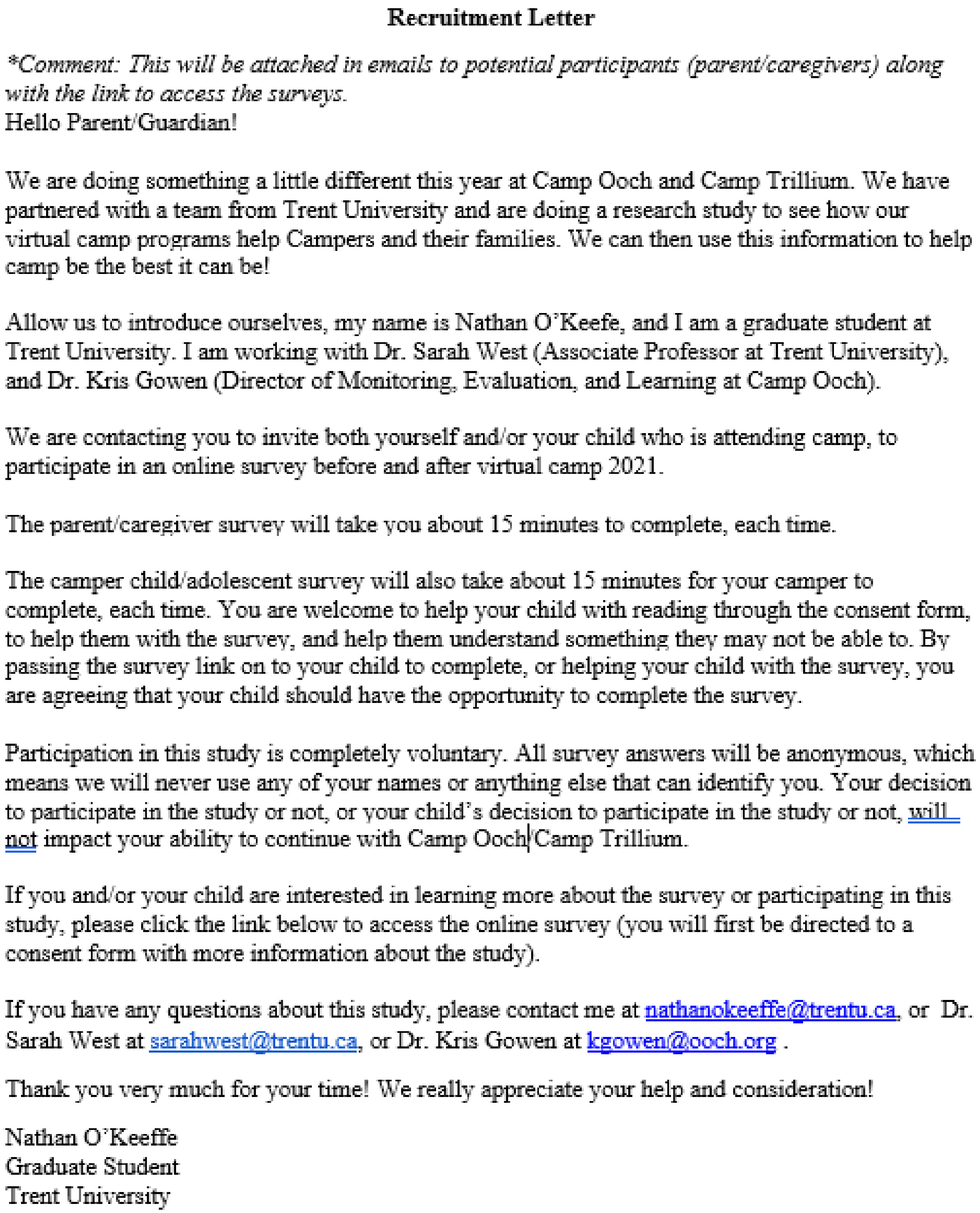
Below is a unique study ID code that only you will be able to see.

${e://Field/Random%20ID}

Members of our research team will not know that this code is yours.

We ask that you please write down this code somewhere (in a note on your phone, tablet, notepad, for example) for you to remember, because when you complete this survey again, we will ask you to enter this code.

5.6 Study Invitation Letter



Recruitment Letter

**Comment: This will be attached in emails to potential participants (parent/caregivers) along with the link to access the surveys.*

Hello Parent/Guardian!

We are doing something a little different this year at Camp Ooch and Camp Trillium. We have partnered with a team from Trent University and are doing a research study to see how our virtual camp programs help Campers and their families. We can then use this information to help camp be the best it can be!

Allow us to introduce ourselves, my name is Nathan O'Keefe, and I am a graduate student at Trent University. I am working with Dr. Sarah West (Associate Professor at Trent University), and Dr. Kris Gowen (Director of Monitoring, Evaluation, and Learning at Camp Ooch).

We are contacting you to invite both yourself and/or your child who is attending camp, to participate in an online survey before and after virtual camp 2021.

The parent/caregiver survey will take you about 15 minutes to complete, each time.

The camper child/adolescent survey will also take about 15 minutes for your camper to complete, each time. You are welcome to help your child with reading through the consent form, to help them with the survey, and help them understand something they may not be able to. By passing the survey link on to your child to complete, or helping your child with the survey, you are agreeing that your child should have the opportunity to complete the survey.

Participation in this study is completely voluntary. All survey answers will be anonymous, which means we will never use any of your names or anything else that can identify you. Your decision to participate in the study or not, or your child's decision to participate in the study or not, will not impact your ability to continue with Camp Ooch/Camp Trillium.

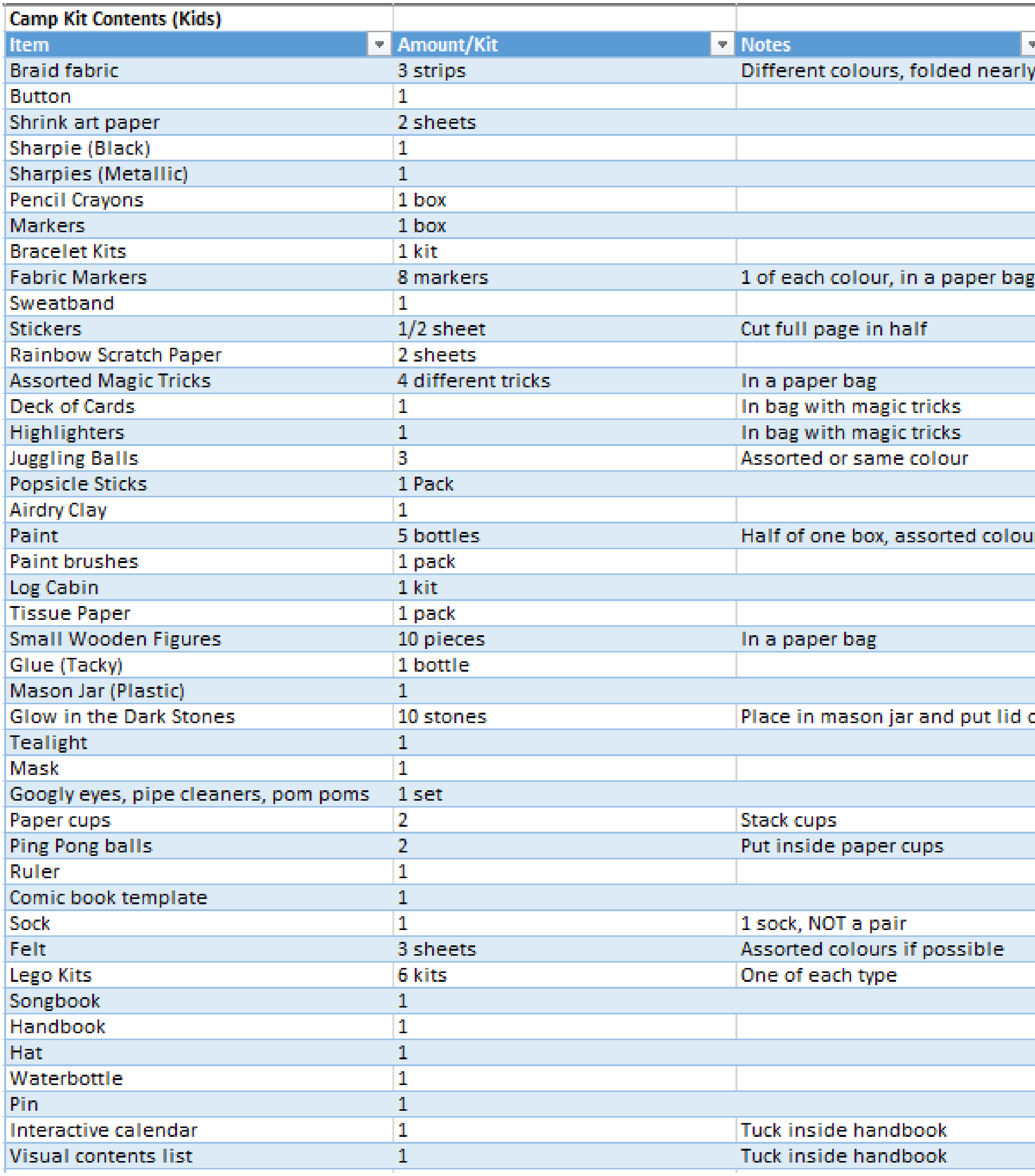
If you and/or your child are interested in learning more about the survey or participating in this study, please click the link below to access the online survey (you will first be directed to a consent form with more information about the study).

If you have any questions about this study, please contact me at nathanokeeffe@trentu.ca, or Dr. Sarah West at sarahwest@trentu.ca, or Dr. Kris Gowen at kgowen@ooch.org .

Thank you very much for your time! We really appreciate your help and consideration!

Nathan O'Keeffe
Graduate Student
Trent University

5.7 Camp in a Box Material List



Camp Kit Contents (Kids)

Item	Amount/Kit	Notes
Braid fabric	3 strips	Different colours, folded nearly
Button	1	
Shrink art paper	2 sheets	
Sharpie (Black)	1	
Sharpies (Metallic)	1	
Pencil Crayons	1 box	
Markers	1 box	
Bracelet Kits	1 kit	
Fabric Markers	8 markers	1 of each colour, in a paper bag
Sweatband	1	
Stickers	1/2 sheet	Cut full page in half
Rainbow Scratch Paper	2 sheets	
Assorted Magic Tricks	4 different tricks	In a paper bag
Deck of Cards	1	In bag with magic tricks
Highlighters	1	In bag with magic tricks
Juggling Balls	3	Assorted or same colour
Popsicle Sticks	1 Pack	
Airdry Clay	1	
Paint	5 bottles	Half of one box, assorted colou
Paint brushes	1 pack	
Log Cabin	1 kit	
Tissue Paper	1 pack	
Small Wooden Figures	10 pieces	In a paper bag
Glue (Tacky)	1 bottle	
Mason Jar (Plastic)	1	
Glow in the Dark Stones	10 stones	Place in mason jar and put lid c
Tealight	1	
Mask	1	
Googly eyes, pipe cleaners, pom poms	1 set	
Paper cups	2	Stack cups
Ping Pong balls	2	Put inside paper cups
Ruler	1	
Comic book template	1	
Sock	1	1 sock, NOT a pair
Felt	3 sheets	Assorted colours if possible
Lego Kits	6 kits	One of each type
Songbook	1	
Handbook	1	
Hat	1	
Waterbottle	1	
Pin	1	
Interactive calendar	1	Tuck inside handbook
Visual contents list	1	Tuck inside handbook