THE EFFECT OF ONCOLOGY CAMP ON THE PSYCHOSOCIAL HEALTH OF CHILDHOOD CANCER PATIENTS

A Thesis Submitted to the Committee on 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 oncology camp on the psychosocial health of childhood cancer patients

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Objectives/purpose: This study examined the psychosocial health (including resilience, hope, social functioning, mental wellbeing, and stress) of childhood cancer patients attending a recreational oncology camp (ROC).

Methods: Childhood cancer patients enrolled for ROC participated in a survey on the first (T1) and last (T2) day of camp, and 3 months post-camp (T3). This survey included the: Child and Youth Resilience Measure (CYRM), Children's Hope Scale (CHS), Social Provisions Scale (SPS-5), and Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS). Afternoon saliva samples were collected at T1 and T2 to determine cortisol (ELISA).

Results: CYRM, SPS-5, and SWEMWBS scores were high but did not differ between timepoints. CHS scores at T3 were lower compared to T1 and T2 (F=9.388, p=0.008). Salivary cortisol levels were within normal ranges.

Conclusion/clinical implications: Childhood cancer patients have high levels of positive psychosocial variables and normal stress levels while attending ROC.

Keywords: Children, cancer, oncology camp, psychosocial health, resilience, hope, social support, mental wellbeing, stress

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List of Abbreviations

Adrenocorticotropic hormone: ACTH

Analysis of variance: ANOVA

Central nervous system: CNS

Child and Youth Resilience Measure: CYRM

Children's Hope Scale: CHS

Children's Oncology Camps of America, International: COCA-I

Corticotrophin-releasing-hormone: CRH

Hypothalamic-pituitary-adrenal: HPA

Oncology camp: OC

Recreational oncology camp: ROC

Short Warwick Edinburgh Mental Wellbeing Scale: SWEMWBS

Social Provisions Scale: SPS

Sympathetic-adrenal-medullar: SAM

Glossary

Late effects: complications of cancer treatment that arise after the completion of treatment

Resilience: the process in which individuals display the ability to use internal and external resources to adapt to or manage stressful life events or trauma

Hope: the ability to produce routes towards goals in combination with the self-belief that one can initiate and sustain their progression towards these goals

Social support: one's perception that support will be available from others as needed

Mental wellbeing: a positive mental state that allows individuals to realise their abilities, work productively, and cope with stressors effectively

Stress: a physiological state in which the body defends homeostasis and responds to stressors

Stressor: any physical or psychological stimuli that disrupt homeostasis

Chapter 1: Introduction

Approximately 1,000 children in Canada are diagnosed with cancer each year (Ellison et al., 2021). Fortunately, survivorship has steadily increased due to advancements in cancer treatment, including improvements in diagnostic procedures, the development of new multimodal cancer treatment strategies, and the optimization of chemotherapy (Zahnreich & Schmidberger, 2021). The 5-year survival rate for childhood cancer is now greater than 80% in North America (Ellison et al., 2021). However, cancer treatment is often invasive with cytotoxic effects on organ systems in addition to significant disruption to the daily lives of childhood cancer patients and their families (Ness & Gurney, 2007). Cancer treatment can lead to long-term physical and psychosocial complications, commonly referred to as late effects of cancer, and children with cancer are particularly susceptible to late effects as they undergo cancer treatment during a critical period for physical and psychosocial development (Chong Hong et al., 2021; Iii et al., 2019; Ness & Gurney, 2007).

Some childhood cancer survivors experience psychosocial distress throughout survivorship (Hudson et al., 2003; Kunin-Batson et al., 2016; Mertens et al., 2014; Schultz et al., 2007), and many childhood cancer survivors experience academic difficulties and poor self-esteem (Tremolada et al., 2017). Additionally, childhood cancer survivors appear to be at an increased risk of poor mental health as they are more likely to be prescribed antidepressants and be hospitalized due to mental illness when compared with the general population (Barrett et al., 2020). The psychosocial difficulties that survivors face highlight the importance of nurturing the psychosocial health of childhood cancer patients.

Childhood cancer patients encounter numerous significant stressors including painful procedures, significant physical changes, treatment-related functional impairments, and dealing with a life-threatening disease (Gerali et al., 2011; Rodriguez et al., 2012). These children also appear to experience more psychosocial issues, including clinical depression and anxiety, in the months following their diagnosis when compared to their healthy peers (Gerali et al., 2011; Myers et al., 2014). Furthermore, children with cancer are removed from their normal environments and routines for months to years of in-hospital treatment. They are often absent from school and extracurricular activities thereby causing them to miss key opportunities to interact with peers (Tsimicalis et al., 2018). As such, it is important to develop and introduce interventions that promote psychosocial health and provide opportunities for social interaction for this patient population, particularly considering childhood is a critical period for psychosocial growth (Iii et al., 2019).

Psychosocial health is a construct that encompasses emotional, psychological, and social health (Eiroa-Orosa, 2020). It is important to note that good psychosocial health is not only determined by low levels of negative affect and psychological symptoms (e.g., anxiety) but also by the presence of positive aspects of psychosocial wellbeing, like positive mood and life satisfaction (Karademas, 2007). As such, both positive and negative predictors of psychosocial health should be assessed to obtain a more complete indication of psychosocial health (Margraf et al., 2020). For instance, stress-related factors, like life stress and negative coping strategies (e.g., denial and avoidance), have been identified as negative predictors of psychological wellbeing (Karademas, 2007). Conversely, resilience (Kermott et al., 2019), hope (Laranjeira & Querido, 2022), overall mental wellbeing (Eiroa-Orosa, 2020), and social support (Labrague, 2021), are positive indicators of good psychosocial health. Furthermore, hope and social support are coping resources which mitigate the effects of stressors thereby protecting individuals' psychosocial health (Roesch et al., 2010; Roohafza et al., 2014). It is particularly important to evaluate these psychosocial outcomes in a pediatric cancer population as children may be negatively impacted by cancer diagnosis and treatment and improving these psychosocial outcomes may also help children to adapt to cancer-related barriers and adversity (Christiansen et al., 2015; Decker, 2007; Lee et al., 2012; Neville et al., 2019; Seiler & Jenewein, 2019; Snyder et al., 1997). For instance, resilience refers to the ability to adapt to and manage significant sources of stress (Lee et al., 2012). Therefore, highly resilient childhood cancer patients may be able to overcome cancer-related barriers, like school absences and missed social opportunities, to become well-adjusted survivors.

Recreational oncology camps (ROCs) may be an appropriate psychosocial intervention as they provide a medically safe and supportive environment where childhood cancer patients/survivors can engage in social interaction and take part in a traditional camp experience. Depending on the ROC, they may offer day camp or overnight camp programming for children and/or families affected by childhood cancer. They often provide traditional outdoor camp activities like waterskiing, arts and crafts, swimming, fishing, and archery, that are accommodated to meet the unique needs of this population. For instance, a high ropes course may have a wheelchair-accessible section so that all campers can participate in this activity even if they have different mobility needs. In addition to adapting camp programming to meet the needs of campers, ROCs often have medical staff onsite and can provide medical support to ensure the safety of children undergoing cancer treatment. Currently, there are only 16 ROC organizations in Canada, and Campfire Circle (formerly Camp Oochigeas and Camp Trillium) is the only organization that provides intravenous chemotherapy and blood transfusions onsite (Campfire Circle, n.d.).

ROCs allow childhood cancer patients/survivors and their families to interact with others who have had similar medical experiences. Qualitative studies suggest that ROCs foster a communal environment where children feel accepted by others, experience a sense of normalcy and respite from the daily challenges of cancer treatment, and develop friendships (Beckwitt, 2014; Gillard & Watts, 2013; Riley, 2018; Ryan, 2017; Stevens et al., 2004). ROCs have been shown to have positive effects on friendship skills (Martiniuk et al., 2014), self-esteem (Mcgrane, 2016; Torok et al., 2006), the use of coping strategies (Ryan, 2017), and health-related quality of life (Békési et al., 2011). Despite being a promising psychosocial intervention for this patient population, there are limited quantitative studies that evaluate the impact of ROCs on the psychosocial health (both positive and negative psychosocial outcomes) of childhood cancer patients (Stein, 2017; Torok et al., 2006; Wellisch et al., 2006). Therefore, my thesis assessed the impact of a 10-day, in-person ROC experience (Campfire Circle) on childhood cancer patients' psychosocial health. The results of this thesis will highlight the importance of childhood ROCs, as one type of intervention targeted at improving the psychosocial outcomes in pediatric cancer patients, and will contribute to the current published literature.

1.1 Objectives

While research suggests that ROCs may have a positive impact on camp attendees (Beckwitt, 2014; Békési et al., 2011; Dawson et al., 2012; Gillard & Watts, 2013; Kelada et al., 2020; A. Martiniuk et al., 2014; Martiniuk et al., 2014; Mcgrane, 2016; Moola et al., 2023; Neville et al., 2019; Riley, 2018; Ryan, 2017; Torok et al., 2006; Wellisch et al., 2006; Wu et al., 2016), most studies that have investigated the psychosocial impact of ROCs included childhood cancer patients, long-term survivors, and sometimes their siblings in their participant samples. Childhood cancer patients, long-term survivors, and their siblings are three distinct groups with different psychosocial needs. For example, childhood cancer patients must adapt to the stressors of cancer treatment, whereas their siblings must adjust to altered routines and less parental involvement (Tsimicalis et al., 2018). Therefore, further research is necessary to determine whether ROCs have a positive impact on the psychosocial health of childhood cancer patients. Additionally, to our knowledge, no quantitative studies have directly investigated the impact of an in-person ROC on the resilience, hope, overall mental wellbeing, or stress of childhood cancer patients.

The current study aimed to contribute to knowledge gaps in this area of research by evaluating the impact of a 10-day, in-person ROC session on the psychosocial health of childhood cancer patients. The primary objective of this study was to evaluate the impact of a 10-day, in-person ROC session (Campfire Circle) on resilience, hope, social support, overall mental wellbeing, and stress in pediatric cancer patients.

1.2 Research Hypotheses/Predictions

We hypothesize that the psychosocial health of childhood cancer patients is improved after attending a 10-day in-person ROC. To evaluate childhood cancer patients' psychosocial health, we will measure both positive (resilience, hope, perceived social support, and mental wellbeing) and negative (stress) indicators of psychosocial health. We predict the following:

1. Resilience is improved after attending a 10-day, in-person ROC in childhood cancer patients as measured by the Child and Youth Resilience Measure (CYRM).

Rationale: For this thesis, resilience is defined as the process whereby individuals use internal and external resources to adapt to or manage stressful life events or trauma (Lee et al., 2012). Previous studies have found associations between ROC attendance and improvements in components of resilience including social support (Beckwitt, 2014; Martiniuk et al., 2014; Oppenheim, 2017), self-esteem (Mcgrane, 2016; Torok et al., 2006), and emotional wellbeing (Beckwitt, 2014; Martiniuk et al., 2014). Furthermore, pilot research from our group suggested that resilience was improved in childhood cancer patients and survivors who participated in a one-month virtual ROC program during the COVID-19 pandemic (O'Keeffe, 2022). Although virtual ROC differs from in-person ROC, and O'Keeffe's study (2022) was limited by a small sample size, these findings suggest that we may also find improvements in resilience following a 10-day, in-person ROC session in childhood cancer patients.

2. Hope is improved after attending a 10-day, in-person ROC experience in childhood cancer patients as measured by the Children's Hope Scale (CHS).

Rationale: Hope involves both the ability to produce routes toward goals and the self-belief that one can initiate and sustain their progress toward these goals (Snyder et al., 1997). This definition encompasses two major conceptualizations of goal orientation: agency thinking (determination to work toward goals) and pathways thinking (development of routes to reach goals) (Snyder et al., 1997).

At ROCs, childhood cancer patients interact with counsellors and older campers who are long-term childhood cancer survivors (Gillard & Watts, 2013). Interviews with campers on active treatment revealed that feelings of hope were produced because of these exposures (Gillard & Watts, 2013). Additionally, a 2013 study conducted by Woods et al. found that agency-related hope was improved in youth that attended a summer camp designed for children with chronic disease. Although this study did not evaluate ROCs specifically, it does offer support for our hypothesis. Furthermore, pilot research from our group suggests that hope, as measured by the Children’s Hope Scale, was improved in childhood cancer patients and survivors following their participation in a one-month virtual ROC program during the COVID-19 pandemic (O’Keeffe, 2022). Despite virtual ROCs offering a different experience than in-person ROCs, the findings of this pilot study support our hypothesis.

3. Social support is improved after attending a 10-day, in-person ROC experience in childhood cancer patients as measured by the Social Provisions Scale (SPS).

Rationale: Social support refers to one’s perception that support will be available from others as needed (Uchino et al., 2012). Literature suggests that ROCs provide childhood cancer patients with social support, opportunities for social interaction, and similar peer comparisons (Beckwitt, 2014; Gillard & Watts, 2013; Meltzer & Rourke, 2005;

Oppenheim, 2017; Riley, 2018). Children and adolescents with cancer experience physical changes which may cause them to feel different from their peers at home (Gerali et al., 2011). When children feel different from their peers, they are more likely to experience loneliness and social isolation (Meltzer & Rourke, 2005). One study reported that adolescents felt more like their camp peers than their peers from home (Meltzer & Rourke, 2005). These similar peer comparisons at ROC were associated with positive psychosocial outcomes (Meltzer & Rourke, 2005). Additionally, a study conducted by Martiniuk et al. (2014) found that children reported improvements in their ability to make friends after attending ROC. These findings suggest that we may find that ROC has a positive impact on social support as ROC provides childhood cancer patients with opportunities to engage in social interaction with children who have similar illness-related experiences.

4. Mental wellbeing is improved after attending a 10-day, in-person ROC experience in childhood cancer patients as measured by the Short Warwick Edinburgh Mental Wellbeing Scale (SWEMWBS).

Rationale: Current literature suggests that ROCs are associated with improved emotional wellbeing (Beckwitt, 2014), self-esteem (Mcgrane, 2016), and self-efficacy (Torok et al., 2006). These constructs are associated with overall mental wellbeing (Feller et al., 2018; Lyyra et al., 2021). Mental wellbeing refers to a positive mental state that allows individuals to realise their abilities, work productively, and cope with stressors effectively (Tennant et al., 2007). Previous studies found that ROC attendance was associated with reduced internalizing behaviours, such as depression, in childhood cancer patients and survivors (Stein, 2017; Wellisch et al., 2006). As poor mental wellbeing is associated with depression symptoms (Grant et al., 2013), these findings suggest that the mental wellbeing of childhood cancer patients may improve after attending ROC.

5. Stress is reduced after attending a 10-day, in-person ROC experience in childhood cancer patients as measured by salivary cortisol.

Rationale: Stress refers to a physiological state in which the body responds to physical or psychological stimuli that disrupt homeostasis (White et al., 2021). ROCs may reduce stress through increased physical activity (Salmon, 2001), immersion in nature (Li, 2010), and/or improved psychological and emotional regulation (Bernstein & McNally, 2018; Southwick et al., 2005). First, ROCs provide an environment that promotes physical activity through various camp activities (Gillard & Watts, 2013; Wu et al., 2016). Physical activity has been shown to reduce stress and as such, ROCs may reduce stress levels in childhood cancer patients (Silverman & Deuster, 2014). Immersion in nature has also been shown to reduce stress levels (Li, 2010) and because ROCs offer various outdoor activities, they may lead to reduced stress in childhood cancer patients. Finally, studies suggest that camp programs may improve psychological or emotional regulation in general youth populations (Henderson et al., 2007). Improved emotional regulation aids in stress management (Kalia & Knauft, 2020), thereby reducing stress in childhood cancer patients.

Chapter 2: Review of the Literature

2.1 Pediatric Cancer

Pediatric cancer refers to cancers that develop between birth and 14 years of age (Ellison et al., 2021). In Canada, there are approximately 1,000 pediatric cancer diagnoses every year (Ellison et al., 2021). Leukemia (cancer of the blood and bone marrow) is the most common type of pediatric cancer accounting for approximately 31.1% of yearly diagnoses (*Childhood Cancer Counts in Canada*, 2022). Central nervous system tumours (brain and spine) are the second most common pediatric cancer accounting for approximately 24.0% of yearly diagnoses, and they are the leading cause of pediatric cancer-related deaths (Casey & Stewart, 2020; *Childhood Cancer Counts in Canada*, 2022). Pediatric cancers also include: lymphoma (lymph nodes, bone marrow, & blood; 12.1%), neuroblastoma (nerve cells/tissue, 7.7%), soft tissue sarcoma (muscle; 6.0%), renal tumours (kidney; 4.5%), bone tumours (3.9%), germ cell tumours (ovaries or testes; 3.6%), carcinomas & melanomas (skin, thyroid, adrenal gland, nasopharynx; 3.1%), hepatic tumours (liver; 1.8%), retinoblastoma (eyes; 1.8%), among others (4%) (*Childhood Cancer Counts in Canada*, 2022).

Approaches to cancer treatment include: 1) surgical removal of tumours, 2) immunotherapy (stimulation of the immune system for cancer treatment), 3) radiotherapy, and 4) chemotherapy (Kattner et al., 2019). For children with leukemia, oncologists rely on risk stratification to create treatment regimens, treating children at a higher risk of poor outcomes more aggressively (Cooper & Brown, 2015). The first stage of treatment for leukemia is called remission induction where patients are treated with chemotherapy (typically a combination of vincristine, corticosteroids, asparagine, and anthracycline) (Cooper & Brown, 2015; Kim, 2020). As cancer can spread to the cerebrospinal fluid in leukemia patients, they are often treated with intrathecal chemotherapy (chemotherapeutic agents are injected directly into the cerebrospinal fluid) and/or cranial radiation (Cooper & Brown, 2015; Kim, 2020). This stage lasts approximately four to six weeks and children are usually admitted to the hospital at the beginning of this stage but can complete the rest of this stage of treatment at home with close monitoring (Cooper & Brown, 2015). About 95% of leukemia patients achieve remission, meaning the cancer is non-detectable, by the end of this first stage (Cooper & Brown, 2015). Patients who do not achieve remission are often treated with an allogeneic bone marrow transplant (Cooper & Brown, 2015). The next phase of leukemia treatment is often completed on an outpatient basis and is referred to as consolidation (Cooper & Brown, 2015). Consolidation lasts approximately six to nine months and aims to ensure there are no remaining cancer cells within the body (Cooper & Brown, 2015). Patients are treated with a variety of chemotherapeutic agents and sometimes allogeneic hematopoietic stem cell transplantation for higher risk patients (Kim, 2020). Maintenance chemotherapy, a less intensive, outpatient treatment regimen, follows the consolidation phase and lasts for approximately two years (Cooper & Brown, 2015).

Tumours of the central nervous system are typically treated with a combination of surgical tumour removal, chemotherapy, and radiation; however, approaches to treatment depend on the tumour type and location (Frühwald & Rutkowski, 2011; Lutz et al., 2022). Ideally, tumours can be removed surgically, but in cases where this is not possible, children with tumours of the central nervous system may be treated with radiation to stop or slow the growth of the tumour (Aiuppa et al., 2020). Following surgical resection of their tumours, these pediatric cancer patients are often treated with chemotherapy for approximately a year and a half on average (Aiuppa et al., 2020). The length of time that these children spend in-hospital and undergoing active treatment is variable and patient-dependent (Aiuppa et al., 2020). Regardless of cancer diagnosis, active treatment is intensive and often takes place over a span of months to years (Brand et al., 2017).

Fortunately, survivorship has steadily increased due to advancements in cancer treatment, including improvements in diagnostic procedures, the optimization of chemotherapy and radiation therapy to balance treatment efficacy with its toxicity, and the development of new multimodal cancer treatment strategies such as the addition of newer, more targeted drugs (e.g., antibody-based therapies) to conventional chemotherapy treatment (Dixon et al., 2020; Friedman et al., 2010; Zahnreich & Schmidberger, 2021). The 5-year survival rate for childhood cancer is now greater than 80% in North America (Ellison et al., 2021). While survival rates are improving, there are many negative physical and psychosocial effects of the necessary and intensive therapy regimes (Ness & Gurney, 2007).

The current literature review will begin by discussing the acute physical and psychosocial effects of pediatric cancer treatment followed by potential long-term (late) effects of treatment. It will also summarize literature focusing on the resilience, hope, social functioning, mental wellbeing, and stress of childhood cancer patients. Finally, potential psychosocial interventions for pediatric oncology populations will be examined with a particular emphasis on ROCs.

2.1.1 Acute Physical Effects of Pediatric Cancer Treatment

Although the focus of this thesis is the psychosocial health of childhood cancer patients, it is important to acknowledge the physical effects of cancer treatment as these may also contribute to psychosocial outcomes (Chong Hong et al., 2021). In the context of this thesis, acute physical effects refer to the physical symptoms/side effects of cancer and cancer treatment. Childhood cancer patients experience several negative physical outcomes due to treatment (Ness & Gurney, 2007). The physical effects of treatment include the cytotoxic effects of medication on various organ systems including cardiac, pulmonary, and musculoskeletal systems, which increase risk of morbidity and early mortality (Ness & Gurney, 2007).

Corticosteroids, such as prednisone or dexamethasone, are commonly used in the treatment of childhood cancer (Mrakotsky et al., 2011). However, various studies have shown that childhood cancer patients are more likely to experience acute behavioural side effects directly related to taking corticosteroids (Harris et al., 1986; Mrakotsky et al., 2011; Pound et al., 2012). Side effects can include irritability, issues with emotional control and behaviour regulation, sadness, and aggression (Harris et al., 1986; Mrakotsky et al., 2011; Pound et al., 2012).

Hair loss, weight change, fever, pain, and diarrhea are commonly experienced physical effects in youth with cancer receiving chemotherapy (Baggott et al., 2009). Nausea and vomiting are also common side effects of chemotherapy with over 50% of childhood cancer patients reporting nausea while receiving chemotherapy (Hooke & Linder, 2019; Miller et al., 2011). Nausea may also have a negative impact on physical health outcomes as one study found nausea to be positively correlated with length of hospital stay (Baggott et al., 2011).

A 2019 review of cancer-related physical effects reported that fatigue is prevalent among children and adolescents undergoing active treatment (Hooke & Linder, 2019). Another study found fatigue to be greater in childhood cancer patients undergoing treatment compared with their healthy peers (Daniel et al., 2013). This cancer-related fatigue may lead to lower levels of physical activity thereby potentially contributing to sarcopenia (loss of skeletal muscle mass) in childhood cancer patients through muscle disuse (Ritz et al., 2022). Chemotherapy may also contribute to sarcopenia as some chemotherapeutic agents have been found to cause muscle degradation in mice models (Ritz et al., 2022). Loss of appetite, nausea, and vomiting are also common side effects of chemotherapy which could lead to malnutrition and/or cause patients to be in a state of low energy availability (Ritz et al., 2022). These energy and nutrient deficits can lead to muscle wasting (Ritz et al., 2022). Childhood cancer patients who have just completed active treatment may also perform worse on tests of motor functioning, including coordination, flexibility, speed, and strength, when compared with age- and gender-matched healthy children (Götte et al., 2015). Taken together, childhood cancer patients may experience functional impairments due to the physical effects of cancer treatment which could act as a barrier to participating in regular activities (e.g., school, extracurricular sports, or other lessons/activities).

This literature highlights that it is not only the demands of in-hospital treatment that limit childhood cancer patients' opportunities for psychosocial growth, but the physical effects of treatment also limit these opportunities. It is important to provide childhood cancer patients with opportunities for psychosocial growth while accommodating the physical effects they experience due to cancer and cancer treatment, and/or implement strategies to minimize these physical effects.

2.1.2 Acute Psychosocial Effects of Pediatric Cancer Treatment

2.1.2a Psychosocial Impact

Childhood cancer patients may experience negative psychosocial health due to their diagnosis and treatment (Marcus, 2012). Psychosocial health is a construct that encompasses emotional, psychological, and social health (Eiroa-Orosa, 2020). In a 2011 prospective, quantitative study conducted by Gerali et al., parent reports revealed that children with cancer developed psychological issues, including neurosis and hyperactivity, within the first six months of their treatment. The Rutter instrument was used to assess psychological problems, with a higher score reflecting more severe psychological issues (Gerali et al., 2011). Based on parent and teacher reports, children with cancer had significantly higher Rutter scores 6-months after they began treatment when compared with other children without cancer (Gerali et al., 2011). Furthermore, in their 2005 study investigating the health-related quality of life of children with central nervous system tumors, Bhat et al. found that these children had poorer psychosocial health than healthy controls, as measured by the psychosocial functioning scale of the Pediatric Quality of Life Inventory. These findings indicate that children with cancer experience more frequent/severe psychological problems than children without cancer.

2.1.2b Clinical Outcomes

The negative psychosocial impact of cancer diagnosis and treatment may appear as increased anxiety and depression in childhood cancer patients, including clinical diagnoses of these disorders (Marcus, 2012; Myers et al., 2014; Yardeni et al., 2020, 2021; Yildirim et al., 2017). A 2014 study conducted by Myers et al. showed that symptoms of depression and anxiety were significant issues in children one month following their diagnosis of standard-risk acute lymphoblastic leukemia. Furthermore, depressive symptoms persisted throughout the first year of cancer at a minimum (Myers et al., 2014). In another study, it was found that 48% of the childhood cancer patients who participated in their study met the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) criteria for depression or anxiety at least once within the year following their cancer diagnosis (Yardeni et al., 2021). Childhood cancer patients may also experience worse psychosocial health during periods of active treatment as a prospective study found that pediatric cancer patients' depression and anxiety scores were significantly higher during treatment compared to their scores before and after treatment periods (Yildirim et al., 2017).

2.1.2c Social Isolation & Missing Out on Social Opportunities

Childhood cancer patients commonly report feelings of "missing out" (Rollins, 2005). Throughout their treatment, childhood cancer patients are often unable to attend school full-time due to periods of in-hospital treatment, appointments, and/or treatment-related isolation requirements (Brand et al., 2017; Christiansen et al., 2015). Reduced social opportunities are problematic as peer interactions are a key component of children's socialization (Christiansen et al., 2015). Additionally, many children experience treatment-related functional impairments, such as fatigue, which prevent them from engaging in their regular activities at full capacity (Al-Gamal & Long, 2016). These physical limitations appear to contribute to low self-esteem in childhood cancer patients (Al-Gamal & Long, 2016). For instance, one participant in a 2005 qualitative study reported that he believed that he was no longer good at football as he had not made the connection that he was unable to run as fast because of his cancer-related fatigue (Rollins, 2005).

2.1.2d Stage of physical development

The psychological impact that cancer treatment has on a child is also dependent on their stage of development (Brand et al., 2017; Marcus, 2012). Gerali et al. (2011) found that in childhood cancer patients aged one to fifteen years, older age was associated with less psychological problems, including neurosis and hyperactivity, over the first six months of treatment. Although younger children demonstrated more psychological difficulties at the beginning of treatment, they experienced greater improvements in these problems as treatment progressed (Gerali et al., 2011). Younger children may cope with the cancer-related stressors better as they are in stages of development that are less focused on independence and developing friendships (Gerali et al., 2011). As such, their social lives may be impacted to a lesser extent than that of an older child or adolescent (≥12 years old) (Gerali et al., 2011).

Although adolescents may face greater challenges in terms of disruptions to their social lives, it should be noted that infancy (newborn to one year old) is an important time for emotional development, particularly in terms of creating secure attachments with parents (Brand et al., 2017). Through cancer treatment, infants encounter unfamiliar situations/people and painful procedures, and their regular routines are disrupted (Brand et al., 2017). These circumstances can hinder an infant’s ability to develop trust and a sense of security with their caregivers (Brand et al., 2017).

Children between the ages of two and five years are challenged in that they are unable to fully understand their diagnosis, the reason they must undergo the painful procedures that treatment involves, or that their cancer or treatment is causing them to feel ill (Marcus, 2012). At this stage of development, children may believe that something they said or did caused them to become ill (Brand et al., 2017). Older children, (five to twelve years old) are increasingly interested in developing friendships and belonging to a group (Brand et al., 2017). The desire to make social connections during this stage of development may create difficulties as many childhood cancer patients are unable to attend school full time thereby causing them to miss out on opportunities to interact with their peers (Tsimicalis et al., 2018).

Adolescents (twelve to eighteen years old) are at a stage of development where autonomy and the search for identity are critical (Brand et al., 2017). Adolescent cancer patients must rely on their caregivers and medical support throughout treatment, and this may conflict with their efforts to establish independence (Mavrides & Pao, 2014). Their opportunities to interact with friends and attend school or other social events are limited by treatment which is particularly problematic as adolescents place greater importance on peer relationships compared with younger age groups (Brand et al., 2017). These limitations may cause frustration and lead to risk-taking behaviours such as medication non-adherence (Brand et al., 2017). Furthermore, treatment causes body changes, such as hair loss, which often have significant impacts on adolescents (Marcus, 2012).

Adolescents are more developed and self-aware than younger children which may contribute to them having more concerns regarding their appearance and illness-related worries (Bhat et al., 2005). Additionally, as adolescents place importance on their appearance and social life, they may avoid their peers and isolate themselves due to their treatment-related body changes (Brand et al., 2017; Mavrides & Pao, 2014). This self-isolation may hinder their social development (Mavrides & Pao, 2014).

The focus of this thesis is on pediatric cancer patients aged six to 18 years old as youth in these age groups, particularly those over the age of 12, are more focused on forming social relationships and establishing independence (Brand et al., 2017). However, cancer treatment acts as a barrier to these developmental goals (Brand et al., 2017). As such, it is important to provide youth in these age groups opportunities to socialize with peers.

2.1.3 Physical and Psychological Late Effects

Late effects are defined as complications of cancer treatment that arise at any point after the completion of treatment (Chong Hong et al., 2021). Late effects can be physical or psychosocial, and they are present in approximately a third to half of childhood cancer survivors (Chong Hong et al., 2021; Seth et al., 2017).

2.1.3a Physical Late Effects

Cancer treatments target fast growing cells as cancerous cells grow rapidly and uncontrollably (Ness & Gurney, 2007). As such, treatment often has negative effects on healthy cells and organ systems as well, but the negative impact of cancer treatment may be amplified in pediatric cancer patients because childhood is marked by growth and children’s organ systems are still developing (Ness & Gurney, 2007). As a result of cancer treatment, childhood cancer survivors are at a greater risk for early mortality, immune system suppression, endocrine deficiencies, neurocognitive deficits, and cardiac, pulmonary, musculoskeletal, gastrointestinal, and genitourinary disorders/impairments (Hudson et al., 2013; Ness & Gurney, 2007). Childhood cancer survivors are also at a greater risk of developing malignancies compared with the general population (Erdmann et al., 2021).

Late effects of cancer treatment can develop at any point in survivorship, even years after acute physical effects of cancer treatment are resolved (Ness & Gurney, 2007). Factors including age at diagnosis, type/location of cancer, and treatment modality have been shown to affect risk of developing late effects, with childhood cancer survivors who had a brain tumour and/or received treatment targeting the central nervous system at the greatest risk (Erdmann et al., 2021). Late effects may also worsen throughout survivorship (Hoppe-Hirsch et al., 1990). For instance, one prospective study reported that the percentage of childhood brain cancer survivors who did not meet an adequate intelligence score threshold increased from 42% four years after treatment cessation to 75% of survivors 10 years after treatment cessation (Hoppe-Hirsch et al., 1990).

Childhood cancer survivors are more likely to report functional limitations when compared with adults who did not have cancer and these limitations could be attributed to physical late effects (Dowling et al., 2010). For instance, physical late effects may impair childhood cancer survivors’ ability to gain further education, care for themselves independently, attend work or school, or develop and maintain their social relationships

(Ness & Gurney, 2007; Tremolada et al., 2017). As such, physical late effects could also contribute to psychosocial late effects (Erdmann et al., 2021).

2.1.3b Psychosocial Late Effects

Literature suggests that a subset of childhood cancer survivors experience psychosocial late effects (Erdmann et al., 2021; Glover et al., 2003; Hudson et al., 2003; Mertens et al., 2014; Schultz et al., 2007). Psychosocial late effects may include, but are not limited to: distress, anxiety, depression, poor self-esteem, and impaired social functioning (Bitsko et al., 2016; Tremolada et al., 2017). Approximately 6%, 7%, and 13% of childhood cancer survivors have scored within the clinical range for depression, anxiety, and global distress, respectively (Kosir et al., 2019). Furthermore, one study found that childhood cancer survivors who had completed treatment at least five years prior were more likely to have symptoms of depression and anxiety when compared with a sibling group (Schultz et al., 2007). Childhood cancer survivors are also at a greater risk of distress based on the following risk factors: female sex, unmarried, only child, brain tumor diagnosis, diagnosis during adolescence, and higher intensity treatment (Bitsko et al., 2016). For example, adolescent and young adult cancer survivors who previously received the highest treatment intensity had greater symptoms of anxiety when compared with survivors who previously received less intense cancer treatment (Kazak et al., 2010).

Particularly concerning are findings from a 2013 study suggesting that childhood cancer survivors are more likely to experience suicidal ideation compared with a sibling control group (Brinkman et al., 2014). As physical health was negatively associated with risk of suicidal ideation, the presence of physical late effects may also contribute to the increased risk of suicidal ideation found in childhood cancer survivors (Bitsko et al., 2016; Brinkman et al., 2014).

Self-esteem is another issue among adolescent childhood cancer survivors (Tremolada et al., 2017). Most pre-adolescent and adolescent childhood cancer survivors who completed treatment five years prior have reported levels of global self-esteem below the 50th percentile, with levels of self-esteem related to interpersonal relationships being the poorest (Tremolada et al., 2017). Poor self-esteem in this area could contribute to the social isolation that some childhood cancer survivors report throughout survivorship (Howard et al., 2014). Adult survivors of childhood cancer also reported significantly lower global self-worth when compared with a sibling control group, and childhood cancer survivors who believed their employability was limited due to their previous cancer treatment were at a greater risk of experiencing poor self-worth (Seitzman et al., 2004).

Childhood cancer survivors who were diagnosed with brain tumours may experience a greater number of psychosocial late effects in comparison to other childhood cancer survivors (Bhat et al., 2005). Furthermore, childhood cancer survivors who had brain tumours and/or were treated with cranial radiation therapy are at a greater risk for cognitive deficits (Bhat et al., 2005; Ness & Gurney, 2007). These cancer-related cognitive deficits could contribute to the findings of approximately 40% of childhood cancer survivors struggling academically (Tremolada et al., 2017). Adult survivors of childhood brain tumours are also more likely to be unemployed and unable to drive, thereby limiting their independence (Bhat et al., 2005).

Overall, childhood cancer patients experience significant adversity during a critical period for psychosocial growth, and cancer treatment may have caused them to miss out on social experiences/interactions and educational achievements, and develop maladaptive coping strategies (e.g., self-isolation, rumination, avoidance) (Erdmann et al., 2021). These acute psychosocial effects of treatment may lead to the psychosocial late effects that a subset of childhood cancer survivors experience (Erdmann et al., 2021).

2.1.4 Resilience

Resilience is a complex, multidimensional construct (Lee et al., 2012). An operational definition for resilience was challenging to develop as it can be studied from various perspectives (Lee et al., 2012). For instance, the American Psychological Association defined resilience as a process that individuals go through to adapt to significant stress or trauma and return to normal functioning (American Psychological Association, n.d.). However, this definition was found to be too broad with large variance in the proportion of youth who were determined to be resilient by the standards of this definition (Vanderbilt-Adriance & Shaw, 2008). Resilience can also be viewed as an individual’s capacity to effectively adapt to stress or trauma through healthy and flexible means (Catalano et al., 2004). Others view resilience as a result in which there are positive outcomes that stem from successfully adapting to significant stress or trauma (Masten et al., 1990).

After accounting for different constructs of resilience research in their literature review, Lee et al. (2012) determined that there are three conditions that are critical for resilience. First, an individual must be exposed to adversity. Second, protective factors must be available to an individual. Finally, an individual must achieve positive adjustment/outcomes. After combining these critical components of resilience, Lee et al. (2012) defined resilience as the process in which individuals display the ability to use internal and external resources to adapt to or manage stressful life events or trauma. For this thesis, we will be using this definition of resilience.

2.1.4a Adversity, Protective Factors, and Adaptation

Adversity refers to any disadvantages or negative life circumstances that increase an individuals' risk of poor adjustment or development (Luthar & Cicchetti, 2000). In the context of this project, adversity can include a cancer diagnosis, cancer treatment, painful procedures, school absences, among other stressful or traumatic events associated with childhood cancer. People dealing with a life-threatening illness, like cancer, typically experience psychological trauma (Seiler & Jenewein, 2019). As such, building resilience should be an aspect of cancer care so that cancer patients are able to adapt despite cancer-related adversity (Seiler & Jenewein, 2019).

Protective factors are internal and/or external resources that can reduce the risk associated with adversity (Luthar & Cicchetti, 2000). Internal resources include positive personal characteristics and attributes, whereas external resources refer to positive resources outside of oneself such as positive personal relationships (Lee et al., 2012; Vanderbilt-Adriance & Shaw, 2008). Examples of internal resources include self-esteem, optimism, and hope (Lee et al., 2012; Seiler & Jenewein, 2019). External resources may include social support and connectedness (Lee et al., 2012; Seiler & Jenewein, 2019; Sharp et al., 2015). These resources can be used to "protect" individuals by mitigating the negative effects of stressful events and helping individuals to adapt to and overcome adversity (Lee et al., 2012; Masten, 2014). Children and adolescents must develop these protective factors and develop their ability to access and use these resources in order to adapt to adversity, thereby demonstrating resilience (Lee et al., 2012; Masten, 2001).

Positive adjustment/adaptation typically refers to behavioural demonstration of social competence and the achievement of developmentally normal tasks (Luthar & Cicchetti, 2000). In children who have had chronic illness, resilience has been associated with positive outcomes like reduced social anxiety, and improved character of moral behaviour, confidence, and social connectedness (Lee et al., 2012; Mccarroll et al., 2009; Zebrack & Chesler, 2001). Additionally, resilience may contribute to positive youth development (Lee et al., 2012; Masten, 2001, 2014). Another measure of positive adjustment in children is good academic performance (Luthar & Cicchetti, 2000). Therefore, building the resilience of childhood cancer patients could help them to achieve academic success and become well-adjusted throughout survivorship despite missing school and social activities due to cancer treatment.

2.1.4.b Resilience in Childhood Cancer Patients

Several studies have concluded that most childhood cancer survivors are resilient as they do not differ significantly from healthy peers in terms of various positive outcomes thereby indicating that they were able to adapt to the significant adversity brought about by their cancer (DeJong & Fombonne, 2006; Glover et al., 2003; Mertens et al., 2014; Noll et al., 1997; Sharp et al., 2015). However, many studies have also identified that there is a subset of childhood cancer survivors (largely survivors whose cancer or treatment involved the central nervous system) who experience psychosocial distress or impairments throughout survivorship (Glover et al., 2003; Howard et al., 2014; Hudson et al., 2003; Kunin-Batson et al., 2016; Mertens et al., 2014; Schultz et al., 2007). This evidence suggests that resilience is lacking in a subset of childhood cancer patients as they have not been able to adapt to the adversity brought upon them by their cancer.

In addition to childhood cancer survivor studies, there is also evidence that a subpopulation of current pediatric cancer patients experiences significant distress throughout treatment (Mitchell et al., 2016; Myers et al., 2014). For example, a greater proportion of children diagnosed with standard-risk acute lymphoblastic leukemia had anxiety and/or depression at subclinical/clinically significant levels compared with population norms (Myers et al., 2014). Anxiety levels dropped six-months post-diagnosis, however, depression continued to be a significant problem for a some of these pediatric cancer patients at six- and twelve-months post-diagnosis (Myers et al., 2014). In addition to this research suggesting that symptoms of anxiety and depression may be an issue in pediatric cancer populations, another study found poor health-related quality of life in most standard-risk acute lymphoblastic leukemia patients at 1-month post-diagnosis (Mitchell et al., 2016). While most of these pediatric cancer patients experienced improvements in health-related quality of life throughout treatment, about a quarter of these patients experienced impaired physical and social functioning that persisted throughout the course of the study (Mitchell et al., 2016). The findings from these studies suggest that some pediatric cancer patients do not exhibit resilience as they fail to adapt to the major sources of stress and trauma that accompany cancer diagnosis and treatment.

2.1.4c Factors Influencing the Resilience of Childhood Cancer Patients

The absence of certain protective factors may contribute to the lack of resilience found in a subset of childhood cancer patients/survivors. Connectedness refers to reciprocal relationships that children both contribute to and gain support from (Sharp et al., 2015). Sharp et al. (2015) found that children who were more connected across all social domains experienced the least posttraumatic stress symptoms and highest benefit-finding. Conversely, they found that children who were connected across fewer social domains experienced the most posttraumatic stress symptoms and lowest benefit finding (Sharp et al., 2015). Few posttraumatic stress symptoms and high benefit finding are indicative of resilience and growth (Sharp et al., 2015). As such, it appears that connectedness may be a factor in facilitating growth in children with cancer (Sharp et al., 2015). Similarly, social support appears to be a protective factor for children (Lee et al., 2012; Southwick et al., 2005), adult cancer patients (Seiler & Jenewein, 2019), and childhood cancer patients (Trask et al., 2003; Varni & Katz, 1997). Myers et al. (2014) also found that poor family functioning was predictive of anxiety, and less reliance on social support was associated with depression in childhood cancer patients. Based on these findings, it appears as though the absence of protective factors like social support and connectedness may contribute to the poor adjustment observed in a subset of childhood cancer patients and survivors.

Resilience could also be influenced by biological sex and the age at which children are diagnosed with cancer (Mertens et al., 2014). In an ancillary study to the Childhood Cancer Survivor Study, Mertens et al. (2014) compared factors of health-related quality of life of adolescent childhood cancer survivors to that of siblings. While they found that health-related quality of life was similar in survivors and siblings, female survivors were more likely to report problems with resilience and lack protective factors (e.g., family support) than male survivors. Furthermore, adolescent survivors who were diagnosed between the ages of two and four were more likely to report problems with resilience as measured by the Child Health and Illness Profile-Adolescent Edition when compared with survivors diagnosed before the age of two.

The type of cancer a child has and the type of treatment they receive also appears to influence the adjustment of childhood cancer patients/survivors. Mertens et al. (2014) found that childhood cancer survivors who had been diagnosed with a central nervous system (CNS) tumor scored lower on satisfaction with their overall health, self-esteem, and their history of disorders when compared with leukemia survivors. Furthermore, Bhat et al. (2005) found that childhood cancer patients with CNS tumors had significantly worse health-related quality of life compared with healthy controls. Childhood CNS tumor patients treated with radiation treatment, but not chemotherapy, experienced worse psychosocial, emotional, and social functioning compared with children receiving other treatments and other combinations of treatments (Bhat et al., 2005). High dose cranial radiation treatment is also associated with various negative outcomes such as lower cognitive and academic performance (Glover et al., 2003). Cognitive functioning contributes to the ability to cope with stressors effectively (Lee et al., 2012). As such, poorer adjustment and lower levels of resilience in this group of childhood cancer patients/survivors may be explained by more significant cancer- and treatment-related impairments of cognitive functioning.

In conclusion, current literature suggests that a large proportion of childhood cancer patients/survivors demonstrate resilience (DeJong & Fombonne, 2006; Glover et al., 2003; Mertens et al., 2014; Noll et al., 1997; Sharp et al., 2015). However, there appears to be a subgroup of children with cancer who struggle to adapt to the adversity associated with cancer (Glover et al., 2003; Howard et al., 2013; Hudson et al., 2003; Kunin-Batson et al., 2016; Mertens et al., 2014; Schultz et al., 2007). Children may be at a greater risk of experiencing poor outcomes based on their access to internal and/or external resources, gender, age at diagnosis, cancer diagnosis, and the type of treatment they receive (Bhat et al., 2005; Glover et al., 2003; Myers et al., 2014; Sharp et al., 2015; Trask et al., 2003; Varni, 1997). Although many of these risk factors cannot be changed, interventions aimed at building childhood cancer patients' repertoire of internal and external resources should be introduced in this population to increase their likelihood of becoming well-adjusted survivors.

2.1.5 Hope in Childhood Cancer Patients

Children's hope, as defined by Snyder et al. (1997), involves both the ability to produce routes towards goals and the self-belief that one can initiate and sustain their progression towards these goals. This definition encompasses two major conceptualizations of goal orientation: agency and pathways thinking (Snyder et al., 1997). Pathways thinking refers to the development of plans to reach goals whereas agentic thinking refers to goal-directed energy, like the confidence and determination to initiate goals and sustain progress toward these goals (Snyder et al., 1997).

Cancer and cancer treatment may act as barriers to the goals of childhood cancer patients (Germann et al., 2015; Snyder et al., 1997). For instance, children may not be able to attend school due to cancer treatment which could impede their progress toward their academic goals. As a result, they must develop their ability to create alternative pathways toward their goals (pathways thinking) and potentially focus on creating new goals (agentic thinking) (Snyder et al., 1997). Hopeful thinking could act as a resource for childhood cancer patients to help them cope with cancer-related stressors as well as develop and work toward goals relating to positive health outcomes (Germann et al., 2015; Rosenberg et al., 2019; Snyder et al., 1997).

Research on hope in childhood cancer patients is relatively limited; however, some studies have found associations between hope and positive outcomes in populations including childhood cancer patients or childhood cancer survivors (Ho et al., 2021; Woods et al., 2013; Yuen et al., 2014). Hope has been found to be negatively correlated with anxiety and depression in children with chronic diseases and childhood cancer survivors (Ho et al., 2021; Woods et al., 2013; Yuen et al., 2014). Additionally, higher levels of hope have been found to be associated with higher levels of positive outcomes including posttraumatic growth (positive psychological growth resulting from exposure to adversity) (Yuen et al., 2014), self-esteem, health-related quality of life (Ho et al., 2021), and the use of positive coping strategies in childhood cancer survivors and children with chronic diseases (Woods et al., 2013). Furthermore, hope is an internal factor related to resilience (Seiler & Jenewein, 2019; Solano et al., 2016). As such, fostering hope in childhood cancer patients could improve their resilience, thereby increasing their likelihood of adjusting to the adversity brought upon them by their cancer (Seiler & Jenewein, 2019). Therefore, this research suggests that hope may promote positive adjustment to cancer-related adversity in children with cancer throughout treatment and survivorship.

A qualitative study conducted by Ebrahimpour et al. (2021) investigated objects, people, and circumstances in a pediatric oncology ward in Iran that elicited feelings of hope in childhood cancer patients between the ages of 6 and 12 (Ebrahimpour et al., 2021). Six main themes emerged: (1) emotional connectedness with nurses; (2) the playroom; (3) the presence of a parent; (4) symbols of recovery; (5) nature in the hospital environment; (6) escaping the "hospital cage". Nurses who created emotional bonds with patients and cared for the emotional needs of their patients, thereby promoting their emotional wellbeing, appeared to improve levels of hope in these children. This finding highlights the importance of promoting patient wellbeing throughout cancer treatment. Many children derived hope from the playroom in the hospital as it offered them some respite from cancer-related stressors while also providing them with opportunities to interact with other children and make friends. Pieces of nature within the hospital, such as plants or paintings of nature, offered signs of hope to childhood cancer patients. Additionally, many children discussed that they felt confined within the hospital space as they were isolated from family and friends while being subjected to painful procedures. As such, brief moments outside of the hospital offered childhood cancer patients a sense of hope as it liberated them from their hospital confinement. The findings of Ebrahimpour et al. (2012) suggest that providing childhood cancer patients with experiences, such as a ROC, where they can form emotional bonds with others, interact with other children, leave the hospital setting, and immerse themselves in nature, may have a positive impact on their levels of hope.

Although associations between social support and hope have not been investigated in pediatric cancer populations, studies in adults suggest that social support may also protect against hopelessness in cancer patients (Seiler & Jenewein, 2019). A quantitative study conducted by Bao et al. (2019) found that adult CNS tumour patients who had higher levels of social support tended to have higher levels of hope and fewer depressive symptoms (Bao et al., 2019). They determined that hope could explain much of the negative relationship between social support and depressive symptoms (Bao et al., 2019). This relationship between social support and hope may partially explain the increased hope found in children with chronic illnesses after attending disease-specific camps as these camps offer children opportunities to engage in social interaction and gain social support (Woods et al., 2013). It is also possible that camp promotes a goal-oriented environment where children focus on personal and collaborative goals, thereby facilitating hope in campers (Woods et al., 2013).

Overall, there is limited literature investigating hope in childhood cancer patients specifically. However, the associations found between hope and positive outcomes in adult cancer patients, childhood cancer survivors, and children with chronic diseases, suggest that hope should be promoted in pediatric oncology patients.

2.1.6 Social Support

Social support can be divided into received and perceived social support (Uchino et al., 2012). Received social support refers to the exchange of resources within a support network, whereas perceived social support refers to one’s perception that support will be available from others as needed (Uchino et al., 2012). There are also different types of social support (received and perceived) which include, emotional support (e.g., encouragement), informational support (e.g., offering advice/information), instrumental support (e.g., providing useful material resources), appraisal support (e.g., providing feedback), supportive social network, and positive social interactions (Wallace et al., 2019). For this thesis, social support is defined as perceived social support.

2.1.6a Social Support in Childhood Cancer Patients

Pediatric cancer patients commonly miss out on opportunities for social interaction with peers due to lengthy periods of in-hospital treatment (Christiansen et al., 2015; Tsimicalis et al., 2018). While childhood cancer patients often receive much of their social support from their parents, it is important that they have peer support as well, especially in adolescents who place greater importance on support from friends than younger children (Barrera et al., 2008; Wesley et al., 2013). Childhood cancer patients may struggle to maintain their relationships with peers due to school absences thereby placing them at a greater risk of experiencing lower levels of perceived social support (Cavusoglu, 2000). For example, a qualitative study conducted by Moola et al. (2013) described the experiences of children with cancer and some children discussed losing touch with their friends during treatment.

Cancer treatment and treatment-related side effects (e.g., hair loss) may also cause children with cancer to feel different from their peers which increases their risk of social isolation (Meltzer & Rourke, 2005). The increased risk of social isolation in this patient population also increases their risk of impaired social development (Kelada et al., 2020). Furthermore, social support is recognized as being an important factor in improving wellbeing of cancer patients (Seiler & Jenewein, 2019). As such, it is important to provide childhood cancer patients with opportunities to interact with children who have faced similar health challenges.

Lengthy periods of in-hospital treatment also commonly cause childhood cancer patients to miss out on opportunities for social interaction with peers, which is problematic as peer social interaction is an important aspect of developing their social functioning (Christiansen et al., 2015; Tsimicalis et al., 2018). Their social development may be negatively impacted due to this interference (Mavrides & Pao, 2014). Social impairments appear to be problematic following childhood cancer diagnosis (Mitchell et al., 2016). In their 2016 prospective study, Mitchell et al. found social impairments in children with standard-risk acute lymphoblastic leukemia one month after their diagnosis. While social functioning seemed to improve in most patients throughout their treatment, there was still a subgroup of patients (approximately 26%) whose social impairment persisted through treatment until the last study testing timepoint, 3-months after the completion of treatment (Mitchell et al., 2016).

2.1.6b Social Support in Childhood Cancer Survivors

Missed social opportunities during cancer treatment may have long-term impacts on the social skills of these children throughout survivorship (Mavrides & Pao, 2014). For example, one study found that childhood cancer survivors were more likely to report antisocial behaviours when compared to a sibling group (Schultz et al., 2007). Another study also found that almost two-thirds of their sample of childhood cancer survivors experienced social isolation at some point throughout cancer treatment and survivorship, and one-third experienced social isolation that either persisted throughout survivorship or developed at some point during survivorship (Howard et al., 2014).

2.1.6c Associations Between Social Support and Psychosocial Health

Social support is associated with various psychosocial outcomes including self-esteem, quality of life, and sense of wellbeing, and it has been identified as an external resource that can be used in the resilience process (Costa et al., 2017; Lee et al., 2012; Seiler & Jenewein, 2019; Sharp et al., 2015; Uchino et al., 2012). Furthermore, in adolescents undergoing active cancer treatment, higher levels of social support from friends were found to be associated with greater positive affect (Wesley et al., 2013). This positive association may be due to friendships providing youth undergoing active treatment with a sense of normalcy (Wesley et al., 2013).

In addition to the research that suggests that social support may contribute to positive aspects of psychosocial health, there is also research suggesting that social support may contribute to reductions in negative indicators of psychosocial health. For instance, in children with malignant tumours, social support was found to be both directly and indirectly (through self-efficacy or coping style) associated with reduced psychological stress (Liu et al., 2020). High levels of social support have also been associated with less negative affect in newly diagnosed childhood cancer patients (Varni & Katz, 1997). Therefore, perceived social support in childhood cancer patients may promote overall psychosocial health through improving positive aspects and reducing negative aspects of psychosocial health.

2.1.6d Associations Between Social Support and Physical Health

Social support for childhood cancer patients is not only important to prevent potential long-term negative social implications, like social isolation, and promote positive psychosocial outcomes, but it has also been associated with positive physical outcomes (Uchino et al., 2012). Social support has been associated with positive cardiovascular health outcomes, like reduced blood pressure and cardiovascular reactivity during acute stress (Uchino et al., 2012). Additionally, negative correlations have been found between social support and stress (Costa et al., 2017; Li et al., 2016; Uchino et al., 2012). This negative association could be attributed to the belief that one will be able to cope with stressors as they have the resources from and support of others (Uchino et al., 2012). The potential for social support to reduce stress in children with cancer is important as stress is associated with impaired immune function which may lead to increased tumor progression and metastasis in individuals with cancer (Ben-Eliyahu et al., 1999, 2000; Li et al., 2005; Lutgendorf et al., 2005). Therefore, high levels of social support may improve childhood cancer patients' physical and cancer-related outcomes.

2.1.6e Social Support Conclusions

In conclusion, social support may positively impact the physical and psychosocial health of childhood cancer patients. However, these children frequently miss out on opportunities to interact with friends who may provide social support (Cavusoglu, 2000; Christiansen et al., 2015; Tsimicalis et al., 2018). Limited social interactions and feelings of social isolation may have negative effects on children during cancer treatment and throughout survivorship, such as antisocial behaviour and persistent social isolation (Howard et al., 2014; Mavrides & Pao, 2014; Meltzer & Rourke, 2005; Mitchell et al., 2016; Schultz et al., 2007). As such, there is a need for programs or interventions aimed at promoting social support within pediatric cancer populations (Lewandowska et al., 2021).

2.1.7 Mental Wellbeing

Mental wellbeing refers to a positive mental state that allows individuals to realise their abilities, work productively, and cope with stressors effectively (Tennant et al., 2007). This is a complex construct that differs from mental health (Galderisi et al., 2015). Although mental wellbeing and mental health are terms that are often used synonymously, mental wellbeing refers to a state of positive feelings and functioning whereas mental health is comprised of three components of wellbeing: emotional wellbeing, psychological wellbeing, and social wellbeing (Galderisi et al., 2015). In some instances, exhibiting a state of mental wellbeing would be unhealthy (Galderisi et al., 2015). For example, a mentally healthy person would not experience mental wellbeing while fighting in a war (Galderisi et al., 2015). In the context of this thesis, a mentally healthy child may still experience poor mental wellbeing when diagnosed with cancer.

2.1.7a Theories of Mental Wellbeing

There are several theories of mental wellbeing, but hedonic theories of wellbeing have been the most popular focus of wellbeing research (Gallagher et al., 2009). Hedonic wellbeing, described by Diener (1984) as subjective wellbeing, primarily refers to experiences of pleasant emotions and moods. There are three components of hedonic wellbeing: 1) high levels of positive affect, 2) low levels of negative affect, and 3) life satisfaction, which refers to an individual's positive evaluation of their life (Diener, 1984). In their review of research on subjective/hedonic wellbeing, Diener (1984) suggests that personality traits, like self-esteem, may partially account for variance in hedonic wellbeing. However, life circumstances likely explain a majority of the variance in hedonic wellbeing (Diener, 1984). To contextualize this information, childhood cancer patients may exhibit lower levels of hedonic wellbeing as they encounter numerous negative life events like cancer diagnosis and treatment.

Other theories of wellbeing centre around eudaimonic wellbeing (Gallagher et al., 2009). Eudaimonic wellbeing refers to positive psychological functioning and the belief that one is living a purposeful life, unlike hedonic wellbeing which largely refers to presence of pleasurable emotions and absence of negative emotions (Gallagher et al., 2009). Eudaimonic wellbeing is more long-term than hedonic wellbeing and tends to be less impacted by external factors (Ryff, 1989). Ryff (1989) developed a six-component model of eudaimonic wellbeing which includes, 1) self-acceptance, 2) positive relations with others, 3) autonomy, 4) environmental mastery, 5) purpose in life, and 6) personal growth. Therefore, an individual exhibiting high levels of eudaimonic wellbeing will likely hold a positive attitude towards themself, have intimate relationships with others involving feelings of affection and empathy, have the ability to independently make life decisions, have the capacity to manage their life and environment, believe their life has meaning, and continue to grow and develop as a person (Ryff, 1989).

Social wellbeing is like eudaimonic wellbeing in that it refers to an individual’s functioning (Gallagher et al., 2009). However, social wellbeing differs from eudaimonic wellbeing in that it focuses more on interpersonal functioning (e.g., social integration, social acceptance) rather than intrapersonal functioning (e.g., autonomy, self-acceptance, personal growth) (Gallagher et al., 2009; Keyes, 1998). Keyes (1998) developed a five-component model of social wellbeing that included: 1) social actualization (realization of one’s potential in society), 2) social acceptance (inclusion of an individual in social groups), 3) social integration (the degree to which one feels they belong in their community), 4) social contribution (one’s social value in their community/society), and 5) social coherence (the strength of the relationships within a community).

Gallagher et al. (2009) integrated, hedonic, eudaimonic, and social theories of wellbeing to create a hierarchical structure of wellbeing. Hedonic, eudaimonic, and social wellbeing were highly correlated second-order factors in this hierarchical structure which suggests that changes in one dimension of wellbeing could lead to changes in the other dimensions of wellbeing (Gallagher et al., 2009). As such, the overall mental wellbeing of childhood cancer patients could be negatively impacted by cancer treatment as treatment may compromise certain aspects of wellbeing (e.g., autonomy). However, it is also possible that targeting certain aspects of wellbeing (e.g., social acceptance and integration) through psychosocial interventions could improve overall mental wellbeing in these children.

2.1.7b Mental Wellbeing in Childhood Cancer Patients

Chronic illness is associated with poor mental health (Friend et al., 2018). Although mental health and mental wellbeing differ, they are closely related constructs and as such, children with cancer may also experience lower levels of mental wellbeing (Galderisi et al., 2015). Current literature primarily focuses on the mental wellbeing of childhood cancer survivors rather than childhood cancer patients.

Positive self-concept and self-esteem are factors that contribute to good overall mental wellbeing and hedonic wellbeing (Diener, 1984; Tremolada et al., 2017). However, many childhood cancer survivors struggle with self-concept, self-esteem, and their sense of identity (Madan-Swain et al., 2000; Tremolada et al., 2017). For example, when compared with normative population values or their siblings, childhood cancer survivors have lower self-esteem (Seitzman et al., 2004; Speechley et al., 2006). Furthermore, one cross-sectional study reported that almost 90% of pediatric chemotherapy patients with acute lymphoblastic leukemia had low self-esteem (Sherief et al., 2015). Another study found that adolescent cancer patients undergoing active treatment were less likely to reach identity achievement status (highest identity development status) than their healthy peers (Gavaghan & Roach, 1987). This literature supports the need for interventions that promote self-esteem, self-efficacy, and sense of self as improvements in these areas could lead to improvements in the overall mental wellbeing of childhood cancer patients (Diener, 1984; Tremolada et al., 2017).

A 2010 systematic review concluded that completing cancer treatment can lead to lower levels of psychological wellbeing in children and adolescents as they transition from patients to survivors (Wakefield et al., 2010). Another study found that childhood cancer survivors tended to have greater negative affect (depression, anxiety, etc.) compared with a sibling comparison group and population normative values (Zeltzer et al., 2009). Furthermore, they found that brain tumour survivors were more likely to experience lower life satisfaction when compared with the sibling comparison group and leukemia survivors (Zeltzer et al., 2009). As higher levels of negative affect and lower life satisfaction are associated with lower hedonic wellbeing, the findings of this study suggest that childhood cancer survivors may be more likely to experience poor mental wellbeing compared with their siblings or the general population (Gallagher et al., 2009; Zeltzer et al., 2009). These results also suggest that the type of cancer diagnosis may influence mental wellbeing throughout survivorship as brain cancer tumour survivors differed from leukemia survivors in terms of life satisfaction (Zeltzer et al., 2009).

Social connectedness during adolescence and cancer treatment may promote higher future levels of mental wellbeing (Olsson et al., 2013). A 32-year longitudinal study found that social connectedness during adolescence was related to eudaimonic and social wellbeing in adult survivors of childhood cancer (Olsson et al., 2013). Specifically, the importance of social connectedness during adolescence was enduring, as 10 years later positive social relationships remained of significant importance to individuals who were highly socially connected (Olsson et al., 2013). As such, providing childhood cancer patients with opportunities to connect with others in a social setting may not only improve eudaimonic and social wellbeing in the short-term, but through survivorship as well. Adolescent and young adult cancer patients have previously indicated that there is a need for improved mental health support group services (Close et al., 2019). These support groups or other social interventions could help to improve long-term mental wellbeing in this oncology patient population.

The social comparisons childhood cancer patients make with their peers may also have negative effects on their hedonic wellbeing (Diener, 1984). The social comparison theory posits that evaluations of ones’ worth are based on comparisons with others (Diener, 1984). If a person is in a subjectively superior position to others, they will be satisfied thereby promoting hedonic wellbeing (Diener, 1984). If an individual feels they are inferior to those that they compare themselves, that comparison group could act as a role model that can inspire the individual (Meltzer & Rourke, 2005). However, it is also possible that the individual would feel discouraged and engage in negative self-evaluations, thereby reducing their hedonic wellbeing (Meltzer & Rourke, 2005). Adolescents with cancer reported feeling more like other adolescents with cancer than their peers from home (Meltzer & Rourke, 2005). Youth with cancer often engage in social comparison with healthy peers at school (Meltzer & Rourke, 2005). These peer groups are less like them and have less health-related barriers, and as a result, youth with cancer may experience poorer hedonic wellbeing (Meltzer & Rourke, 2005). Therefore, providing childhood cancer patients with an opportunity to engage in social comparison with other childhood cancer patients may lead to improved mental wellbeing as they would be able to make similar peer comparisons (Meltzer & Rourke, 2005).

2.1.8 Stress

Stress refers to a physiological state in which the body defends homeostasis and responds to stressors (White et al., 2021). Stressors refer to physical or psychological stimuli that disrupt homeostasis (White et al., 2021). Cognitive appraisal of environmental cues first occurs to determine whether a stimulus is a stressor (White et al., 2021). If exposure to a stressor has occurred, a stress response, which functions to maintain homeostasis, will follow (White et al., 2021).

2.1.8a The Stress Response

A stress response refers to the body's physiological responses to a stressor (Antoni & Dhabhar, 2019). A stress response involves the activation of the sympathetic-adrenal-medullar (SAM) axis and hypothalamic-pituitary-adrenal (HPA) axis (Chu et al., 2022). Following exposure to a stressor the SAM axis is rapidly activated which leads to increased secretion of norepinephrine and epinephrine (also known as noradrenaline and adrenaline) from the adrenal medulla and increased secretion of norepinephrine from the sympathetic nerves (Chu et al., 2022). Norepinephrine and epinephrine bind to α-adrenergic and β-adrenergic receptors within the body (Chu et al., 2022). The binding of these hormones to α-adrenergic receptors causes vasoconstriction of the blood vessels in the skin, gastrointestinal system, kidneys, and brain, while binding to β-adrenergic receptors causes vasodilation of the blood vessels in skeletal muscle, liver, and heart (Gordan et al., 2015; Reid, 1986). As a result, blood is shunted to the skeletal muscle, liver, and heart, providing these target areas with greater oxygenation (Gordan et al., 2015). The β-adrenergic receptors also lead to increased heart rate (Gordan et al., 2015). The combination of these physiological responses is called the "fight or flight" response (Gordan et al., 2015).

The HPA axis contributes to a slower, longer-acting stress response in comparison to the SAM activation (Russell & Lightman, 2019). After exposure to a stressor, the paraventricular nucleus releases corticotrophin-releasing hormone (CRH) which then binds to CRH-R1 and CRH-R2 receptors (Chu et al., 2022). Binding of CRH to CRH-R1 stimulates the anterior pituitary to release adrenocorticotropic hormone (ACTH) into circulation (Chu et al., 2022). ACTH then stimulates the adrenal cortex to secrete glucocorticoids which have much longer half-lives than epinephrine and norepinephrine (White et al., 2021). Cortisol is the primary glucocorticoid secreted in humans and it functions to promote glucose synthesis, and fat and protein metabolism, among other functions (White et al., 2021). Cortisol levels reach their peak about 15 to 20 minutes after the beginning of the stress response (Russell & Lightman, 2019). Through negative feedback loops, cortisol terminates the stress response (Hunter et al., 2011; White et al., 2021).

It should be noted that only unbound cortisol, which accounts for approximately 10% of circulating cortisol in humans, is biologically active (Chu et al., 2022). Circulating cortisol concentrations also follow a diurnal rhythm with cortisol levels starting high upon waking, increasing to peak levels within 30-40 minutes of waking, and then decreasing throughout the day (Adam et al., 2017).

2.1.8b Chronic Stress

Acute stress responses, typically lasting minutes to hours, are often beneficial as they prepare the body to respond to the challenges caused by stressors (Antoni & Dhabhar, 2019; Chu et al., 2022). However, chronic stress, which lasts from weeks to years, is maladaptive and has negative impacts on the body (Antoni & Dhabhar, 2019; Chu et al., 2022; Ketchesin et al., 2017; Russell & Lightman, 2019). Chronic stress is associated with impaired immune function (Antoni & Dhabhar, 2019), cardiovascular disease, cognitive impairment (Ketchesin et al., 2017), mental health disorders, metabolic disease, and obesity (Russell & Lightman, 2019).

2.1.8c Chronic Stress in Childhood Cancer Patients

In the context of cancer, chronic stress can be particularly problematic as it could contribute to cancer progression or poor response to cancer treatment (Antoni & Dhabhar, 2019). For instance, chronic stress may suppress protective immunity (Antoni & Dhabhar, 2019). The suppression of protective immunity is problematic as it is responsible for eliminating cancers that induce an immune response (immunogenic cancers), such as basal cell carcinoma, and it is critical for the success of cancer treatments, particularly tumour immunotherapy (Antoni & Dhabhar, 2019). Additionally, chronic stress may lead to increased circulating levels of proinflammatory markers which lead to chronic inflammation (Elenkov & Chrousos, 2002; Gouin et al., 2011). Chronic inflammation is a factor in the development, progression, and metastasis of cancers (Coussens & Werb, 2002). Taken all together, chronic stress has the potential to lead to poorer cancer-related outcomes (Antoni & Dhabhar, 2019).

Throughout the duration of their treatment, pediatric oncology patients encounter numerous significant stressors, such as painful procedures, significant body changes, and treatment-related functional impairments (Gerali et al., 2011; Rodriguez et al., 2012). A qualitative study reported that childhood cancer patients often have stressful emotional reactions regarding their cancer and side effects of cancer treatment including fear of death, dealing with uncertainty and pain, missing friends/school, and anxieties about treatment procedures (Hildenbrand et al., 2011). These stressors are problematic as high cortisol levels have been associated with psychological symptoms in cancer patients (Li et al., 2020). For instance, one study found significant positive associations between cancer-related stress and depressive symptoms in children with cancer (Miller et al., 2009).

Chronic stress in childhood can also lead to dysfunctional stress regulation (White et al., 2021). A 2011 systematic review found that 27 out of 30 studies reported associations between early childhood adversity and altered HPA axis response to stress (Hunter et al., 2011). Dysfunctional stress regulation is associated with neurological impairments (e.g., impaired memory and executive functioning), abnormal physiological differences (e.g., alterations in hippocampal structure), and psychosocial impairments (White et al., 2021). As such, the significant chronic stress childhood cancer patients experience throughout treatment can have a long-lasting negative impact on their physical and psychosocial health (White et al., 2021).

Cancer treatment could also impact circulating levels of free cortisol as treatment may increase childhood cancer patients'/survivors' risk of endocrine dysfunction (Wei & Crowne, 2018). Literature suggests that radiotherapy is implicated in HPA axis dysfunction (Wei & Crowne, 2018). For instance, one study found that 19% of childhood brain cancer survivors who were treated with cranial irradiation presented with HPA axis dysfunction as evidenced by low basal and peak cortisol levels (Schmiegelow et al., 2003). HPA axis dysfunction in childhood cancer survivors is not as common as other endocrine disorders (Wei & Crowne, 2018). However, if children experience HPA axis dysfunction causing them to be deficient in cortisol during periods of physiological stress, it could be life-threatening (Wei & Crowne, 2018).

Pediatric oncology patients who receive chemotherapy and/or synthetic glucocorticoids are at a greater risk of developing impairments in many neurocognitive functions, some of which are associated with effective coping (White et al., 2021). Coping impairments could place children at a greater risk of experiencing high levels of chronic stress as positive forms of coping have previously been associated with lower levels of distress in adolescents with cancer (Trask et al., 2003). Additionally, coping strategies involving social support and physical activity have been shown to effectively reduce levels of stress (Costa et al., 2017; Hill et al., 2008; Li et al., 2016; Uchino et al., 2012). However, the effects and restrictions of treatment may limit childhood cancer patients' ability to engage in these coping strategies due to functional impairments and absences from social spaces (e.g., school and/or extracurricular activities) (Christiansen et al., 2015; Götte et al., 2015).

In conclusion, the combination of chronic stress and cancer treatment without appropriate or sufficient coping responses may place childhood cancer patients at a greater risk of late effects, stress dysregulation, impaired coping, and poor psychological and physical health outcomes (Miller et al., 2011; Schmiegelow et al., 2003; Wei & Crowne, 2018; White et al., 2021). As such, stress management and monitoring of stress dysregulation should be a focus of care in pediatric cancer patients (Wei & Crowne, 2018).

2.2 Psychosocial Interventions for Pediatric Cancer Patients

Given the aforementioned psychosocial changes, targeting psychosocial interventions in this pediatric oncology group is important. Most literature on psychosocial interventions focuses on childhood cancer survivors rather than childhood cancer patients. Psychosocial interventions commonly aim to improve social skills and provide children with social support (Peikert et al., 2018). These psychosocial interventions can include outpatient group interventions, psychoeducational programs, family-oriented rehabilitation programs, computer-based interventions, outpatient individual programs, and oncology camps (Peikert et al., 2018). For this thesis, I will be focusing on the use of oncology camps as a psychosocial intervention for childhood cancer patients.

2.2.1 Recreational Oncology Camps

The development of ROCs began in the 1970s with the intent of using outdoor adventure programming to offer children with cancer and their families respite from the daily challenges of cancer treatment (Laing & Moules, 2016). Coinciding with the development of ROCs was an increase in the 5-year survival rate of childhood cancer from 58% to 85%, and the emergence of pediatric psycho-oncology which is a branch of psychiatry focusing on the psychosocial health of childhood cancer patients (Schepers, 2019). The increased focus on the psychosocial health of children with cancer and the increased number of childhood cancer survivors may have contributed to the development of ROCs. After observing the positive impact that ROC had on the lives of children with cancer, the administration of 12 original ROCs founded the Children's Oncology Camps of America in 1982 (Children's Oncology Camp Association, 2021). In 1996, the name of this organization changed to the Children's Oncology Camps of America, International (COCA-I) (Children's Oncology Camp Association, 2021). As of 2021, COCA-I consisted of 130 member ROCs across Canada and the United States (Children's Oncology Camp Association, 2021).

ROCs provide a medically safe environment for pediatric oncology patients to partake in a traditional overnight camp experience that is accommodated to meet their needs (Kelada et al., 2020; Martiniuk et al., 2014). Some ROCs, including Campfire Circle, offer day camp experiences as well. There are medical staff on-site which allows childhood cancer patients to attend camp even if they require treatment. Additionally, camp activities are accommodated to meet the needs of the camper population. For instance, high-ropes courses at these camps may have wheelchair-accessible portions for children with different mobility needs.

ROCs seem to have a positive impact on various psychosocial outcomes in campers, particularly in the areas of social support, psychosocial functioning, and self-esteem (Kelada et al., 2020; Martiniuk et al., 2014; Neville et al., 2019). A large portion of current literature investigating the psychosocial impact of ROCs has been qualitative. However, Moola et al. (2023) highlighted the need for more theoretically informed qualitative research. Qualitative studies have been beneficial for contributing to knowledge in this area as they explore the ROC experience, summarize camper attitudes towards ROC, and highlight potential benefits of ROCs. Although qualitative research suggests that childhood cancer patients have positive attitudes toward ROCs, further quantitative research should be conducted to determine if ROCs have a quantifiable impact on the psychosocial health of childhood cancer patients. Additionally, many quantitative methods could be employed relatively easily by ROC organizations to evaluate the efficacy of their programs. Randomized controlled trials are also lacking in this area of research thereby limiting the ability to determine whether causal relationships exist between ROC and psychosocial outcomes.

2.2.1a Impact of ROC on Social Outcomes

ROCs appear to have positive effects on social outcomes including social functioning (Gillard & Watts, 2013; Kiernan & Maclachlan, 2002; Neville et al., 2019; Wu et al., 2016), social support (Beckwitt, 2014; Békési et al., 2011; Dawson et al., 2012; Moola et al., 2023; Neville et al., 2019; Oppenheim, 2017; Riley, 2018; Ryan, 2017), and friendship making skills (Martiniuk et al., 2014). Most studies evaluating these outcomes obtained data from campers attending residential ROCs (between 6 to 10 days) for children with cancer and/or their siblings. For instance, in a large, multisite, cross-sectional study, the pediatric camp outcome measure was used to collect data from 2,114 oncology camp attendees including childhood cancer patients/survivors and their siblings aged 6 to 18 years old (Wu et al., 2016). Based on camper reports collected at the end of camp, social functioning was high in ROC attendees. Additionally, the number of years that children attended camp previously was positively correlated with social functioning. Therefore, social functioning appears to be high in children with cancer and their siblings while attending ROC and is higher in children who have previously attended ROC.

Several studies reported that campers at ROCs felt that they improved their social (Gillard & Watts, 2013; Kiernan & Maclachlan, 2002; Neville et al., 2019) and friendship skills (Martiniuk et al., 2014), felt a sense of normalcy and acceptance, and were able to develop positive social relationships with campers and counsellors that created a sense of community while at camp (Beckwitt, 2014; Dawson et al., 2012; Moola et al., 2023; Riley, 2018; Ryan, 2017). In a 2010 quantitative study, adolescent oncology camp attendees reported feeling more similar to other campers than their peers from home (Meltzer & Rourke, 2010). These similar peer comparisons were associated with positive psychosocial outcomes, including social acceptance, in adolescents with cancer (Meltzer & Rourke, 2010). Furthermore, a recent qualitative study reported that many ROC attendees felt they were able to form close relationships with other children and camp counsellors more quickly than they were able to form relationships outside of ROC (Moola et al., 2023). Some campers also discussed the sense of community that the ROC environment fostered and described this community to be like a family (Moola et al., 2023).

Overall, qualitative research suggests that ROCs have a positive impact on social outcomes, including social support, in childhood cancer patients and survivors (Beckwitt, 2014; Dawson et al., 2012; Moola et al., 2023; Riley, 2018; Ryan, 2017). However, some quantitative studies have not supported this (Békési et al., 2011; Oppenheim, 2017). A 2011 quantitative, repeated measures study investigated the impact of therapeutic recreation camp programming on health-related quality of life in children with cancer, diabetes, and juvenile arthritis (Békési et al., 2011). Overall health-related quality of life improved from two months pre-camp to two months post-camp; however, children with cancer did not experience a significant improvement on the social support subscale of the KIDSCREEN-52 questionnaire between these timepoints (Békési et al., 2011). It is possible that these null findings could also be explained if children with cancer did experience an improvement in social support during camp that was not sustained two months post-camp. Another quantitative, repeated measures study found that perceived levels of social support increased significantly in adolescent female campers between the first day of camp and four to six months post-camp, but decreased in adolescent male campers (Oppenheim, 2017). Notably, this study did not use a validated measure of social support, and over half of the participants in this study were siblings of children with cancer. It is possible that the siblings of childhood cancer patients do not experience the same level of social isolation as childhood cancer patients because they can continue going to school with fewer disruptions. Therefore, baseline social support levels may have been inflated in this participant sample leading to mixed results regarding social support changes after ROC.

2.2.1b Impact of ROC on Psychosocial Health & Wellbeing

In their narrative review, Neville et al. (2019) concluded that ROC participation may protect against negative psychosocial health implications of cancer treatment. They also suggest that ROCs may promote the wellbeing of children with cancer by addressing their social health, improving attitudes, mental health (e.g., anxiety), sense of self (e.g., self-esteem), and dimensions of wellbeing (e.g., quality of life), and providing them with a sense of normalcy. Although current literature suggests that ROC may promote children’s wellbeing, to our knowledge, there have been no published quantitative studies that directly measure mental wellbeing in childhood cancer patients attending an ROC.

Li et al. (2013) conducted the only randomized controlled trial to date that investigates a type of oncology camp programming. However, this study implemented a four-day health education and adventure-based training program rather than a traditional ROC. They compared the physical activity levels, self-efficacy, and quality of life of childhood cancer survivors in the adventure-based training program to childhood cancer survivors who completed leisurely activities instead. Childhood cancer survivors in the adventure-based training program had significantly higher levels of physical activity and self-efficacy than the controls. Consistent with findings of adventure-based training having a positive effect on self-efficacy in childhood cancer survivors, several studies suggest that ROCs have a positive impact on confidence and self-esteem in children with cancer (Békési et al., 2011; Dawson et al., 2012; Mcgrane, 2016; Riley, 2018; Torok et al., 2006). Perseverance during challenging ROC or adventure-based training activities could build confidence in these children (Kelada et al., 2020).

Li et al. (2013) found that the adventure-based training program did not have any significant effects on childhood cancer survivors’ quality of life. However, the experimental group experienced significant increases in quality of life between pre-intervention, and three, six, and nine months after starting the adventure-based training program. This improvement in quality of life is consistent with other studies’ findings of improved health-related quality of life in childhood cancer patients/survivors who attend ROCs or adventure therapy programs (Békési et al., 2011; Stevens et al., 2004). Therefore, ROCs and/or adventure therapy program participation may contribute to improvements in the (health-related) quality of life of childhood cancer patients/survivors, thereby promoting their overall wellbeing (Békési et al., 2011; Li et al., 2013; Stevens et al., 2004).

Research also suggests that ROC attendance is associated with improvements in attitude and mental health (Neville et al., 2019). Following overnight ROC attendance (approximately one-week sessions), studies have reported high levels of emotional functioning (Wu et al., 2016), increased positive attitudes (Gillard & Watts, 2013), decreased internalizing behaviours (Stein, 2017), and improved affective symptoms (Wellisch et al., 2006) in children with cancer. Prior ROC attendance has also been found to be associated with higher levels of benefit-finding (ie. finding positive outcomes from challenging life events like cancer treatment) and the total number of strategies used to cope with cancer-related stressors (Ryan, 2017) in childhood cancer patients/survivors. Oppenheim (2017) found improvements in the psychosocial adjustment of adolescent female ROC attendees; however, it is unclear how psychosocial adjustment was measured in this study. Another quantitative, repeated measures study investigated trait anxiety in adolescents who attended camp programs for youth with either cancer or diabetes (Torok et al., 2006). Trait anxiety did not change from the first to last day of camp; however, it increased significantly from the end of camp to 2-months post-camp (Torok et al., 2006). It is possible that disease-specific camp created an environment where campers felt safe thereby resulting in lower levels of trait anxiety while at camp.

In conclusion, current literature suggests that ROC attendance may promote positive health outcomes and the wellbeing of children with cancer. However, mental wellbeing has not yet been directly evaluated in a pediatric oncology population attending ROC.

2.2.1c Impact of ROC on Resilience & Hope

Only one study has investigated the impact of ROC on resilience and hope in childhood cancer patients/survivors. O'Keeffe (2022) found clinically meaningful improvements in the resilience and hope of childhood cancer patients/survivors after participating in a one-month virtual ROC. However, this study was limited by a small sample size and the virtual ROC experience differs from in-person ROC, therefore these results may not be generalizable. As such, it is important to directly measure whether in-person ROCs will facilitate resilience and hope in this patient population. Another quantitative, repeated measures study investigated hope in youth aged eight to 19 years old who had a chronic illness and attended a week of camp programming designed for children with chronic medical conditions (Woods et al., 2013). They found that hope increased significantly in children with chronic illnesses from pre-camp to the last day of camp (Woods et al., 2013). Although these findings are not specific to ROCs, there are similarities between camps for children with chronic medical conditions and ROCs. Therefore, these studies suggest that hope may be improved in children with chronic medical challenges following disease-specific camp programming (O'Keeffe, 2022; Woods et al., 2013).

2.2.1d Impact of ROC on Stress

There have been no quantitative studies evaluating the impact of ROCs on stress in childhood cancer patients. However, a cross-sectional study reported that repeat ROC attendance was associated with a greater number of strategies used to cope with cancer-related stressors in childhood cancer patients/survivors (Ryan, 2017). These results suggest that ROCs may contribute to the development of coping strategies in childhood cancer patients/survivors thereby promoting healthy management of stress in this patient population.

Gillard & Watts (2013) identified respite from daily life as a primary feature of ROCs. At ROCs, children with cancer can experience freedom by being able to participate in activities that they may be deterred from at home due to parental worries about risk (Gillard & Watts, 2013). These camps offer children with cancer the opportunity to engage in developmentally appropriate activities and "just be a kid" while still managing the demands of their cancer, such as treatment that they can receive on-site (Gillard & Watts, 2013). By providing childhood cancer patients with a medically safe environment where they can experience respite from daily life, ROCs may help to reduce stress in these children.

2.2.1e Limitations & Future Directions of ROC Research

Most studies evaluating the psychosocial impact of ROCs included childhood cancer patients, long-term survivors, and sometimes their siblings as participants. Wu et al. (2016) reported that scores on the pediatric camp outcome measure were similar between patient and sibling campers, except for emotional functioning and self-esteem subscales where patients scored higher. Interestingly, the scores of campers who were on active treatment, or had a sibling on active treatment, were lower than those of campers who were off treatment (Wu et al., 2016). These findings suggest that childhood cancer patients (on and off active treatment), survivors, and their siblings may have different psychosocial needs. As such, psychosocial interventions may affect these children differently. Therefore, the impact of ROCs on childhood cancer patients should be evaluated independently of their siblings, particularly considering the impact of ROC has already been investigated in childhood cancer survivors and siblings exclusively.

There is further research investigating ROCs; however, these additional studies have been excluded from the current review of the literature as they either a) did not include childhood cancer patients or survivors as participants, or b) focused primarily on family oncology camps, and as such, are not relevant to the topic of this thesis. Current literature supports ROCs as a promising psychosocial intervention for childhood cancer patients/survivors; however, literature in this area has been limited due to a lack of comparison groups, little long-term evidence of psychosocial benefits, the use of non-validated quantitative measures (Oppenheim, 2017; Stein, 2017), participant samples that include a combination of childhood cancer patients/survivors and their siblings, and relatively small sample sizes (Beckwitt, 2014; Békési et al., 2011; Mcgrane, 2016; Oppenheim, 2017; Stein, 2017; Torok et al., 2006; Wellisch et al., 2006). It is necessary to further investigate the impact of ROCs on childhood cancer patients’ psychosocial health, including resilience, hope, social functioning, mental wellbeing, and stress, as the impact of ROCs on social functioning/social support is unclear, and no studies have directly evaluated resilience, hope, mental wellbeing, or stress as psychosocial outcomes of in-person ROC.

Chapter 3: Materials and Methods

3.1 Ethics Approval

This study was approved by the Research Ethics Board at Trent University on June 14th, 2022 (REB #28022).

3.2 Study Population & Recruitment

In this prospective study, we worked with childhood cancer patients who attended one session (session 2; July 17th, 2022 – July 28th, 2022) of the in-person oncology overnight camp programming at Campfire Circle, Muskoka. Prospective participants were contacted via email from the Campfire Circle registration list. A recruitment email containing a letter of consent and study information was sent to children and their parents/caregivers on June 30th, 2022 (see Appendix 6.1 and 6.2). Approximately 80 children were invited to participate in this study. Participants were made aware that their participation was voluntary, they could choose not to complete the survey and/or provide saliva samples, and they could withdraw from the study at any point without affecting their ability to participate in camp programming. Eligibility criteria for the study included: 1) aged 6 to 18 years; 2) has a cancer diagnosis; 3) is at any stage of treatment, including post-treatment; 4) determined to have the capacity to assent and complete study testing.

All campers followed regular camp programming, regardless of their decision to participate in the study. Informed consent was obtained before study testing through a detailed information letter/letter of consent signed by both the participant and their caregiver. Signed consent forms were either emailed to Campfire Circle or printed and brought to camp with the child. Upon arrival at camp, all campers met with medical staff for a wellness check-in. At this time, campers who had provided a signed consent form met with a member of the research team. Only campers with a consent form signed by themselves and their parent/guardian were eligible to participate. Participants were compensated for their time with a $50 gift card to Mastermind. The gift cards were mailed to participants following the end of the 10-day in-person camp.

3.3 Overview of Study Design

This was a prospective study designed to examine the impact of a ten-day oncology camp experience on multiple aspects of psychosocial health including the resilience, hope, perceived social support, mental wellbeing, and stress of childhood cancer patients. Participants completed study testing at three timepoints: baseline (day 1; upon arrival at camp), post-camp 1 (day 10; the last full day of camp), and post-camp 2 (three months after camp). Data for the first two timepoints were collected in person at Campfire Circle by members of the research team. Post-camp 2 data were collected virtually via the Qualtrics online survey platform.

3.4 Intervention

Campfire Circle (formerly Camp Trillium and Camp Ooch) is a privately funded charity organization that provides camp programming designed specifically for supporting children and families affected by childhood cancer. Their mission is to "foster resilience, well-being, and lifelong connections for children with serious illness and their families through camp-inspired programs" (CampfireCircle, 2022). Through Campfire Circle's children and family camps, childhood cancer patients/survivors, their families, and bereaved families can attend camp programming at no cost to them. For this study, data was collected during the second session of overnight camp for summer 2022 (July 17th, 2022 to July 28th, 2022) at Campfire Circle, Muskoka. This camp session was exclusively for the attendance of childhood cancer patients (and not siblings and/or their families). Campers participated in various activities throughout the 12-day camp session, including waterskiing, arts and crafts, high-ropes courses, pottery, music, campfires, canoeing, kayaking, swimming, fishing, among other activities.

3.5 Study Measures

Surveys were administered at baseline, post-camp 1, and post-camp 2 via the Qualtrics survey platform (Appendix 6.3). Each survey took approximately 10 minutes to complete. The following validated scales were included in the survey: Child and Youth Resilience Measure (Jefferies et al., 2019), Children's Hope Scale (Snyder et al., 1997), Social Provisions Scale-5 (Orpana et al., 2019), and Short Warwick-Edinburgh Mental Wellbeing Scale (Stewart-Brown et al., 2009). The surveys were identical at each timepoint with a couple of exceptions. First, the survey administered at baseline testing included demographic-related questions (self-reported age, gender, and race) before the scales. Second, the surveys administered at baseline and post-camp 1 were administered by a member of the research team who sat with each participant, and it included a question for a member of the research team to input the participant's study ID. The post-camp 2 survey did not include a question about study ID, but instead, personalized links associated with each study ID were created and emailed to the appropriate participant in order to connect survey responses to study IDs. At post-camp 2, surveys were completed independently by participants.

Saliva samples were collected at baseline and post-camp 1 testing only. These samples were used to determine salivary cortisol concentrations as cortisol is a biomarker of stress (White et al., 2021).

3.5.1 Study Timeline

The study timeline, including the measures used at each timepoint, is summarized in Figure 1.

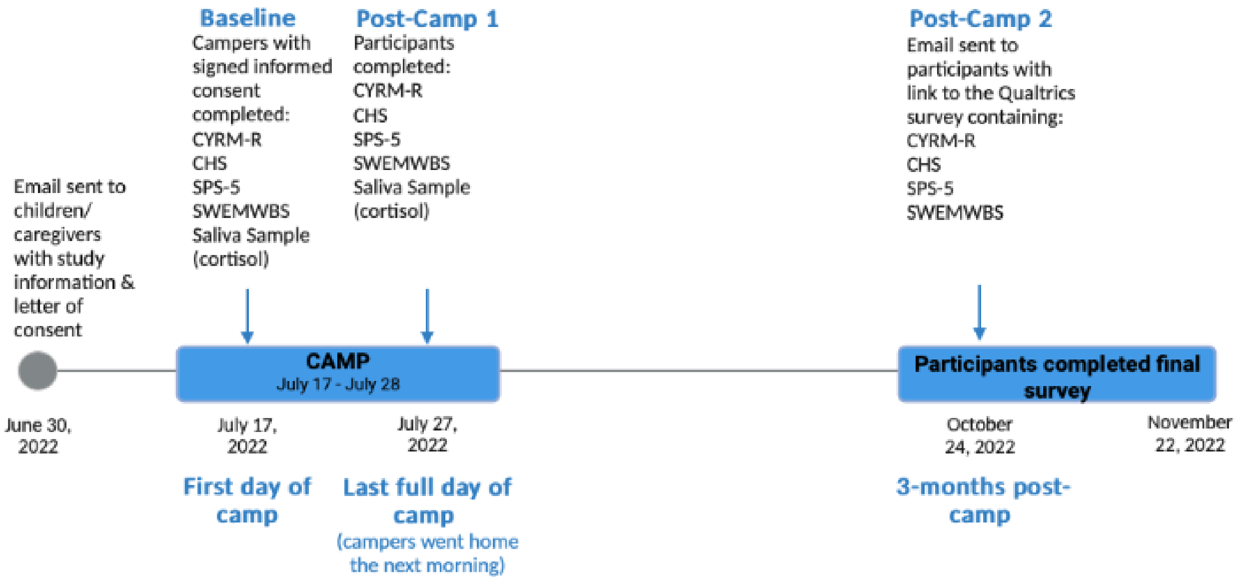

Figure 1. Study timeline including three timepoints: 1) baseline (first day of camp); 2) post-camp 1 (last full day of camp); 3) post-camp 2 (three months post-camp). Child and Youth Resilience Measure (CYRM); Children's Hope Scale (CHS); Social Provisions Scale-5 (SPS-5); Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS).

3.5.2 Resilience

We measured resilience using the Child and Youth Resilience Measure (CYRM-R) (Appendix 6.4). The CYRM-R is a 17-item scale that is validated against the Rasch model. This scale uses two subscales: intra/interpersonal resilience (10 items; items 1, 2, 3, 7, 9, 10, 12, 13, 14, 16) and caregiver resilience (7 items; items 4, 5, 6, 8, 11, 15, 17) (Jefferies et al., 2019). The personal resilience subscale relates to intra/interpersonal characteristics, whereas the caregiver resilience subscale relates to items associated with the relationship between the participant and their caregiver(s) (Resilience Research Centre, 2018). The CYRM-R indicates the extent to which children use internal and external resources to adapt to or manage significant sources of stress (Jefferies et al., 2019; Liebenberg et al., 2012). This scale has been validated in individuals aged 5 to 23 years and has demonstrated high internal reliability through a Cronbach's alpha of 0.82 for both subscales and 0.87 for overall resilience (Jefferies et al., 2019; Resilience Research Centre, 2018).

Following recommendations from our partner (Campfire Circle) to contextualize the CYRM (Resilience Research Centre, 2018), two items were removed from this measure as they were not relevant to the children's camp experience. Item 6, "Is there enough to eat in your home when you are hungry?", and item 4, "Do you feel that your parent(s)/caregiver(s) know where you are and what you are doing all of the time?", were removed. As such, 15 items remained on the CYRM that was administered for this study (Appendix 6.5).

When completing this scale, children scored each item on a 5-point Likert scale ranging from "not at all" which was associated with the lowest score of 1, to "a lot" which was associated with the highest score of 5. Participants were also provided with a pictorial scale using smiley faces ranging from happy to very happy as recommended by Hall et al. (2016) (Appendix 6.4). Scores for all items were directly summed to obtain a total score. As we used a 15-item scale for this study, the lowest possible score was 15 and the highest possible score was 75, with higher scores reflecting higher levels of resilience. Scores for items 1, 2, 3,7, 9, 10, 12, 13, 14, and 16 were directly summed to obtain a score for the personal resilience subscale with possible scores ranging from a minimum score of 10 to a maximum score of 50. As two items were removed from the caregiver resilience subscale, this subscale was not scored independently.

3.5.3 Hope

We assessed hope using the Children's Hope Scale (CHS) (Appendix 6.6). The CHS is a 6-item scale that encompasses agency and pathways thinking to assess overall levels of hope (Snyder et al., 1997). The three odd-numbered items on the CHS measure agentic thinking, while the three even-numbered items measure pathways thinking. This scale has demonstrated convergent, discriminant, and incremental validity. It has also been validated in children aged 7 to 17 with no significant gender, racial, or age differences in scoring (Snyder et al., 1997; Valle et al., 2004). Snyder (1977) reported Cronbach's alpha values ranging from 0.72 to 0.86, thus supporting the internal reliability of the CHS. Test-retest reliability was acceptable, ranging from 0.71 over a one-month period, to 0.73 over a one-week period.

Participants were instructed to think about how they are in most situations when responding to each item. Responses to each item were on a 6-point Likert scale ranging from "none of the time" which was associated with the lowest score of 1, to "all of the time" which was associated with the highest score of 6. Scores for all items were directly summed to obtain a total hope score, and scores for the odd-numbered and even-numbered items were directly summed to calculate the total agency and pathways scores, respectively. Therefore, individual scores for agency and pathways could range from 3 to 18, while total hope scores could range from 6 to 36. Higher scores indicated a child demonstrated higher levels of hope through their ability to develop routes towards their goals (pathways) and to initiate and sustain their progression towards their goals (agency) (Snyder et al., 1997).

3.5.4 Social Support

We used the Social Provisions Scale-5 (SPS-5) as a measure of social support (Appendix 6.7). The SPS-5 is a brief version of the original SPS developed by Cutrona & Russel (1987) and the first short form of the SPS (SPS-10). This scale uses positively worded items to assess perceived social support. It includes 5-subscales (one item per scale) and each subscale measures a different social function (provision) that can be obtained from interpersonal relationships as described by Weiss' (1974) model of social provisions (Orpana et al., 2019; Weiss, 1974). These social provisions include guidance (advice or information that can be used in the context of problem-solving), reliable alliance (the sense that one can count on others to support and assist them), reassurance of worth (an individual's value is recognized by others), attachment (emotional bond that creates a sense of security), and social integration (sense of belonging to a group) (Orpana et al., 2019).

The SPS-5 has been validated against the first short-form of the SPS (SPS-10) and demonstrated criterion-related and structural validity (Orpana et al., 2019). A modified version of the original SPS developed by Cutrona & Russel (1987) was validated in adolescent females in grades 7 and 8 (Motl et al., 2004), and the SPS-10 was validated in individuals as young as 16 years old (Steigen & Bergh, 2019). The SPS-5 demonstrated high internal reliability with a Cronbach's alpha value of 0.88 (Orpana et al., 2019).

Before responding, children were instructed to indicate the extent to which they agreed that each item described their current social relationships. Responses were based on a 4-point Likert scale ranging from “strongly disagree” which was associated with the lowest score of 1, to “strongly agree” which was associated with the highest score of 4. Scores for all items were directly summed to obtain a total score. Therefore, total scores could range from 5 to 20, with higher scores reflecting higher levels of perceived social support.

3.5.5 Mental Wellbeing

We assessed mental wellbeing using the Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWS) (Appendix 6.8). This is a 7-item scale that assesses overall mental wellbeing through measures of feeling good (hedonia) and functioning well (eudaimonia) (Shah et al., 2021). The original WEMWBS was 14 items; however, 7 items from this scale were removed, creating the SWEMWBS, due to misfit with the Rasch model and gender bias (Stewart-Brown et al., 2009). The SWEMWBS has been validated against the Rasch model and demonstrated construct validity (Koushede et al., 2019; Mckay & Andretta, 2017; Melendez-Torres et al., 2019; Ringdal et al., 2018; Shah et al., 2021; Stewart-Brown et al., 2009). This scale also demonstrated high internal reliability with a Cronbach’s alpha of 0.88 (Koushede et al., 2019; Ringdal et al., 2018). The SWEMWS has been validated in adolescents aged 11 years and older (Mckay & Andretta, 2017; Melendez-Torres et al., 2019; Ringdal et al., 2018; Stewart-Brown et al., 2009).

Before providing responses, children were instructed to select the response that best suited their experience of each item over the previous two weeks. Responses to items were on a 5-point Likert scale ranging from “none of the time” which was associated with the lowest score of 1, to “all of the time” which was associated with the highest score of 5. Scores for all items were directly summed to obtain a total score. Therefore, total scores could range from 7 to 35, with higher scores reflecting better overall mental wellbeing.

3.5.6 Cortisol Concentrations to Estimate Stress Levels

Saliva samples were collected using the Salimetrics® SalivaBio Oral Swab collection method at baseline and post-camp 1 testing (Salimetrics, 2022). Most samples were collected between 5:00 pm and 8:00 pm at baseline testing, and between 2:00 pm and 6:00 pm at post-camp 1 testing. The SalivaBio oral swab is a small cotton swab. Participants removed the swab from its packaging and held it under their tongue. After one minute, they spit the swab into a falcon tube labelled with their study ID. The falcon tubes were stored at 4°C in a cooler before being transported back to Trent University on the same day as data collection. The falcon tubes were then stored at -20°C.

Four months after data collection, the samples were thawed (approximately two hours), and centrifuged at 1500g for 15 minutes at 21°C. The centrifugation of the falcon tubes caused the saliva in the oral swab to collect in the bottom of the falcon tube. The Salimetrics® Cortisol Enzyme Immunoassay Kit and protocol were used to assess the salivary cortisol concentrations of each sample (Salimetrics, 2021). This competitive immunoassay used a microtitre plate with antibody binding sites specific to cortisol. The cortisol enzyme conjugate (cortisol conjugated to horseradish peroxidase) competed with the cortisol within the standards, samples, and high and low cortisol concentration controls for the antibody binding sites in the wells of the microtitre plate. All samples, standards, controls, zeros, and non-specific binding wells were run in duplicate. The standard curve was appropriate, and all samples fell within the range of the standard curve, so sample dilutions were not necessary (Salimetrics, 2021). The optical densities of the wells were read on a standard plate reader at 450 nm within 10 minutes of adding the stop solution.

The mean optical density of the non-specific binding wells was subtracted from that of the other wells to account for any binding of proteins (other than cortisol) to the antibodies. The mean adjusted optical density values were divided by the mean adjusted optical density for the zeros to calculate the percent bound for each sample, standard, and control. A standard curve was created using the standard concentration versus percent bound values (see Appendix 6.9). From this standard curve, the cortisol concentrations of the samples were interpolated.

3.5.7 Demographic Measures

Demographic questions pertaining to age, race, and gender were included in the survey completed at baseline testing (Appendix 6.3). Participants had the option to not answer any of these questions if that was their preference. Cancer-specific information, including primary cancer diagnosis, date of first cancer diagnosis, treatment status, and the number of years of camp attendance, were extracted from camp records by staff from Campfire Circle.

3.6 Statistical Analysis

Repeated-measures analysis of variance (ANOVA) tests were used to determine whether there were statistically significant differences in resilience, hope, social support, and mental wellbeing between the three timepoints (baseline, post-camp 1, and post-camp 2). Tukey's post-hoc tests were used to determine where the differences were between each timepoint. Additionally, Cohen's d was used to measure effect size between each timepoint (0.20 = small effect size; 0.50 = medium effect size; 0.80 = large effect size) (Sullivan & Feinn, 2012).

Shapiro-Wilk tests were performed to determine whether baseline and post-camp 1 data followed a normal distribution. Paired t-tests (normal data; mental wellbeing) and Wilcoxon signed ranks tests (non-normal data; resilience, hope, social support, and salivary cortisol concentrations) were performed to evaluate whether levels of each outcome differed between baseline and post-camp 1. Using the paired t-test/Wilcoxon signed ranks test to compare outcomes for the first two timepoints allowed us to use a larger sample size as we were missing data at the third timepoint due to attrition. As survey responses were connected to participants' study IDs, we were able to determine which participants completed which timepoints and evaluate outcomes accordingly. Thus, data was used from all participants who completed baseline and post-camp 1 testing for the paired t-tests/Wilcoxon signed ranks tests, but only data from participants who completed study testing at all three timepoints were used for the repeated-measures ANOVAs. If a participant did not complete all scale items, their data for that scale was excluded from analyses.

For statistical tests of evaluating changes in resilience, mean CYRM total score and mean CYRM personal resilience score were dependent variables and timepoint was a factor variable. When evaluating changes in hope, mean CHS total score, mean CHS agency score, and mean CHS pathways score were dependent variables and timepoint was a factor variable. To assess social support, mental wellbeing, and stress, mean SPS-5 score, mean SWEMWBS score, and mean salivary cortisol concentration were dependent variables of their respective statistical tests and timepoint was a factor variable.

Pearson correlation coefficient (normal data) and Spearman's correlation (non-normal data) were used to measure associations between psychosocial outcomes (resilience, hope, social support, mental wellbeing) and the number of years participants attended ROC, as well as the number of years since participants' primary cancer diagnosis. Spearman's correlation (non-normal data) was also used to evaluate associations between positive psychosocial outcomes (resilience, hope, social support, mental wellbeing). All statistical analyses were performed using SPSS (version 29.0) statistical software and significance was accepted at $p<0.05$.

Chapter 4: Results

4.1 Participants

The study team received 26 consent forms signed by both the camper and their parent/caregiver prior to baseline testing. Due to timing issues (delay of camper arrival and the start of camp programming), we were unable to collect data from two participants during baseline testing, but they were able to participate in post-camp 1 and post-camp 2 testing. Out of the 24 participants who completed baseline testing, one participant went home before the end of camp and did not complete post-camp 1 or post-camp 2 testing. The remaining 23 participants who completed baseline testing also completed post-camp 1 testing. One of these participants had not answered a question on the SWEMWBS scale. As such, their SWEMWBS score was not calculated and their data for the SWEMWBS scale was excluded from analysis; however, their data from the other scales was used for analysis. There were 10 participants who completed study testing at all three timepoints, and all surveys administered to these participants were complete. Therefore, when we present data for all 3 time points (baseline, post-camp 1, and post-camp 2; repeated measures ANOVA) this is data from an N=10; when we present data between 2 time points (baseline and post-camp 1; T-test) this is from an N=23.

For this thesis, we excluded the data collected from the participants that had not completed both baseline and post-camp 1 testing (see Figure 2).

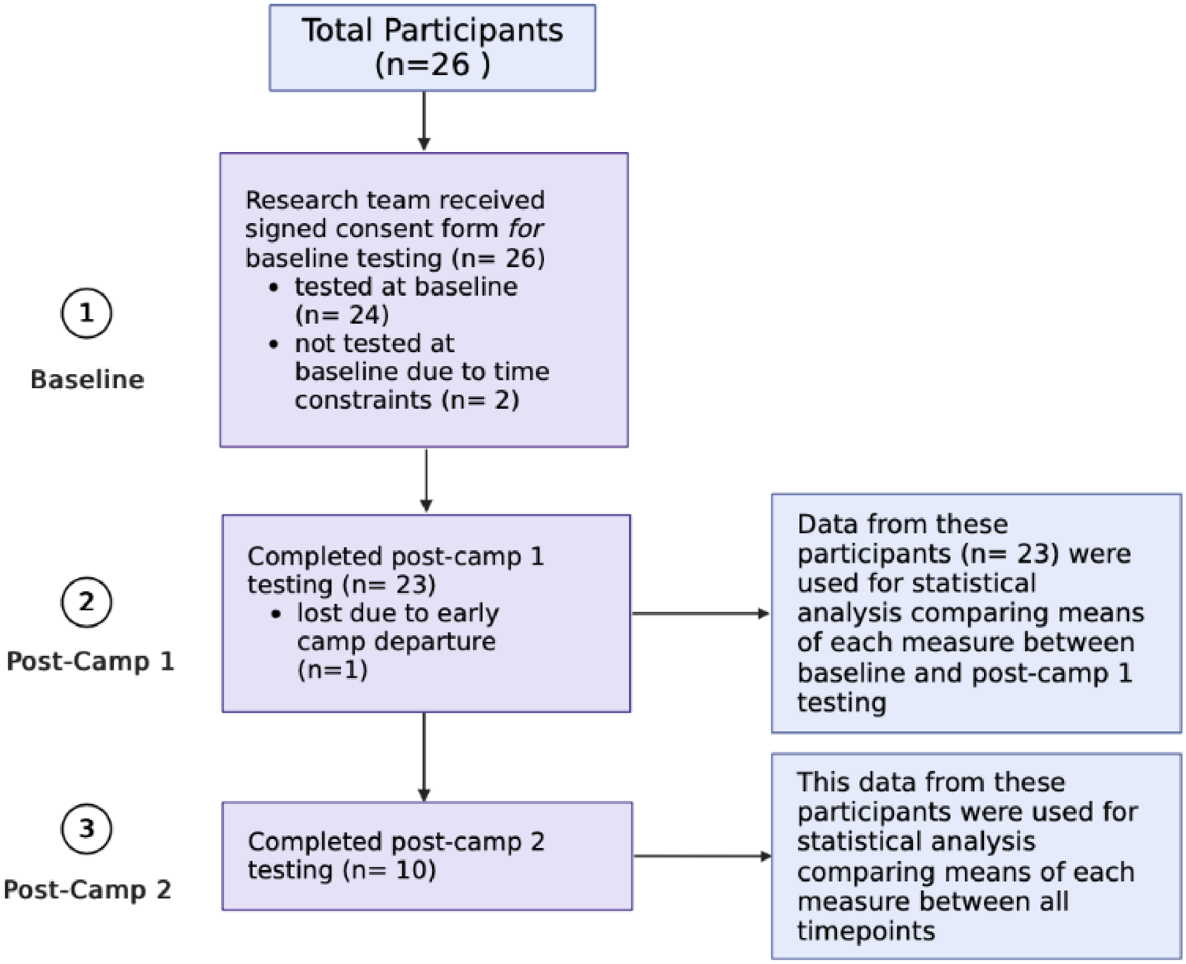

Figure 2. Flow chart of participation at recruitment (June 30th – July 17th, 2022), baseline testing (July 17th, 2022), post-camp 1 testing (July 27th, 2022), and post-camp 2 testing (October 24th – November 22nd, 2022).

4.2 Demographic Characteristics

Demographic characteristics are summarized in Table 1. Over half of the participants identified as female, with most participants identifying as Caucasian. The primary cancer diagnosis was leukemia, and the mean number of years that participants had been attending ROC was ~ 4 years.

Table 1: Descriptive statistics of participants from the first two timepoints (baseline and post-camp 1) and all 3 timepoints (baseline, post-camp 1, and post-camp 2).

	2 Timepoints (N=23)	**3 Timepoints (N=10)**
Mean Age (SD)	12.9 (2.7)	14.1 (2.5)
Median Age	13	13.5
Number of Participants On Active Treatment	1	1
Gender (%)		
Female	52.2%	60.0%
Male	43.5%	40.0%
Non-binary	4.3%	0.0%
Race (%)		
Southeast Asian	8.7%	20.0%
Caucasian	69.6%	50.0%
Chinese	13.0%	30.0%
Asian/Hispanic	4.3%	0.0%
Black/Caucasian	4.3%	0.0%
Diagnosis (%)		
Leukemia	60.9%	70.0%
Solid Tumour	21.7%	20.0%
Brain Tumour	17.4%	10.0%
Mean Number of Years Since Primary Cancer Diagnosis (SD)	7.7 (3.4)	7.6 (4.3)
Median Number of Years Since Primary Cancer Diagnosis	8	8
Mean Number of Years Attending Overnight ROC (SD)	4.1 (2.2)	4.7 (2.5)
Median Number of Years Attending Overnight ROC	4	6
Mean Number of Years Attending Any ROC (SD)	5.3 (2.5)	6.2 (2.7)
Median Number of Years Attending Any ROC	5	7.5

4.3 Pediatric Cancer Patient Resilience

4.3.1 Comparison of Baseline, Post-Camp 1, and Post-Camp 2

CYRM data from baseline, post-camp 1, and post-camp 2 testing (N=10) are illustrated in Figure 3. Figure 4 illustrates the CYRM scores of each participant across timepoints. Repeated measures ANOVA found no significant differences between baseline, post-camp 1, and post-camp 2 in the CYRM scores of participants (F=2.536, p=0.140) (see Figure 3). However, Cohen's d revealed a large effect size (decrease) in CYRM scores from post-camp 1 to post-camp 2 (d=0.76). No significant differences were found between baseline (42.60±6.26), post-camp 1 (42.30±5.25), and post-camp 2 (39.70±5.10) in the CYRM personal resilience subscale scores of participants (F=1.760, p=0.233).

4.3.2 Comparison of Baseline and Post-Camp 2

A Wilcoxon signed ranks test (N=23) found differences in mean CYRM scores between baseline (67.30±7.41) and post-camp 1 (66.67±6.99) to be insignificant (Z=-0.768, p=0.442). Additionally, there were no significant differences between the mean CYRM personal resilience subscale score at baseline (44.22±5.01) and post-camp 1 (43.39±4.93) (Z=-1.298, p=0.194).

4.3.3 Correlations

Baseline and post-camp 1 CYRM scores were not associated with the number of years children had attended ROC (r(21) = 0.116, p = 0.598; r(21) = 0.159, p = 0.468). However, baseline and post-camp 1 CYRM scores were positively correlated with the number of years since children received their cancer diagnosis (r(21) = 0.458, p = 0.028; r(21) = 0.523, p = 0.010). Mean baseline CYRM scores were also associated with baseline hope (CHS) scores, but not with baseline social support (SPS-5) or mental wellbeing (SWEMWBS) scores (r(21) = 0.707, p<0.001; r(21) = 0.329, p = 0.125; r(20) = 0.034, p = 0.880).

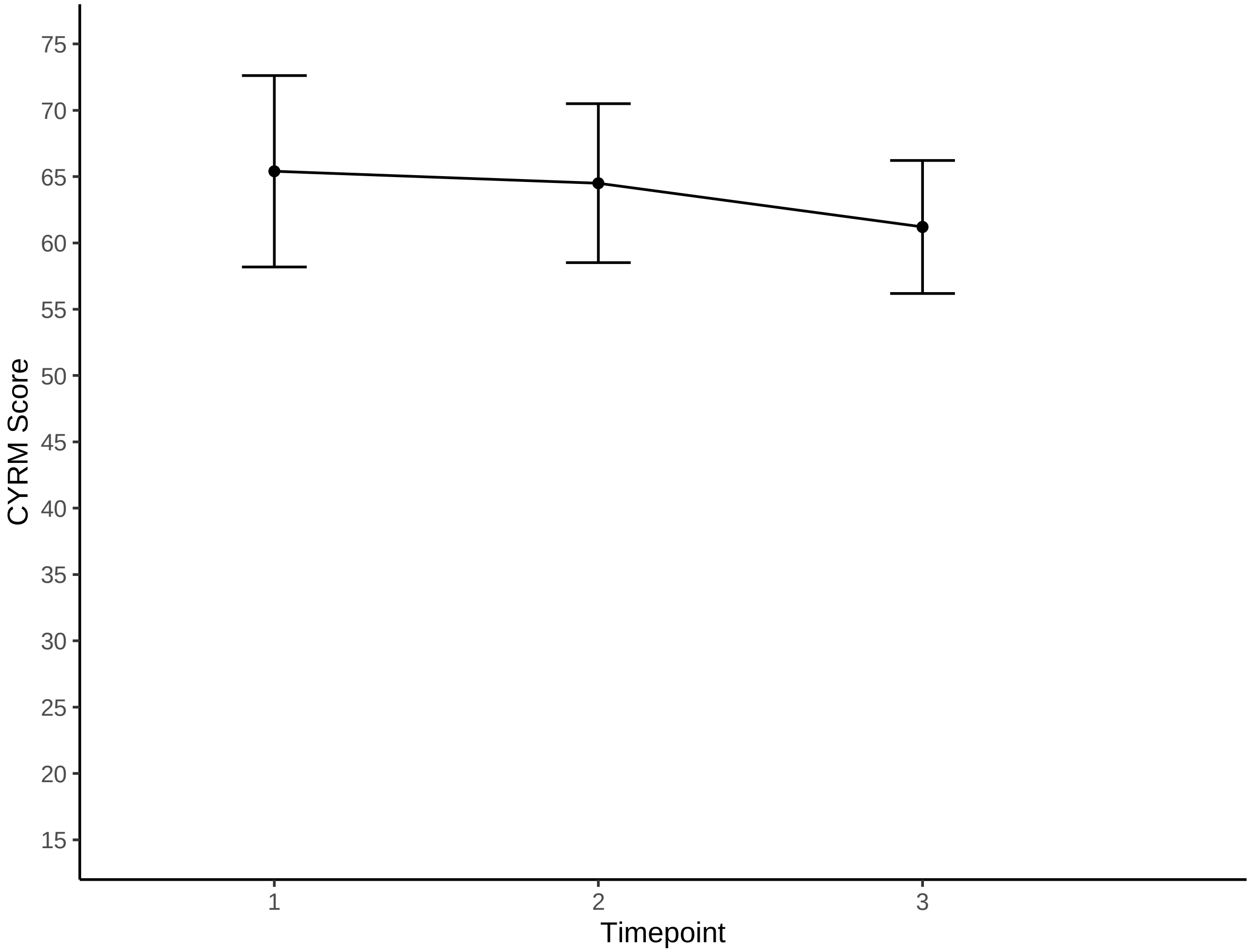

Figure 3. Mean total resilience scores from the Child and Youth Resilience Measure (CYRM) across timepoints (1 = baseline; 2 = post-camp 1; 3 = post-camp 2). Error bars represent standard deviation (N= 10).

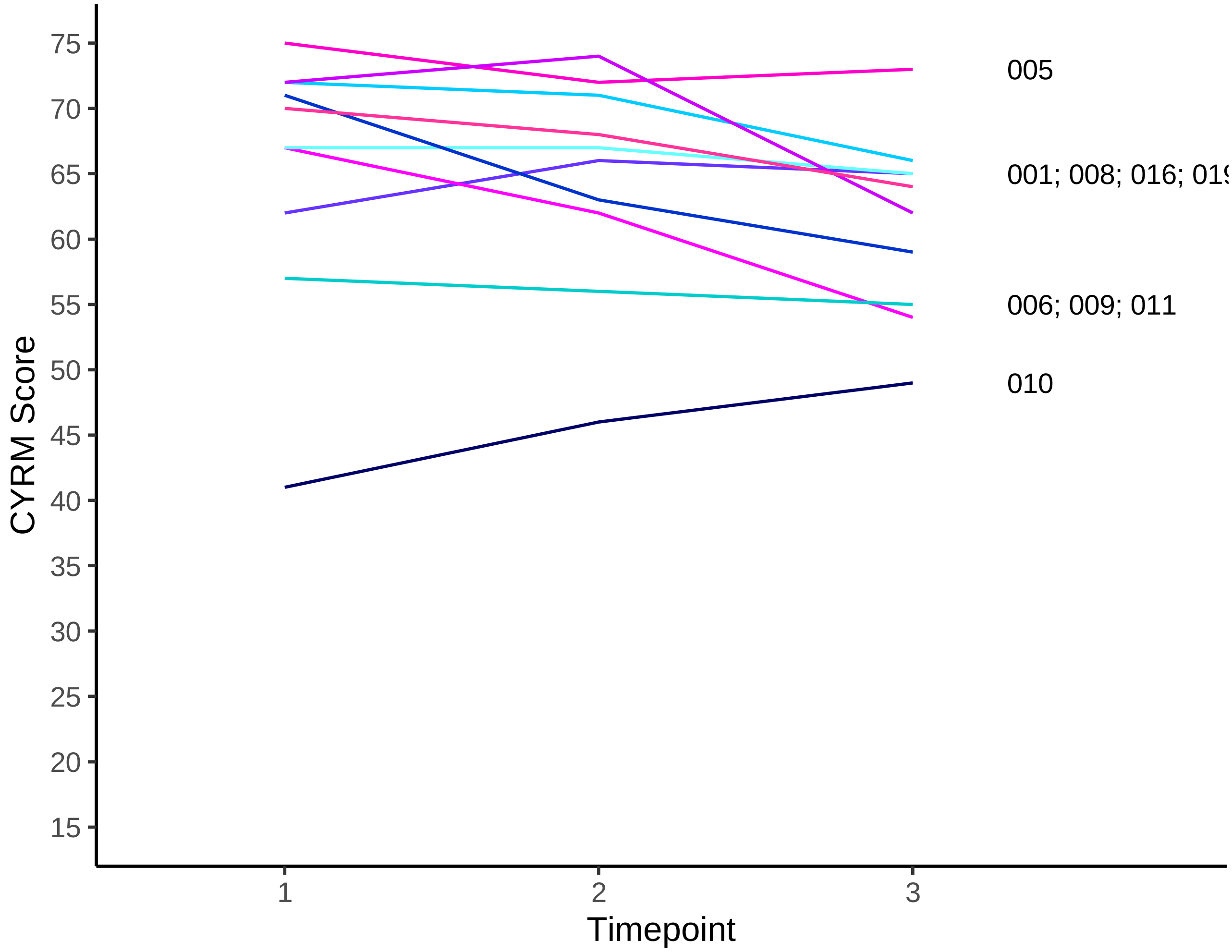

Figure 4. Total resilience scores from the Child and Youth Resilience Measure (CYRM) across timepoints (1 = baseline; 2 = post-camp 1; 3 = post-camp 2) for each participant. Each line represents the CYRM scores of a participant and the lines are labelled by the participants' study IDs.

4.4 Pediatric Cancer Patient Hope

4.4.1 Comparison of Baseline, Post-Camp 1, and Post-Camp 2

Mean total hope CHS scores are illustrated in Figure 5 (N = 10). Figure 6 illustrates the total hope CHS scores of each participant across timepoints (N = 10).

Repeated measures ANOVA found no significant change in CHS scores from baseline to post-camp 1; however, CHS scores at post-camp 2 were significantly lower than those at baseline and post-camp 1 among participants (F=9.388, p=0.008) (see Figure 5). Similarly, CHS scores on the agency and pathways subscales at post-camp 2 (12.30±3.917; 11.40±3.688) were significantly lower than those at baseline (14.40±3.169; 13.70±3.020) and post-camp 1 (15.00±2.906; 14.30±3.945) among participants (F=5.233, p=0.035; F=9.084, p=0.009).

4.4.2 Comparison of Baseline and Post-Camp 1

A Wilcoxon signed ranks test (N=23) revealed no significant differences in total hope scores on the CHS between baseline (28.78±4.908) and post-camp 1 (29.78±6.431) (Z=-1.050, p=0.294). Additionally, no significant differences were found in agency and pathways CHS subscale scores between baseline (14.78±2.486; 13.91±2.762) and post-camp 1 (15.22±2.860; 14.57±3.691) among participants (Z=-1.081, p=0.280; Z=-1.033, p=0.301).

4.4.3 Correlations

Baseline and post-camp 1 CHS scores were not associated with the number of years children had attended ROC (r(21)=0.188, p=0.391; r(21)=0.091, p=0.679). Additionally, baseline and post-camp 1 CHS scores were not associated with the number of years since children received their cancer diagnosis (r(21)=0.143, p=0.516; r(21)=0.343, p=0.109). Mean baseline CHS scores were associated with baseline resilience (CYRM) scores, but not with baseline social support (SPS-5) or mental wellbeing (SWEMWBS) scores (r(21) = 0.707, p<0.001; r(21) = 0.336, p = 0.117; r(20) = 0.394, p = 0.069).

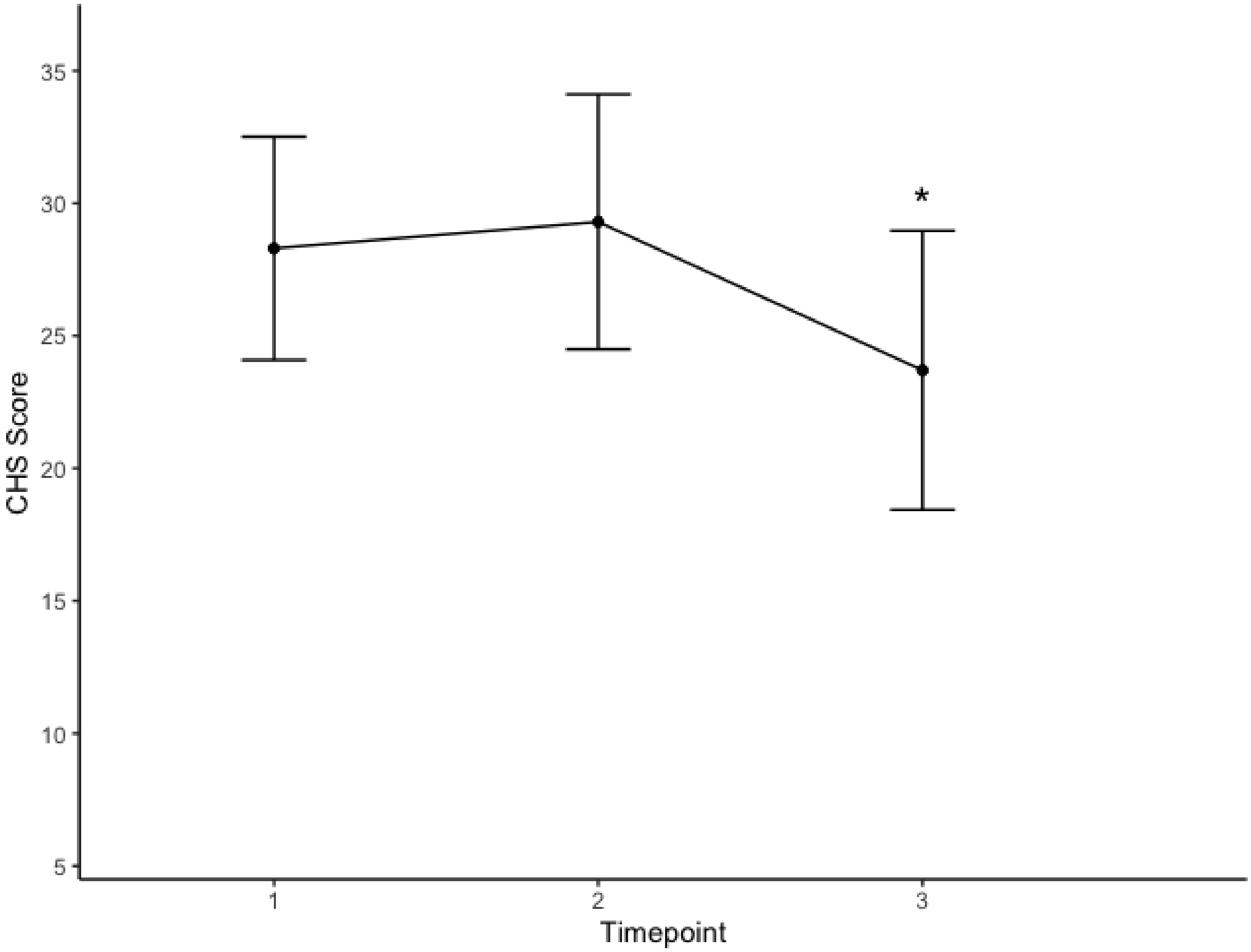

Figure 5. Mean total hope scores from the Children's Hope Scale (CHS) across timepoints (1 = baseline; 2 = post-camp 1; 3 = post-camp 2). Error bars represent standard deviation (N = 10). * denotes a significant difference between post-camp 2 CHS scores vs. CHS scores at baseline and post-camp 1 (p=0.047; p=0.023).

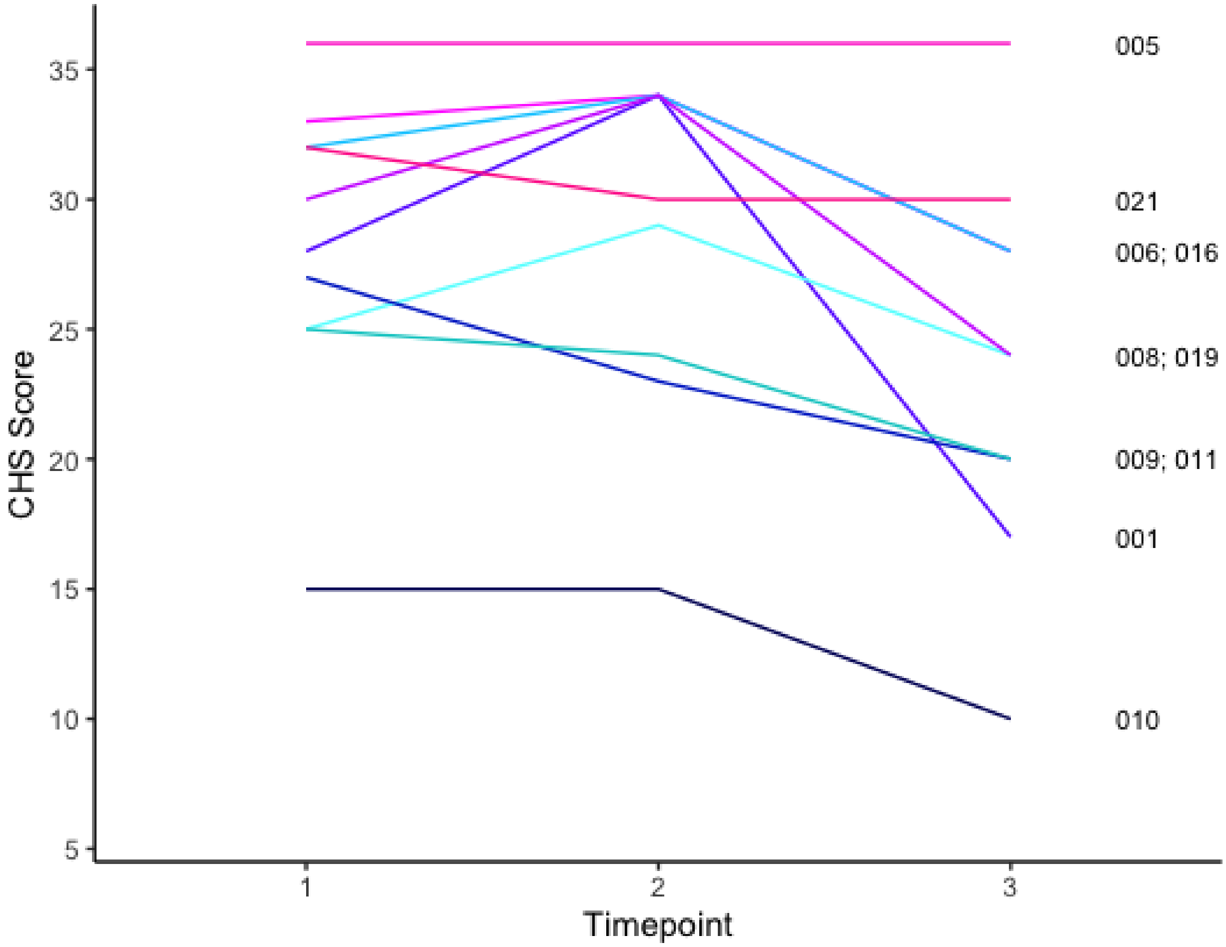

Figure 6. Total hope scores from the Children's Hope Scale (CHS) across timepoints (1 = baseline; 2 = post-camp 1; 3 = post-camp 2) for each participant. Each line represents the CHS scores of a participant and the lines are labelled by the participants' study IDs.

4.5 Pediatric Cancer Patient Social Support

4.5.1 Comparison of Baseline, Post-Camp 1, and Post-Camp 2

Mean SPS scores across timepoints are illustrated in Figure 7. Figure 8 illustrates the SPS scores of each participant across timepoints (N = 10). Repeated measures ANOVA revealed no significant differences in mean SPS scores between baseline, post-camp 1, and post-camp 2 among participants (F= 1.594, p=0.261) (see Figure 7). However, Cohen's d revealed a moderate effect size (decrease) in SPS-5 scores from post-camp 1 to post-camp 2 (d=0.56).

4.5.2 Comparison of Baseline and Post-Camp 1

A Wilcoxon signed ranks test (N=23) revealed no significant differences in SPS scores between baseline (17.87±0.45) and post-camp 1 (18.09±0.37) (Z=-0.494, p=0.621).

4.5.3 Correlations

Baseline and post-camp 1 SPS scores were not associated with the number of years children had attended ROC (r(21)=-0.164, p=0.456; r(21)=0.355, p=0.096). Additionally, no associations were found between baseline or post-camp 1 SPS scores and the number of years since children received their cancer diagnosis (r(21)=0.089, p=0.688; r(21)=0.141, p=0.520). Mean baseline SPS-5 scores were not associated with baseline resilience (CYRM), hope (CHS), or mental wellbeing (SWEMWBS) scores (r(21) = 0.329, p = 0.125; r(21) = 0.336, p = 0.117; r(20) = 0.058, p = 0.799).

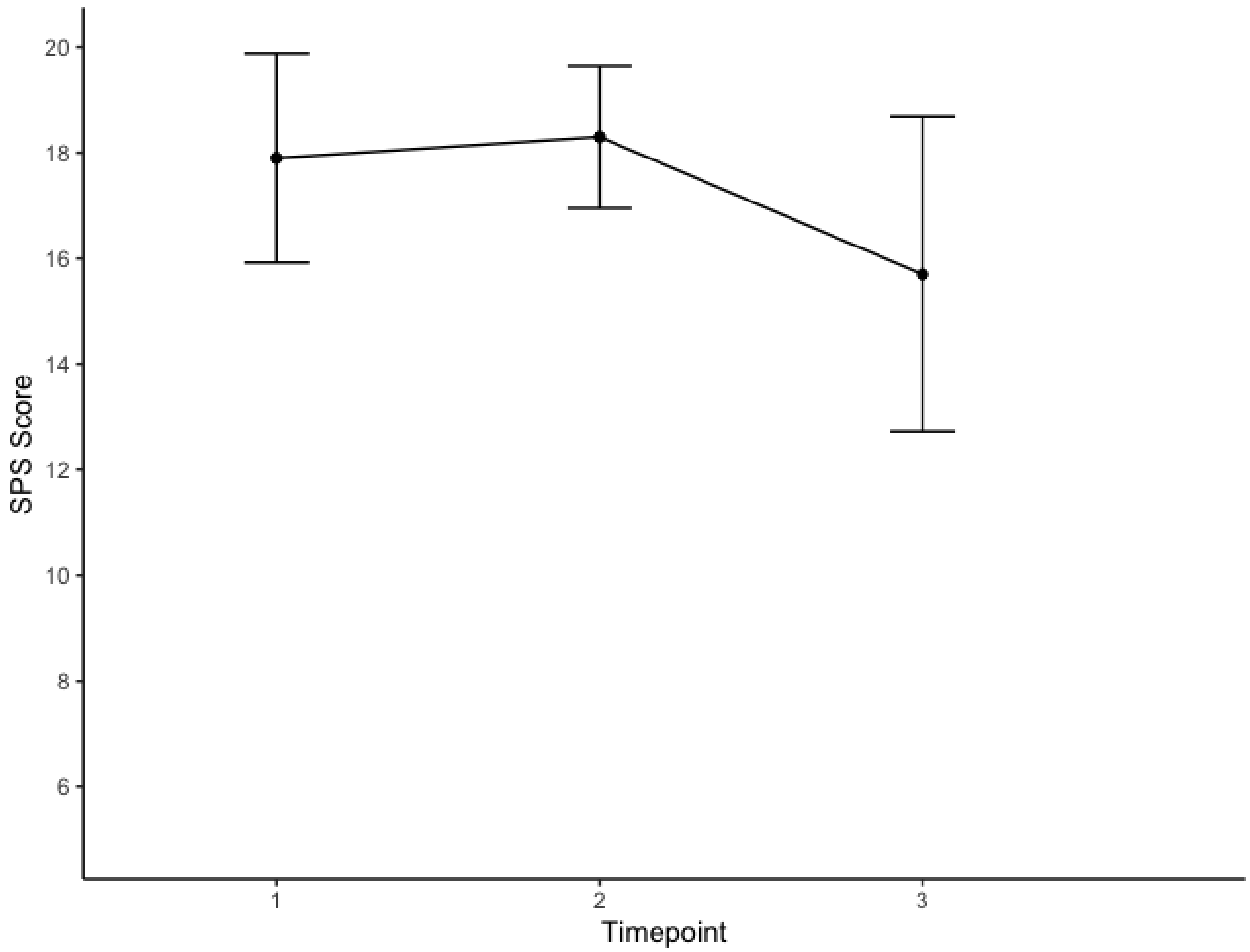

Figure 7. Mean total social support scores from the Social Provisions Scale (SPS) across timepoints (1 = baseline; 2 = post-camp 1; 3 = post-camp 2). Error bars represent standard deviation (N = 10).

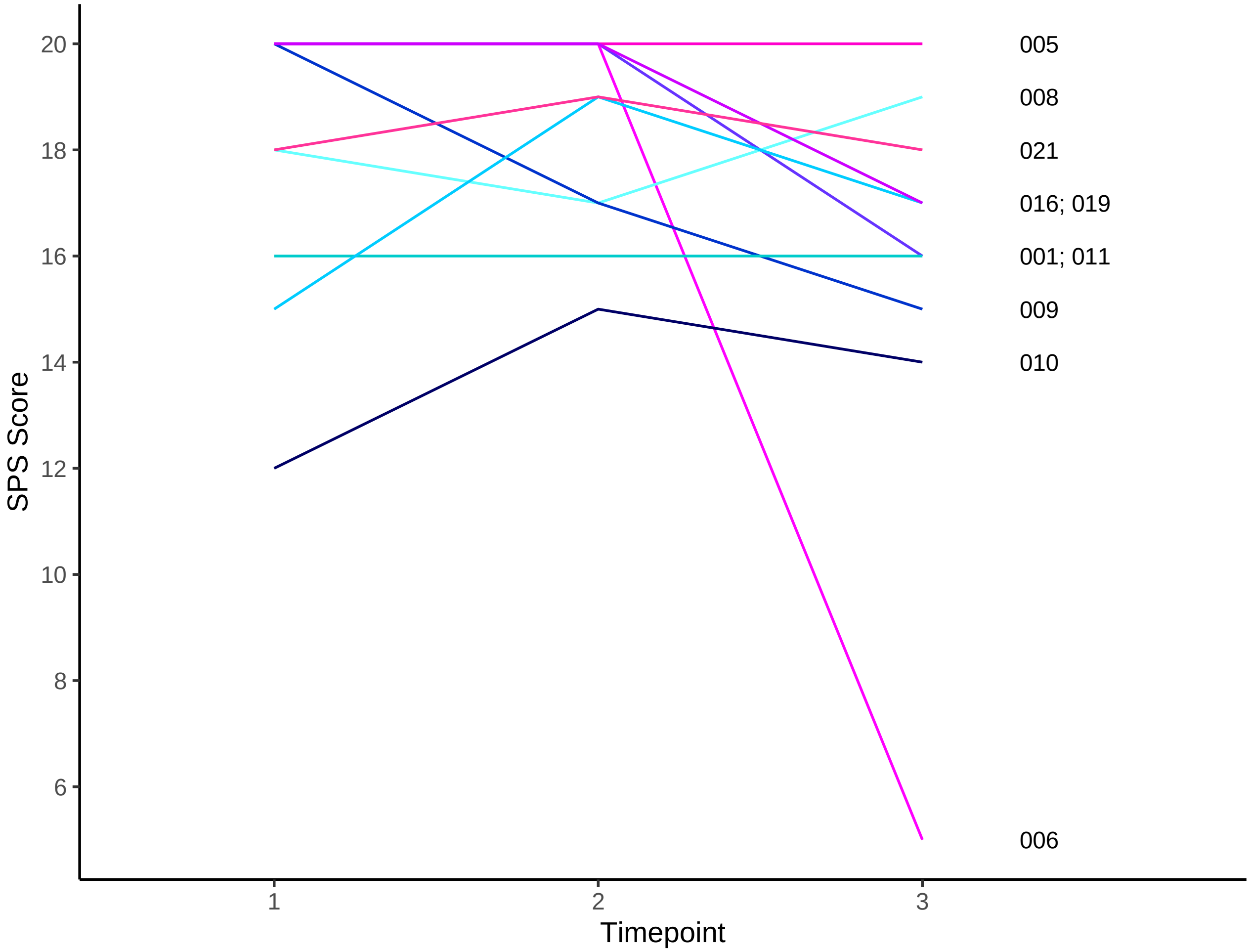

Figure 8. Total social support scores from the Social Provisions Scale (SPS) across timepoints (1 = baseline; 2 = post-camp 1; 3 = post-camp 2) for each participant. Each line represents the SPS scores of a participant and the lines are labelled by the participants' study IDs.

4.6 Pediatric Cancer Patient Mental Wellbeing

4.6.1 Comparison of Baseline, Post-Camp 1, and Post-Camp 2

Mean SWEMWBS scores across timepoints are illustrated in Figure 9 (N = 10). Figure 10 illustrates the SWEMWBS scores of each participant across timepoints.

Repeated measures ANOVA revealed no significant differences in mean SWEMWBS scores between baseline, post-camp 1, and post-camp 2 among participants (F = 1.594, p = 0.261) (see Figure 9). However, Cohen's d revealed a large effect size (decrease) in SWEMWBS scores from post-camp 1 to post-camp 2 (d=0.83).

4.6.2 Comparison of Baseline and Post-Camp 1

A paired t-test found no significant difference in SWEMWBS scores between baseline (27.73±3.88) and post-camp 1 (28.55±4.24) among participants (t(21)=-1.306, p=0.206).

4.6.3 Correlations

Baseline and post-camp 1 SWEMWBS scores were not found to be associated with the number of years children had attended ROC (r(20)=-0.022, p=0.922; r(20)=0.133, p=0.557). Baseline and post-camp 1 SWEMWBS scores were also not associated with the number of years since children received their cancer diagnosis (r(20)=0.174, p=0.439; r(20)=0.312, p=0.158). Mean baseline SWEMWBS scores were not associated with baseline resilience (CYRM), hope (CHS), or social support (SPS-5) scores (r(20) = 0.034, p = 0.880; r(20) = 0.394, p = 0.069; r(20) = 0.058, p = 0.799).

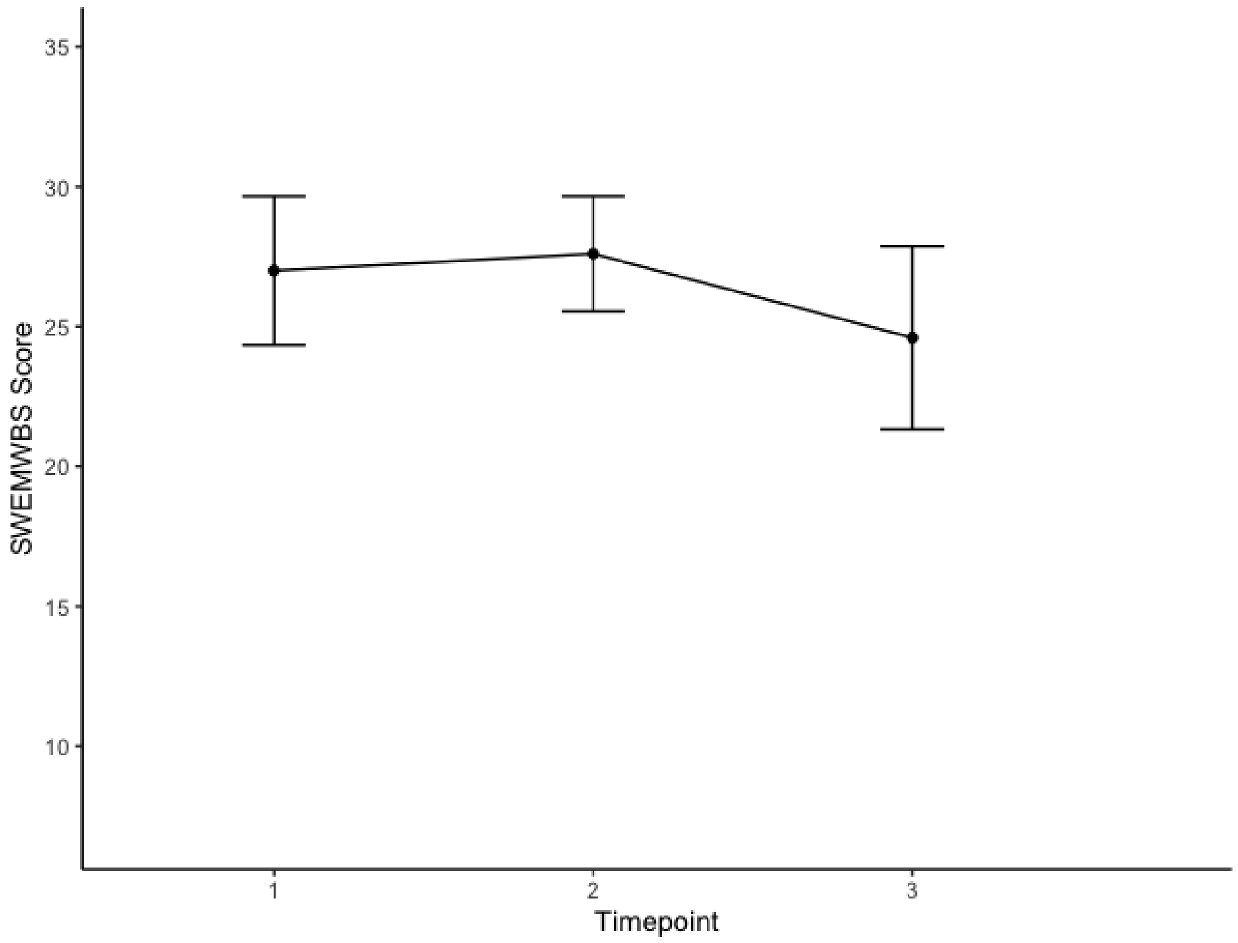

Figure 9. Mean overall mental wellbeing scores from the Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS) across timepoints (1 = baseline; 2 = post-camp 1; 3 = post-camp 2). Error bars represent standard deviation (N = 10).

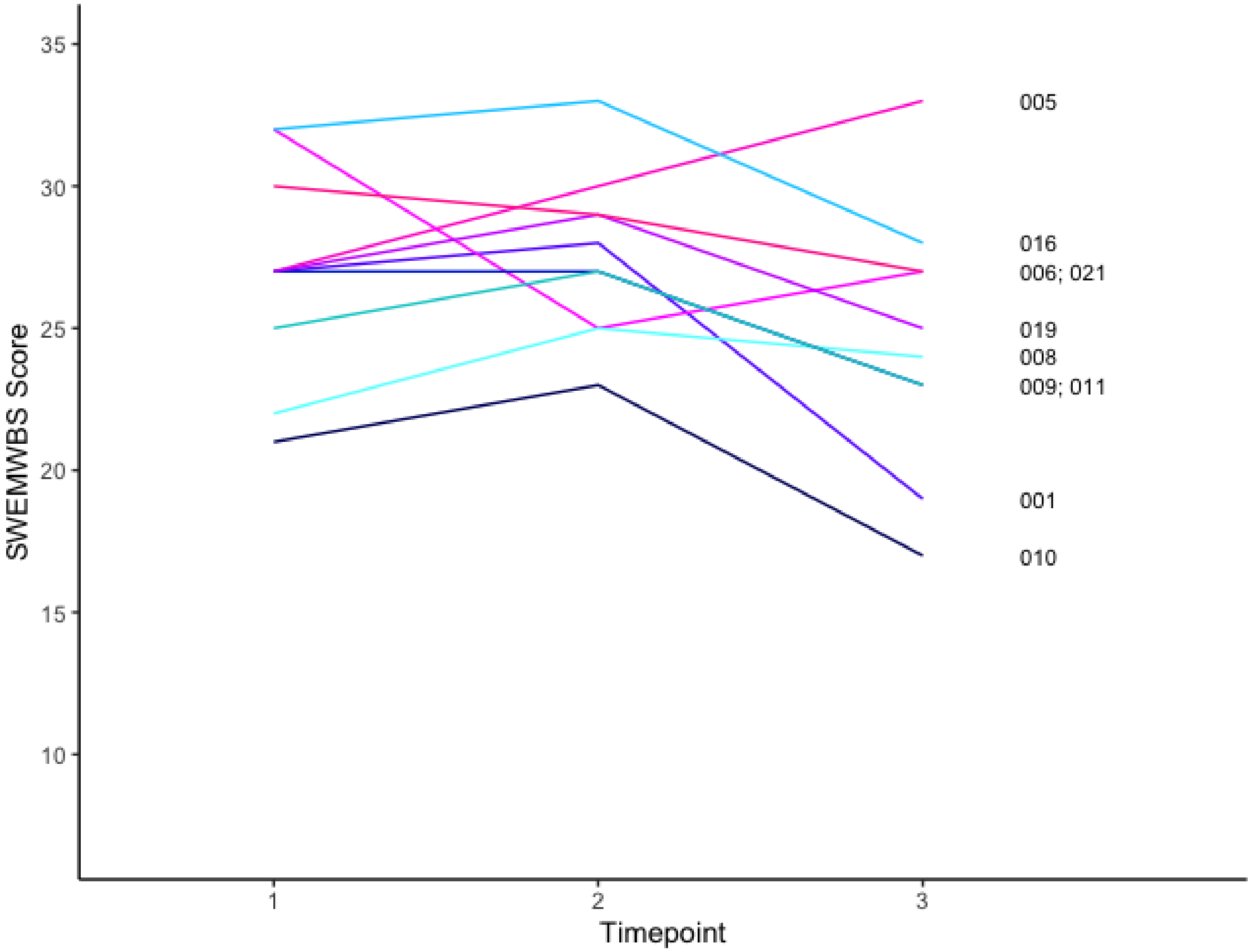

Figure 10. Total mental wellbeing scores from the Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS) across timepoints (1 = baseline; 2 = post-camp 1; 3 = post-camp 2) for each participant. Each line represents the SWEMWBS scores of a participant and the lines are labelled by the participants' study IDs.

4.7 Pediatric Cancer Patient Cortisol Concentrations: Estimation of Stress

Salivary cortisol concentration for baseline and post-camp 1 testing is illustrated in Figure 11. A Wilcoxon signed ranks test (N=23) revealed no significant differences in salivary cortisol concentrations between baseline (0.121 μg/dL ± 0.140) and post-camp 1

(0.151 µg/dL ± 0.145) (Z = -1.065, p = 0.287). While there was no significant difference in salivary cortisol concentration among participants, the salivary cortisol concentrations at baseline and post-camp 1 were within the normative range for the afternoon time period in children ages 8 to 11 years of age (nondetectable to 0.215 µg/dL) and adolescents ages 12 to 18 years of age (nondetectable to 0.259 µg/dL).

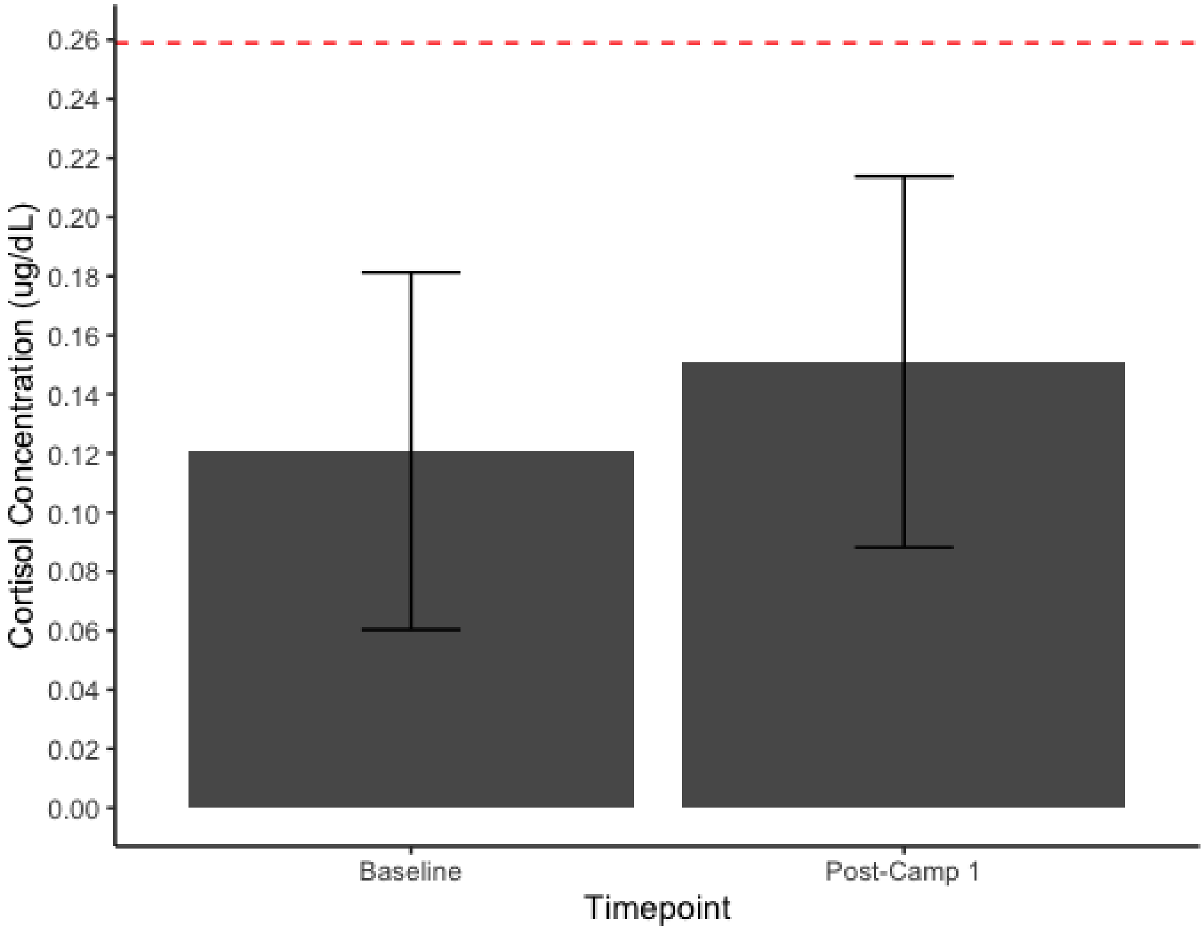

Figure 11. Mean salivary cortisol concentrations, in micrograms per decilitre, across timepoints at baseline and post-camp 1 testing. Error bars represent standard deviation (N = 10). Red dashed line represents the maximum normative, afternoon salivary cortisol concentration for adolescents aged 12 to 18 (Salimetrics, 2021).

4.8 Reference Values

Mean scores for each scale at baseline, post-camp 1, and post-camp 2, along with their corresponding reference ranges are summarized in Table 2.

Table 2: Mean scores for the Child and Youth Resilience Measure (CYRM), Children's Hope Scale (CHS), Social Provisions Scale-5 (SPS-5), and Short Warwick-Edinburgh Mental Wellbeing Scale (SWEMWBS) for participants (N=10) at baseline, post-camp 1, and post-camp 2. Reference ranges for the baseline, post-camp 1, and post-camp 2 mean scores are provided with scoring thresholds in brackets (Bickman et al., 2007; *Collect, Score, Analyse and Interpret WEMWBS*, 2021; Orpana et al., 2019; Resilience Research Centre, 2018).

	CYRM	**CHS**	**SPS-5**	**SWEMWBS**
Mean: Baseline	65.40±10.08	28.30±5.889	17.90±2.78	27.00 ±3.71
Reference Range: Baseline	High (63-67)	High (25-36)	High (15-20)	>75th percentile (27-35)
Mean: Post-Camp 1	64.50±8.38	29.30±6.717	18.30±1.89	27.60±2.88
Reference Range: Post-Camp 1	High (63-67)	High (25-36)	High (15-20)	>75th percentile (27-35)
Mean: Post-Camp 2	61.20±7.02	23.70±7.364	15.70±4.17	24.60±4.58
Reference Range: Post-Camp 2	Moderate (56-62)	Moderate (19-24)	High (15-20)	<75th percentile (<27)

Chapter 5: Discussion

This study investigated the impact of a 10-day, overnight ROC experience on the psychosocial health of childhood cancer patients. We hypothesized that the psychosocial health of childhood cancer patients would be improved by ROC attendance. However, this hypothesis was not supported by our results as there were no significant improvements between the first and last day of camp in any of the psychosocial outcomes measured (resilience, hope, perceived social support, overall mental wellbeing, and stress). While we found no change in outcomes on the first vs. last day of ROC, we report that psychosocial outcomes in our participants (resilience, hope, perceived social support, overall mental wellbeing) were all in a high range, and stress was normal, while attending ROC. Finally, we found that levels of hope decreased significantly in childhood cancer patients three months post-camp, suggesting that the ROC environment was associated with higher levels of hope compared with children's regular environments.

5.1 Resilience in Childhood Cancer Patients

For this study, resilience was defined as the ability to use internal and external resources to adapt to or manage stressful life events (Lee et al., 2012). I predicted that levels of resilience, as measured by the CYRM, would improve in childhood cancer patients after attending a 10-day session of ROC. However, our results do not support this prediction as levels of resilience did not change between timepoints. We also found that mean CYRM scores at baseline and post-camp 1 were positively associated with the number of years since the participants' cancer diagnosis but were not associated with age. This positive correlation between resilience and years since cancer diagnosis suggests that childhood cancer patients may build their repertoire of internal and external resources over time so they can better manage cancer-related stressors.

Our results suggest that childhood cancer patients who attended ROC experienced high levels of resilience based on comparison group threshold values from a large sample of youth aged 11-20 living in urban centres in Eastern Canada (Resilience Research Centre, 2018). On average, the childhood cancer patients who participated in our study scored within a high resilience range (63-67 on 15-item scale) immediately before and after camp (baseline and post-camp 1) and then in the moderate range (56-62 on 15-item scale) three months post-camp (Resilience Research Centre, 2018). In other words, while attending ROC, childhood cancer patients had high levels of resilience compared with scores from otherwise healthy youth, but they had only moderate levels of resilience three months post-camp. This change from high to moderate resilience may be clinically meaningful. Clinically meaningful findings refer to treatment or intervention effects that have a real impact on individuals' daily life including their quality of life, their ability to function, and/or how the treatment makes them feel (Sharma, 2021). In other words, treatments/interventions like ROC could have an impact that individuals are able to feel but that may not be detected through statistical analysis. Therefore, it is important to consider the clinical effects as well. Additionally, upon comparing resilience scores between post-camp 1 and post-camp 2, we found the effect size to be large which further suggests that there may be a clinically meaningful decrease in the resiliency of children with cancer after leaving the ROC environment.

O'Keeffe (2022) used the same measure (CYRM) to evaluate levels of resilience in childhood cancer patients/survivors one week before a one-month virtual oncology camp, immediately post-camp, and three months post-camp. O'Keeffe (2022) reported a clinically meaningful improvement in levels of resilience from pre-camp to post-camp which was sustained three months post-camp. Our findings are inconsistent with those of O'Keeffe (2022) as our participants' CYRM scores did not change over time. However, like the CYRM scores of our participants on the first and last days of in-person ROC, the CYRM scores reported by O'Keeffe (2022) immediately post-camp and three months post-camp were within the high resilience range (Resilience Research Centre, 2018).

One important point to note is that the current thesis study design may not have a true baseline measurement. Our baseline assessment occurred upon arrival on the first day of camp and as such, children's feelings of excitement or nervousness regarding starting the ROC session could have affected their baseline scores. A pre-camp baseline measure, perhaps one month prior to camp beginning, may have provided a better assessment of what outcomes were prior to camp. Unfortunately, due to timing issues we were limited in our ability to conduct a baseline data collection point prior to arrival at camp. However, O'Keeffe (2022) did measure resilience one-month prior to camp. They reported their mean pre-camp resilience (CYRM) score (M=57.20±7.82); this score is lower than all mean CYRM scores obtained in our study. Their lower baseline resilience score may be attributed to multiple factors, including differences in participant demographics or differences in restrictions caused by the COVID-19 pandemic.

Similar to our three months post-camp resilience (CYRM) scores, the pre-camp CYRM scores reported by O'Keeffe (2022) fell into the moderate resilience range (Resilience Research Centre, 2018). This may support our speculation that the three months post-camp resilience scores we obtained may be more reflective of an "at home" score versus the scores we obtained on the first day of camp (Resilience Research Centre, 2018). Therefore, had we collected data prior to participants arriving at ROC, our baseline

CYRM scores may have been similar to that of O’Keeffe (2022) and a change in resilience may have been noted between timepoints. Future studies that collect baseline data prior to the beginning of the ROC session are necessary to determine whether resilience differs between baseline and post-camp.

One other study investigated the resilience of childhood cancer survivors, aged 17 to 21, who participated in an adventure therapy program that involved an eight-day wilderness journey in New Zealand (Wynn et al., 2012). The adventure therapy program was similar to traditional ROC in that it was designed for childhood cancer patients/survivors, focused on activities and challenges, and provided an environment where children with cancer were surrounded by peers with similar illness-related experiences (Wynn et al., 2012). They used a different measure of resilience (14-item Resilience Scale) and reported improvements in 12 of 14 aspects of resilience from the beginning to the end of the program. Additionally, some of the childhood cancer survivors reported feeling pride and increased confidence after completing the adventure therapy program and the challenges it involved. While this study provides some support for the improvement of resilience following recreational programming designed for childhood cancer patients/survivors, this study was limited by a small sample size (n=5), and analysis was not performed to determine whether there were statistically significant differences in resilience scores between the beginning and end of the adventure-based training program. Additionally, adventure therapy programming does differ from the traditional overnight ROC experience. Therefore, the discrepancy between this study and our study may be explained by their lack of statistical analysis and the differences between adventure therapy and traditional overnight ROC.

Our finding of sustained high levels of resilience in children attending ROC is consistent with some literature which suggests that childhood cancer patients/survivors as a group are resilient considering they were similar to their healthy peers in terms of various psychosocial outcomes including mood, health-related quality of life, connectedness, and behavioural and emotional problems (DeJong & Fombonne, 2006; Glover et al., 2003; Mertens et al., 2014; Noll et al., 1997; Sharp et al., 2015). However, multiple studies have identified a subset of childhood cancer survivors who experience psychosocial distress or impairments throughout survivorship (Glover et al., 2003; Howard et al., 2014; Hudson et al., 2003; Kunin-Batson et al., 2016; Mertens et al., 2014; Schultz et al., 2007). This subset of childhood cancer survivors may not demonstrate high levels of resilience as they were unable to build and use their repertoire of internal and external resources throughout cancer treatment.

ROC may promote resilience in childhood cancer patients by allowing them to build a repertoire of internal and external resources that they can utilize to adjust to adversity. Hope is one internal resource that has been associated with higher levels of resilience (Seiler & Jenewein, 2019; Solano et al., 2016). Goal orientation, which is a large component of the definition of hope used in this thesis, is also a resilience factor (Mesman et al., 2021). In this study, we found that childhood cancer patients demonstrated significantly higher levels of hope while attending ROC (baseline and post-camp 1) compared with when they were back in their regular environments (three months post-camp). Similarly, we observed a clinically meaningful decrease in resilience from the high range while children were in the ROC environment to the moderate range three months post-camp (Resilience Research Centre, 2018). The downward trend in resilience scores could be partially attributed to the decrease in hope, and presumably goal orientation, that childhood cancer patients experienced three months post-camp. This notion is supported as we found hope and resilience scores to be correlated with each other in this study. As such, it may be beneficial to both the hope and resilience of childhood cancer patients to focus on implementing ROC programming periodically throughout the year so that children can maintain high levels of resilience.

Social support and connectedness (ie. reciprocal social relationships) are external resources that can be used to facilitate resilience (Seiler & Jenewein, 2019). Some studies suggest that childhood cancer patients with higher levels of social support and connectedness may be more well-adjusted despite cancer-related adversity thereby demonstrating higher levels of resilience (Myers et al., 2014; Sharp et al., 2015). Numerous studies have identified ROC as an environment that provides childhood cancer patients/survivors with social support and social connections (Beckwitt, 2014; Gillard & Watts, 2013; Martiniuk et al., 2014; Oppenheim, 2017; Ryan, 2017). We also found that childhood cancer patients had high levels of social support in the ROC environment. As social support is an external resource, these high levels of social support may have contributed to the high levels of resilience that childhood cancer patients demonstrated while in the ROC environment (Seiler & Jenewein, 2019). However, it is unlikely that social support was the only factor contributing to resilience as high levels of social support were sustained three months post-camp whereas there was a clinically meaningful decrease in resilience three months post-camp. Furthermore, we did not find social support scores to be associated with scores for resilience in this study.

This was the first quantitative study to evaluate the impact of traditional, in-person ROC programming on resiliency in childhood cancer patients. Overall, childhood cancer patients who participated in this study demonstrated high levels of resilience as evidenced by high scores on the CYRM (Resilience Research Centre, 2018). These high scores indicate that our group of childhood cancer patients may have both internal and external resources available to them that they can utilize to overcome the adversity brought upon them by their cancer (Lee et al., 2012). Additionally, there may have been a clinically meaningful decrease in resilience scores three months post-camp which suggests that continued intervention may be necessary to promote resilience in this group throughout the year (Resilience Research Centre, 2018). Overall, we found ROC to be an environment associated with high levels of resilience in childhood cancer patients which is important as this resiliency may help children to overcome future cancer-related adversity, such as painful treatments and relapses, and become well-adjusted survivors.

5.2 Hope in Childhood Cancer Patients

In the current thesis, hope refers to the ability to initiate and sustain progression towards goals (agentic thinking) and produce different routes towards these goals (pathways thinking) (Snyder et al., 1997). I predicted that hope, as measured by the CHS, would improve in childhood cancer patients after attending a 10-day session of overnight ROC. The results of this study do not directly support this prediction as hope scores were similar between the first and last day of camp. However, overall hope, agency, and pathways scores decreased three months post-camp. Additionally, hope scores were within the highly hopeful range (25 - 36) while childhood cancer patients were at ROC (baseline and post-camp 1) but fell into the moderately hopeful range (19 - 24) three months post-camp (Bickman et al., 2007).

O’Keeffe (2022) used the same hope measure (CHS) to evaluate the impact of a one-month virtual OC program on childhood cancer patients/survivors. They reported a clinically meaningful increase in the levels of hope of childhood cancer patients/survivors from pre-camp to post-camp, and this improvement was sustained three months post-camp. The hope score they reported post-camp (M = 28.60±6.8) appears similar to our hope scores while childhood cancer patients were in the ROC environment (M = 28.30±5.89; 29.30±6.72). This suggests that levels of hope were similar among childhood cancer patients/survivors who had just completed a one-month virtual ROC session and childhood cancer patients who were in the in-person ROC environment.

O’Keeffe (2022) reported lower baseline hope (CHS) scores than we obtained at our baseline measure (moderately hopeful range vs. highly hopeful range, respectively) (Bickman et al., 2007). This discrepancy could be attributed to the timing of baseline data collection. As previously discussed, O’Keeffe (2022) was able to collect baseline data within the month leading up to participants’ virtual OC participation. Conversely, we collected baseline data on the first day of the ROC session when children arrived. As such, our baseline scores may have been affected by emotions, like excitement, that were high during camp arrival. Therefore, it is possible that the baseline hope scores reported by O’Keeffe (2022) are a better representation of hope scores that children experience within their regular environments. However, this is speculation, and further studies are necessary to confirm the true baseline hope levels of patients in their regular environments.

The impact of camp programming on the agency and pathways thinking of children with chronic illnesses, including cancer, is unclear based on other current literature. We found that childhood cancer patients demonstrate high levels of both agency and pathways thinking while in the ROC environment, but these high levels decrease three months post-camp. Another study conducted by Woods et al. (2013) used the same measure (CHS) to evaluate hope in youth aged 8 to 19 years who participated in summer camp programming designed for children with chronic illnesses including cancer. They found total hope scores and pathways scores to increase from pre- to post-camp. However, this is contrary to our findings, as we observed no change in scores for agency thinking. Also using the CHS to evaluate hope, O'Keeffe (2022) found agency thinking to improve in childhood cancer patients/survivors after a one-month virtual ROC; however, they did not find scores on the pathways CHS subscale to be impacted by virtual OC. O'Keeffe's (2022) study was small and did not include the same participants at all three timepoints, which could account for some discrepancies. These discrepancies could also be attributed to differences between the camps. It is possible that the experiences offered by in-person ROC, virtual ROC, and non-disease specific camp differ in ways that affect pathways and agency thinking differently. However, further research into the impact of ROC on hope is needed to determine how it impacts agency and pathways thinking and whether different types of camps impact the components of hope differently.

The decreased levels of hope that we observed in our participants three months post-camp could be attributed to multiple factors, such as changes in the severity of their illness or their prognosis, as well as other general life factors (e.g., family-, school-related factors). Children with higher levels of hope have slight positive cognitive distortions that give them a sense of being invulnerable to harm (Snyder et al., 1997). However, children's ability to engage in positive distortions about themselves may be limited by physical problems, such as physical challenges resulting from cancer and cancer treatment (Snyder et al., 1997). One study investigating hope in children and adolescents diagnosed with sickle cell disease found hope and disease severity were negatively correlated (Kliewer & Lewis, 1995). This finding suggests that the reality of one's physical condition could limit one's ability to engage in the slight positive distortions that have been associated with higher levels of hope (Snyder et al., 1997). Therefore, if the childhood cancer patients who participated in our study experienced worsened physical health, potentially due to treatment regimens with more severe physical side effects or cancer progression, their ability to engage in positive distortions may be limited thereby reducing levels of hope.

Snyder et al. (1997) also found only a slight negative correlation between hope and hopelessness which suggests that if children have positive expectations regarding their goals, they can still have negative expectations about future outcomes. In pediatric cancer populations, it may be important to redirect children's focus to their positive goal expectations rather than their negative expectations (Snyder et al., 1997). As such, the association we found between the ROC environment and high levels of hope in childhood cancer patients could be partially attributed to children's focus on their positive goal expectancies (that is, their belief that they can attain certain goals) instead of negative goal expectancies.

The ROC environment may promote hope in childhood cancer patients in various other ways. Campers encounter new activities and challenges while attending ROC (e.g., waterskiing). These challenges may help childhood cancer patients to develop goals (agentic thinking) and through accomplishing their goals they build their confidence and self-esteem (Gillard & Watts, 2013; Stevens et al., 2004). Self-esteem promotes motivation, which is a major factor in the agency component of hope (Hutz et al., 2014). As such, improvements in self-esteem that childhood cancer patients may experience by participating in ROC programming may also promote hopeful thinking. Additionally, ROC is associated with improvements in freedom and self-efficacy (Moola et al., 2023; Torok et al., 2006), which provides individuals with a sense of control, thereby promoting hope (Venning et al., 2007). If our participants returned to their normal environments and experienced less freedom, thereby compromising their self-efficacy and sense of control, this could explain their decreased levels of hope three months post-camp.

Gillard and Watts (2013) reported that some children felt a sense of hope at ROC as they were able to look up to older campers and camp counsellors who were childhood cancer survivors. As all our participants were childhood cancer patients, interacting with counsellors who were long-term survivors may have provided participants with a sense of hope. Through these interactions, childhood cancer patients could make upwards comparisons (comparison with someone an individual perceives to be in a better situation) which can facilitate hope and motivation to improve their own life situation (Dawson et al., 2012). Additionally, these children would have the opportunity to engage in social comparisons with individuals who had similar illness-related experiences (Meltzer & Rourke, 2005; Neville et al., 2019). Conversely, when childhood cancer patients return to their normal environments and are surrounded by healthier individuals, their ability to make social comparisons with an appropriate comparison group is limited (Meltzer & Rourke, 2005). Social comparisons with an inappropriate comparison group can lead to frustration (Meltzer & Rourke, 2005). For instance, a childhood cancer patient may have a goal related to physical functioning. If they were to compare their physical functioning to other childhood cancer patients, they may feel better about their abilities because they may have better physical functioning than others. They may also feel more hopeful and motivated to achieve their physical goals because they see other children who are similar to them who have attained their physical goals. However, if they compare their physical functioning to that of their healthy peers, they may feel discouraged or frustrated in the pursuit of their physical goal as this goal may begin to feel unattainable (Meltzer & Rourke, 2005). Therefore, upwards social comparisons at ROC could have contributed to the higher levels of hope that our participants demonstrated in the ROC environment, and unmatched social comparisons could have contributed to the decreased levels hope these childhood cancer patients experienced three months post-camp.

In conclusion, although we did not find that hope was improved in childhood cancer patients by attending ROC, our results suggest that being in the ROC environment is associated with high levels of hope. These findings are promising as hope has been associated with lower levels of distress and better quality of life in adolescents and young adults with cancer (Martins et al., 2018; Rosenberg et al., 2018; Santos et al., 2015). Hope may also help to reduce anxiety and depression in childhood cancer patients (Germann et al., 2015). Furthermore, hope has been associated with medication adherence in children with chronic diseases and this is especially important as adolescents with cancer may not adhere to their treatment regimen in an effort to feel more “normal” (Brand et al., 2017). Hope has also been associated with reduced fatigue and pain in adult cancer patients (Berendes et al., 2010).

We found that childhood cancer patients experienced decreased levels of hope three months post-camp. These decreased levels of hope are concerning as hope is a key factor that allows childhood cancer patients to create different routes towards their goals when they face cancer-related disruptions in their goal pursuits (Snyder et al., 1997). As such, it is important to provide childhood cancer patients with continued interventions to sustain their high levels of hope following summer ROC. Campfire Circle offers fall and winter ROC programming, but these camp sessions tend to be shorter in duration and less popular than summer ROC programming. These fall and winter programs may provide a solution for decreased levels of hopeful thinking in childhood cancer patients after summer ROC sessions; however, future research is needed to determine whether these programs are an effective solution.

5.3 Social Support in Childhood Cancer Patients

I predicted that perceived social support, as measured by the SPS-5, would improve in childhood cancer patients after attending a 10-day session of overnight ROC; however, my results did not support this prediction as levels of social support did not change between timepoints. A score of 15 or higher on the SPS-5 corresponds with high levels of perceived social support (Orpana et al., 2019). Based on this published threshold value, the childhood cancer patients who participated in the current study exhibited high levels of perceived social support, in comparison to Canadians aged 15 years and older, at all timepoints. However, based on effect sizes, we report a moderate, potentially clinically meaningful decrease in perceived social support from post-camp 1 to post-camp 2. To our knowledge, this is the first study to use the SPS-5 in an exclusively pediatric population.

Our finding of high levels of perceived social support in childhood cancer patients while attending ROC is consistent with current qualitative literature. Most qualitative studies investigating the experiences of children with cancer who attend ROC report that these children develop close relationships with other campers, feel a sense of community, and/or feel they have a social support network at ROC (Beckwitt, 2014; Dawson et al., 2012; Moola et al., 2023; Riley, 2018; Ryan, 2017). This is particularly important considering a recent 2023 study conducted by Moola et al. reported that several children with cancer experienced challenges with maintaining friendships with their peers from school due to cancer, particularly during times that they were hospitalized. Children with cancer often indicate that they are accepted by their camp peers and are free to be their authentic selves (Gillard & Allsop, 2016; Moola et al., 2023; Riley, 2018). Additionally, a 2014 study conducted by Martiniuk et al. reported improvements in the friendship skills of youth attending ROC. It is possible that through ROC, children develop their friendship skills, and these have a prolonged positive impact on their perceived levels of social support. Considering most of our participants attended ROC previously, this speculation could explain why we found levels of social support were similar across timepoints.

Our finding that levels of social support did not change across timepoints is consistent with quantitative literature investigating social support in children attending ROC (Békési et al., 2011; Oppenheim, 2017). Békési et al. (2011) reported that levels of social support did not change from pre- to post-camp in their pediatric cancer population attending camp designed for children with chronic diseases. Similarly, Oppenheim (2017) reported no changes in levels of perceived social support in children attending ROC, as measured by a non-validated measure of perceived social support. Therefore, our findings are consistent with those of other quantitative studies which do not suggest that ROC participation leads to changes in perceived levels of social support among youth with cancer.

Although most repeated-measures quantitative studies, including our study, suggest that ROC is not associated with changes in levels of social support in childhood cancer patients/survivors, most qualitative studies investigating the experiences of these children highlight social support and other social benefits as dominant themes of the ROC experience (Beckwitt, 2014; Dawson et al., 2012; Gillard & Watts, 2013; Moola et al., 2023; Neville et al., 2019; Riley, 2018). Additionally, Beckwitt (2014) reported that childhood cancer survivors received continued social support from the ROC community into adulthood, particularly considering many campers return to ROC as camp counsellors when they reach adulthood. This continued social support could help to explain why we did not find levels of social support to change as the high level of social support our participants may have gained from the ROC community could have been sustained when they were not in the ROC environment.

Although we did not find perceived social support to improve in childhood cancer patients after participating in ROC programming, we report high levels of social support among these children. Our finding of high levels of social support is consistent with the findings of a 2016 cross-sectional study (Wu et al., 2016). Wu et al. (2016) reported that children who attended ROC exhibited high levels of social functioning at the end of ROC sessions as measured by the Pediatric Camp Outcome Measure. They also reported associations between social functioning and repeated ROC attendance such that children who were attending ROC for the first year had lower social functioning scores compared with children who had previously attended ROC. Unlike these findings, our study did not find the number of years of ROC attendance to be associated with perceived levels of social support. This discrepancy may be explained by our small sample size or the limited number of participants who had not previously attended overnight ROC programming. It is also possible that repeated ROC attendance is associated with higher levels of an aspect of social functioning that is different from perceived social support.

Children with cancer have also reported feeling accepted by their camp peers and feeling as though they develop close relationships with other campers more quickly and easily than peers from home (Moola et al., 2023). Although quantitative research, including our study, has not captured improvements in social support with ROC attendance, qualitative research strongly supports social benefits associated with ROC participation (Beckwitt, 2014; Dawson et al., 2012; Gillard & Watts, 2013; Moola et al., 2023; Neville et al., 2019; Riley, 2018). Perhaps qualitative research captures certain aspects of social support or the social experience of ROC that quantitative research has not yet been able to effectively capture. It is also possible that ROC does not have a significant impact on levels of perceived social support in childhood cancer patients.

From a developmental perspective, social support may be particularly important within our cohort of childhood cancer patients as most of our participants were adolescents. Adolescence is a developmental stage where autonomy and the search for identity are critical, and there is an increased importance placed on peer relationships versus family relationships (Brand et al., 2017; Christiansen et al., 2015). Additionally, adolescents tend to place greater importance on their physical appearance and evaluate their physical and emotional functioning based on peer comparisons (Mavrides & Pao, 2014; Meltzer & Rourke, 2005). However, cancer treatment often prevents adolescents with cancer from partaking in developmentally normal social activities through school and extracurricular activities where they can develop their relationships with peers (Neville et al., 2019). ROCs not only provide adolescents with opportunities to interact with peers and develop social relationships during a stage of their lives when these opportunities are critical for their social development, but they also offer adolescent cancer patients the unique experience of interacting with peers they feel similar to due to their similar health journeys (Brand et al., 2017; Meltzer & Rourke, 2005; Moola et al., 2023; Neville et al., 2019). As such, ROCs may help to reduce the negative impact cancer has on the social development of adolescent cancer patients (Neville et al., 2019). Additionally, the similar peer comparisons adolescent cancer patients make at ROC may help to reduce feelings of loneliness and dissatisfaction with their physical appearance, and they may feel more accepted by peers and have higher self-worth (Meltzer & Rourke, 2005). Although we did not find ROC to improve perceived social support in childhood cancer patients, ROC may provide other social benefits that we did not assess.

It is important to provide childhood cancer patients with an environment, such as the ROC environment, that allows them to form social relationships in which they can derive social support as social isolation is common in childhood cancer patients/survivors (Howard et al., 2014). One study reported that 19 out of 30 of their participants who were adults that survived childhood cancer experienced social isolation at some point in their lives (Howard et al., 2014). These participants experienced either 1) social isolation during cancer treatment that improved over time, 2) social isolation during cancer treatment that persisted throughout survivorship, or 3) social isolation that began at some point during survivorship (Howard et al., 2014). We found that levels of perceived social support were high within the ROC environment and these high levels of perceived social support were sustained three months post-camp in childhood cancer patients. Additionally, a 2014 qualitative study investigating the experiences of adult childhood cancer survivors who attended ROC found that many childhood cancer survivors experienced continued social support through survivorship and adulthood from the people they formed connections with at camp (Beckwitt, 2014). Therefore, the social support that childhood cancer patients receive at ROC may be one contributing factor to prevent social late effects and social isolation during treatment and throughout survivorship.

Overall, we did not find significant differences in the perceived levels of social support among childhood cancer patients attending a 10-day ROC session. However, we did find that perceived levels of social support were high in our participants. This finding is positive as social support is associated with other positive psychosocial outcomes for childhood cancer patients including increased resilience, hope, self-esteem/self-image, and reduced behavioural and mental health problems (Decker, 2007; Li et al., 2016; Mesman et al., 2021; Wu et al., 2013). Overall, ROC appears to be a healthy social environment for childhood cancer patients as their high levels of social support were maintained from the beginning to end of the camp session. Additionally, our finding of sustained high levels of social support three months post-camp are encouraging as this suggests that childhood cancer patients have continued access to support outside of the ROC environment.

5.4 Mental Wellbeing in Childhood Cancer Patients

Mental wellbeing refers to a positive mental state that allows individuals to realise their abilities, work productively, and cope with stressors effectively (Tennant et al., 2007). I hypothesized that the overall mental wellbeing of childhood cancer patients, as measured by the SWEMWBS, would improve after the attendance of a 10-day session of overnight ROC. However, our results did not support this hypothesis and mental wellbeing scores were similar across timepoints. That said, it is important to consider the clinical significance of our findings. When compared to the available normative population values for the SWEMWBS, scores of the childhood cancer patients in this study were above the 75th percentile while at ROC (*Collect, Score, Analyse and Interpret WEMWBS,* 2021), and mean SWEMWBS scores dropped below the 75th percentile three months post-camp (*Collect, Score, Analyse and Interpret WEMWBS*, 2021). Upon comparing mental wellbeing scores between post-camp 1 and post-camp 2, we found the effect size to be large (decrease). This suggests there may be a clinically meaningful change in mental wellbeing when children are back in their regular environment compared to when they were at camp. It should be noted that the available population norms are based on data from adults, so comparisons should be made with caution as they may not be generalizable to a pediatric population.

Two components of mental wellbeing were assessed in this study: hedonia and eudemonia (Shah et al., 2021). Hedonic wellbeing refers to positive feelings and emotions whereas eudaimonic wellbeing refers to positive functioning (Gallagher et al., 2009). It is important to highlight that the SWEMWBS was not designed to assess social wellbeing which, like eudaimonic wellbeing, refers to an individual's functioning. However, social wellbeing differs from eudaimonic wellbeing in that it focuses more on interpersonal functioning (e.g., social integration, social acceptance, etc.) rather than intrapersonal functioning (e.g., autonomy, self-acceptance, personal growth, etc.) (Gallagher et al., 2009). Gallagher et al. (2009) determined that hedonic, eudaimonic, and social wellbeing can be integrated into a hierarchal structure of wellbeing; however, their findings suggest that measures of social wellbeing may require a longer and more thorough list of items to accurately measure this construct. Considering the pediatric population participating in our study, we attempted to keep our survey brief to be minimally invasive. As such, a longer measure of wellbeing that included measures of social wellbeing was unrealistic. Additionally, there is a greater emphasis on the hedonic and eudaimonic dimensions of wellbeing in literature, and we evaluated social functioning separately through the use of the SPS-5 (Gallagher et al., 2009).

Although our findings do not suggest that ROC improves the mental wellbeing of childhood cancer patients, the potentially clinically meaningful decrease in our participants' mental three months post-camp suggests that the ROC environment is associated with high levels of mental wellbeing. Our findings of high levels of mental wellbeing in childhood cancer patients while attending ROC are largely consistent with the current literature. In their narrative review, Neville et al. (2019) concluded that most findings in literature published between 2007 and 2018 suggest that ROCs have a positive impact on the psychosocial wellbeing of childhood cancer patients/survivors. For instance, one study reported improvements in the health-related quality of life of youth after attending a camp designed for children with chronic diseases (including cancer) (Békési et al., 2011). Psychological wellbeing is a component of health-related quality of life and as such, their findings suggest that mental wellbeing may improve with disease-specific camp attendance (Békési et al., 2011).

Neville et al. (2019) suggested that the psychosocial wellbeing of childhood cancer patients/survivors is promoted through improved social health. As such, the high levels of perceived social support that our participants reported while at ROC may have contributed to our finding of high levels of mental wellbeing, particularly considering loneliness is a risk factor for poor mental wellbeing (Guo et al., 2018; Lyyra et al., 2021). Youth with cancer may feel dissimilar to their healthy peers which places them at an increased risk of loneliness and social isolation (Meltzer & Rourke, 2005). However, ROC provides an environment where youth with cancer are surrounded by peers with similar illness-related experiences and they have reported feeling more similar to their camp peers than their peers from home (Meltzer & Rourke, 2005). Therefore, the high levels of mental wellbeing that our participants experienced while in the ROC environment could be partially attributed to the social support and similar peer comparisons they make within this environment. However, it is unlikely that social support contributed significantly to levels of mental wellbeing in these childhood cancer patients as we did not find scores for social support and mental wellbeing to be correlated in this study.

Hedonic wellbeing is associated with various personality traits including self-esteem (Lyyra et al., 2021; Myers & Diener, 1995). The high levels of mental wellbeing we found in this study could be attributed to improvements in children’s self-esteem while attending ROC. Several studies with a pretest/post-test design have reported improvements in the self-esteem of childhood cancer patients and survivors after attending ROC (Dawson et al., 2012; Mcgrane, 2016; Torok et al., 2006). Additionally, one study reported that childhood cancer patients/survivors who previously attended ROC had significantly higher levels of self-esteem than children who were attending ROC for the first time (Wu et al., 2016). Although we did not find mental wellbeing to be associated with the number of years children previously participated in either overnight ROC programming or other types of ROC programming, it is possible that improved self-esteem at ROC contributed to our participants’ high levels of mental wellbeing.

Hedonic wellbeing is also associated with hope (Pleeging et al., 2019). Due to associations between hope and hedonic wellbeing, the high levels of mental wellbeing children in this study experienced at ROC could be partially attributed to the high levels of hope they experienced while in the ROC environment. We also found that the levels of hope of childhood cancer patients were significantly higher in the ROC environment compared to when children are back to their normal environments (three months post-camp). The decrease in levels of hope childhood cancer patients experienced three months post-camp may have contributed to the potentially clinically meaningful decrease we observed in mental wellbeing three months post-camp. However, we did not find hope and mental wellbeing scores to be correlated in our participants, so it is unlikely that hope was a large factor that impacted levels of mental wellbeing in the childhood cancer patients who participated in this study.

Our findings of high levels of mental wellbeing are promising as cancer poses a threat to children's mental wellbeing (Mavrides & Pao, 2014). For instance, one dimension of eudaimonic wellbeing involves a sense of self-determination (Gallagher et al., 2009). The self-determination of childhood cancer patients may be compromised during cancer treatment as they must listen to healthcare professionals, adhere to a treatment plan, and they may be prevented from participating in activities they enjoy (Brand et al., 2017). Furthermore, adolescents with cancer must rely more heavily on their parents/caregivers during a developmental stage where independence is critical (Brand et al., 2017). As such, the mental wellbeing of childhood cancer patients could be negatively impacted by cancer-related factors. However, ROC may improve children's sense of autonomy as they have the opportunity to choose from different camp activities (Moola et al., 2023), and many children report enjoying the freedom they have while at ROC (Moola et al., 2023; Neville et al., 2019). As mental wellbeing is associated with a sense of control and self-determination, the sense of freedom and control childhood cancer patients experience while at ROC could have contributed to the high levels of mental wellbeing that our participants demonstrated (Carver et al., 2000; Gallagher et al., 2009; Moola et al., 2023; Neville et al., 2019).

From a developmental perspective, ROC may have offered our participants unique experiences that could promote their overall wellbeing, particularly considering most of our participants were adolescents and in a stage of development where establishing a sense of autonomy and identity is critical (Brand et al., 2017; Mavrides & Pao, 2014). Youth with cancer commonly report frustrations with establishing their identity apart from their cancer or others' perceptions of them as the "kid with cancer" (Brand et al., 2017; Moola et al., 2023). Furthermore, adolescents with cancer commonly report feeling different from their healthy peers which is problematic as peer relationships aid in the formation of identity in adolescents (Meltzer & Rourke, 2005; Morgan et al., 2010). Difficulties with developing a sense of identity and/or belonging with a peer group can lead to role confusion. This role confusion can not only be harmful to the wellbeing of adolescents, but it may also lead them to engage in risk-taking behaviours, like medication non-adherence, as they may attempt to regain some sense of normalcy (Brand et al., 2017). However, adolescents attending ROC have reported feeling accepted by and similar to their camp peers (Meltzer & Rourke, 2005; Moola et al., 2023; Neville et al., 2019). ROC may also provide youth with cancer a sense of freedom and normalcy (Beckwitt, 2014; Dawson et al., 2012; Moola et al., 2023; Neville et al., 2019; Ryan, 2017). As such, ROC may promote the wellbeing of adolescents with cancer by reducing role confusion by providing them with normalizing experiences, an accepting environment in which they can explore their identity, and a sense of belonging to a peer group (Meltzer & Rourke, 2005; Moola et al., 2023; Neville et al., 2019).

Overall, our findings suggest that ROC is associated with high levels of overall mental wellbeing in childhood cancer patients. Although levels of mental wellbeing were similar between timepoints, there may have been a clinically meaningful decrease in overall mental wellbeing three months post-camp. Therefore, it may be beneficial to introduce continued interventions for pediatric cancer patients to maintain their mental wellbeing throughout the year.

5.5 Stress in Childhood Cancer Patients

I hypothesized that stress, as measured by salivary cortisol concentration (as a predictor of stress), would decrease in childhood cancer patients after attending a 10-day session of overnight ROC. The results did not support this hypothesis. However, it should be highlighted that salivary cortisol concentrations at baseline and post-camp 1 testing were within the normative range for the afternoon time period in youth aged 8 to 11 (0.012 µg/dL to 0.215 µg/dL) and 12 to 18 years of age (0.012 µg/dL to 0.259 µg/dL) (Salimetrics, 2021). These results suggest that ROC is not a stressful environment and did not yield a stress response from children who attended camp.

Childhood cancer patients encounter numerous stressors throughout cancer treatment (Gerali et al., 2011; Rodriguez et al., 2012). This is problematic as chronic stress in childhood can lead to dysfunctional stress regulation which is associated with neurological impairments (e.g., impaired memory and executive functioning), abnormal physiological differences (e.g., alterations in hippocampal structure), and psychosocial impairments (White et al., 2021). Furthermore, high cortisol levels have been associated with psychological symptoms in cancer patients (Li et al., 2020). One study found significant positive associations between cancer-related stress and depressive symptoms in children with cancer (Miller et al., 2009). Additionally, research in both animal models and humans suggests that stress impairs immune function, specifically natural killer cells, which may lead to increased tumor growth and metastasis in individuals with cancer (Ben-Eliyahu et al., 1999, 2000; Li et al., 2005; Lutgendorf et al., 2005) . As such, it is important for childhood cancer patients to maintain healthy levels of stress as chronic stress could negatively impact their cancer treatment, prognosis, and psychosocial health, while also potentially leading to various late effects. Therefore, our findings of healthy levels of stress within our participants while attending ROC is positive.

At ROC, there are healthcare professionals onsite to ensure that the medical needs of childhood cancer patients are met. As such, childhood cancer patients may feel comfortable in the ROC environment because they know it is a medically safe environment in which they do not have to worry about their medical needs. Current literature also suggests that ROCs provide a sense of community for children with cancer, with some youth even saying that their camp community feels like a family (Dawson et al., 2012; Moola et al., 2023; Ryan, 2017). Additionally, youth with cancer have reported feeling safe to be their authentic selves while attending ROC (Moola et al., 2023). These feelings of safety, comfort, and acceptance at ROC may contribute to our findings of ROC not being a stressful environment for childhood cancer patients.

The Theory of Supportive Design posits that positive outcomes in a healthcare setting are associated with that setting’s ability to promote stress reduction (Ulrich, 2012). Ulrich (2012) proposed that a supportive healthcare environment should promote social support. One study found social support to be directly and indirectly (through self-efficacy or coping style) associated with reduced psychological stress in children with malignant tumours (Liu et al., 2020). Another study found social support to be negatively associated with perceived stress in adult colorectal cancer patients undergoing chemotherapy (Costa et al., 2017). Qualitative research strongly suggests that ROC provides childhood cancer patients with social support (Beckwitt, 2014; Dawson et al., 2012; Gillard & Watts, 2013; Moola et al., 2023; Neville et al., 2019; Riley, 2018). Additionally, our participants demonstrated high levels of perceived social support while attending ROC. Therefore, although we did not detect decreased levels of stress as estimated by salivary cortisol concentrations, the availability of social support at ROC may have contributed to the healthy levels of stress we observed in our participants.

The ROC environment may also promote healthy levels of stress in childhood cancer patients by exposing them to nature. Ulrich (2012) also proposed that to create a supportive healthcare environment, patients should have access to nature. One study found that, while undergoing treatment, adult cancer patients with a window view of nature had significantly lower levels of stress compared with their counterparts who did not have a positive window view (Wang, 2017). As treatment is inherently stressful and uncomfortable, childhood cancer patients at ROC may experience better stress-related outcomes because of their exposure to nature. Furthermore, exposure to nature appears to be associated with faster stress recovery and reduced levels of stress (Li, 2010; Ulrich, 2012; Ulrich et al., 1991). Another study found that recovery from a stressor was significantly faster in undergraduate students who watched a video of a nature setting compared with students who watched a video of an urban setting (Ulrich et al., 1991). In their 2010 study, Li found that levels of adrenaline and noradrenaline in urine were lower in adult male and female participants who were immersed in nature compared with participants who went on a trip to a city. Adrenaline and noradrenaline in the urine are reflective of stress levels, and as such, these results suggest that individuals who were immersed in nature experienced lower levels of stress than individuals in an urban setting (Li, 2010). Similar results have been reported using salivary cortisol concentration as a measure of stress (Park et al., 2007). Therefore, our participants may have maintained healthy levels of stress due to their exposure to nature while in the ROC environment.

ROC may have also promoted healthy levels of stress by providing opportunities for childhood cancer patients to engage in physical activity. It is unlikely that physical activity would explain our results of normal stress levels at baseline as the participants had just arrived at ROC and had not engaged in specific activities before data collection. However, their participation in physical activity while at ROC could have contributed to our findings of healthy stress levels in childhood cancer patients on the last day of the ROC session. In their qualitative study, Gillard and Watts (2013) reported that childhood cancer patients were provided opportunities to engage in physical activity while attending ROC. These children may be more sedentary while at home because activities are not accommodated to meet their needs or they are unable to keep up with their healthy peers (Gillard & Watts, 2013). However, ROC encourages childhood cancer patients to engage in physical activity by providing patience, acceptance, and full accommodations (Gillard & Watts, 2013). Low intensity exercise is associated with reduced levels of circulating cortisol (Hill et al., 2008). As such, the walking and activities childhood cancer patients participate in while attending ROC could help to lower circulating cortisol levels, thus contributing to the healthy stress levels we observed at post-camp 1.

To the best of our knowledge, this was the first study to investigate the impact of ROC on a biological marker of stress in childhood cancer patients. Although our findings suggest that being in the ROC environment is associated with physiological stress within normative age-based ranges, we did not find ROC participation reduced stress over time. This lack of change in stress levels could be attributed to our use of salivary cortisol as a measure of stress. Salivary cortisol has been shown to be a good marker of physiological stress (Allen et al., 2014; Lee et al., 2015); however, salivary cortisol levels are not necessarily indicative of children’s perceived levels of stress. For instance, a 2019 study found perceived levels of stress to be within a normal range among children with type I diabetes (Davis et al., 2019). Contrary to their findings of normal levels of perceived stress, 40% of their participants demonstrated increased cortisol levels between two collection timepoints approximately 200 minutes apart (Davis et al., 2019). As such, these children exhibited abnormal cortisol rhythms that were indicative of physiological stress, thereby suggesting that perceived levels of stress are not necessarily consistent with physiological stress (Davis et al., 2019). Therefore, our participants may not have experienced significant reductions in physiological stress after attending a ROC session; however, it is possible that they experienced changes in their levels of perceived stress that were not captured by our stress measure. Future studies are needed to determine whether the perceived levels of stress of childhood cancer patients are affected by ROC attendance.

It may also be beneficial to measure perceived stress as cancer treatment can impact circulating levels of free cortisol and increase childhood cancer patients’/survivors’ risk of endocrine dysfunction (Wei & Crowne, 2018). Literature suggests that radiotherapy is implicated in HPA axis dysfunction (Wei & Crowne, 2018). For instance, one study found that 19% of childhood brain cancer survivors who were treated with cranial irradiation presented with HPA axis dysfunction as evidenced by low basal and peak cortisol levels (Schmiegelow et al., 2003). Glucocorticoids are also commonly used to treat cancer or reduce the side effects of cancer treatment like nausea and inflammation (Pufall, 2015). However, due to the feedback systems of the HPA axis, glucocorticoid treatment can suppress the release of corticotrophin-releasing hormone and adrenocorticotropic hormone (ACTH) from the pituitary glands (Rensen et al., 2017). The suppression of these hormones can cause childhood cancer patients to experience secondary adrenal insufficiency (Rensen et al., 2017; Wei & Crowne, 2018). Adrenal insufficiency occurs when insufficient amounts of ACTH are released by the pituitary glands (Husebye et al., 2021). As ACTH stimulates the adrenal glands to secrete cortisol, adrenal insufficiency leads to low levels of circulating cortisol and impaired stress responses (Husebye et al., 2021; Rensen et al., 2017). In their literature review of HPA axis suppression with glucocorticoid therapy in children with acute lymphoblastic leukemia, Rensen et al. (2017) reported that most children experienced adrenal insufficiency in the days following cessation of glucocorticoid treatment and this adrenal insufficiency could persist for up to 34 weeks. Therefore, our findings of normal cortisol levels in childhood cancer patients could be reflective of treatment-related endocrine dysfunction rather than the ROC environment.

Increased salivary cortisol levels in response to acute stressors occur within minutes of exposure (Allen et al., 2014). As such, our findings of normal stress levels in children attending ROC suggest that childhood cancer patients may not encounter numerous acute stressors while in the ROC environment. However, the impact of chronic stressors (e.g., cancer-related stressors) on cortisol levels is less clear. A 2017 study found that prolonged perceived stress was not associated with morning or evening salivary cortisol levels in Danish public service employees (Mikkelsen et al., 2017). As such, we may not have observed reduced stress levels from the first to last day of the ROC session because our measure of stress may have been reflective of acute changes in stress rather than chronic perceived stress. Studies have reported that ROC offers children some respite from the daily stressors associated with cancer and cancer treatment (Gillard & Watts, 2013; Riley, 2018). Therefore, had we used a measure of perceived stress (e.g., the Feel Bad Scale), we may have found stress to be improved in childhood cancer patients after participating in ROC programming.

Many studies investigating stress measure the degree of change in cortisol levels throughout the day (diurnal cortisol slope) (Adam et al., 2017). In future studies, it may be better to compare the diurnal cortisol slopes of participants between the first and last days of a ROC session as this would account for acute changes in salivary cortisol concentrations caused by time of day and mood changes (Adam, 2006; Adam et al., 2017). Furthermore, diurnal cortisol slopes may reveal abnormal cortisol rhythms that single timepoint saliva sample collection would not detect (Adam et al., 2017). A 2017 meta-analysis reported that flatter diurnal cortisol slopes were associated with worse health outcomes including outcomes related to cancer, mental health, and immunity/inflammation (Adam et al., 2017). Both hypo- and hypercortisolism contribute to flattened diurnal cortisol slopes as cortisol levels would be lower in the morning and heightened in the afternoon/evening (Adam et al., 2017). Considering we only collected afternoon saliva samples, our participants may have had clinically meaningful cortisol rhythm abnormalities that were not detected by our measure of stress. For instance, participants could have had lower waking cortisol levels which are associated with increased fatigue (Bower et al., 2005; Kumari et al., 2009). Detecting low waking cortisol levels in childhood cancer patients could be particularly important as fatigue is a major physical implication of cancer and cancer treatment (Al-Gamal & Long, 2016). Therefore, evaluating the diurnal cortisol slopes of participants at the beginning and end of a ROC session would account for diurnal changes in cortisol levels and changes in mood, while also potentially revealing clinically important trends in cortisol rhythms (Adam et al., 2017).

Our ability to accurately compare physiological stress levels between the first and last day of camp was also limited by the timing and frequency of our saliva sample collection. Circulating cortisol concentrations follow a diurnal rhythm with cortisol levels starting high upon waking, increasing to peak levels within 30-40 minutes of waking, and then decreasing throughout the day (Adam et al., 2017). Due to the diurnal changes in cortisol, a large proportion of variance in salivary cortisol concentrations can be attributed to time of day as evidenced by one study with adolescent participants (Adam, 2006). To account for this circadian variation in cortisol levels, we attempted to collect saliva samples around the same time and all samples were collected in the afternoon during baseline and post-camp 1 testing. However, sample collection still took place over the course of several hours which could account for some of the variation in our salivary cortisol concentrations between the two timepoints. Furthermore, we may have encountered a floor effect due to the timing of sample collection. As cortisol levels decline throughout the day, salivary cortisol concentrations tend to be quite low or non-detectable in the afternoon (Adam, 2006; Adam et al., 2017; Salimetrics, n.d.). Therefore, the afternoon saliva samples we collected may have had cortisol concentrations that were too low to detect any significant changes between baseline and post-camp 1.

It should also be noted that the saliva sample collection protocol we used for this study indicated that sample collection should not occur within 60 minutes after eating (Salimetrics, n.d.). However, due to time constraints during data collection, some saliva samples were obtained within 60 minutes after the participant consumed a meal. The ELISA assay performance may have been compromised for these saliva samples as acidic food could impact the pH of the sample (Salimetrics, n.d.). However, the pH of our samples did not appear to be affected as the addition of a pH indicator in the assay diluent did not result in any abnormal colour changes (yellow for acidic solutions, purple for alkaline solutions) in any of the samples (Salimetrics, n.d.).

While we did not observe decreased salivary cortisol concentrations from the first to last day of the ROC session, our results suggest that childhood cancer patients have healthy levels of stress while in the ROC environment. These results are promising as high levels of stress are associated with various negative outcomes in childhood cancer patients (White et al., 2021). Therefore, ROC does not appear to be a stress-inducing environment and as such, implementing ROC as a psychosocial intervention for childhood cancer patients appears to be safe.

5.6 Limitations

While some limitations have been discussed throughout this thesis, it is important to note that there were several limitations to this study. As mentioned previously, we were unable to collect data prior to the participants arriving at camp (i.e., a baseline collection point while children/adolescents were in their usual environments) due to the limited time between research ethics approval and the beginning of the ROC session. As we collected baseline data when participants arrived at camp on the first day of the ROC session, they had already begun the camp experience and were likely experiencing heightened emotions, such as excitement, which could have affected their survey scores. Although we hypothesize that the scores participants obtained three months post-camp may be more reflective of true baseline values as children had returned to their normal environment, future studies with baseline testing taking place before the start of the camp session are needed. Furthermore, survey scores were quite high at baseline and as such, we may have encountered a ceiling effect which prevented us from observing significant improvements in measures of resilience, hope, social support, and mental wellbeing.

This study was limited in its ability to determine causal relationships as we did not collect data from a comparison group of children who did not attend ROC. As such, we were only able to infer correlational relationships between ROC attendance and the psychosocial outcomes of interest. With only one randomized controlled trial investigating the impact of ROC on childhood cancer patients/survivors (Li et al., 2013) , research in this area is largely limited in its ability to infer causal relationships (Kelada et al., 2020). Considering the nature of ROCs and the psychosocial needs of children with cancer, it would likely be unethical to ask eligible children in a control group to refrain from participating in ROC programming. Instead, future studies may opt to use a comparison group of childhood cancer patients who decided not to participate in ROC programming, who were unable to attend a ROC, or other chronically ill children who did not participate in any disease-specific camp programming.

Our relatively small sample size was another limitation of this study. Although we collected data from 24 participants at baseline, we only obtained data from ten participants at all three timepoints. This small sample size increases the risk of a type II error (null hypothesis accepted when it is false) and as such, ROC may have had a more significant impact on the measured variables that we did not find due to insufficient statistical power. This small sample size also increases the risk of selection bias. Although this study was limited by a small sample size, we were able to pilot new protocols with Campfire Circle so that we will be able to conduct future studies and address the limitations of the current study. Additionally, more than half of the children who attended this ROC session wanted to participate in this study; however, due to miscommunication regarding the consent forms, we did not receive the consent forms of an additional 16 children before baseline data collection. Therefore, we suggest that future studies with Campfire Circle may not encounter these same issues with sample size and potential for selection bias.

Participants completed surveys at baseline and post-camp 1 with a member of the research team which could have increased the risk of response bias. Fatigue effect could also be a limitation of this study. Although the survey was brief, taking about 8 minutes to complete, we were working with a pediatric population that was eager to return to their camp activities. This could have led to reduced attention while completing the survey and/or increased the likelihood that they would choose the same responses for each item toward the end of the survey (Lavrakas, 2011). In the future, it may be better to randomize the order of the scales so that if fatigue effect does occur, it does not heavily impact one measure. Furthermore, Neville et al. (2019) reported that the use of questionnaires/surveys was less preferable for children attending ROC compared with qualitative approaches to psychosocial data collection including arts-based approaches and interviews. Although the psychometric tools we used in this study were validated for use in pediatric/adolescent populations, these tools may be less engaging and more difficult to understand than other approaches (Neville et al., 2019). As we were collaborating with Campfire Circle on this study, our use of psychometric tools was beneficial as we were able to pilot their use so that our partner could easily implement these tools in future to evaluate outcomes. However, research may benefit from using a combination of psychometric tools and more in-depth analyses of the psychosocial health of childhood cancer patients such as child-centred arts-based approaches which could reveal underlying thoughts and themes that may not be captured by quantifiable measures (Driessnack, 2005).

This study was also limited in terms of racial diversity as our participant population was largely Caucasian (69.6% in campers who participated at baseline and post-camp 1, 50.0% in campers who participated at all timepoints). Residential camps are part of EuroWestern tradition, but Black and/or Indigenous families may feel uncomfortable sending their child to ROC due to a lack of cultural safety and the history of residential schooling in Canada (Hallmon et al., 2020; Moola et al., 2023; Shore, 2015). As such, it is necessary to focus on diversifying the ROC environment, removing racial and cultural barriers to ROC participation, and investigating the impact of ROC on the psychosocial health of childhood cancer patients navigating multiple marginalities (Moola et al., 2023).

Finally, it should be taken into consideration that the data collection for this study took place the first summer that traditional camp programming at Campfire Circle resumed since the beginning of the COVID-19 pandemic. The psychosocial outcomes we investigated may have been impacted by the COVID-19 pandemic and as such, our findings may have also been influenced by the pandemic and its impact on psychosocial health.

5.7 Conclusions

This study found that levels of resilience, hope, perceived social support, and overall mental wellbeing were high in childhood cancer patients while attending a 10-day ROC. Additionally, we found that childhood cancer patients had healthy levels of stress, within normative age-based ranges, while at ROC. Although we did not find significant improvements in these psychosocial outcomes from the first to last day of the ROC session, our results do suggest that the ROC environment is associated with excellent psychosocial health in children with cancer. To the best of our knowledge, this is the first quantitative study to examine resilience, hope, overall mental wellbeing, and a biological marker of stress in childhood cancer patients attending an ROC.

Levels of hope were significantly lower and there were clinically meaningful decreases in the resilience and mental wellbeing of childhood cancer patients three months post-camp compared to scores while at camp. These results suggest that the positive psychosocial outcomes associated with ROC may not be sustained once children return to their regular environments. As such, it may be beneficial to implement continued psychosocial interventions for childhood cancer patients throughout the year so that they maintain their psychosocial health. Based on the results of this study, placing a greater focus on fall and winter ROC sessions may help to support the psychosocial health of childhood cancer patients throughout the year.

Overall, the results of this study suggest that while attending ROC, childhood cancer patients experience healthy levels of stress and high levels of resilience, hope, perceived social support, and overall mental wellbeing. These psychosocial outcomes could help childhood cancer patients to cope with and adapt to the adversity brought upon them by cancer and cancer treatment, while also providing them with resources to become well-adjusted survivors.

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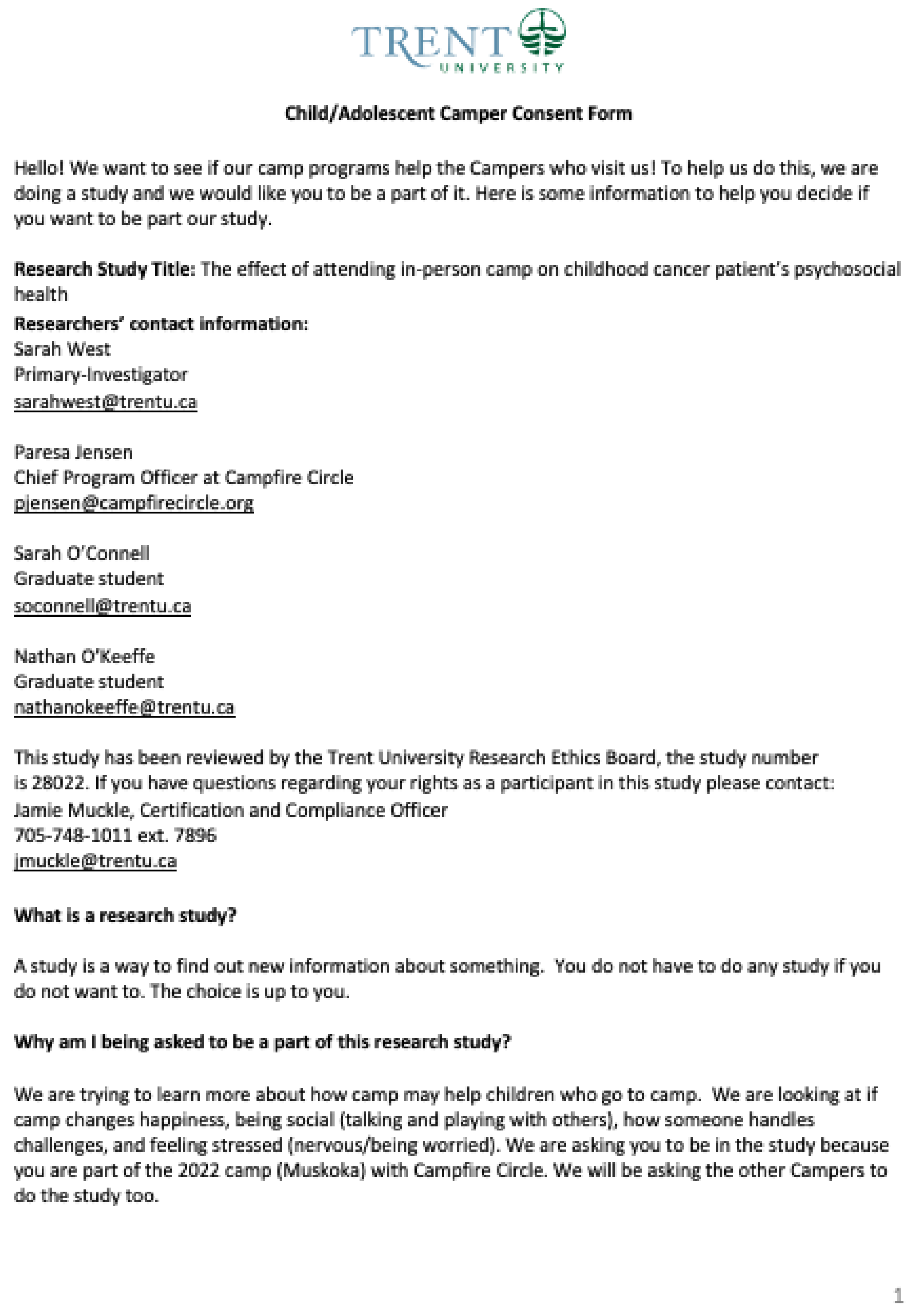
6.0 Appendix

6.1 Letter of Consent



Child/Adolescent Camper Consent Form

Hello! We want to see if our camp programs help the Campers who visit us! 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 attending in-person camp on childhood cancer patient's psychosocial health

Researchers' contact information:
Sarah West
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Paresa Jensen
Chief Program Officer at Campfire Circle
pjensen@campfirecircle.org

Sarah O'Connell
Graduate student
soconnell@trentu.ca

Nathan O'Keeffe
Graduate student
nathanokeeffe@trentu.ca

This study has been reviewed by the Trent University Research Ethics Board, the study number is 28022. If you have questions regarding your rights as a participant in this study please contact:
Jamie Muckle, Certification and Compliance Officer
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 may help children who go to camp. We are looking at if camp changes happiness, being social (talking and playing with others), how someone handles challenges, and feeling stressed (nervous/being worried). We are asking you to be in the study because you are part of the 2022 camp (Muskoka) with Campfire Circle. We will be asking the other Campers to do the study too.

If I join the study what will happen?
If you say yes:

- We will as you some questions (like how old you are), and camp staff will tell us if you have been to camp before, and a bit about your cancer (what kind, and how long)
- You will answer questions 3 different times, on the first day of camp, on the last day of camp, and then 3 months after camp is done.
- We will ask you questions about your friends, family and how you feel.
- The questions will take about 10-15 minutes for you to answer, each time (a total of 30-45 minutes).
- We will also collect some of the spit in your mouth 2 different times, on the first day of camp and on the last day of camp. We will ask you to put a piece of cotton under your tongue for one minute. We will use this spit to look at something that tells us about your stress.
- The spit collection will take less than 5 minutes each time (a total of 10 minutes)
- If you would like to only to answer the questions, and not collect your spit, you can also do that. You can also say no to answering any question(s) as well (and only answer some of them).

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 upset. The cotton swab may make your mouth feel a little dry when it is in your mouth for one minute.

Will the study help you/others?

This study might find out things that will help other children who have cancer. This study can help us learn how camp makes children feel.

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 when you are reading this form.

Who will see the information collected about you?

The information collected about you will only be able to be looked at by the research team. We will not ask for your name or birthday. You will get a special code, which will be used instead of your name for the study. The spit collection will have your study code written on it. Your spit collection will be stored safely in a locked laboratory in a freezer at Trent University. After we measure the stress level from your spit, any leftover sample will be thrown away.

What are the benefits for being enrolled in the study?

There are no benefits from being in the study. Your answers may help us learn about how camp makes children feel.

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. It's up to you. You can also think about being in the study, and talk to the researchers at camp about it. You can still go to Camp like usual even if you say no to 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, tell the researchers you don't want to do the study, or you can tell your parent/guardian. It's okay. No one will be upset. You can still go to Camp. Also there are no right or wrong answers. You can also say you don't want to answer any question, but still do the rest of the questions and spit collection.

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!). This is the same for your stress levels we measure in your spit. Your answers may also be used by Campfire Circle to help future camp. All of your answers will be collected on a Trent University survey system (called Qualtrics), and your answers will be stored on the secure Trent University OneDrive Network System. Your answers 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 deleted.

We will keep all of your answers private (just the researchers will see them), as long as they are within ethical principles and/or the law (for example, if you tell us about getting hurt by someone, we will have to tell someone else about this as well).

What if you have any questions?

If you, or if your parents/ caregivers have any questions you can call or email our team. Sarah O'Connell (soconnell@trentu.ca), Dr. Sarah West (Primary Investigator, Trent University; sarahwest@trentu.ca), or Paresa Jensen (Chief Program Officer at Campfire Circle, pjensen@campfirecircle.org).

Consent: If you select the option "YES", you are agreeing to the following:

- You have read, or have had your parent/guardian read to you, the consent form above
- You are attending camp with Campfire Circle in the summer 2022
- You and your parents/caregivers have discussed you doing the study
- You understand what you have to do in the study
    - You are saying yes to answering questions about how you feel and your family at 3 different times
- 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

I say yes to taking part in this study:

____
Printed Name of Participant

______________________________________ ________________________
Signature of Participant Date

Consent: If you select the option "YES", you are agreeing to the following:

- To also give us 2 collections of your spit so we can measure stress

____
Printed Name of Participant

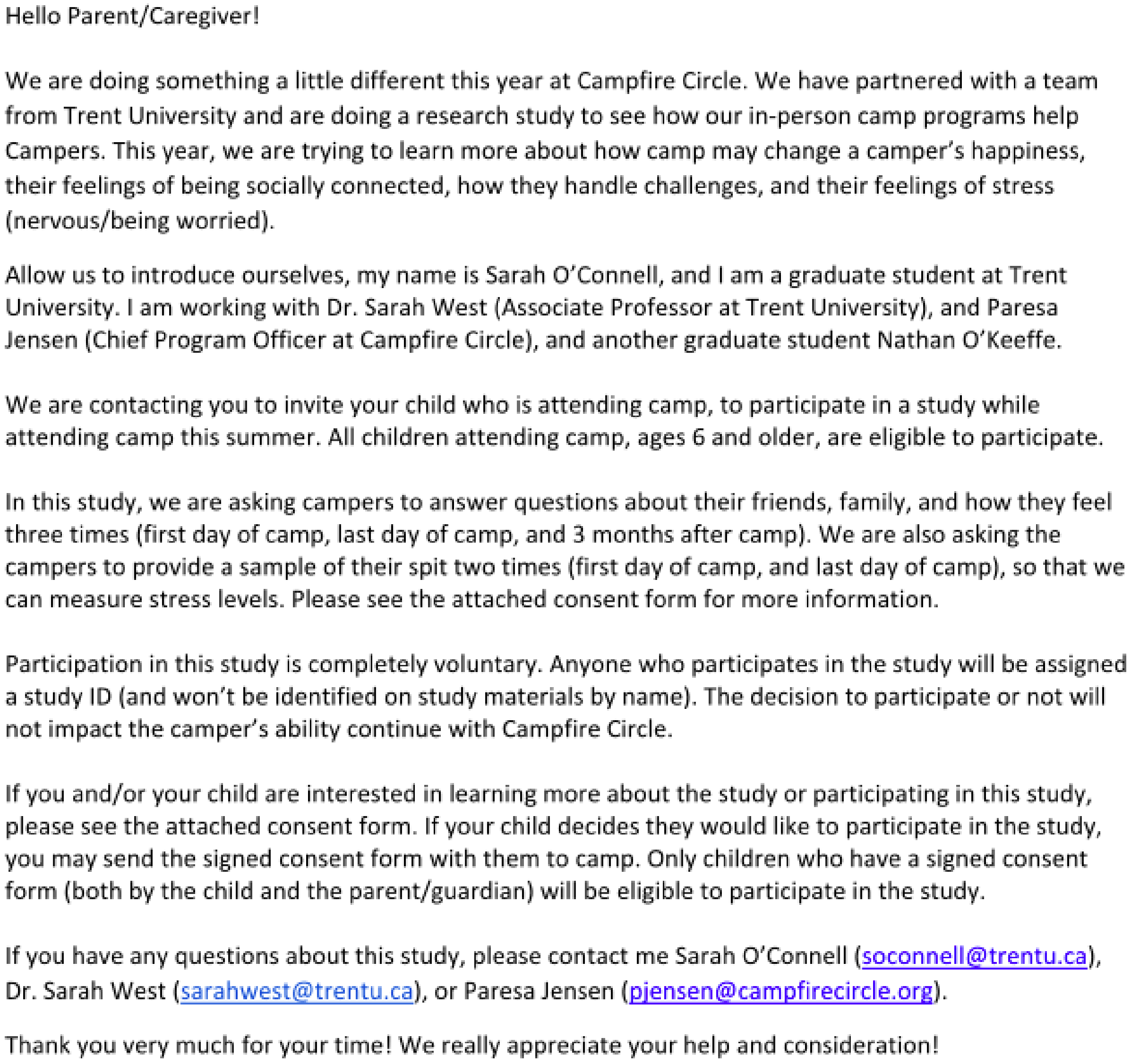
______________________________________ ________________________
Signature of Participant Date

Does your parent/guardian say yes for you to take part in this study?

____
Printed Name of Parent/Guardian

______________________________________ ________________________
Signature of Parent/Guardian Date

6.2 Recruitment Email



Hello Parent/Caregiver!

We are doing something a little different this year at Campfire Circle. We have partnered with a team from Trent University and are doing a research study to see how our in-person camp programs help Campers. This year, we are trying to learn more about how camp may change a camper’s happiness, their feelings of being socially connected, how they handle challenges, and their feelings of stress (nervous/being worried).

Allow us to introduce ourselves, my name is Sarah O’Connell, and I am a graduate student at Trent University. I am working with Dr. Sarah West (Associate Professor at Trent University), and Paresa Jensen (Chief Program Officer at Campfire Circle), and another graduate student Nathan O’Keeffe.

We are contacting you to invite your child who is attending camp, to participate in a study while attending camp this summer. All children attending camp, ages 6 and older, are eligible to participate.

In this study, we are asking campers to answer questions about their friends, family, and how they feel three times (first day of camp, last day of camp, and 3 months after camp). We are also asking the campers to provide a sample of their spit two times (first day of camp, and last day of camp), so that we can measure stress levels. Please see the attached consent form for more information.

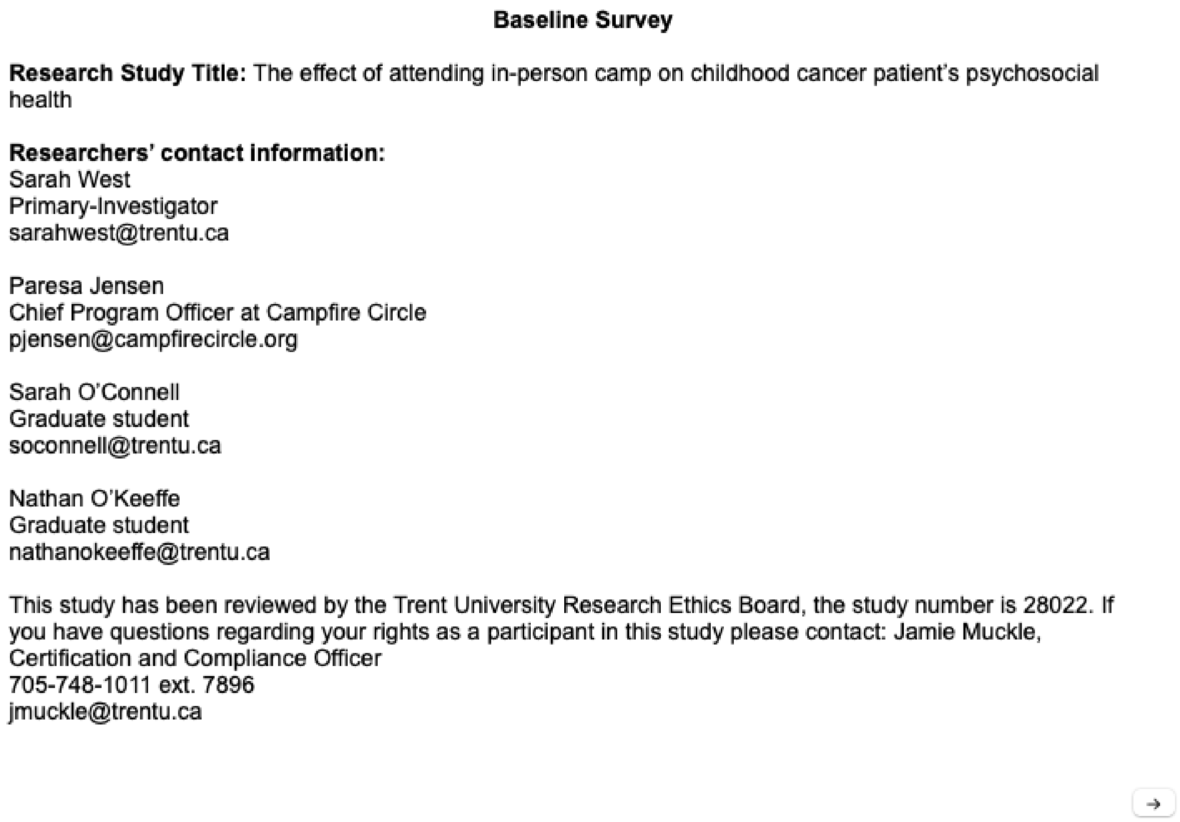
Participation in this study is completely voluntary. Anyone who participates in the study will be assigned a study ID (and won’t be identified on study materials by name). The decision to participate or not will not impact the camper’s ability continue with Campfire Circle.

If you and/or your child are interested in learning more about the study or participating in this study, please see the attached consent form. If your child decides they would like to participate in the study, you may send the signed consent form with them to camp. Only children who have a signed consent form (both by the child and the parent/guardian) will be eligible to participate in the study.

If you have any questions about this study, please contact me Sarah O’Connell (soconnell@trentu.ca), Dr. Sarah West (sarahwest@trentu.ca), or Paresa Jensen (pjensen@campfirecircle.org).

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

6.3 Qualtrics Survey



Baseline Survey

Research Study Title: The effect of attending in-person camp on childhood cancer patient's psychosocial health

Researchers' contact information:
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Chief Program Officer at Campfire Circle
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Nathan O'Keeffe
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This study has been reviewed by the Trent University Research Ethics Board, the study number is 28022. If you have questions regarding your rights as a participant in this study please contact: Jamie Muckle, Certification and Compliance Officer
705-748-1011 ext. 7896
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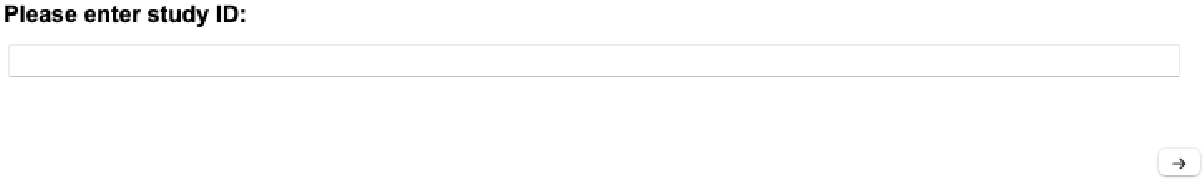

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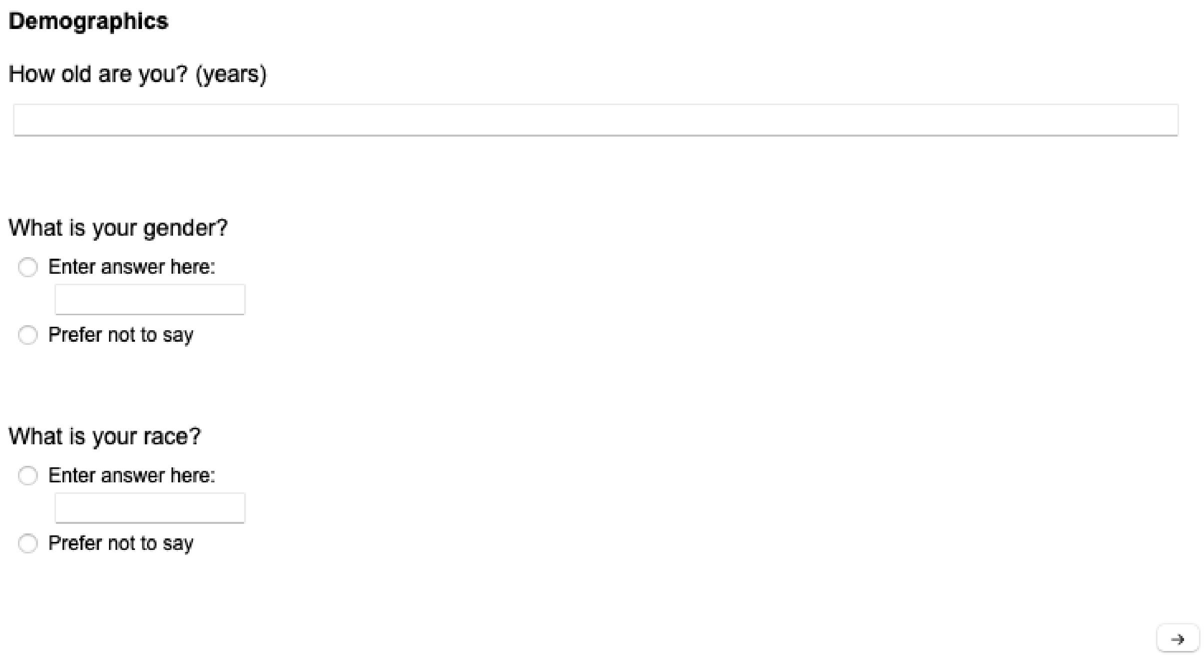


Demographics

How old are you? (years)

What is your gender?

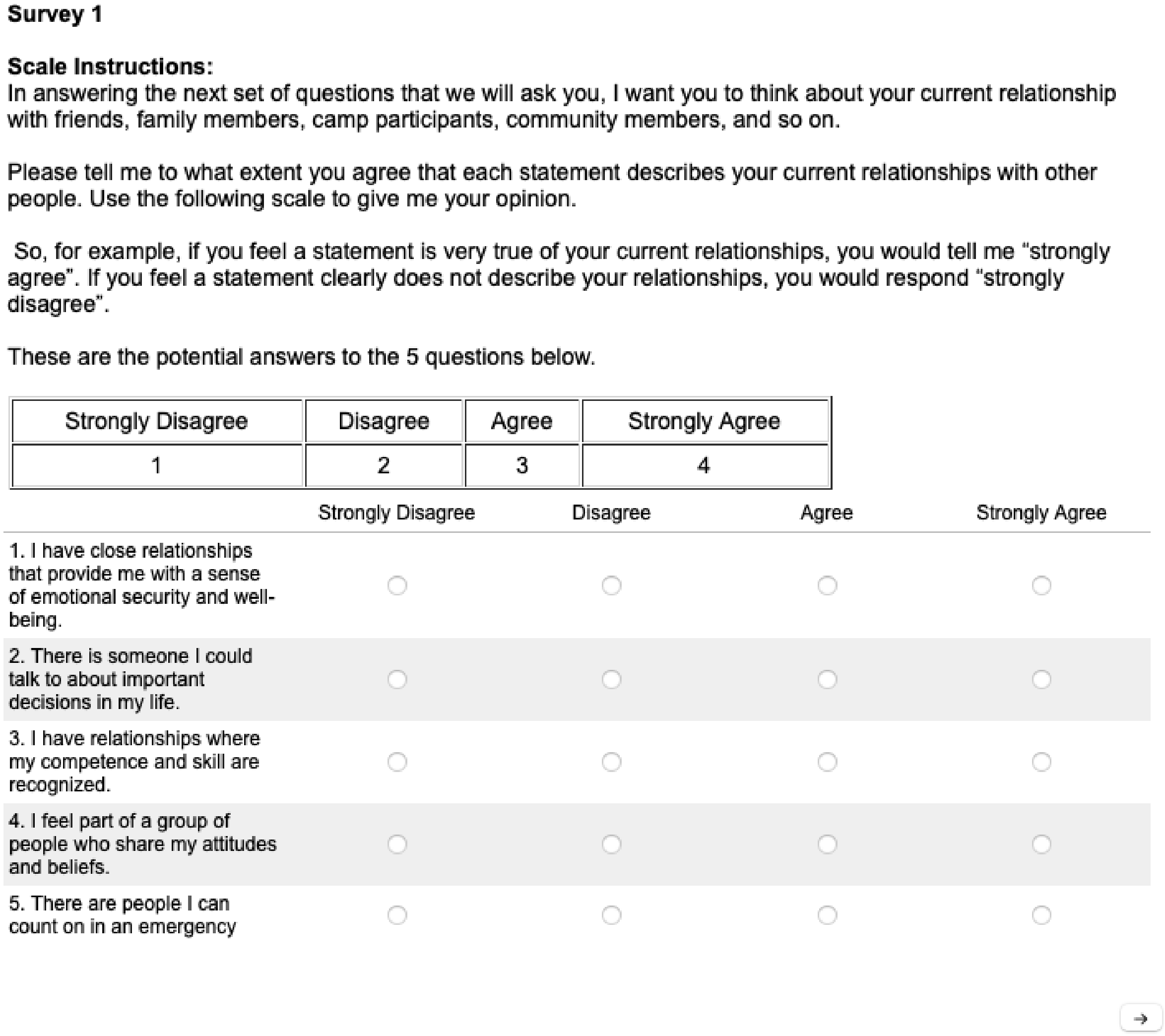
○ Enter answer here:

○ Prefer not to say

What is your race?

○ Enter answer here:

○ Prefer not to say



Survey 1

Scale Instructions:
In answering the next set of questions that we will ask you, I want you to think about your current relationship with friends, family members, camp participants, community members, and so on.

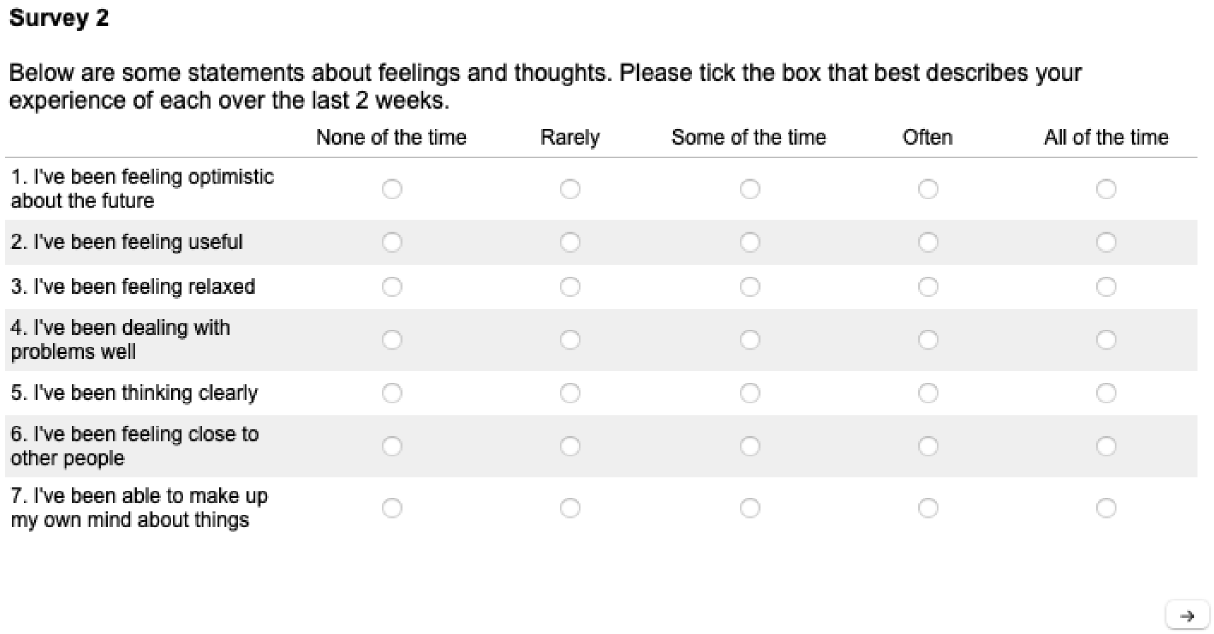
Please tell me to what extent you agree that each statement describes your current relationships with other people. Use the following scale to give me your opinion.

So, for example, if you feel a statement is very true of your current relationships, you would tell me "strongly agree". If you feel a statement clearly does not describe your relationships, you would respond "strongly disagree".

These are the potential answers to the 5 questions below.

Strongly Disagree	Disagree	Agree	Strongly Agree
1	2	3	4

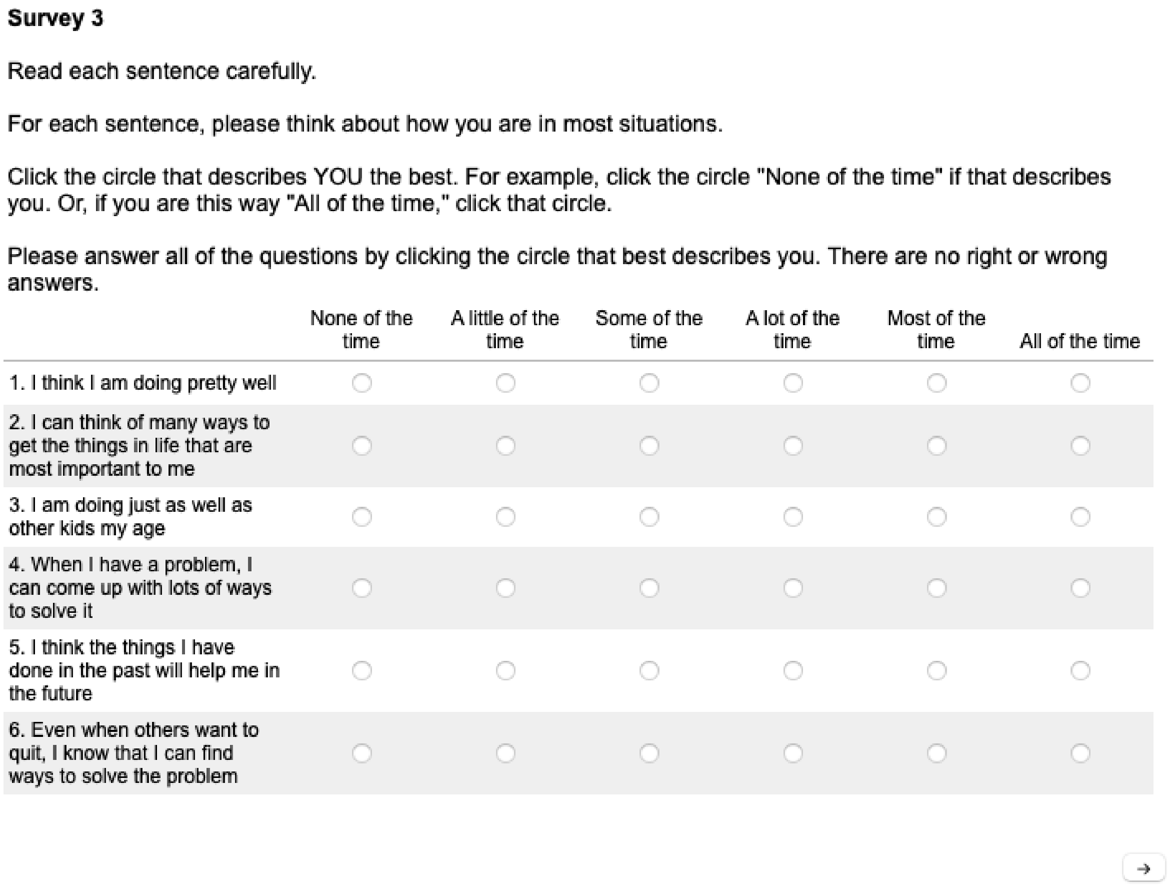
	Strongly Disagree	Disagree	Agree	Strongly Agree
1. I have close relationships that provide me with a sense of emotional security and well-being.	○	○	○	○
2. There is someone I could talk to about important decisions in my life.	○	○	○	○
3. I have relationships where my competence and skill are recognized.	○	○	○	○
4. I feel part of a group of people who share my attitudes and beliefs.	○	○	○	○
5. There are people I can count on in an emergency	○	○	○	○



Survey 2

Below are some statements about feelings and thoughts. Please tick the box that best describes your experience of each over the last 2 weeks.

	None of the time	Rarely	Some of the time	Often	All of the time
1. I've been feeling optimistic about the future	○	○	○	○	○
2. I've been feeling useful	○	○	○	○	○
3. I've been feeling relaxed	○	○	○	○	○
4. I've been dealing with problems well	○	○	○	○	○
5. I've been thinking clearly	○	○	○	○	○
6. I've been feeling close to other people	○	○	○	○	○
7. I've been able to make up my own mind about things	○	○	○	○	○



Survey 3

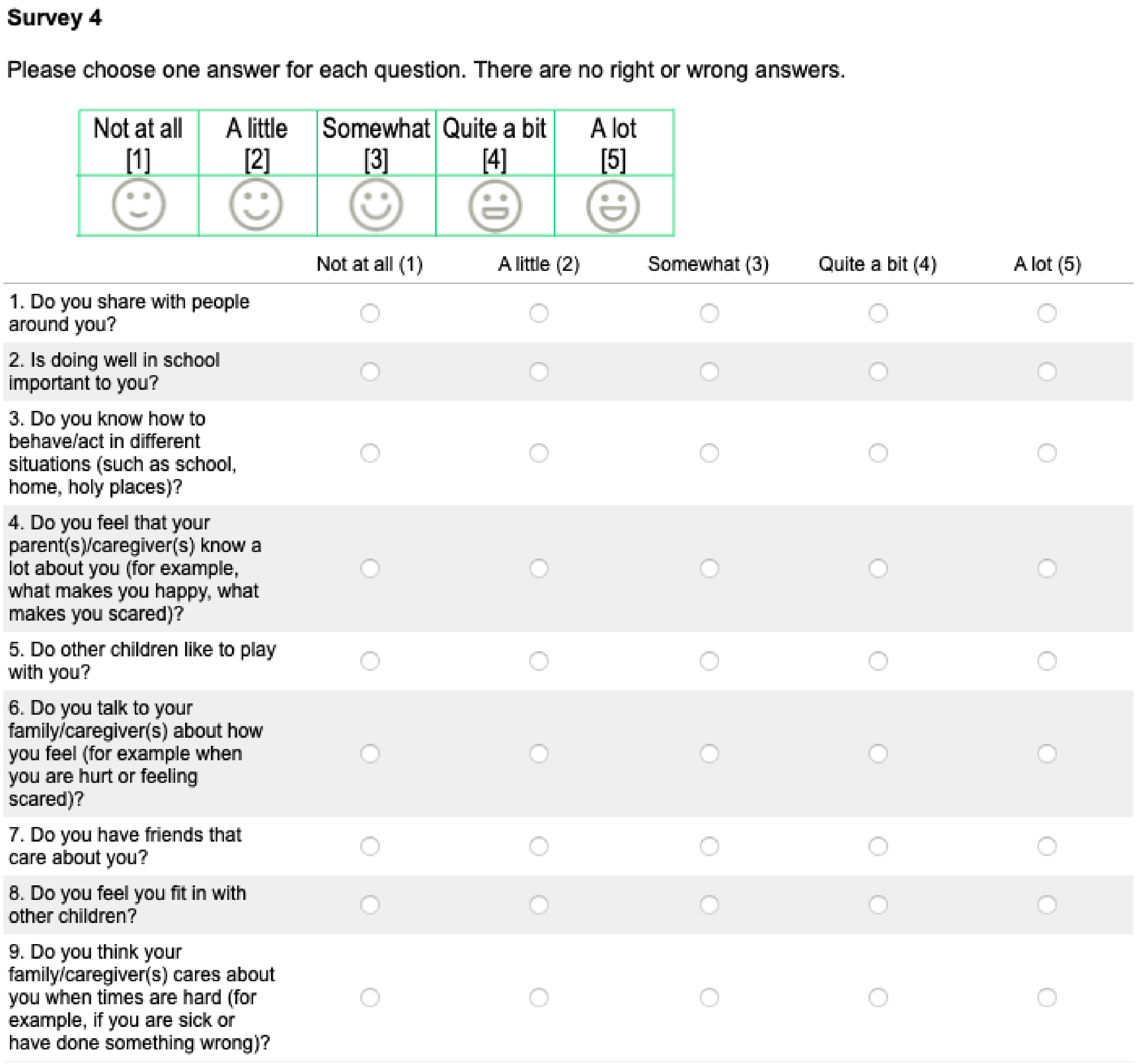
Read each sentence carefully.

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

Click the circle that describes YOU the best. For example, click the circle "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 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 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	○	○	○	○	○	○

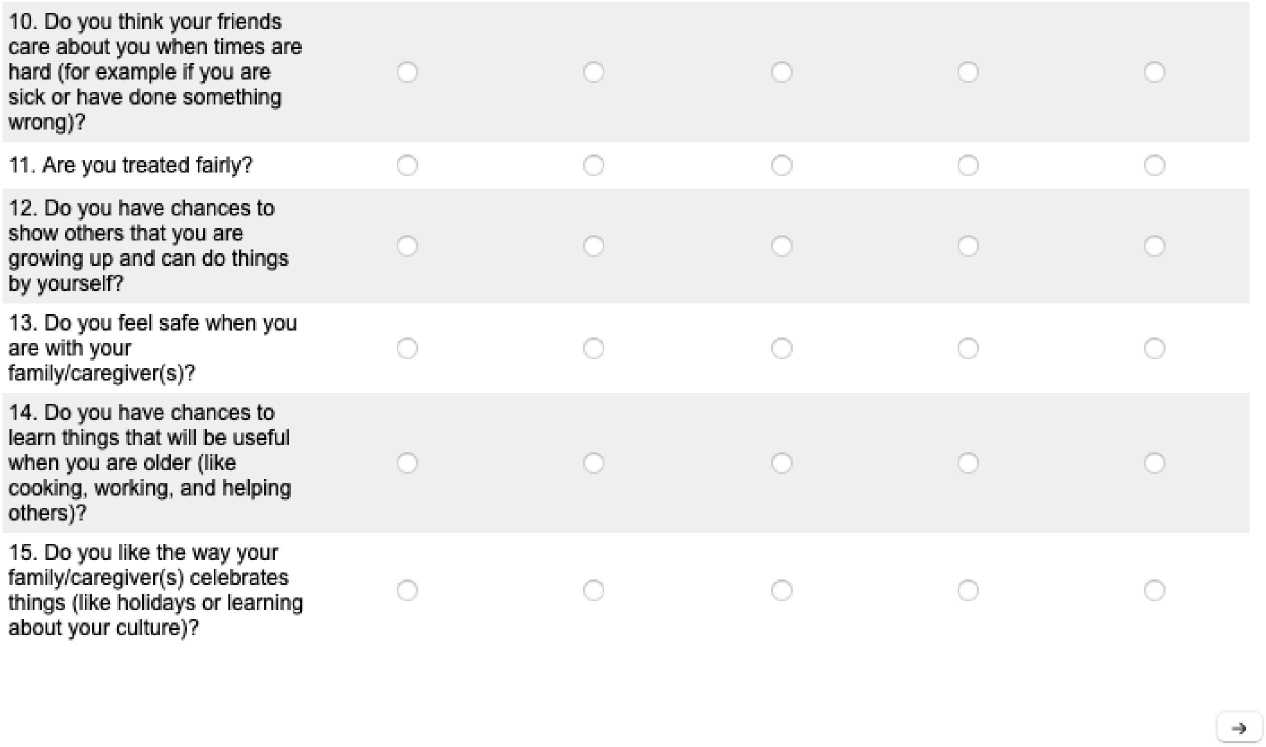


Survey 4

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

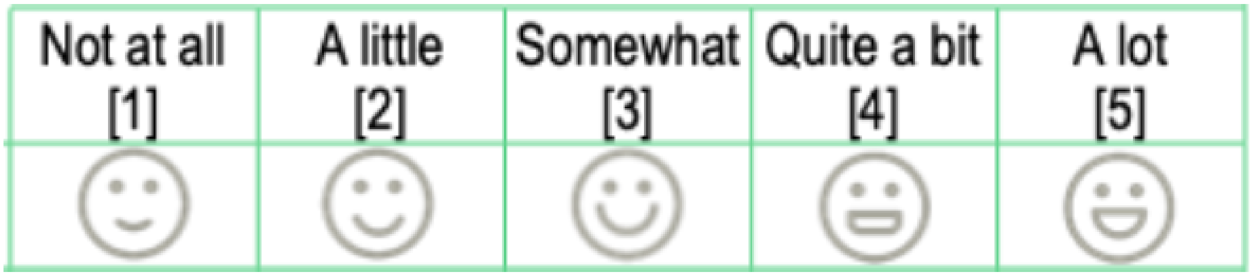
Not at all [1]	A little [2]	Somewhat [3]	Quite a bit [4]	A lot [5]
🙂	🙂	🙂	😬	😀

	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 a lot about you (for example, what makes you happy, what makes you scared)?	○	○	○	○	○
5. Do other children like to play with you?	○	○	○	○	○
6. Do you talk to your family/caregiver(s) about how you feel (for example when you are hurt or feeling scared)?	○	○	○	○	○
7. Do you have friends that care about you?	○	○	○	○	○
8. Do you feel you fit in with other children?	○	○	○	○	○
9. 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)?	○	○	○	○	○



10. Do you think your friends care about you when times are hard (for example if you are sick or have done something wrong)?	○	○	○	○	○
11. Are you treated fairly?	○	○	○	○	○
12. Do you have chances to show others that you are growing up and can do things by yourself?	○	○	○	○	○
13. Do you feel safe when you are with your family/caregiver(s)?	○	○	○	○	○
14. Do you have chances to learn things that will be useful when you are older (like cooking, working, and helping others)?	○	○	○	○	○
15. Do you like the way your family/caregiver(s) celebrates things (like holidays or learning about your culture)?	○	○	○	○	○

6.4 Rasch Validated Child and Youth Resilience Measure (17-item)



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

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)?	☺	☺	☺	☺	☺

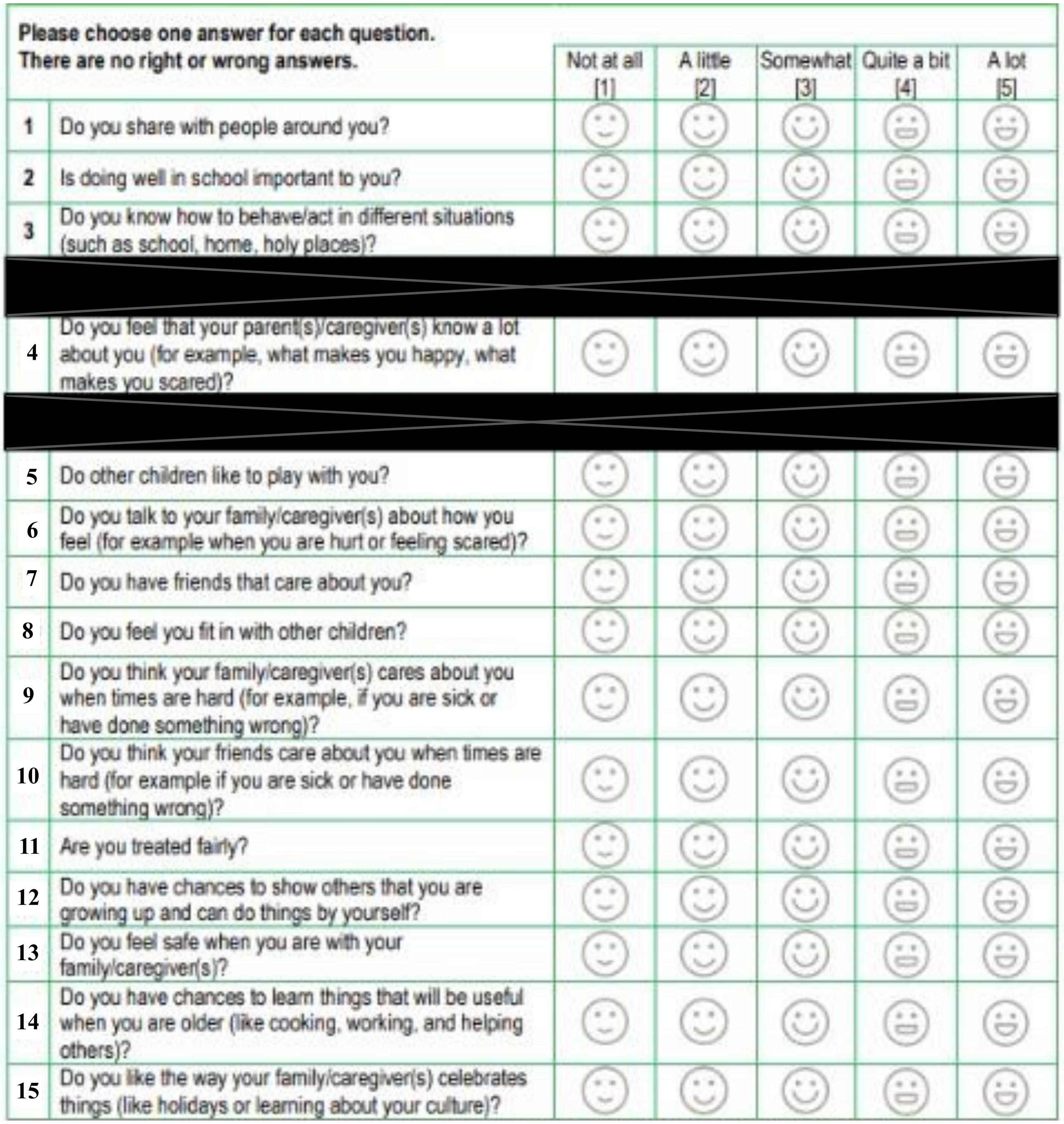
For administration instructions and scoring, please refer to the accompanying manual.

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/

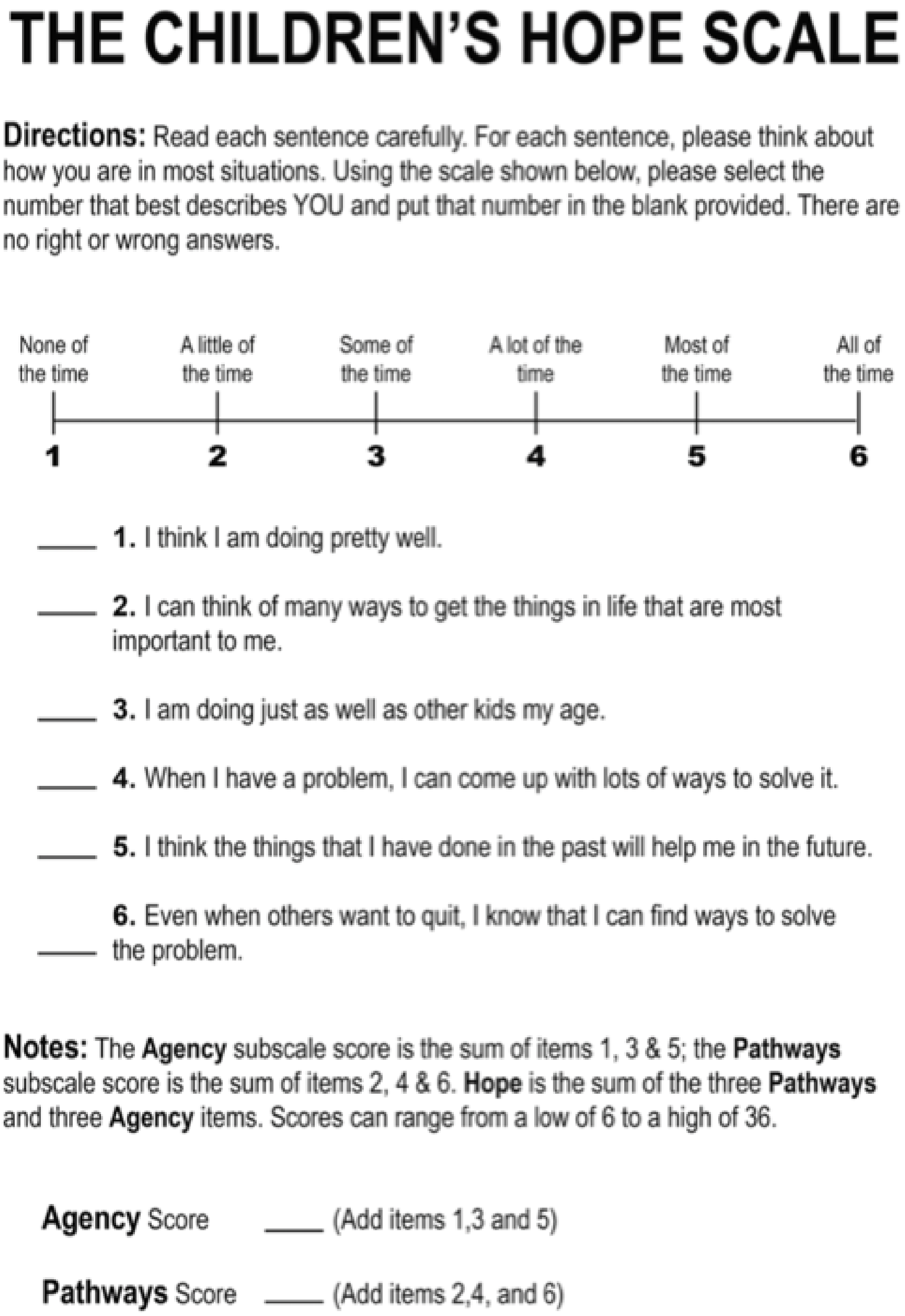
Jefferies, P., McGarrigle, L., & Ungar, M. (2018). The CYRM-R: a Rasch-validated revision of the Child and Youth Resilience Measure. *Journal of Evidence-Informed Social Work*, 1-24. https://doi.org/10.1080/23761407.2018.1548403

6.5 Child and Youth Resilience Measure (15-item)



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)?	☺	☺	☺	☺	☺
[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]
4	Do you feel that your parent(s)/caregiver(s) know a lot about you (for example, what makes you happy, what makes you scared)?	☺	☺	☺	☺	☺
[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]	[redacted]
5	Do other children like to play with you?	☺	☺	☺	☺	☺
6	Do you talk to your family/caregiver(s) about how you feel (for example when you are hurt or feeling scared)?	☺	☺	☺	☺	☺
7	Do you have friends that care about you?	☺	☺	☺	☺	☺
8	Do you feel you fit in with other children?	☺	☺	☺	☺	☺
9	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)?	☺	☺	☺	☺	☺
10	Do you think your friends care about you when times are hard (for example if you are sick or have done something wrong)?	☺	☺	☺	☺	☺
11	Are you treated fairly?	☺	☺	☺	☺	☺
12	Do you have chances to show others that you are growing up and can do things by yourself?	☺	☺	☺	☺	☺
13	Do you feel safe when you are with your family/caregiver(s)?	☺	☺	☺	☺	☺
14	Do you have chances to learn things that will be useful when you are older (like cooking, working, and helping others)?	☺	☺	☺	☺	☺
15	Do you like the way your family/caregiver(s) celebrates things (like holidays or learning about your culture)?	☺	☺	☺	☺	☺

6.6 Children's 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.

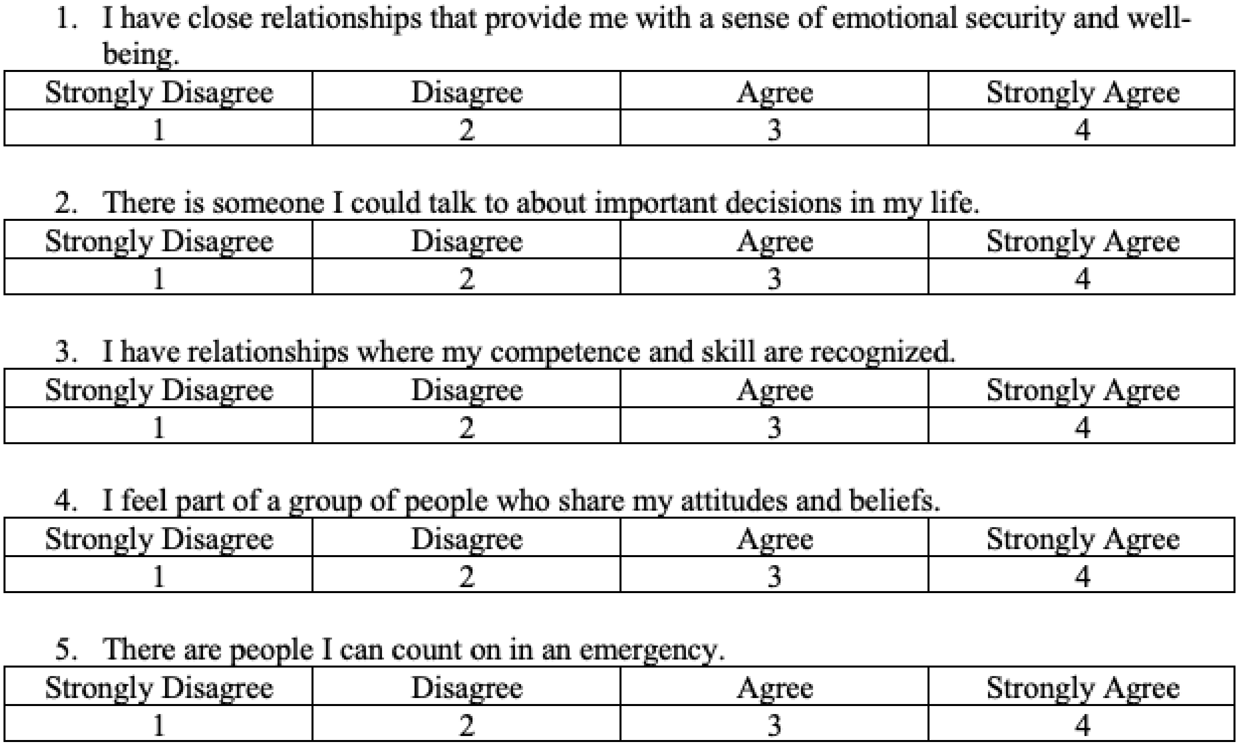
____ **6.** Even when others want to quit, I know that I can find ways to solve the problem.

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)

6.7 Social Provisions Scale 5



1. I have close relationships that provide me with a sense of emotional security and well-being.

Strongly Disagree	Disagree	Agree	Strongly Agree
1	2	3	4

2. There is someone I could talk to about important decisions in my life.

Strongly Disagree	Disagree	Agree	Strongly Agree
1	2	3	4

3. I have relationships where my competence and skill are recognized.

Strongly Disagree	Disagree	Agree	Strongly Agree
1	2	3	4

4. I feel part of a group of people who share my attitudes and beliefs.

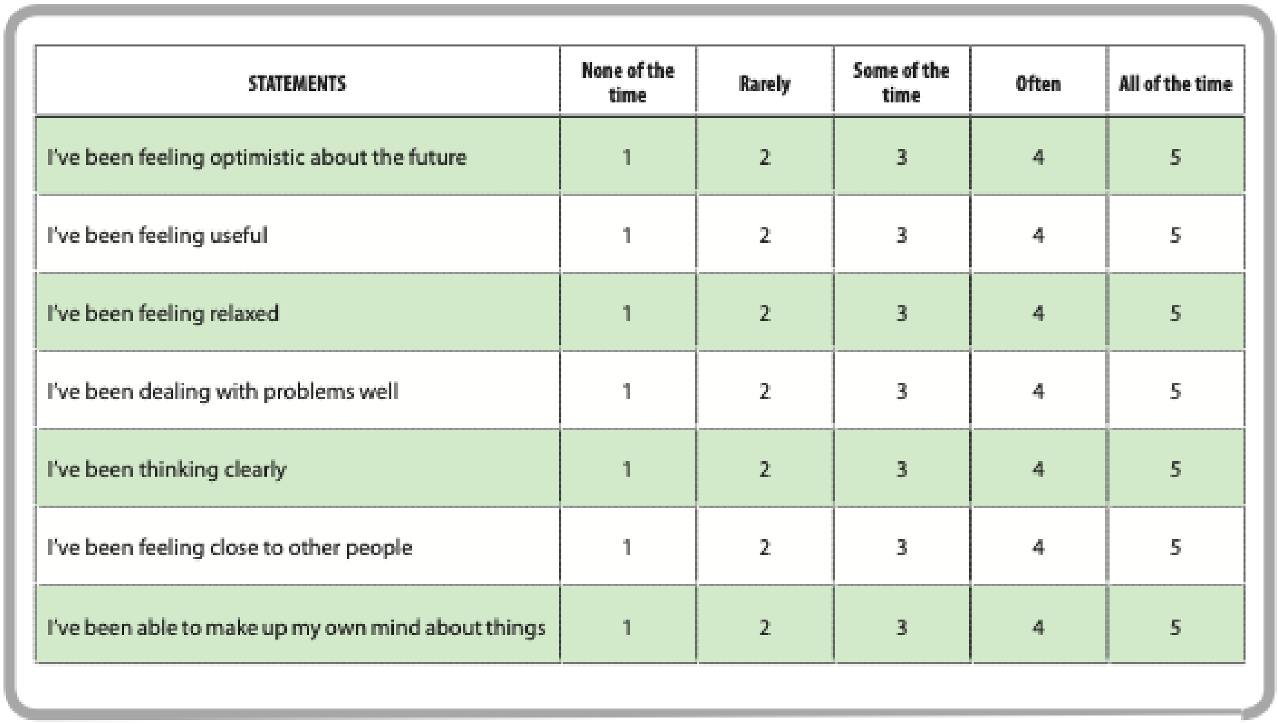
Strongly Disagree	Disagree	Agree	Strongly Agree
1	2	3	4

5. There are people I can count on in an emergency.

Strongly Disagree	Disagree	Agree	Strongly Agree
1	2	3	4

6.8 Short Warwick Edinburgh Mental Wellbeing Scale

Below are some statements about feelings and thoughts.
Please tick the box that best describes your experience of each over the last 2 weeks



STATEMENTS	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future	1	2	3	4	5
I've been feeling useful	1	2	3	4	5
I've been feeling relaxed	1	2	3	4	5
I've been dealing with problems well	1	2	3	4	5
I've been thinking clearly	1	2	3	4	5
I've been feeling close to other people	1	2	3	4	5
I've been able to make up my own mind about things	1	2	3	4	5

6.9 Salivary Cortisol Standard Curves

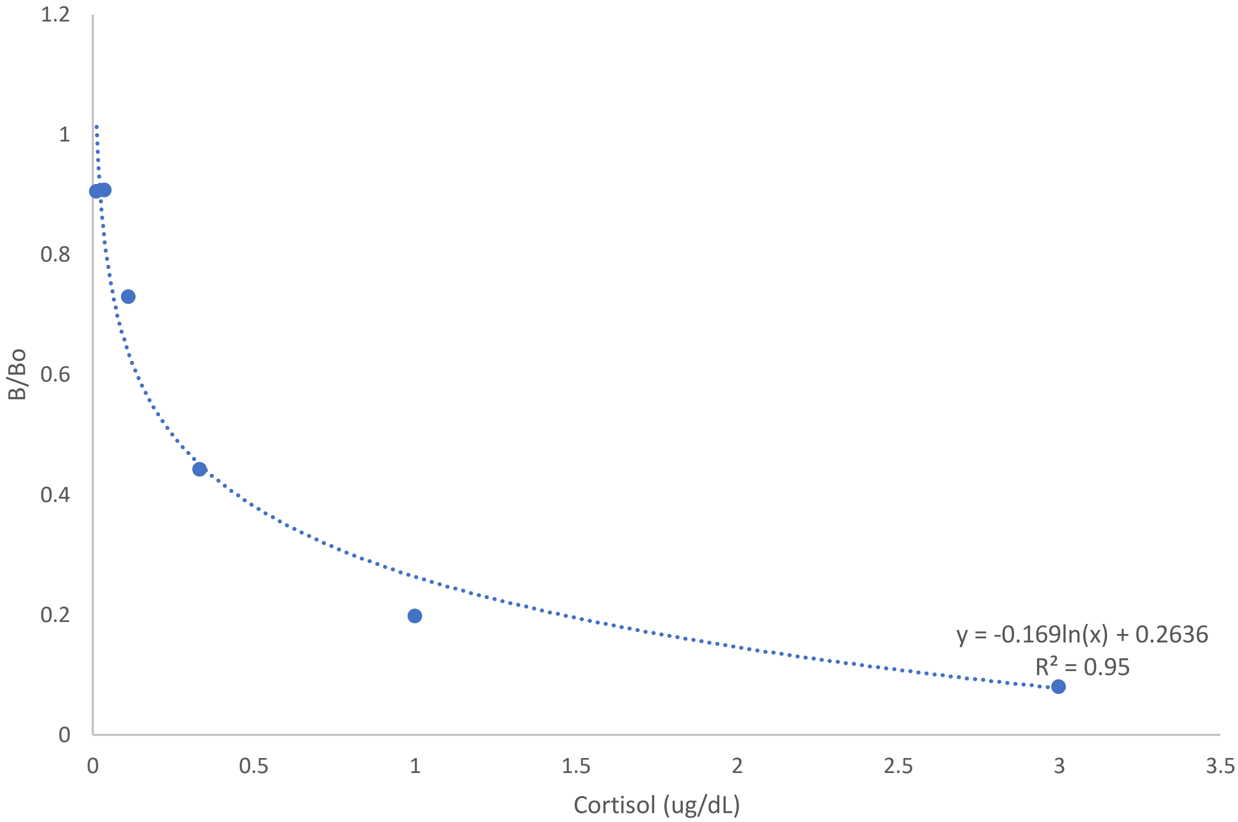


Figure 12. Standard curve, percent bound (B/Bo) versus salivary cortisol concentration, used for interpolation of salivary cortisol concentrations of samples collected at baseline testing.

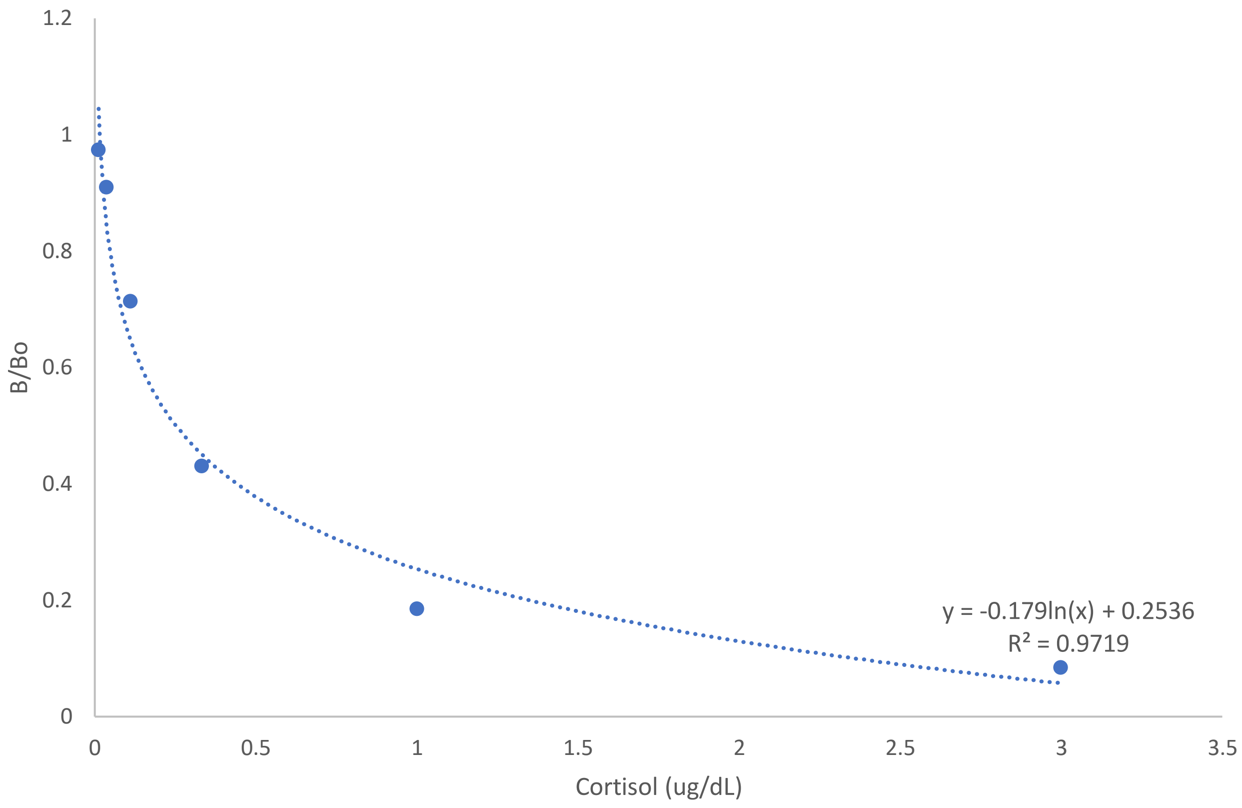


Figure 13. Standard curve, percent bound (B/Bo) versus salivary cortisol concentration, used for interpolation of salivary cortisol concentrations of samples collected at post-camp 1 testing.