A Therapeutic Recreation Camp for Children with Congenital Heart Disease: Examining Impact on the Psycho-social Well-being of Caregivers and their Children

by

Lauren White

A thesis submitted in conformity with the requirements for the degree of Master of Science,
Graduate Department of Exercise Sciences
University of Toronto

© Copyright by Lauren White 2014
A Therapeutic Recreation Camp for Children with Congenital Heart Disease: Examining Impact on the Psycho-social Well-being of Caregivers and their Children

Lauren White
Master of Science
Exercise Sciences
University of Toronto
2014

Abstract

Therapeutic recreation camps are thought to be an effective context to improve the psycho-social functioning among children with congenital heart disease. However, there is limited research regarding their impact on caregivers. Nine caregivers participated in two interviews before and after their children attended Camp Oki. Caregivers discussed their perceptions of their children’s camp experience, and identified the psycho-social utility of camp for themselves and their children. Camp allowed caregivers to let their children grow and be independent, and to engage in less restricting behaviours. Camp also provided caregivers with respite care, which alleviated their need to be ‘cardiac’ caregivers. Lastly, camp equipped children with self-confidence and independence, and offered them the opportunity to interact with their peers and be exposed to new activities. These findings strengthen the case for therapeutic recreation camps and underscore the importance of expanding camp access to more families affected by congenital heart disease.
Acknowledgments

I wish to thank my Master’s supervisor, Dr. Guy Faulkner, for providing me with continuous support and guidance throughout the entire research process. Thank you for providing me with several learning opportunities that have allowed me to gain different research skills and knowledge.

A special thank you to Dr. Fiona Moola, for your continuous guidance throughout the past three years. I greatly appreciate all the advice and knowledge you have given me. Thank you for allowing me to continue on with your work within this field.

To the remainder of my committee and external reviewer, Dr. Kelly Arbour-Nicitopoulos and Dr. Amy McPherson, thank you for your in depth insights and valuable suggestions for my thesis. You challenged my thinking and brought a different perspective to my research, for that I thank you.

I would also like to acknowledge Dr. Joel Kirsh and Rachael Baker at the Hospital for Sick Children. Thank you for providing me with the opportunity to not only conduct research for Camp Oki, but to also volunteer for the past three seasons. I am so grateful for the opportunity to be involved within the camp environment.

A special thank you to my study participants for rearranging their schedules to dialogue about their camp experiences. Your contribution and commitment to this study and Camp Oki are greatly appreciated.

Thank you to all my wonderful labmates and friends at the Health and Exercise Psychology Unit for your friendship, support, and guidance. A special thank you to Alicia for your friendship, patience, and dedication to making me laugh everyday.

Lastly, I would like to thank my parents, boyfriend, and friends at home. Thank you for teaching me to always follow my dreams and never give up on something you love to do. Thank you for your inspiration, patience, and unconditional love and support while trying to keep me grounded.
# Table of Contents

Acknowledgments ......................................................................................... iii

Table of Contents ........................................................................................ iv

List of Tables ............................................................................................... vii

List of Figures ............................................................................................. viii

Chapter 1 Introduction .................................................................................. 1
  1.1 Background of congenital heart disease .......................................... 1
  1.2 Psycho-social burden for children and their caregivers ................. 1
  1.3 The rationale for summer recreation camps .................................. 3
  1.4 Objectives ....................................................................................... 4
  1.5 Review of the literature ................................................................... 4
    1.5.1 Camp for children with chronic illnesses .............................. 5
    1.5.2 Camp for children with congenital heart disease ................. 6
    1.5.3 Qualitative camp literature from the children’s perspective ..... 8
    1.5.4 Parenting a child with a chronic illness ............................... 10
    1.5.5 Psycho-social impact of camp on the caregivers ................. 13
    1.5.6 Caregiver reports as proxy measures for their child’s health behaviours ......... 16
    1.5.7 Summary of the literature ....................................................... 17

Chapter 2 Methodology .............................................................................. 18
  2.1 Rationale for a qualitative approach .............................................. 18
  2.2 Philosophical assumptions ............................................................... 19
  2.3 Sample size .................................................................................... 20
  2.4 Recruitment and description of participants ................................ 20
  2.5 Description of settings .................................................................. 21
    2.5.1 The Hospital for Sick Children ............................................. 21
    2.5.2 Camp Oki ............................................................................... 21
  2.6 Data collection .................................................................................. 22
    2.6.1 Interviews .............................................................................. 22
      2.6.1.1 Interview guides .............................................................. 25
    2.6.2 Procedures ............................................................................ 25
  2.7 Data analysis .................................................................................... 26
  2.8 Provisions of trustworthiness ......................................................... 27
3.5.2 Life lessons .................................................................................................................. 57
3.6 Psycho-social impact of camp for the caregivers ............................................................... 58
  3.6.1 Increased independence – ‘I must let them go’ .......................................................... 59
  3.6.2 Camp alleviated the ‘need’ to be CHD caregivers ...................................................... 61
  3.6.3 CHD caregivers’ interactions – ‘Not what I expected’ ............................................... 63
3.7 Perceived psycho-social impact of camp for children .................................................... 64
  3.7.1 Reduced parental attachment – ‘I’ve grown up’ ......................................................... 64
  3.7.2 Sense of community, acceptance, and camaraderie ................................................. 65
  3.7.3 Improved determination to engage in activities ......................................................... 67
3.8 Advice for future caregivers of children going to camp ................................................. 68
3.9 Summary of results ........................................................................................................ 69

Chapter 4 Discussion ......................................................................................................... 71
  4.1 Parenting children with CHD ...................................................................................... 71
  4.2 Psycho-social utility of Camp Oki ................................................................................ 75
     4.2.1 Psycho-social utility of camp for the caregivers ...................................................... 75
     4.2.2 Perceived psycho-social utility of camp for children ........................................... 79
  4.3 Limitations and recommendations .............................................................................. 82
  4.4 Novel contributions and study implications ............................................................... 85
  4.5 Conclusion .................................................................................................................... 88

References .......................................................................................................................... 88

Appendix A - Recruitment E-mail .................................................................................... 93
Appendix B - Consent Form ............................................................................................... 95
Appendix C - Interview Guides .......................................................................................... 99
Appendix D - Demographic Questionnaire ....................................................................... 105
List of Tables

Table 1. Caregivers’ Demographics .................................................................................. 23
Table 2. Children’s Demographics and Medical History ................................................. 24
List of Figures

Figure 1. Overview of Themes ..........................................................................................32
Chapter 1
Introduction

1.1 Background of congenital heart disease

Affecting about 1% of live births, congenital heart disease (CHD) is the most common birth
defect among newborns (Heart and Stroke Foundation: HSF, 2012; Canadian Congenital Heart
Alliance: CCHA, 2013). Currently, there are approximately 180,000 Canadian children and
adults living and managing their heart condition (CCHA, 2013). Congenital heart disease is a
spectrum of heart conditions that occur due to a structural abnormality of the heart. This has
resulted in malformations of specific heart features and/or disruptions of blood flow throughout
the heart (HSF, 2012; CCHA, 2013).

Given the nature of the defect and where it falls along the continuum, children experience a
wide variety of signs and symptoms. Some commonly occurring symptoms are breathing
difficulties, heart murmurs, and/or blue discoloration of the skin (HSF, 2012). As a result of
children’s heart conditions, differing levels of treatment are required depending on the severity
of the heart defect. Thus, treatment is highly variable, and may involve complex medication
regimens and non-surgical and surgical procedures (HSF, 2012). In addition to complex
treatment regimens, children experience prolonged hospitalizations, and have additional medical
complications such as malnutrition, growth failure, and neurodevelopmental abnormalities
(Green, 2004).

1.2 Psycho-social burden for children and their caregivers

Advances in medicine and technology have prolonged life expectancy among children with
CHD. This has resulted in more children reaching adulthood and living, managing, and coping
with a chronic illness (Moola, Faulkner, Kirsh & Kilburn, 2008; Spurkland, Bjørnstad, Lindberg
& Seem, 1993). Despite improved prognosis and longevity, these children often experience
continued psycho-social distress and a compromised quality of life (QOL) (Spurkland et al.,
1993; Czosek et al., 2012). Children living with CHD are more likely to experience behavioral
disorders, social problems, psychiatric disorders such as anxiety and depression, and a reduced
quality of life (Fredriksen, Mengshoel, Frydenlund, Sørbye, & Thaulow, 2004; Spurkland et al.,
1993; Czosek et al., 2012). As a result of managing a chronic illness, these children experience
greater psycho-social morbidity. However, it is important to note that the psycho-social burden
of a childhood disease is not isolated to the children themselves. Caregivers of children with CHD have often reported poor psychological outcomes.

There is an abundance of literature that demonstrates the immediate and long-term burdens or dilemmas that caregivers face as their child with CHD matures. Throughout the child’s life, these caregivers often experience guilt, anxiety, maternal distress, attachment issues, and a reduced quality of life (Lawoko & Soares, 2006; Frank, Mcquillan, Wray, Grocott, & Goldman, 2010; Lawoko & Soares, 2003). Sparacino and associates (1997) identified that caregivers encountered dilemmas that concerned their children’s illness management and coping strategies, as well as challenges with social integration. Caregivers reported struggling with the expectations of having a normal child, and adjusting to a child who may look normal but has physical, emotional, and social issues. As well, these caregivers revealed problems surrounding their child’s independence, specifically at what age to allow their child to take full responsibility of their own health (Sparacino et al., 1997). In addition, caring for a child with CHD caused a great deal of uncertainty for caregivers, in terms of the diagnosis, treatment and management of their child’s disease, and most importantly uncertainty about the future (Connor, Kline, Mott, Harris, & Jenkins, 2009).

It is also important to note the role caregivers play in terms of their child’s functioning and well-being. This is evident in mothers of children with CHD, where the mothers’ attitudes towards some behaviours have a significant impact on their child’s actual behaviours (Bar-Mor, Bar-Tal, Krulik, & Zeevi, 2000). For instance, a child’s self-efficacy towards physical activity (PA) is significantly influenced by the attitudes of their mothers (Bar-Mor et al., 2000). Additionally, caregivers’ stress and social support networks have an influence on their child’s behaviour. For example, Visconti, Saudino, Rappaport, Newburger, and Bellinger (2002) concluded that caregivers who reported more stress consequently reported more behavioural problems, specifically externalizing behaviours, among their children with CHD. However, caregivers with higher levels of social support reported less behavioural problems among their children (Visconti et al., 2002).

It is well established that children with CHD are overprotected by their caregivers throughout their lifetime (Linde, Rasof, Dunn, & Rabb, 1966; Sparacino et al., 1997; Ong, Nolan, Irvine, & Kovaecs, 2010; Luychx, Goosens, Missotten, & Moons, 2011). Thomasgard and Metz (1997)
examined the correlates of parenta
l overprotection where they concluded that parents were more protective of their children if they were of a younger age, had a medical condition, and were perceived as vulnerable. Parental overprotection has been shown to contribute to poor emotional adjustment, frequent substance abuse, decreases in physical activity participation, and delays in developmental milestones among children with CHD (Linda et al., 1966; Linde, Rasof, & Dunn, 1970; Luychx et al., 2011; Moola, Fusco, & Kirsh, 2011). It is important to acknowledge how parental overprotection during childhood greatly affects children’s behaviours as they transition into adulthood (Ong et al., 2010). This is evident in the way that adults with CHD, who reported significant overprotective behaviours by their caregivers during childhood and adolescence, described more heart-focused anxiety. Moreover, adults with CHD who experienced activity restrictions during their childhood were more likely to adopt restricting behaviours in their adult life (Ong et al., 2010). It is clear that the psycho-social burden of a chronic illness affects both the child and their caregiver. Therefore, there is a need for health experts to develop interventions that enhance the psycho-social well-being and QOL of both children with CHD and their caregivers.

1.3 The rationale for summer recreation camps

Summer recreation camps have been proposed as one intervention to address some of these lingering psycho-social issues that caregivers and children face on a daily basis. Camps for children with a variety of chronic diseases have been in existence for several decades. However, there are few camps designed for children with CHD in Canada. Summer camps have been suggested to be a ‘therapeutic landscape’, as it removes the stresses and strains of the home and hospital life, and provides children with a safe and inclusive environment (Goodwin & Staples, 2005; Walker & Pearman, 2009). As well, camps can be viewed as a source of respite for the child’s caregivers (Meltzer & Johnson, 2004; Wu, Prout, Roberst, Parikshak, & Amylon, 2011). While children are attending camp, caregivers are relieved of the daily demands and stresses of managing their child’s illness. Additionally, camp seems to improve the psychological functioning of caregivers, specifically reducing anxiety, depression, maternal distress, and feelings of overload during camp (Simons et al., 2007; Meltzer & Johnson, 2004). However, not all psychological benefits were maintained after camp participation. There is limited empirical evidence on the psycho-social impact of camp for children with CHD and their caregivers. By way of a rationale, it is essential to examine the psycho-social utility of camp for children and their caregivers through the perspective of the caregivers.
1.4 Objectives

This study is a part of a larger research program, in which the main objective is to explore the psycho-social utility of Camp Oki, Canada’s first and only summer camp for children with CHD. This program may help advance the qualitative camp literature and help develop the camp experience to maximize potential benefits. In order to accomplish these goals, we first conducted a systematic review evaluating camp participation and the psycho-social well-being among children with a variety of chronic illnesses (Moola, Faulkner, White, & Kirsh, 2013). Then we conducted a qualitative study examining the psycho-social impact of Camp Oki from the children’s perspectives (Moola, Faulkner, White, & Kirsh, 2014). The next step is to qualitatively evaluate the impact of Camp Oki through the perspective of the caregivers. In this qualitative study the following primary objectives are addressed:

1) To examine what psycho-social benefits caregivers obtain from their child attending camp
2) To understand how caregivers perceive their child’s camp experience and health behaviours

Finally, the findings from this study will advance the qualitative literature surrounding the camp experience and help develop ideal camp settings and if necessary, a better camp experience.

1.5 Review of the literature

As stated previously, the main focus of this study concerns the psycho-social benefits of camp for the caregivers, and their perceptions of the camp experience. However, the following section will begin with a systematic review and critique of the literature surrounding the psycho-social benefits that children with chronic illnesses can obtain from the camp experience. Then more specifically, a detailed review of camps for children with CHD is provided, and the qualitative evidence attesting to the camp benefits is recognized and critiqued. This review is essential to conduct to understand the benefits children can obtain from the camp experience, and to acknowledge the gaps within the qualitative literature. In order to contextualize the need for a caregiver’s perspective, the review of the literature surrounding the parenting process, how caregivers can benefit from camp, and how caregivers’ reports have been previously utilized is warranted. These three sections concerning the caregivers are necessary to develop a comprehensive understanding of the caregiver’s role and experiences they encounter within the camp context.
1.5.1 Camp for children with chronic illnesses

Moola and colleagues (2013) conducted a systematic review to identify the psycho-social impact of summer recreation camps for children living with chronic illnesses. Camps have been created for children with cancer (Barr et al., 2010; Meltzer & Rourke, 2005; Wu et al., 2011), diabetes (Cheung, Cureton, & Canham 2006; Hunter, Rosnov, Koozt, & Roberts, 2006; Santiprabhob et al., 2008), congenital heart disease (Moons et al., 2006a; Moons et al., 2006b; Simons et al., 2007), asthma (Nicholas et al., 2009; Pulgaron et al., 2010), celiac disease (Bongiovanni et al., 2010), craniofacial differences (Devine & Dawson, 2010), epilepsy (Cushner-Weinstein et al., 2007), irritable bowel syndrome (Shepanski et al., 2005), HIV and AIDS (Gillard et al., 2011), and multiple chronic illnesses (Békési et al., 2011; Goodwin & Staples, 2005; Kiernan, Gormley, & MacLauchlan, 2004; Kiernan, Guerin, & MacLachlan, 2005; Török, Kokanyei, Karolyi, Ittzes, & Tomcsanyi, 2006). Various study designs were implemented such as a randomized control trial (\( n = 1 \)), pre and post test design (\( n = 6 \)), repeated measures design (\( n = 8 \)), qualitative methods (\( n = 3 \)), cross sectional design (\( n = 2 \)), and one study conducted a historical cohort analysis.

A variety of psychometric questionnaires were administered at multiple time intervals such as the weeks leading up to camp, during camp, and following camp attendance. However, only three of the eight repeated measures studies investigated outcomes beyond three months after camp (Cushner-Weinstein et al., 2007; Kiernan et al., 2004; Santiprabhob et al., 2008). Furthermore, for the pre and post test methods, children’s psycho-social well-being were examined between three days (Moons et al., 2006b) and fourteen days (Nicholas et al., 2009). Over time, children displayed positive changes in some psycho-social parameters such as improved adaptive behavioural functioning, social acceptance and competence, self management, perceived health status, self-esteem, and overall quality of life (Cushner-Weinstein et al., 2007; Kiernan et al., 2005; Devine & Dawson, 2010; Meltzer & Rourke, 2005; Goodwin & Staples, 2005; Gillard et al., 2011; Pulgaron et al., 2011; Hunter et al., 2006; Moons et al., 2006a; Moons et al., 2006b; Santiprabhob et al., 2008; Török et al., 2006; Shepanski et al., 2005). Furthermore, children reported improvements in emotional outlook, physical functioning, and coping and practical skills (Bongiovanni et al., 2010; Moons et al., 2006a; Moons et al., 2006b; Nicholas et al., 2009; Gillard et al., 2011; Kiernan et al., 2005). Researchers also found that camp reduced parent and child anxiety, as well as children’s physical distress (Simons et al.,
Lastly, of the twenty-one studies included in this review, only two articles found no benefits for attending camp (Békési et al., 2006; Cheung et al., 2006).

Due to the short-term length of camp and follow-up measures, the sustainability of the reported improvements is unknown. Furthermore, there are methodological limitations that need to be addressed. Theoretical models rarely informed the conceptualization of the camp experience. These models are essential to research in order to identify mediators of psycho-social and behavioural change. Additionally, the majority of camps did not employ a behavioural intervention. Pulgaron and associates (2010) were the only research team to include an intervention component, however there was insufficient information provided regarding the development of the intervention. Taken together, there is insufficient evidence to make robust claims about the long-term psycho-social benefits of camp for children with chronic illnesses. However, results do suggest that camp for children with chronic illnesses may offer some short-term psycho-social benefits and reduce psycho-social morbidity. Future researchers need to develop appropriate camp interventions that are theoretically informed, identify potential mechanisms of change, and follow established protocols for describing their methodology (Moola et al., 2013).

1.5.2 Camp for children with congenital heart disease

Based on the aforementioned systematic review, there are only three studies that have examined the psycho-social utility of camp for children with congenital heart disease. For example, Moons and associates (2006a) assessed children’s self-perceived physical and psycho-social health status during a three-day multisport camp program. Sixteen children aged 10 to 14 years completed the Child Health Questionnaire before and after attending the camp. Children’s responses were compared to healthy peers. Results displayed that children with CHD reported significant improvements in physical and role functioning. Furthermore, these children demonstrated improvements in self-esteem, mental health, and general behaviour that surpassed the scores of their healthy peers. Moons and associates (2006a) suggested that attending a sports camp for children with CHD can improve children’s self-perceived health status.

A similar study was conducted one year later by Moons and associates (2006b) where 25 children aged 10 to 15 years completed questionnaires concerning their self-perceived physical and health status, and habitual physical activity levels. These questionnaires were administered
at three time points: before camp (T1), after camp (T2), and at a three-month follow-up (T3). Children showed improvements across all self-perceived health status domains between T1 and T2. Specifically, children with CHD exhibited enhanced physical and role functioning, general health, bodily pain, and self-esteem. However, only physical and role functioning scores continued to persist at the three-month follow-up. No changes were exhibited on the Baecke Questionnaire, which measured habitual physical activity. Moons and associates (2006b) further demonstrated the physical and psycho-social health benefits that children with CHD can derive from camp participation. However, due to the short-term follow-up, no robust conclusions can be made about the sustainability of the reported improvements.

Lastly, Simons and associates (2007) implemented a repeated measures study where children with cardiac malformations and their parents reported on their camp expectations and levels of anxiety before camp, after camp, and at a four-week follow-up. This is the only cardiac camp study where parental evaluations and experiences were documented. Parents completed questionnaires concerning their expectations of the camp, their child’s previous separation experiences, and rated their own separation anxiety. Overall anxiety levels of campers were significantly reduced after they attended camp, and these levels remained lower at the four-week follow-up. As well, parents’ separation anxiety levels were significantly reduced after the four-week follow-up. Simons et al. (2007) found that camper expectations and previous separation experiences among children accounted for the highest amount of variance in anxiety. Children of parents who reported negative expectations interestingly reported the greatest reductions in anxiety. Simons and associates (2007) expressed the need to educate parents about the camp experience in order to reduce parental anxiety and fears, as well as to enhance the benefits that their children can derive from camp participation.

Although these studies did report improvements among some psycho-social indicators of health, long-term benefits are inconclusive. To my knowledge the majority of research dedicated to camps for children with CHD is quantitative in nature. The pre and post camp measures were between three and five days, and follow-up measures were conducted either four weeks or three months post camp. As well, not all psycho-social improvements were maintained at the follow-up assessments. Furthermore, all measures were self-report, which are subjected to social desirability bias. Additionally, the studies that examined psycho-social parameters were assessed from the view point of the children. However, Simons and associates (2007) are the
only research team who has examined the impact of camp for the parents of children with CHD. Based on these three studies, attending camp for children with cardiac conditions seems to improve children’s psycho-social morbidity, as well as having an impact on their parents’ psychological functioning such as separation anxiety. However, there is still limited evidence surrounding camp for children with CHD, in general, specifically within the Canadian context.

1.5.3 Qualitative camp literature from the children’s perspective

To my knowledge, only four research teams have implemented a qualitative approach to evaluate the meanings that children with a chronic illness ascribe to the camp experience. For example, Goodwin and Staples (2005) employed a variety of methodological tools to investigate how nine children and their mothers experienced a camp for children with disabilities. Over a six-month period after camp, researchers utilized semi-structured telephone interviews, letters, and photographs to better understand the camp experience. Children conveyed how camp reduced their disability related isolation by connecting them with other children who have gone through similar life and health experiences. Additionally, camp fostered a sense of independence and encouraged children to push their limits and boundaries. Mothers’ responses echoed that of their children’s reflections in which they noted how camp enhanced their children’s social maturity, and provided children with an opportunity to become more autonomous. These mothers also expressed the need for communities to build upon the lessons learned at camp, and provide the families with the resources to pursue new avenues related to physical activity. Goodwin and Staples (2005) advocated for the benefits of a camp for children with disabilities that fosters a sense of “coming home”.

Kiernan and associates (2005) utilized a thematic analysis of written responses that were a component of a larger quantitative study. Two hundred and forty children with multiple chronic illnesses responded to open-ended questions two weeks prior to camp, two weeks following camp, and at a six-month follow-up. Questions regarding children’s camp expectations, their camp experience, and how camp impacted their life were provided on the questionnaire. Children conveyed how they were looking forward to participating in new activities and forming social relationships. Given that one third of children did not report learning new skills, it is important to acknowledge the skills that were acquired. For example, campers reported learning new social, psychological, and practical skills such as improved communication, cooperation, self-confidence, and physical abilities.
Gillard and associates (2011) conducted an interpretive case study using semi-structured interviews, focus groups, participant observations, and reviewed artifacts over three different time points between the years of 2007 and 2008. Thirty-six children with HIV and AIDS, and fifteen staff members commented on their camp experience. Children and youth can often experience stigma and stereotyping related to their illness, and camp provided them with an opportunity to interact with their peers within a safe and inclusive environment. Campers expressed how they were able to form caring connections with their peers and staff members, and felt a sense of relief from their daily stresses. Furthermore, children expressed how camp provided them with an opportunity to participate in recreational activities and increase their knowledge, attitudes, and skills. Staff members commented on the camper-counselor interactions, and how camp related activities were modified so all children could participate. Gillard and colleagues (2011) acknowledged the importance of camp to provide developmental support for children with HIV and AIDS.

In our preliminary developmental research with the congenital heart disease population, we have found that children do experience psycho-social distress as a result of their disease, and camp seems to address some of these health-related issues (Moola et al., 2014). Fifteen children with CHD were interviewed four months after their camp attendance at Camp Oki. These children described their camp experience, and discussed how camp may have impacted their psycho-social well-being. Through an interpretive phenomenological analysis, four central psychological processes were identified when children attended camp. First, camp provided children with a sense of bodily freedom that allowed them to participate in free and unrestricted activity. Second, camp was used as a platform for children to develop relationships amongst their peers. This allowed children to share experiences and gain a sense of belonging and acceptance. Third, children identified how they had pleasurable, relaxing experiences outdoors at Camp Oki. Lastly, due to the time lapse between camp sessions (one year), camp was the initial opportunity to forge relationships that were then maintained over time through social media. Through this study, children with CHD were able to express how their camp participation addressed some psychological and social dilemmas they frequently experienced throughout their daily living.

The qualitative literature surrounding the camp experience confirms the psycho-social improvements that were exhibited throughout the quantitative camp literature stated above.
Although qualitative evaluations of the camp experience are minimal, the assessments revealed that camp provides children with chronic illnesses an opportunity to engage in recreational activities, acquire new practical skills and knowledge, interact with children who have encountered similar experiences, and provide them with a sense of inclusion and social support. Amongst these qualitative studies, a variety of methodological tools were utilized to assess the psycho-social utility of camp. The main form of data collection was semi-structured interviews, which took 40 to 60 minutes to complete, and only two studies conducted interviews in person. Furthermore, most of the qualitative methods occurred either during or following camp participation (Gillard et al., 2011; Goodwin & Staples, 2005; Moola et al., 2014). Kiernan and associates (2005) were the only research team to examine the children’s expectations and concerns before camp. To my knowledge no research team has conducted interviews assessing the camp experience pre and post camp. As well, most of the qualitative literature regarding the camp experience is conducted from the viewpoint of the children. To my knowledge, there is limited qualitative camp literature assessing the psycho-social utility of camp from solely the caregivers’ perspectives, especially for children with CHD.

1.5.4 Parenting a child with a chronic illness

The parenting process is a constantly changing, difficult, and emotional process. However, raising a child with a chronic illness, poses additional burdens to the family lifestyle. Bowen (1966; 1974) acknowledges the family as a system where all members of the family unit play an essential role in the way the family functions. Thus, family systems theory was developed in which a change in the functioning of one member results in a compensatory change in another member (Bowen, 1966; 1974). However, this can sometimes cause an over functioning of one member, which consequently produces a long-term imbalance within the family (Bowen, 1974). With advances in medicine and technology, the health care of children with chronic illnesses has been primarily placed on the family members. This has resulted in more parents taking on a ‘healthcare provider’ role within the family, thus increasing the psycho-social burden experienced by the entire family system (McDaniel & Campbell, 1998). However, family involvement is critical in the treatment and management of chronic illnesses (Sholevar & Perkel, 1990). It is also important to understand the cyclical nature of a chronic illness where the illness impacts the child and then their family. The family unit accommodates and organizes the family life around their child’s illness, which further affects the child with a chronic illness (Sholevar & Perkel, 1990). Furthermore, the family systems theory speaks to the concept of social support as
an essential part of the family system. In times of great stress, the family can encompass a ‘nuclear family’ that includes extended family members, friends, and individuals from schools, clinics, and social agencies, (Bowen, 1966).

To understand the processes and challenges that families experience as a result of parenting a child with a chronic illness, Coffey (2006) conducted a meta-synthesis. Eleven qualitative studies were included in the review, and both the mother and father’s perspectives on parenting a child were synthesized. Coffey (2006) combined the themes from each study and created seven overarching themes to describe the struggles caregivers experienced. The living worried, staying in the struggle, carrying the burden, survival as a family, bridge to the outside world, critical times, and taking charge, were the seven themes created to better understand the parenting world. The first theme described the parenting role as an endless sense of worry. Worry was a “bona fide part of everyday life” that occurred in the present and in the future (Coffey, 2006, p. 53). Parents were concerned about their child’s constantly changing health status, the impact the disease would have on the sibling and family relationships, and were uncertain about their child’s future. Parents expressed worry specifically towards their child aging and reaching developmental milestones. The second theme displayed how parents were ‘staying in the struggle’ and were overwhelmed with various emotions (Coffey, 2006). Parents felt helpless and overwhelmed with the diagnosis and management of their child’s condition. Furthermore, parents conveyed how they were protective of their children and felt sadness, anger, and/or frustration towards the health care system.

Parents of children with a variety of chronic medical conditions frequently expressed the ‘burden of care’ that was placed upon them. Parents had to rearrange their work and family lifestyles to provide the complex care for their children (Coffey, 2006). Moreover, these parents acknowledged that the impact of raising a child was not isolated to themselves. Siblings and extended family members were also impacted, which sometimes resulted in negative experiences (Coffey, 2006). Coffey (2006) recognized how parents lost their sense of freedom and support systems as a result of raising a child with a medical condition. However, some parents did describe how they gained support through religious beliefs, friends, and/or family members. The first year of life was considered the most critical time for parents, as they were uncertain about their child’s diagnosis and life expectancy (Coffey, 2006). Furthermore, feelings of isolation and depression were commonly acknowledged throughout this parent population.
Lastly, Coffey (2006) conveyed how the parenting role consisted of parents being vigilant and taking charge of their child’s condition. A major issue that all parents conveyed was the lack of information provided by health professionals. Thus, Coffey (2006) advocates for medical professionals to become more proactive in providing parents with relevant health information and support systems to help them better manage their child’s care.

To determine if the parenting experiences have changed within the past decade, Kepreotes, Keatinge, and Stone (2010) conducted a meta-synthesis between the years of 2000 and 2009 to build upon Coffey’s (2006) evidence on parenting a child with a chronic illness. Ten new articles were included in the review and additional themes emerged from the data. The new literature surrounding this topic echoed that of Coffey’s (2006) results in which parents experienced helplessness and uncertainty, had communication issues with health care providers, had to learn from previous experiences, and were increasingly watchful of their child’s condition and behaviours (Kepreotes et al., 2010). The new themes that were developed focused on parents experiencing a lack of control that contributed to feelings of sadness, isolation, and chronic grief, and parents dealing with a new reality. Parents acknowledged the need for balance in order to gain control over their new lifestyle. Due to their child’s medical condition, these parents had to adjust to a new reality in which parents “needed to make sense of their new lives” (Kepreotes et al., 2010, p. 59). Consistent with Coffey (2006), the parent and health professional relationship is pivotal, and parents displayed a need for additional information and support systems. Thus, health professionals and parents need to work together to provide “safe and effective care for their children” (Kepreotes et al., 2010, p. 60).

According to Knafl and Deatrick (1986) the concept of normalization is the most common management style that parents adopt in order to come to terms with caring for a child with a chronic illness. Knafl and Deatrick (1986) suggest four criteria for defining normalization: 1) parents must acknowledge the existence of the child’s chronic illness; 2) parents must define and recognize their family life as normal; 3) parents must accept that the social consequences of parenting their child is minimal; and 4) the family needs to participate in activities that demonstrate to others that their family is essentially normal. Moreover, the parents’ ability to normalize their child’s situation is dependent upon the child’s age and severity of their medical condition, and the parents’ external support systems (e.g., programs and information available for the parents) (Knafl & Deatrick, 1986). This concept of normalization has been utilized by
caregivers of children with CHD. For example, caregivers of children with CHD struggled with the idea that they may not have a ‘normal’, healthy child. It was difficult for caregivers to come to terms with a situation in which their child looked normal but experienced psychological, social, and medical issues as they matured (Sparacino et al., 1997). However, despite their children’s altered physical capacity, parents still encouraged their children to engage in regular physical activity.

Furthermore, Rempel, Harrison, and Williamson (2009) described how parents understood the precariousness of their child’s survival, and had to adjust to the new expectations of raising their ‘ill’ child. Parents implemented specific strategies to normalize their child’s experiences. For instance, parents attributed their child’s delayed growth and/or development to alternative explanations such as personality traits, levels of physical activity, and desire for certain foods, instead of relating these issues to the cardiac condition itself (Rempel et al., 2009). In addition, these parents conveyed how their child’s delayed growth and/or development was not a dilemma for them. All parents were very satisfied with and celebrated any development that occurred throughout their child’s life span (Rempel et al., 2009).

Coffey (2006), Kepreotes and associates (2010), and Rempel and colleagues (2009) have demonstrated the psycho-social distress and burdens caregivers experience as a result of caring for a child with a chronic illness. Regardless of their child’s type of diagnosis, caregivers experience similar psycho-social morbidity and stressors in their daily life. Feelings of uncertainty with the diagnosis and management of their child’s disease, and dealing with a new reality are major dilemmas that these caregivers encountered. The family systems theory and the concept of normalizations provide a new perspective on the parenting role that includes the entire family. The parenting role is a constantly changing process, and parents encounter new dilemmas throughout their child’s lifespan. Therefore, it is essential that resources are made available to help guide caregivers throughout this emotional and demanding process.

1.5.5 **Psycho-social impact of camp on the caregivers**

Given that caregivers of children with chronic illnesses also experience psychological and social distress (Frank et al., 2010; Lawoko & Soares, 2003; Lawoko & Soares, 2006; Sparacino et al., 1997), it is important to acknowledge that the benefits of children attending camp may not be isolated to the children themselves. Within the past decade, there has been an additional focus
on the benefits that caregivers can obtain from their child attending camp. For example, a repeated measures study conducted by Simons and associates (2007) determined that camp attendance impacts maternal anxiety. Twenty-nine parents of children with cardiac defects completed the Maternal Separation Anxiety Scale prior to camp, immediately after camp, and at a four-week follow-up. Parents reported that their separation anxiety decreased following camp, and these reductions were maintained at the four-week follow-up. Since overprotection is a main challenge for parents of children with cardiac defects (Linde et al., 1966; Sparacino et al., 1997; Luychx et al., 2011; Moola et al., 2011), Simons and colleagues (2007) recognized the potential for these reductions in anxiety to decrease parental overprotection.

Moreover, Smith, Gotlieb, Gurwitch, and Blotcky (1987) discovered how mothers of children with cancer increased their family and peer interactions while their children attended camp. Eighteen mothers completed an Interaction with Environment Checklist, prior to camp, during camp, and two and four weeks post camp. The questionnaire assessed the types of activities parents engaged in with their family members and other individuals. As a result of camp attendance, changes in mothers’ interactions occurred over time. During and following camp, mothers increased their activity engagement, as well as interactions with their family and other peers. Smith and colleagues (1987) demonstrated how a one-week camp experience had significant effects on mothers’ social interactions.

Furthermore, Meltzer and Johnson (2004) undertook a study to determine if camp was a source of respite care, and to examine what impact camp had on the psycho-social well-being of 161 mothers of children with multiple chronic illnesses. Taking into consideration the caregiving demands and the psychological distress mothers experience, Meltzer and Johnson (2004) administered telephone questionnaires addressing these issues. Measures were completed four weeks prior to camp, during camp, and two and five weeks post camp attendance. Mothers reported a temporary relief from the daily demands and stressors of managing their child’s illness while their child attended camp. Furthermore, overload, depression, anxiety, and maternal distress levels were significantly reduced during camp. However, only some psychological parameters were maintained following camp participation. There is some evidence to conclude that camp attendance does provide respite care, and improves psychological functioning of mothers of children with chronic illnesses (Meltzer & Johnson, 2004). These researchers advocated for the re-conceptualization of camp programing and
existing resources to encourage families to focus not only on the benefits that children can obtain from the camp experience, but also the positive impact camp has upon the families themselves.

Through the use of qualitative approaches, caregivers of children with disabilities were able to express how camp provided them with an opportunity to “relax, or ‘recharge their batteries’” (Shelton & Witt, 2011, p. 24). Shelton and Witt (2011) conducted interviews with nine caregivers of children who attended a disability camp to further explore how camp benefited these families. A therapeutic disability camp allowed caregivers to spend more time with their partners and children, interact more with friends, and complete household tasks. Furthermore, these aspects that contributed to respite care were maintained after their children returned home. Parents noted several camp aspects that contributed to their respite benefits such as the psychological and social improvements, and enjoyable experiences that their children acquired. Shelton and Witt (2011) state that future research should explore how to maximize respite benefits for parents, as it is an “integral part of maintaining positive family functioning” (p. 26).

The potential for camp to be a source of relief for parents is also documented in Wu and associates (2011) cross sectional study. Parents expressed how camp provided their children with a safe environment, medical care, transportation to and from camp, and relieved them from their caretaking responsibilities. Together these components allowed parents to feel a sense of respite from their daily stress of caring for their child while their child attended camp. This research is consistent with the work of Shelton and Witt (2011) in which specific camp aspects greatly contributed to the respite benefits. Furthermore, Warady (1994) stated that an important benefit of a therapeutic camp was the “long-awaited period of respite” for parents of children with end-stage renal disease (p. 390). Due to the constant care parents provided, they felt a sense of freedom from their demands, and were grateful for the time period away from their responsibilities.

There is some evidence to conclude that caregivers obtain specific benefits from their child attending camp. However, research that investigated caregivers’ benefits were mainly from the mothers’ perspective. There were only three studies that included both caregivers of children with chronic illnesses, however fathers were still a minority sample (Simons et al., 2007; Shelton & Witt, 2011; Wu et al., 2011). As well, the only qualitative research conducted from the caregivers’ perspective occurred following camp attendance. Those studies that included a
pre post camp assessment were quantitative in nature and had a four-week follow-up (Meltzer & Johnson, 2004; Simons et al., 2007; Smith et al., 1987). Lastly, the majority of research has examined how camp provided respite care and a sense of freedom from the daily responsibilities of caring for a child with a chronic illness. There is still limited research investigating other psychological and social benefits caregivers can derive from the camp experience. Researchers suggest that future studies should further examine the impact camp has upon caregivers to determine if benefits are generalizable to other illness populations, and to determine which camp features influence specific benefits in order to encourage more caregivers to send their children to camp (Wu et al., 2011; Meltzer & Johnson, 2004; Simons et al., 2007).

1.5.6 Caregiver reports as proxy measures for their child’s health behaviours

Multiple researchers who examined the psycho-social benefits of camp for children have utilized parents’ reports as proxy measures for their children’s psychological and social well-being. For example, Pulgaron and associates (2010) administered self and parent-reported child health related quality of life questionnaires. Health related quality of life outcomes reported by campers and parents, prior to camp, showed high internal consistency (Pulgaron et al., 2010). In addition, Hunter and colleagues (2006) have demonstrated the effectiveness of using parents’ reports as proxy measures for their child’s health behaviours. This research team administered surveys evaluating self-management skills, family responsibility, and activity levels to children and their parents. The authors discovered that children and parents’ reports at pre camp, post camp, and at the three-month follow-up, were significantly correlated in a positive direction. Furthermore, Goodwin and Staples (2005) displayed how parents’ perceptions of their child’s camp experiences echoed that of their children’s responses. Both campers and parents described how a disability camp provided them with an opportunity to gain independence, interact and connect with other peers with disabilities, and understand their own capabilities. These studies concluding a positive correlation between children and parents’ reports are consistent with a systematic review conducted by Eiser and Morse (2001). This research team examined the relationship between parent and self-reported ratings of children’s health related quality of life. Results from the review found that there is high accordance between parents’ and children’s ratings on health related quality of life. However, there is greater agreement among observable behaviours (e.g., physical symptoms) compared to non-observable functioning (e.g., emotional functioning) (Eiser & Morse, 2001). Therefore, researchers need to take into consideration the
types of research questions that they are asking parents to comment on to best describe their child’s experiences. For instance, parents may not be able to provide as much detail on their children’s psychological quality of life compared to their own children’s reports.

1.5.7 Summary of the literature

Despite improved prognosis and longevity, children with CHD and their caregivers experience continued psycho-social distress and a poor quality of life (Czosek et al., 2012; Lawoko & Soares, 2003; Spurkland et al., 1993). Although long-term benefits of camp are equivocal, the camp experience is associated with improved psycho-social well-being for children on some psychometric and social parameters. Caregivers are of interest for this study as they encounter various dilemmas and challenges with parenting their child with a chronic illness (Coffey, 2006; Kepreotes et al., 2010). These caregivers often experience psycho-social distress and camp may be a resource for them to utilize to help relieve them from their daily responsibilities of caring for their child (Meltzer & Johnson, 2004). Due to the limited evidence attesting to the impact of camp for both children with CHD and their caregivers, it is necessary to conduct this qualitative study. Additionally, there is a lack of qualitative evidence concerning the camp experience from the caregivers’ perspectives. The qualitative evidence that does exist has been conducted either during or after camp (Gillard et al., 2011; Goodwin & Staples, 2005; Shelton & Witt, 2011). Thus, conducting pre and post camp interviews offers a novel perspective to the camp literature. During the pre camp interviews, caregivers will be able to express their expectations and address concerns regarding their child’s camp experience. Then issues that surfaced prior to camp will be addressed in the follow-up interviews. Throughout the follow-up interviews, caregivers will be able to clarify and reflect on their expectations, and provide further knowledge into their children’s actual camp experience. This type of qualitative design allows an opportunity to examine how expectations can transition into actual benefits, and compare and contrast the differences between pre and post camp experiences. As well, this study seeks to understand which caregiver and child specific psycho-social factors were actually influenced by Camp Oki. This study attempts to fill the gaps in the camp literature by providing a novel qualitative approach, and investigating the caregivers’ perspectives, which will illustrate a new understanding of the camp experience for children with CHD.
Chapter 2
Methodology

The purpose of the research topic guides the specific research questions, and thus determines the methods and methodologies undertaken by researchers (Morse & Richards, 2002). The purpose of this thesis is to explore what impact camp has on the caregivers’ psycho-social well-being, and to further examine the psycho-social impact of camp for children with CHD. Therefore, specific qualitative methods were conducted to collect and analyze data to understand the camp experience (Morse & Richards, 2002). Interviews were the data collection tools utilized to understand and interpret how caregivers perceived their child’s experiences. This chapter provides a brief overview of the rationale for qualitative research, as well as my philosophical assumptions relating to the study. Then descriptions of the sample, recruitment methods, and participants’ demographics are provided. As well, information regarding the data collection tools utilized and procedures undertaken are presented. Lastly, a description of the data analysis conducted, issues surrounding trustworthiness of the data, and ethical considerations are presented.

2.1 Rationale for a qualitative approach

Based on the review of the literature there is still limited research examining the caregivers’ perspective of the camp experience, specifically through qualitative methods. Examining the caregivers’ perspectives of their child’s camp experience is necessary, as they are important and active decision makers regarding their child’s behaviours (Goodwin & Staples, 2005). This perspective would contribute to a form of triangulation where different sources of data are collected investigating the same phenomena. Thus, to explore how camp impacts caregivers and their children, and to better understand the meanings caregivers ascribe to the camp experience, a qualitative approach is warranted. Qualitative research explores the newness or novelty of a specific topic (Munhall, 2012; Esterberg, 2002), and “celebrates discovering the taken-for-granted meanings” that individuals ascribe to a specific experience (Charmaz, 2004, p. 982). Thus, through the use of qualitative approaches, researchers are able to enter into a phenomenon and “sense, feel and fathom” how individuals subjectively experience it (Charmaz, 2004, p 981). Qualitative researchers learn what is significant about a specific experience, through the perspectives of the individuals who are involved in them (Esterberg, 2002). For example, this study offers caregivers an opportunity to share their subjective thoughts and feelings towards
their child’s camp experience, and to provide in-depth insights into how camp impacts their own psycho-social well-being. Examining the caregivers’ perspectives help researchers explore caregivers’ meanings and actions as they see and experience them (Charmaz, 2004).

2.2 Philosophical assumptions

Qualitative research involves “complex forms of interpretation” to understand individuals’ subjective experiences (Esterberg, 2002, p. 3). In order to understand and interpret individuals’ experiences, a paradigm must be established. Paradigms are a “basic set of beliefs that guide action”, and provide a worldview of the phenomenon being addressed (Denzin & Lincoln, 2005, p. 183; Munhall, 2012). Therefore, to investigate and interpret the meanings and experiences that caregivers ascribe to camp, I have adopted a constructivist paradigm (Guba & Lincoln, 2005). Denzin and Lincoln (2005) proposed a relativist ontological approach to constructivism in which an individual’s realities are multiple and co-constructed (Guba & Lincoln, 2005). Participants form subjective meanings of their own realities, which allow for multiple meanings of their realities (Bloomberg & Volpe, 2008). Furthermore, a constructivist approach assumes a transactional and subjectivist epistemology, where understandings of knowledge are co-created by the participants and myself (Denzin & Lincoln, 2005; Guba & Lincoln, 2005; Lee, 2012). My primary researcher role is to “discover and understand meaning of experience” discussed by the caregivers (Bloomberg & Volpe, 2008, p. 13). As well, knowledge will be interpreted and collected in a conversational matter between the participants and myself. Furthermore, the knowledge about an experience is accumulated through informed reconstructions and vicarious experiences of the participants (Guba & Lincoln, 2005). Lastly, Guba and Lincoln (2005) proposed that the quality of the data is assessed through the trustworthiness of the knowledge accumulated. This paradigm is appropriate to use particularly for this research study in order to assess the multiple viewpoints of the caregivers, and how their children’s interactions and meanings and experiences that they ascribe to camp are developed. Consistent with the constructivist approach, caregivers are able to play an active role in shaping the research inquiry.

Additionally, Esterberg (2002) states that a constructivist approach explores how social reality is formed, and is based off of three principles: 1) individual’s actions are shaped by the meanings they attribute to them; 2) these meanings are developed through social interactions; and 3) these
meanings are constructed through interpretations. Thus, the ways in which caregivers express their child’s camp experiences can be constructed through their own interactions, the interactions that occur at camp, and the meanings that their child ascribes to attending camp.

2.3 Sample size

It was originally planned to recruit fifteen caregivers of first time Camp Oki campers to participate in this study. Caregivers of first time attendees can provide new insights into the camp experience, specifically their expectations and concerns towards Camp Oki. As this may be their first time sending their child to camp, more issues may surface compared to caregivers of returning campers. Based on previous qualitative research, fifteen participants is an adequate sample size in order to reach data saturation, and to understand the different representations of the camp experience (Gaskell, 2000; Marshall, 1996; Wuest, 2012). This sample size allows for participants to adequately answer the research questions and provide in-depth explanations of how camp impacts them and their child (Marshall, 1996). Caregivers can include mothers, fathers, grandparents or guardians of children with CHD. The following inclusion criteria was required for participation: 1) caregivers must have children between the ages of 8 and 17 years who are registered for Camp Oki 2013; 2) all children must be diagnosed with a congenital heart disease; and 3) caregivers must be English speaking. No caregivers were excluded on the basis of gender, age or socio-economic status.

2.4 Recruitment and description of participants

Purposive sampling was used to recruit caregivers of children with CHD (Lincoln & Guba, 1985; Patton, 1990). In July 2013, Camp Oki staff sent a mass email to caregivers of first time camp attendees (see Appendix A). Due to the limited number of first time camp attendees for Camp Oki 2013 \( (n = 17) \), the email was extended to caregivers whose children were returning for their second year \( (n = 12) \). This email entailed information concerning the purpose, design, and location of the present study, and requested voluntary participation. If caregivers were interested in participating in the study they were asked to email myself and provide additional contact information. Based on the 29 caregivers who received a recruitment email, 15 were interested in participating in the study. The names and information of interested respondents were documented, and consent forms were emailed to the participants to allow them to further review the research study (see Appendix B). Of the 15 respondents, 11 caregivers followed up
with an email requesting an interview date. Although the number of caregivers was less than the anticipated sample size, no new information emerged after the seventh caregiver interview. At this time, data saturation or information redundancy was reached, and there was no need to recruit additional participants to reach the planned sample size of 15 (Lincoln & Guba, 1985).

Eleven caregivers of first time Camp Oki attendees participated in the pre camp interviews in August 2013. Due to scheduling conflicts and dropouts, only nine caregivers completed the follow-up interviews in October 2013. The caregivers included both mothers \((n = 8)\) and fathers \((n = 1)\) of children with CHD. Caregivers were between the ages of 32 and 51 years with a mean age of 42 years. The majority of caregivers were Caucasian \((n = 8)\), married \((n = 9)\) and had completed a post secondary degree \((n = 7)\) (see Table 1). Caregivers’ children had complex congenital heart conditions, were judged by their caregivers as having good or excellent health post surgery, and the age of diagnosis ranged from in utero to two and a half years old (see Table 2). Caregivers’ children were between the ages of 8 and 12 years, and five children were male. For further demographic details regarding caregivers and their children please see Table 1 and Table 2, respectively.

2.5 Description of settings

2.5.1 The Hospital for Sick Children

The Hospital for Sick Children (SickKids) is a world-renowned pediatric centre located in southern Ontario, and is the largest pediatric research institute in Canada. It is the leading pediatric hospital in Canada that is dedicated to improving the health of children and adolescence up until the age of 18 years. With a vision of ‘Healthier Children. A Better World.’ researchers and clinicians work collaboratively across twelve ‘centres’ that specialize in a variety of medical fields such as bone health, cancer, cystic fibrosis, pain, and the heart. The Labatt Family Heart Centre, where participants were recruited from, specializes in heart health, and seeks to be the global leader in congenital cardiac care. Researchers and scientists, who are experts within the fields of health and life sciences, work jointly to advance the health of children in Canada and globally (www.sickkids.ca).

2.5.2 Camp Oki

Camp Oki is Canada’s first and only summer recreation camp for children and youth with congenital heart disease. Camp Oki is currently located 200 km north of Toronto, Canada in a
private facility surrounded by the wilderness and a peaceful lake. This camp originated in 2004 as a long weekend retreat for children who attended a pacemaker clinic at the Hospital for Sick Children. Within the past 10 years, Camp Oki has grown to bring a one-week camp experience to over 100 children and youth with any CHD every summer. Operated by staff and volunteers at the Hospital for Sick Children, Camp Oki provides a safe and inclusive recreational environment where campers can be ‘kids’. Many of these volunteers are child survivors of CHD who are provided with the opportunity to ‘give back’ to their CHD community by mentoring younger children at camp. Campers have the opportunity to participate in various camp activities such as swimming in a lake, engaging in water sports, making arts and crafts, creating musical skits for staff and fellow campers, participating in team activities in a multi-sport complex, and completing adventure courses. With a small camper-to-staff ratio, children are well supervised and if needed, can receive medical treatments at a 24-hour medical shed operated by doctors and nurses. Every day is ended off with a ‘rose, thorn, and bud’ activity where children and counselors come together as cabin groups and reflect on the day’s successes and challenges, and create goals for the following day. Camp Oki seeks to create an enjoyable opportunity for ‘kids with special hearts’ to participate in camping programs, and promotes camaraderie and friendships among campers and counselors.

2.6 Data collection

2.6.1 Interviews

Telephone and in person, semi-structured, and open-ended interviews (Duffy, 2012; Patton, 1990; Wolf, 2012) were conducted to elicit caregivers’ narratives about their child’s camp experience. Conducting interviews can provide the researcher with an in-depth exploration of the participants’ subjective world, and provide detailed rich data (Charmaz, 2006). Informal, flexible, and open-ended questions were created to fit participants’ experiences, and ultimately reconstruct their own realities (Charmaz, 2006). Open-ended questions are “critical to ‘hearing’ authentic language” to establish the meanings of everyday experiences (Munhall, 2012, p. 23). The interviews were participant driven in nature such that the content and flow of the questions were guided by the participants’ responses. Participants were able to share and reflect upon significant experiences that their children or themselves encountered. In addition to open-ended questions, probing techniques were used in order for participants to elaborate or clarify specific experiences (Wolf, 2012).
<table>
<thead>
<tr>
<th>Participant</th>
<th>Gender</th>
<th>Age</th>
<th>Education</th>
<th>Martial Status</th>
<th>Ethnicity</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diana</td>
<td>Female</td>
<td>43</td>
<td>High School</td>
<td>Married</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Sarah</td>
<td>Female</td>
<td>32</td>
<td>University</td>
<td>Married</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Rose</td>
<td>Female</td>
<td>46</td>
<td>College</td>
<td>Married</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Judy</td>
<td>Female</td>
<td>43</td>
<td>University</td>
<td>Married</td>
<td>South Asian</td>
</tr>
<tr>
<td>Danielle</td>
<td>Female</td>
<td>47</td>
<td>High School</td>
<td>Married</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Alicia</td>
<td>Female</td>
<td>42</td>
<td>College</td>
<td>Married</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Henry</td>
<td>Male</td>
<td>51</td>
<td>Post Graduate</td>
<td>Married</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Catherine</td>
<td>Female</td>
<td>39</td>
<td>University</td>
<td>Married</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Julie</td>
<td>Female</td>
<td>37</td>
<td>University</td>
<td>Married</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Child</td>
<td>Child’s Gender</td>
<td>Child’s Age</td>
<td>Type of CHD</td>
<td>Age of Diagnosis</td>
<td>Caregiver’s Perceived Health Status</td>
</tr>
<tr>
<td>-------</td>
<td>----------------</td>
<td>-------------</td>
<td>-------------</td>
<td>-----------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>Chris</td>
<td>Male</td>
<td>8</td>
<td>Tricuspid atresia</td>
<td>5 days</td>
<td>Good</td>
</tr>
<tr>
<td>Philip</td>
<td>Male</td>
<td>8</td>
<td>Tricuspid atresia; TGA</td>
<td>24 weeks in utero</td>
<td>Excellent</td>
</tr>
<tr>
<td>Dan</td>
<td>Male</td>
<td>9</td>
<td>Kawasaki Disease</td>
<td>2.5 years</td>
<td>Excellent</td>
</tr>
<tr>
<td>Adam</td>
<td>Male</td>
<td>12</td>
<td>DORV</td>
<td>At birth</td>
<td>Good</td>
</tr>
<tr>
<td>Christine</td>
<td>Female</td>
<td>9</td>
<td>DILV</td>
<td>37 weeks in utero</td>
<td>Excellent</td>
</tr>
<tr>
<td>Anna</td>
<td>Female</td>
<td>8</td>
<td>TGA; Arrhythmia</td>
<td>1.5 days</td>
<td>Good</td>
</tr>
<tr>
<td>David</td>
<td>Male</td>
<td>9</td>
<td>Ebstein’s Anomaly of the tricuspid valve</td>
<td>At birth</td>
<td>Excellent</td>
</tr>
<tr>
<td>Maria</td>
<td>Female</td>
<td>10</td>
<td>DILV; TGA; Coarctation</td>
<td>20 weeks in utero</td>
<td>Excellent</td>
</tr>
<tr>
<td>Amanda</td>
<td>Female</td>
<td>12</td>
<td>VSD</td>
<td>14 hours</td>
<td>Excellent</td>
</tr>
</tbody>
</table>

Note. ¹All information was reported by caregivers. DORV = double outlet right ventricle; DILV = double inlet left ventricle; TGA = transposition of the great arteries; VSD = ventricular septal defect
2.6.1.1 Interview guides

Two interview guides were created to prompt caregivers’ responses (see Appendix C). The first interview guide consisted of six sections: background and context, diagnosis and understanding, independence and protectiveness, social, psychological and social health, and camp expectations. The first few sections concerned the child’s medical history, issues that may have developed from caring for a child with a chronic illness, and the caregivers’ thoughts and opinions towards specific Camp Oki features. The social and psychological and social health sections contained questions regarding their child’s and their own social interactions and psychological functioning, and how congenital heart disease impacted them psychologically and socially. These questions were important to ask in order to explore how the experience of parenting a child with CHD may shape expectations of the potential benefits to be derived from camp for both the caregiver and child. The last section was about camp expectations, and if caregivers believed their children and themselves could benefit from the camp experience. The follow-up interview guide contained six sections as well, these included: general, independence, social, psychological and social health, overall benefits, and future recommendations. Furthermore, any issues that surfaced in the first interview were addressed at the beginning of this follow-up interview. The first section examined what it was like for their child to attend camp. The independence and social sections pertained to questions about specific camp features, barriers their child had to overcome, and the ability of their child to interact with their peers at camp. Questions concerning the current psycho-social health of the caregivers and their children were asked to determine if changes occurred as a result of camp. The last two sections elicited responses regarding overall benefits of the camp experience and suggestions or advice caregivers would provide to other caregivers of children with CHD.

2.6.2 Procedures

After email correspondence for recruiting participants, phone calls were made to set up convenient times for the 11 caregivers who wanted to participate in this study. Semi-structured interviews were conducted at the Hospital for Sick Children in the Cardiology clinic by the lead author. A demographics questionnaire was administered at the beginning of the first interview (I1) (see Table 1, Table 2, and Appendix D). The first interview occurred one to three weeks prior to their child attending Camp Oki in August 2013. Due to the location of the caregivers and for convenience issues, six interviews were conducted over the phone in the Cardiology
The second interview (I2) occurred six to eight weeks after camp, with seven interviews being conducted over the phone. Within the camp context, qualitative methods were typically conducted during or post camp attendance (Gillard et al., 2011; Goodwin & Staples, 2005; Shelton & Witt, 2011). Therefore, this is a novel approach for caregivers to discuss their experiences with camp, and to further understand the psycho-social impact of camp for the caregivers. Interviews took approximately 45 to 60 minutes to complete.

2.7 Data analysis

Interviews were audio-taped and transcribed verbatim. Transcribing interviews consisted of listening intensely to the audio-taped recordings, and accurately typing what was being stated. The transcribed data was then subjected to thematic analysis (TA), using the procedure described by Braun and Clarke (2006). Thematic analysis is a foundational and flexible research method utilized for a qualitative analysis. TA is a tool that helps researchers identify, analyze, and report on themes that have emerged from within the data (Braun & Clarke, 2006). Themes are a reoccurring pattern that “captures something important about the data” (Braun & Clarke, 2006, p. 82). TA can be conducted in two ways: an inductive or deductive approach. For the purpose of this thesis and consistent with a constructivist paradigm, an inductive analysis occurred such that the analysis was data driven (Bloomberg & Volpe, 2008). An inductive approach is the process of coding data that is not guided by a preexisting coding framework to ensure that the themes are strongly linked to the data itself (Braun & Clarke, 2006).

Four main coding procedures were conducted as described by Braun and Clarke (2006) to obtain rich accounts of data. Data analysis was managed by NVivo 10 software. First, I became immersed within the data through in-depth and repeated readings of the transcribed data. Each transcribed document was read line by line, and a log of initial ideas and overarching themes were kept to help guide the formal coding process. Then I coded the data into multiple relevant units. Primary coding was undertaken in a systematic fashion to ensure the entire data set for each participant was coded. For example, when participants were asked to comment on any benefits that they would obtain from their child’s camp experience, and described how camp would allow them to get a break from their children, not have to worry about their behaviours, and be relieved from the daily responsibilities and medical obligations of being a caregiver, these sentences were coded as three separate units. These primary units were coded as ‘getting a break’, ‘worrying less’, and ‘relief from caregiver duties’. The next step was to group the units
into provisional themes. This entailed merging together the primary codes to form “candidate themes, and sub-themes” (Braun & Clarke, 2006, p. 90). For instance, the three primary units mentioned above were then collapsed into one candidate theme called ‘respite care’. The last step consisted of reviewing and finalizing the themes. I reviewed the primary coding of the entire data set to ensure the validity of the themes, and that the themes and subthemes accurately reflected the data set. For example, all sentences that were originally labeled as ‘getting a break’, ‘worrying less’, and ‘relief from caregiver duties’, were reviewed to confirm that they accurately depicted the theme of ‘respite care’. Once the thematic analysis was completed, I began to write the final report. Throughout the entire writing process I constantly referred back to my primary coding and finalized themes to ensure the final report depicted the participants’ responses. This dissertation consists of a concise, logical report that demonstrates what benefits caregivers and their children obtained from Camp Oki, and how caregivers perceived their child’s camp experience.

2.8 Provisions of trustworthiness

According to Mackey (2012) there is no gold standard to assessing the quality of qualitative research. However, trustworthiness, proposed by Lincoln and Guba (1985), is recognized as one fundamental avenue to critically evaluate qualitative research. In order for the knowledge, which emerged from the data, to be appraised as ‘trustworthy’, it must address the criteria of credibility, transferability, dependability, and neutrality (Lincoln & Guba, 1985). Consistent with a constructivist paradigm, multiple steps throughout the research process were taken to establish the trustworthiness of the data (Bloomberg & Volpe, 2008; Lincoln & Guba, 1985; Mackey, 2012). Thus, I have accounted for trustworthiness where I attempted to give my data credibility and transferability.

2.8.1 Credibility

Credibility, also known as ‘truth value’, refers to the ability of the reader to have confidence in the ‘truth’ of the data being presented (Lincoln & Guba, 1985; Mackey, 2012). In order to enhance the credibility of the research findings, five strategies were employed throughout the research process. First, a reflexive journal was maintained to document my experiences, ideas, and assumptions relating to Camp Oki (see section 2.8.3 “Self-Reflexivity – The reflective stance”). In order to establish triangulation, this journal was reviewed throughout the writing process to ensure the themes accurately illustrated the camp experience. Second, as an active
member of the Camp Oki community, I have had sustained involvement within the camp environment for the past two seasons. This experience has facilitated a more in-depth understanding of the camp experience, and the benefits that caregivers and their children can obtain. Third, credibility was established for the research questions of interest, through the development of an in-depth interview guide. I developed the interview guide and it was then reviewed and supported by two research members (G.F and F.M). This brought credibility to the questions of interest because F.M is a previous counselor at Camp Oki, and G.F and F.M are experts in the field of qualitative inquiry. Fourth, in a form of member checking (Lincoln & Guba, 1985), all transcribed data from the first interview (I1) was summarized and verbally described to the caregivers for clarity, accuracy, and confirmation of results during the beginning of the follow-up interview (I2). All caregivers \( n = 9 \) confirmed that the interpretations and description of their experiences were accurate. Moreover, the themes extracted and reviewed by the participants from the first interview helped guide the second interview. Lastly, peer debriefing was achieved through constant communication between my thesis committee members and myself (Bloomberg & Volpe, 2008). During committee meetings, my supervisor (G.F) and two committee members (F.M and K.A.N) provided insights into the research design and structure of the findings. Furthermore, throughout the entire research process, my supervisor and myself shared ideas relating to the study where he challenged my thinking towards my research findings.

2.8.2 Transferability

Transferability refers to the applicability of the research findings to the reader’s own context or settings (Lincoln & Guba, 1985; Mackey, 2012). Therefore, through a ‘thick description’ of the research contexts, participants, and participants’ experiences, readers will be able to assess the findings as transferable to their own settings (Bloomberg & Volpe, 2008). Transferability was further established by providing an in-depth contextualization and understanding of the struggles caregivers encountered while caring for their child with CHD. To fully understand caregivers’ expectations of the potential impact of camp for caregivers and their children, it was necessary to provide a detailed overview of their current psycho-social well-being.

2.8.3 Self-Reflexivity – The reflexive stance

The reflective process consists of an individual critically reflecting upon their self and becoming self-aware of the researcher role that they exhibit, throughout the entire research study (Finlay,
Reflexivity is the immediate, conscious, subjective self-awareness in which I acknowledge that I am a fundamental part of the research project (Finlay, 2002; Wolf, 2012). Thus, my assumptions and perspectives of the research topic will ultimately influence the “collection, selection and interpretation of data” (Finlay, 2002, p. 1). Therefore, by being aware of the assumptions and preconceived notions that guide the research questions, and by reflecting upon my subjective opinions that may have influenced the data collection and interpretation, I put forth an effort to be self-reflexive. In order to recognize the impact that the participants and myself had upon the research, a reflexive journal was kept. Notes about my experiences and thoughts regarding each interview were written down after each interview was completed.

Moreover, as an active member of the Camp Oki community, I have preconceived notions about the camp experience, and the positive impact that it may have on children and their caregivers. From being a camp counselor for the past two years, I have witnessed the enjoyable and fun activities that children can engage in and the social interactions that occur at camp. I have also observed children and youth push their limits in terms of their physical capabilities and interacting with others. As well, I recognize how camp can improve children’s self-confidence, behavioural functioning, and self-perceptions. Alternatively, it is important to acknowledge the negative outcomes that can occur due to a segregated, congenital heart disease only, camp environment. For example, children may be less inclined to participate in certain activities even if they see their peers participating. This could further their anxiety of not having the physical capacity or confidence to keep up with their peers. Regardless of the camp specific outcomes, and by acknowledging my researcher bias, I was able to give voice to the participants where their own experiences drove the research findings. As well, a reflexive journal was maintained throughout the research process and while attending camp to keep an open-minded stance about the camp experience. While attending camp seasons in 2012 and 2013, my ideas, experiences, and assumptions concerning camp were documented. As well, I made a deliberate effort to look for negative instances at camp to provide an overall understanding of the camp experience. Furthermore, throughout my two years of attendance at Camp Oki, I was a camp counselor for junior and intermediate girl cabins. My primary role was to supervise the girls throughout the day, and accompany them to different activities. This experience allowed me to interact extensively with my cabin groups and in general with the majority of children who attended camp each year. While attending camp, I interacted with children whose caregivers participated...
in my study. However, I did not interact or treat these children differently because they were children of my participants.

A major issue with the reflexive process is how to manage the power relationships within research (Finlay, 2002). Finlay (2002) acknowledged that there is a power imbalance within a research setting, specifically between the participants and the researcher. By acknowledging that the caregivers are ‘experts’ of their child’s camp experience, I attempted to give power and voice of knowledge back to the participants. The interviews were conversational and interactive in nature, and were participant driven such that participants were able to speak for themselves in a safe, non-threatening environment (Guba & Lincoln, 2005).

2.9 Ethical considerations

This qualitative research project obtained ethical approval from the Research Ethics Board at the Hospital for Sick Children and at the University of Toronto. Participants were informed that they might experience some emotional distress when discussing their child’s heart condition. However, this emotional risk was considered no greater than the risk that these caregivers could experience during their daily life. Therefore, if any emotional distress occurred during the interview, it was managed by skipping interview questions, stopping the interview or referring to counseling, if needed. Fortunately, none of the aforementioned issues occurred throughout the interview process. Before the first interview was conducted, informed and written consent was obtained from all participants.

2.10 Presentation of findings

The findings from this qualitative study are presented in a concise written report that provides detailed explanations of the themes that inductively emerged from the interview data. These themes were developed to understand how caregivers perceived their child’s camp experience, and provided insight into the psycho-social utility of camp for the caregivers and their children. Subthemes are presented within each theme to better describe and illuminate the findings from the main themes. Furthermore, original direct quotations from the caregivers’ interviews are inserted into the text to illustrate the caregivers’ experiences. Pseudonyms have been used to maintain confidentiality of the participants and their children.
Chapter 3
Overview of results

Caregivers discussed various life and health experiences that derived from caring for a child with a chronic health condition. Through this, it was established that children and their caregivers do experience psycho-social morbidity. All caregivers perceived camp as a pleasurable environment that would help address the issues that they and their children experience. All caregivers identified various benefits that camp would provide for them and their children. These perceived benefits were identified as being ‘met’ during the follow-up interviews. Following camp, caregivers described additional psycho-social benefits obtained from their child’s camp participation. At the end of the post camp interviews, participants provided advice for future caregivers on their experiences with Camp Oki. Caregivers’ perceptions of the camp experience, the psycho-social benefits that were obtained, and the advice given to future caregivers are reflected and encapsulated into the themes presented in Figure 1.

3.1 Parenting a child with a chronic illness

All caregivers discussed their experiences and issues that developed throughout their child’s childhood. Caregivers described various ways in which they reacted and coped with their child being diagnosed with a chronic illness. As well, the majority of caregivers utilized different parenting techniques to normalize their child’s life. Caregivers’ life experiences and struggles they encountered while caring for a child with CHD are reflected below.

3.1.1 Reactions to child’s diagnosis

Caregivers of children with CHD discussed many different scenarios they encountered when they were first informed about their child’s medical condition. However, among all participants, their experiences and initial reactions were quite similar. Caregivers conveyed three main responses to their child’s diagnosis. First, caregivers expressed feelings of disbelief and shock in which they were not prepared for a medical issue to arise. Then a state of confusion accompanied shock once caregivers had time to understand the situation. Second, participants expressed feelings of being overwhelmed and were unaware of how to proceed with their child’s medical care. This state resulted in many caregivers adopting an ‘auto pilot’ mode to caring for their child:
Figure 1. Overview of Themes
I kind of went into a mode where once she [doctor] noticed it [heart problem] then we went back to the doctors office and she said his heart sounds worse and she was going to send us home and wait for the echo and I said ‘there’s no way I’m taking this baby home – we’re not keeping him here, he needs to go to London’. So we just kind of went into a mode where ok – a fight mode – to get him to where he needs to be. So you kind of just get in that mode and just keep praying. (Diana)

The only concern for caregivers was the health and safety of their children, and these caregivers felt they had to fight and take charge of their child’s health care. Third, regardless of their child’s age or type of diagnosis, all participants were scared about the ‘unknowns’ surrounding their child’s life:

I know one of the first things I asked was ‘was she going to be any different when she got pretty much to where she is now – at the age she is now – will anyone be able to tell and what was her life going to be like’ – that was a big concern. So I had all sorts of things running through my head about ‘is she going to be discriminated against, is she ever going to be able to get insurance, a job?’ You kind of go through their whole life and wonder how it’s going to affect them, even though they are just a newborn sitting there. (Alicia)

The uncertainty of their child’s survival, during birth or post diagnosis, was the main concern for the caregivers. Participants were extremely fearful of the unknowns surrounding surgeries, survival rates, and their child’s future lifestyle and quality of life.

3.1.2 Coping strategies – ‘Acceptance’

The ways in which participants coped with their child’s diagnosis varied from connecting and sharing experiences with their friends and family, to gardening and journal keeping as a therapeutic tool. As well, four caregivers relied on prayer and their church community to help them through the difficult times. While only two caregivers received professional help for their own ongoing psychological issues. However, the main ways in which caregivers dealt with their child’s diagnosis was through positive attitudes, and just dealing with and understanding the situation:
We just accepted it, what can you do. Honestly and that’s the thing you just accept it because nothing I can do or say is going to change the fact that this is the way it is. And the only thing that I can do as a parent is make everything ok for her. I mean that’s the most important part about being a parent and you know the old saying ‘never let them see you sweat’ – don’t let your kid see you freak out because then they’re going to freak out. (Julie)

All participants now accepted their child’s diagnosis, and understood it was going to be an ongoing issue they would always have to deal with.

3.1.3 Taking matters into their own hands

All caregivers had mixed feelings based on the amount and quality of resources provided to them to help manage, cope, and understand their child’s diagnosis. After the child’s initial hospitalization and/or surgeries, most caregivers were pleased about the guidance and informational guides offered by the cardiologist, nurses and/or counselors on site. These health care professionals provided guidance on physical activity restrictions and limitations, information about the transitional period between childhood and adulthood, and general knowledge about the disease itself and its severity. However, all support and guidance caregivers received were offered in-hospital. Alicia explains the lack of guidance and support she received after leaving the hospital:

Yeah I seemed to remember that when we were down at Sickkids we had all these other parents around us for support, we had a social worker. It felt very very supportive when we’re down there and then we came home and all of a sudden we didn’t have any of that.

The majority of caregivers described the lack of information presented to them regarding the management and proper care for their child, as well as what emotions both their children and themselves could experience, outside of the hospital environment.

Since there were minimal resources given to these caregivers, they had to take matters into their own hands and find resources on their own. Four participants researched and became members of other organizations such as the Heart Defect Society, the Heart and Stroke Foundation, or Kawasaki Disease Canada. Not only did these programs provide caregivers with helpful
resources on how to manage and care for their child, but they also provided caregivers with a social network of other families who have gone through similar life experiences. In addition, online websites such as Facebook, blogs, and/or chat rooms, offered caregivers another way to interact and learn from other families. Sarah explains how connecting with other mothers helped her realize she was not alone:

... Getting on the Internet and talking to other moms who had kids with the same defects or something similar or kids who have gone through the same surgeries and stuff life that. And reading their stories and stuff that help me to feel like I wasn’t the only one – that we weren’t the only ones [parents of a child with a heart condition].

The main way in which caregivers learned about their child’s illness, what to expect during surgeries and post surgeries, and how to help manage and take care of their child’s illness was through connecting with other families. Connecting and sharing experiences with other families via social media, hospital programming, or other programming helped caregivers gain a new form of social support.

3.1.4 What is ‘normal’

All caregivers had mixed responses when explaining their child’s psycho-social well-being. Four caregivers expressed that their child was indeed normal and that from an outsider’s perspective, individuals would not know their child was ‘sick’ unless they were explicitly told. As well, three caregivers perceived their child to be ‘special’ or ‘extraordinary’ because they did not like using the term ‘normal’. Danielle explains the way in which she perceives her child:

She’s just her own little wild little girl [laughs]. She – oh how do I explain this – well she’s obviously, she’s a normal kid with a bad heart. If it wasn’t for the scar in her chest she wouldn’t know that there was really anything wrong with her.

Among the two caregivers who did not consider their child to be normal, issues surrounding growth and development, differences in psychological functioning and physical limitations, and illness management surfaced. From the caregivers’ perspective, all children considered themselves to be normal:
I think he does [consider himself normal] yeah because he’s been sick longer than he’s been healthy so he doesn’t really know any different, you know what I mean? He doesn’t know what it’s like not to be sick. So who knows if the way his heart functions is the way it should function or the way his heart functions – he doesn’t know that [laughs]. He only knows that it functions one way. (Rose)

This was especially apparent among the caregivers whose children were diagnosed in utero or in their infancy. Their children have grown up with a lifestyle in which they are accustomed to being ill and/or frequently attending hospitals or clinics.

3.1.5 How to make a child’s life ‘normal’

Caregivers adopted different parenting techniques to make their child’s life as normal as possible. All caregivers explained how they constantly encouraged and tried to provide as much confidence and support for their children throughout their childhood. This was evident through reinforcing conversation where the child was told that they could engage in any type of physical or social activities. The majority of caregivers did not set any restrictions on their children and had the same expectations for their child with CHD as they would for their other children. These caregivers registered their children in various activities in order to help their children feel normal. Catherine comments on her parenting style where she tried to normalize her daughters’ life:

One thing that I thought of when I was carrying her – and just before she was delivered – was I didn’t want her to be different than any other kid and that was really important to me. I didn’t want her to be in a bubble and I didn’t want her to be this fragile little baby. And so we never treated her that way, she was just always treated … just like any other new born or any other toddler or any other kid growing up. She wasn’t ostracized in any way. I tried to get everything I could for her, so there was preschool and there was gymnastic classes and anything I could get her enrolled with. And nobody seemed to balk at the idea that she has this congenital heart defect so I just went forward with it.

Furthermore, two caregivers did not attribute differences in their child’s functioning to the disease itself, but rather to the child’s age or how individuals have different energy levels and/or skill sets. Even though all caregivers expressed how they wanted the best for their children, the
majority of participants still displayed overprotective behaviours. Depending on the type of CHD, these caregivers limited their children’s participation in physical activities and day-to-day play, while other caregivers excluded their children from daycare opportunities and/or interacting with other individuals who were in contact with sick individuals.

3.2 Caregivers’ psycho-social well-being

Parenting a child with a chronic illness is a large undertaking and significantly impacted participants’ psycho-social well-being in both a positive and negative way. All caregivers expressed feelings of anxiety and worry, in which they were constantly on guard and these feelings were always in the back of their minds. Due to this, the majority of caregivers adopted overprotective behaviours that further restricted their children from participating in daily activities. However, all caregivers were thankful for the opportunity to send their children to Camp Oki, wanted to meet other families who had children with CHD, and were more appreciative of how others deal with health and life experiences. The daily struggles caregivers encountered, which influenced their psycho-social functioning, are presented below.

3.2.1 ‘It’s always in the back of our mind’

Caregivers of children with CHD displayed feelings of anxiety, worry, and fear surrounding their child’s medical health and psycho-social functioning. All caregivers were worried about their child’s current and future lifestyle, and health related outcomes. More specifically, they had anxiety relating to the ‘unknowns’ of their child’s life. As their child matured, caregivers still reported being worried and fearful of their child’s unknown future lifestyle and health implications such as sudden deaths or issues arising during clinical appointments:

Really he’s done well for the last four years – like as soon as he had his fenestration closure – he’s been pretty healthy since. Now I mean they’re still always on the back of your mind, like every time he gets sick I worry more about him than I do about my others kids when they’re sick. And sometimes when I hear of other kids where something changes all of a sudden in their health and I worry a little bit that one day something can change for him and he won’t be doing as well as he’s doing now. (Sarah)
Similar to Sarah, Catherine discusses how she has become more fearful for her child with CHD compared to her other children:

I mean I do get sad, I find that I still go up to her bedroom in the morning and I’m fearful that she’s not going to be breathing. That’s my fear everyday and it’s a fear I have to live with everyday. And not every mother has to go through that. Parents have fears right, of course they do, but not every parent is going to have a fear that their child is going to have a heart attack in the middle of the night and you’re not going to be there … I never have that fear about my son – I know I’m going to walk in and he’s going to be fine. But if I go in and she’s laying in an awkward position or I still go in and wake her up in the morning. If she’s laying in an awkward position or I don’t see her chest rising it will be like ‘ahhhh oh my god’.

In addition, participants were fearful of their children overexerting themselves during physical activities and not knowing how to react when something ‘bad happens’. Caregivers were especially worried about the reactions of others; more specifically how friends, teachers and bystanders would react to a heart issue. Therefore, some caregivers were reluctant to allow their children to be away from the family for a significant period of time:

Sometimes when she’s at school, especially when the heat is really bad. There are so many kids and I worry that sometimes the staff won’t take her seriously or take the signs seriously if something is happening. Her teachers, like her actual teachers, have always been great but I know she’s not always with her actual teachers … See we’ve had a couple bad experiences with the school where they haven’t paid attention. And they denied her – a gym teacher denied her to go get her inhalers one day. Yeah and he apparently had no idea she had a heart condition and even though she was on the list in the school and we had to explain ‘do you understand that if she has an asthma attack it’s going to affect her heart and her heart can’t handle going in stress like that’. And so that’s more of the main reasons my confidence is low in the school … It’s hard to trust people who you don’t have a connection to with taking your child’s condition seriously.

(Alicia)
Caregivers also reported emotional distress that related to how their child feels about themselves and the insecurities they exhibit. Participants’ feelings and emotions were not always externally present, as they no longer had to deal with day-to-day medical issues, and have accepted the nature of their child’s illness. However, their children’s health and psychological issues were always in the back of the participant’s minds. Participants would frequently dwell on their feelings when issues surrounding their child’s health would arise.

3.2.2 Overprotectiveness

Due to the overwhelming sense of worry and fear, the majority of caregivers often exhibited overprotective behaviours throughout their children’s childhood. These caregivers were mainly overprotective during activities that included contact sports or strenuous physical activity because of the fear of injury or overexertion. Participants constantly reminded their children to ‘take breaks’ or ‘re-hydrate’ during physical activities; this was especially evident during hot and humid weather. Environmental factors, such as humid environments played a major role in the caregivers’ decision to restrict physical activities that would put their children at a higher risk for breathing complications. Sarah comments on her restricting behaviours:

I have kept him in from soccer one day. This year they ran it even though it was 40 degrees with humidity and I kept him home. So certain things like that where it’s going to be hard to breathe for a normal child – not going to send him out.

As well, two caregivers also limited their children’s participation in day-to-day play in ‘germ infested areas’ such as playgrounds and gyms, and with other children because they believed their child with CHD was more susceptible to becoming ill. Danielle describes how she was overprotective of her daughter:

I don’t really let them go to swim often in Kalahari – those big waterparks things. And I never let her play in McDonalds play land where all the germs, where there’s a lot of germs I don’t go [laughs]. That’s about the only restriction … You don’t want her to get sick. She already has a heart condition if she got some kind of crazy bug that would – just trying to keep her healthy all the time.
All caregivers put forth an effort to not be overly protective and restrictive of their children. However, in some situations, being controlling of their child’s behaviours was perceived as inevitable.

3.2.3 Appreciative of others

The majority of caregivers identified the positive social impact of having a child with CHD, where they became more appreciative of other families and healthcare professionals. This experience allowed caregivers to gain friendships and build connections with other families who have a sick child through various networks such as social media and programs offered through the hospital. Caregivers expressed how they were more sensitive, compassionate, and willing to share experiences with these other families:

I think probably a little more sensitive too and maybe talking to other parents about their kids and things like that. Particularly if they happen, if something that maybe their child has – I think you are more attuned too and can understand that and appreciate maybe what they are going through. But as far as changing socially, yeah I think again may be just a bit more appreciation for how lucky you are if you have full health … Everything seems to be really good right now but again you kind of think jeez ‘this guy has had a rough life’ and so let’s really make sure we’re a little extra sensitive to what he’s going through. (Henry)

Furthermore, this experience strengthened current relationships between caregivers and their friends, as their friends became more understanding of the participants’ own health and life situations. As well, participants expressed how they gained friendships among health care professionals, and became grateful for their support and care received in hospital. Catherine states that, “we’ve met a tremendous amount of people. And all of her doctors and nurses have been phenomenal. None of our friends have treated us any differently or our family have treated us differently, which is fantastic.” The majority of caregivers were thankful for their child’s health experience, and four participants described how they gained relationships and/or improved their social functioning among their family and friends, as a result of their child’s cardiac illness.
3.3 The perceived psycho-social well-being of their child

Participants displayed various ways in which their children experienced a compromised psycho-social well-being and quality of life. This was evident through their children’s frustrations with daily living, lack of self-confidence, and constant anxieties and/or worries they faced. Caregivers expressed how their children’s psycho-social well-being was influenced by the diagnosis of a congenital heart disease.

3.3.1 Frustrations with daily living

All caregivers of children with CHD expressed how their children often became angry and frustrated with day-to-day living, especially with struggles surrounding academic achievement and keeping up with their peers. Three participants discussed how their children have developmental delays, and this lead to frustrations with their own academic achievement, as they were starting to notice differences among their typically developing peers. Sarah comments on her child’s developmental functioning by stating that:

> He has some anxieties, some developmental delays or learning struggles I guess it would be what it is. I think it’s more him feeling like – because he does struggle a little bit developmentally and learning and understanding – I think sometimes he feels that ‘it’s so easy for other kids and it’s not easy for me’.

Moreover, children were irritated with their own physical capabilities, where it was difficult for them to keep up with their peers. Not being able to keep up with their peers during physical activity further discouraged children from being active and interacting with their peers. Danielle explains how her daughter felt during a physical activity incident:

> They were jogging and running and she couldn’t keep up and it bothered her. And I just had to tell her to ‘don’t worry about it, do what you can and go what you can and if you are tired sit down’. She doesn’t like to do that though, she doesn’t want to feel left out.

All caregivers identified that their children were upset and had frustrations with not being able to keep up with their peers in physical, social, and/or academic environments.
3.3.2 Lack of self-confidence – ‘But I can’t do that’

All participants expressed that their children’s ‘frustrated’ attitude further contributed to their lack of self-confidence. Alicia describes her child’s issues surrounding physical activities:

She tends to be far less physical than most kids. In the respect that – like swimming – it takes her a long time for her to learn to swim. She’s still not super comfortable with the water. When all the other kids were climbing at the playground she couldn’t do it or she wouldn’t do it. But I think a lot of that was her confidence – same with swimming. I don’t think that she’s physically not able to do it. I think she just doesn’t have the confidence to believe she can.

As well, many caregivers identified that differences in their children’s physical attributes (e.g., scars or size) and limitations, and learning disabilities were the main reasons for why their children were bullied by their peers. Judy describes how bullying has contributed to her son’s insecurities and poor self-esteem:

I mean he tries to engage with his classmates, like basketball, and he’s small too because of his health – he’s small in size. He’s the size of a grade two, so that’s a challenge for him. He does his best but he does feel insecure of himself and of being called ‘you’re a shrimp’ [laughs] name callings like that … Sometimes apart from feeling insecure, he does feel down – discouraged is the word. That he’s not able to do what other kids do. Keeping up with basketball or soccer and because of his size – that limits his jumping, reaching and all that. So gives up easily … Yeah then he walks away and when he walks away I know he’s feeling discouraged.

These aforementioned factors were the reasons why children with CHD felt discouraged, gave up easily on specific tasks, and ultimately had poor self-confidence. Lastly, the majority of caregivers described that their children often regressed back to an ‘I can’t do that’ or ‘they are better than me’ attitude. In some cases, children with CHD blamed their disease and used it as an excuse for their lack of self-confidence and differences among peers.
3.3.3 Anxieties and worries – ‘But what if it happened’

The majority of participants reported that their children displayed minor issues with respect to anxiety and worry. These caregivers believed that anxieties and issues surrounding the disease itself would begin to surface as their child matures and reaches puberty. They discussed how their children might realize that there are physical differences between them and their peers, and that their heart condition may contribute to their limitations. Furthermore, stress and anxiety around body image could potentially arise when their children become more mindful of their body and scars. Catherine suggests that her daughter:

Don’t have any fears but with her growing up and the different challenges that are going to be put forth with her. She’s naïve when it comes to puberty and stuff like that … She doesn’t have any negative feelings about her scar but like I said she’s 10 now. So it’s starting to get to that point where she’s covering up a little more, she doesn’t want people to see them [scars] as much.

Caregivers also reported that their children were currently anxious and/or worried about day-to-day issues such as making friends and keeping up with their peers within a physical and academic context. This resulted in children becoming nervous and/or anxious about being left out, not fitting in, and/or feeling alone within their social groups. The majority of caregivers expressed that the only time their children were anxious about their heart disease was when they were actively focusing on their illness:

He’s very cautious; he’s a cautious boy in what he does. And when he does an activity, like a strenuous activity, you’ll see him touching his heart. He will touch his heart and feel his heart beat. Yeah and when he doesn’t like it or doesn’t feel comfortable then he will stop. (Judy)

Children became aware of their illness and focused on specific aspects of their heart condition during strenuous physical activity or before clinic appointments. All participants identified that their children exhibited anxious behaviours that surrounded their future lifestyle, ability to make friends and keep up with their peers, and heart-related health.
3.4 The camp experience

After discussing the participants’ and their children’s psycho-social functioning, all caregivers described how their children needed to experience camp. However, these caregivers had mixed feelings in which they were both excited and nervous about their child attending Camp Oki. Caregivers also identified various benefits that they and their children would obtain from camp participation.

3.4.1 They have to have this experience – But how will they handle it?

All caregivers expressed that their children ‘needed’ to have this experience in order to become more independent, gain self-confidence, and meet other children with CHD. This would allow their children to realize that others have gone through similar life and health experiences, and to see that other children also have limitations. Furthermore, caregivers believed camp was an opportunity for children to address their anxieties and social issues. Diana expresses her thoughts about her child leaving for Camp Oki for the first time:

[deep breath] I say I’m fine with it now [laughs] but the day of drop off I might not be so fine. But I feel that it’s something that he needs to have, it’s something that he needs to experience and he should have that opportunity just like all the other kids.

Similar to Diana, all caregivers were nervous and anxious about letting their child go away for one week. For the majority of caregivers, Camp Oki would be the first time that their children were away from the family for an entire week. The main concern caregivers had with the camp experience was how their children would adapt without having their family present. The majority of caregivers were anxious about how their child would interact with their cabin mates, if they would make new friends, and if they would be anxious and/or homesick throughout the day. Rose explains specifically what she was anxious about:

Oh yeah, yeah I’m nervous; I’m nervous how he’s going to be at night. If he wakes up and has a nightmare and he can’t get to me. I’m nervous if he’s gonna make friends that are his own age. I think it’s more that how he’s going to do when I’m not there.
Caregivers perceived that their children would have mixed feelings towards attending camp. Children would either be nervous about leaving their family or excited about meeting new individuals and having the opportunity to attend a camp. In order to calm the nerves of their children, caregivers tried to familiarize their children with the camp experience. This entailed meeting with a camp coordinator, introducing their children to other children with CHD prior to camp, or familiarizing their children with the camp environment and staff through viewings on Facebook and/or YouTube.

3.4.2 Perceived caregiver benefits

Participants described multiple benefits that they would obtain from their children attending Camp Oki. These perceived benefits were condensed into three overarching themes. First, caregivers conveyed how camp would provide them with the opportunity to let go and allow their children to grow and be independent. Second, participants identified that camp would offer them a form of respite care. Third, caregivers expressed how they would be able to spend more quality time with other family members and friends. Caregivers also described an expectation for Camp Oki where they would be provided with the opportunity to interact and share experiences with other families who have children with a cardiac illness.

3.4.2.1 Letting go

Caregivers of children with CHD perceived that they would become better at ‘letting their child go’ once they returned home from camp. Knowing that their child would be away for one week and functioning on their own without their family, provided the caregivers with the comfort and confidence to allow their child to be more independent. Danielle expresses her thoughts on letting her child go:

I think that it will do me good to let her go. Letting her go for a week with people I don’t even know – I’ve never done that before. It will be good for us to know that she can go and she’s going to be fine.

Furthermore, this camp experience would allow caregivers to have more confidence in other individuals taking care of their child. All participants were also satisfied and comfortable knowing that their child could function and adapt without their family members present. Camp Oki would offer these caregivers the opportunity to acknowledge that their children were
growing up and taking positive steps forward in their life. Diana expresses the benefits she would obtain from her son’s camp experience:

Just grow, it’s going to be a growing experience for our family – to be able to let go and be able to allow him to be the child that in our hearts we know that he could be … Oh it will be a wonderful feeling knowing that he has accomplished things that we never thought he would be able to accomplish either. So it would be a great feeling for our family that ‘hey you know what, now we know that this is something he enjoys, we should get him involved in it or look where else we can do it’.

Additionally, caregivers would be able to accept that their children can take care of themselves, travel on their own, and engage in activities they normally would not want to participate in. Participants anticipated that the new behaviours they would exhibit following camp would transition into their daily living.

As mentioned previously, the majority of caregivers displayed overprotective and restrictive behaviours throughout their child’s life. Therefore, caregivers perceived camp as an opportunity to become less overprotective and restrictive of their children, and ultimately worry less:

It’s going to also build in me – when I see her get through the week – I’ll have more confidence that she can do something like this too. That she can go away for a week and have a good time and come out better at the end of it. (Alicia)

Knowing that their children could take care of themselves, be independent, and have fun at the same time, would provide caregivers with the confidence to be less overprotective.

3.4.2.2 Respite care

The majority of caregivers identified that camp would provide them with a form of respite care where they would get a break from their child and relax and have time to themselves. These participants would no longer be the primary caregiver for their child. More specifically, they would not have to monitor their child’s illness or deal with disruptive behaviours. Alicia explains the importance of getting a break from her child, “well it’s going to be the first time in a long time where I’m not her primary caregiver. So I might actually just relax.” Whereas, Catherine conveys how she would be getting a break from dividing up her free time:
I think that we’ll benefit in a way that we will have a break from her and – not that we want to have a break from her – but she constantly wants to go and play and socialize. So it’ll alleviate some of that trying to divide and conquer.

Furthermore, caregivers identified that their children would be in a safe, inclusive, and non-restricting environment surrounded by health care professionals who would be familiar with their child’s health condition. This provided caregivers with a sense of ease knowing that their children would be in the best capable hands:

I think for the parents – a peace of mind – that you know if something happens to your child they’re in good hands. If I sent her off to a week long camp somewhere else and she’s goes in and she can’t breathe and needs to sit, they’re going to panic. They’re going to panic, they’re going to call the ambulance and it’s going to be a big traumatic event for her. If she’s at Camp Oki and she has an issue they’ll be like ‘ok let’s sit for a minute, see how you feel’ – they know the symptoms. And I don’t have to give them sheets and sheets of information on ‘this is what you have to do if this happens’. The fact that she can go to Camp Oki and I don’t have to worry about the heart issue is amazing. And then you know that when she goes there, there’s enough staff and there’s enough people around that they won’t let that [bullying] happen and it makes such a great environment that that’s [bullying] not even an issue. (Julie)

Since Camp Oki is operated by the Hospital for Sick Children, caregivers felt comfortable and confident leaving their child for a week. Caregivers perceived that their children would be surrounded by doctors, nurses, and staff who would be familiar with their child’s medications, be aware of the signs and symptoms of a cardiac episode, and not restrict them from participating in daily camp activities. Participants also expressed that they did not have the same fears that they would normally exhibit if their child would be attending another camp. Judy suggests that:

[laughs] Yeah if it was any other camp I don’t think I would send him away by himself for a whole week. But simply because it’s SickKids and we’re grateful for SickKids and it will be run by a medical team – that was enough for us.
Similarly, for the majority of caregivers, this was their first time sending their child away to camp. Knowing that Camp Oki was managed by the Hospital for Sick Children, made caregivers feel comfortable sending their child away. Additionally, three caregivers had negative experiences with other camps, and now would no longer send their child to a camp unless it was organized by medical professionals.

3.4.2.3 Spending quality time with others

The majority of caregivers perceived that they would have additional time to interact with other individuals while their children attend camp. Camp would provide caregivers with the opportunity to interact with and focus more on their other children while engaging in quality one on one conversations and/or activities. Furthermore, these participants identified that camp would allow them to engage in new activities that they would not normally participate in if their child with CHD was present:

I think a little for us, well it will allow me and Michelle [wife] to spend more time just with Neil and John [other children] … They are getting back into hockey so we’ll be doing some of those. But we’ll probably go camping ourselves for a couple days. There’s just a small camp grounds close by, and try and take some time and go and do that. We’ll probably do a little more biking; the other guys [other children] like to go for longer bike rides and stuff. So they’ll do that probably as often with David [son with heart defect] goes with us, just we need to keep it a little shorter. But when he [son with heart defect] goes, Michelle is with him, we’ll [father and other children] go for a longer route. (Henry)

Similar to Henry, two caregivers expressed various ways in which their family activities had to be modified, either by lowering the intensity level and/or distance, or by not engaging in a particular activity at all. However, these caregivers did not attribute the modifications of activities to their child’s cardiac condition but rather to their child’s personality and/or interests.

Additionally, camp would allow caregivers to spend more quality time with their significant others, and reconnect and rebuild their relationship as ‘husband and wife’. As well, some participants identified that they would be taking a vacation for the one-week and engaging in fun, relaxing activities without worrying about their children. Lastly, caregivers perceived camp as being an opportunity to interact with their other friends and family members.
3.4.2.4 Caregivers’ interactions among the CHD population

Prior to camp, there were minimal interactions with any other caregivers of children with CHD due to time constraints, location, and willingness to network with other families. However, all participants expected that camp would provide them with the opportunity to network and connect with other caregivers to share experiences and advice. The majority of the caregivers wanted the opportunity to interact with other families as it would allow them to learn how others cared for their children, gain knowledge and advice on what not to do, and share life and health experiences with others who would understand the situation. Alicia conveys why she wants to meet other caregivers of children with CHD:

Well I think just talking with someone who’s been through something very similar to you is always good. It’s always nice to share experiences and to hear where someone else comes out on the other end – to help them if you can or to get help from them. I think you just connect with people that you have similar experiences with. And I think as you go through the stages of your child, it’s good to have connections with other parents that have kids in similar situations – talking to parents that maybe their kids are grown up [laughs].

These participants were also looking forward to meeting caregivers of older children with CHD as this would reassure and give hope to the participants about their own child’s future functioning. Caregivers wanted to network with developmentally and/or age appropriate families to gain a better understanding of their own child’s future lifestyle and functioning.

However, there were three caregivers who were unsure and hesitant about meeting other families for two main reasons. First, participants believed that these social interactions would cause unwanted stress upon their family. Caregivers perceived that others would impose their negative experiences and thoughts upon them causing them to dwell on the negative aspects of their own child’s life. Second, caregivers discussed ‘comparative conversations’ that would develop where other families would force their parenting techniques upon them. Sarah explains why she would be hesitant to interact with other families who have children with CHD at camp:

Yeah it depends on the parent. Some parents I find almost want to believe their child is the only one [with a heart condition]. I don’t know what it is – if they like the attention of it or the focus on them and their child. And so sometimes it’s
hard to have a conversation with somebody because Philip does so well. So if their child is doing worse than Philip, it’s not like talking to somebody who identifies with you because they think that their problems are worse or whatever. So there are some parents like that. And I’ve had some parents who don’t really feel the same as me; they don’t want to think about the fact that their kid has a heart defect at all. They just want them to be a normal kid and they don’t want to talk about it – they just want to move on kind of thing.

These caregivers wanted to avoid awkward situations that would potentially make one feel more despondent. However, all caregivers were at least willing to interact with other families if the opportunity arose during camp.

3.4.3 Perceived child benefits

All caregivers anticipated that their children would have a fun and wonderful time while away at camp, and described multiple benefits that their children would obtain from Camp Oki. These benefits were encapsulated and categorized into four central themes. First, caregivers perceived that camp would equip their children with independence. Second, camp would provide children with the opportunity to be exposed to new activities. Third, camp is an environment that would foster relationships among children with CHD. Lastly, caregivers anticipated that camp would alleviate their children’s anxieties and improve their self-confidence. Additionally, caregivers described an expectation for Camp Oki, where they anticipated that their children would adapt fairly well in unfavourable situations at camp.

3.4.3.1 Independence – ‘He’s growing up’

The majority of caregivers perceived that the camp experience would instill independence in their children once they returned home. These caregivers anticipated that their children would learn how to be away from their family, learn to take care of themselves without parental assistance, and ultimately gain independence in activities of daily living. Sarah expresses how camp would influence her son’s independent behaviours:

I’m hoping that it will teach him to be a little more independent. And that he will realize that he can entertain himself – there’s things that he can do, he doesn’t need to have us constantly there telling him what to do. Because for that whole week, he’s not going to have us with him.
Whereas Catherine perceives that her daughter receiving a break from the family would contribute to changes in her independence:

I think it will give her the independence that she wants. I think that she’ll make a lot of really nice friends and I think that she’s really looking forward to that. And just being away from home and being away from us and being with different people. I think everybody just needs a break from their family every once in a while. So I think that it’s nice that she has the opportunity to take a break from us and still feel safe because she knows that this camp is for kids that have heart defects or heart disease … It’ll give her more independence, absolutely. So she’ll be able to – I’m hoping that she’ll come home and be able to pick out her own clothes … But it will give her that boost of being able to do more things independently.

The majority of caregivers perceived that Camp Oki would allow their children to get a break from their families and realize what they can accomplish without their family or friends present. These participants anticipated that their children would be able to grow, mature, and acquire new independent skills.

### 3.4.3.2 Exposure to new activities and experiences

The majority of caregivers discussed how camp would offer their children the opportunity to experience new recreational activities. Like most participants, Henry comments on his son’s ability to acquire new physical skills, “I think it’s about – certainly canoeing, kayaking, archery – all those things that he’s never experienced before. Those are going to be great things for him to learn and he’ll know whether he likes them or doesn’t like them.” While Judy discusses how her son would be able to engage in activities he does not usually participate in at home, “he’s just looking forward to doing activities [laughs]. He doesn’t get to do here like fishing – we don’t fish though; we don’t take him. Like that and just doing activities that he doesn’t get to do here.” In addition, Diana suggests that camp exposes children to different activities that their caregivers may not be aware of or allow their children to participate in:

I think it’s fantastic for all these kids to be able to try things that maybe that we can’t provide our kids. Or we don’t know that they are even out there or we even think our kids could even do. Like zip lining, I never thought Chris would ever be
able to zip line … I just hope that other parents are able to have the experience to give their children the chances to break out of their shells and be able to experience something that other kids get to experience.

Furthermore, participants acknowledged that their lack of presence at camp would instill more confidence in their children to try new activities. Sarah discusses what it would be like for her son to participate in new activities without her present:

I think those kind of risky fun things they have there like wall climbing and the tubing or whatever it is they do in the water. Those are the things that we can’t easily convince him to do but I think that counselors and other kids will be able to convince him easier.

Lastly, these caregivers anticipated that their children would be able to experience camp just like their typically developing peers as Julie describes, “it’ll allow her to actually go to camp and experience canoeing and all the things that every healthy kids gets to experience all the time – in a controlled environment too.” All caregivers were thankful for the ability to send their children to camp, and recognized that camp would provide their children with the opportunity to participate in new activities and be exposed to a variety of different camping experiences.

3.4.3.3 Long lasting friendships

All caregivers described how their children would be able to interact and share experiences with other children with CHD, and in general, build long lasting friendships. These caregivers discussed three benefits that their children would obtain by interacting with other children with CHD. First, participants perceived that their children would be able to share life and health experiences with others, and be able to relate to one another. This would further allow their children to realize that they belong, feel normal, and would be part of a new community. Judy identifies how her son would benefit from building friendships with other children with CHD:

Well I think it’s [interacting with other children with CHD] good for Adam to see that just because you have congenital heart disease that doesn’t mean that you can’t live a full life. I think being among these kids and the activities that they will do together will just help them to see that you can just be as normal as others kids – just be like any other kids.
Second, these camp interactions would allow the participants’ children to understand and observe what other children with CHD can accomplish, and acknowledge that their own condition is not restricting. Alicia expresses the benefits of her child meeting other children with a similar heart condition:

I think it [meeting other children with CHD] will be fabulous because she’s never met another child – other than when we are down at the clinic – that is in a similar situation to her. And like I said she started telling me just in the year that she feels a little different. So I think it will be great to see all different kinds of situations – there’s some kids that have had a lot more surgeries than her. I think it’s going to be really good for her to see that there’s a whole variety of people with different heart conditions and then that they’re living normally and having a good life too. And she’s even said she’s looking forward to meeting other kids who’ve been through what she has … Yeah I think it will give her a less of a – I don’t want to say excuse – but to say that she can’t do something [laughs]. When she sees that there’s other kids out there that are living with it and doing well.

Third, caregivers perceived that camp would be an opportunity for their children to encourage one another and improve their own confidence. Four caregivers identified that their children would either encourage others to participate in activities, or be inspired by others if they were nervous and/or reluctant to engage in an activity. Diana discusses the benefits her son would obtain from gaining new friendships:

Oh I think it [friendships among children with CHD] will be fantastic for him because they can encourage each other – he can realize that he can do just about anything everybody else can, just in moderation. So that way he will be able to just be like everybody else.

Similarly, Judy anticipates that these friendships would help improve her son’s confidence with trying new activities:

I think that [friendships among children with CHD] will inspire him [laughs]. I think when he sees other kids do things that he might be afraid of, I think it will help him to take that leap of faith and inspire him. And he might think ‘oh well let me try that’.
Although all caregivers anticipated that gaining new friendships would be a benefit for their children, these relationships would impact their children’s life in a variety of different ways. Notably, there were four caregivers who expressed negative aspects relating to developing bonds amongst children with CHD. For example, Henry was concerned about his son’s ability to become more aware of the severity of his own illness and exaggerate symptoms:

So I think that there could potentially be a negative of it [interacting with other children with CHD]. If he says ‘ok wait a second, I’ve got a heart disease, these other kids here have a heart disease and perhaps they’re not as well off’. Does he say ‘jeez I’ve got more of an issue that maybe I didn’t even recognize at all?’ Or does it say to him, ‘jeez I’m not as normal as maybe what I was thinking I am’.

Whereas Rose describes how sharing experiences and learning more about what other children have gone through would potentially cause unwanted anxiety and/or fear:

It might instill more fear … For example, he had bypass, but there’s other kids out there that have giant aneurysms on their coronaries and they haven’t had a bypass. So maybe they’ll think ‘am I going to be going down that path?’

Regardless of the positive and negative aspects of interacting with similar children, all caregivers wanted their children to interact with their peers. Caregivers perceived Camp Oki as a welcoming environment that fosters friendships, and allows children to come together and share life and health experiences.

3.4.3.4 Improved self-confidence – ‘I can actually do this and I’m not alone’

All caregivers perceived camp as a pleasurable setting where their children’s anxieties would be addressed, which would further lead to improvements in their self-confidence. As well, the aforementioned benefits that children with CHD would obtain from the camp experience would contribute to their overall improvements in self-confidence. For example, Sarah suggests that her son will, “do those things [try new activities] and then hopefully that will help get rid of some of those anxieties and realize that ‘I can, it’s not that scary – I can do it’.” Similarly, Julie explains how her daughter engaging in new activities would help improve her self-esteem:
I think it’s going to give her such a boost in what she can accomplish. It’s going to give her a look at what she can do. Instead of always being told what you can’t do. She’s going somewhere where she can do everything there – that’s a huge deal.

While Judy perceives that her son interacting with other children would contribute to changes in his self-confidence, “I think he will come home, feel more liberated. Liberated the fact that he will meet and make new friends and he won’t feel alone – I think he will feel more assured of himself.” All caregivers perceived that their children having the opportunity to participate in new activities and interacting with their peers would build confidence within their children, and this would further transition into their activities of daily living. All caregivers wanted their children to come home with a newfound confidence where they would not shy away from physical or social activities.

### 3.4.3.5 Adapting to challenges

All caregivers believed that if their children were put in a situation where they were not able to engage in an activity due to their cardiac limitations, their children would adapt fairly well. Since camp was perceived as a safe environment with staff sensitive to their needs, children would not feel uncomfortable and/or upset if they could not engage in a specific activity:

> I’m hoping they [staff] can get him to try [activities], he knows there’s certain things he can’t do because of the medication he’s on. So it depends on if he’s developed a relationship with someone and he sees a friend going and doing it and if he can’t and he really wants to. But he’s pretty easy going like that so I don’t know if that would be an issue. (Rose)

Four caregivers perceived that their children would initially be frustrated but then would accept being ‘left out’ because their children are aware of their own limitations. Similar to other caregivers’ expectations, Alicia hopes that her daughter would be encouraged to try new activities if put in a restricting situation, “well I’m hoping she feels inspired by it and not intimidated by it. I hope it inspires her to see that she shouldn’t limit herself when it’s not appropriate.” Additionally, two caregivers identified that their children had no physical limitations, however their lack of confidence and willingness to engage in activities were restricting factors to participation.
3.5 A pleasurable camp experience

Following camp participation, all participants discussed enjoyable aspects of their child’s camp experience such as being outdoors and swimming in a lake. While only three of these caregivers mentioned their child experiencing negative outcomes. As well, all caregivers identified several physical skills and life lessons that their children acquired while attending camp.

3.5.1 Children’s camp experience

All caregivers identified that their children had pleasurable experiences while attending camp, and discussed several camp aspects that contributed to their children’s positive experiences. Participating in new camp activities such as rock climbing, waterskiing, and dining hall entertainment, interacting with other children with CHD and building long lasting friendships, and being immersed within an atmosphere that fosters self-confident and independent behaviours, were essential factors that contributed to children’s enjoyable camp experiences. Julie discusses several positive aspects of her child’s camp experience:

She got to – she played with everybody – she tried things that she’d never tried before … And she was telling me about the songs and she said that she was really shy sometimes but that everybody really encouraged her to be outside of herself and do something more.

Similarly, Judy identifies that her son interacting with other children contributed to his positive camp experience:

He said overall just walking away from the trip – he feels better. He feels he has more courage just being at school because he knows that he’s not the only one. And he doesn’t feel like an outcast anymore and that was very encouraging to me … Yeah and I think what helped was he saw that everyone had a common scar – a big scar on the chest. And yeah it really helped him not feel insecure and not to feel like an outcast – that’s the term that he used.

All caregivers acknowledged that their children had positive camp experiences and wanted their children to return to camp in the following years. However, there were three caregivers who described negative aspects of their child’s camp experience. These participants identified that their children were homesick which caused cabin issues at night. This issue surrounding
homesickness was also addressed within my reflexive journal that was maintained while attending camp. These caregivers described homesickness as children missing their family members, not wanting to participate in activities, and/or being scared during nighttime. Although some children did experience homesickness, these issues were relieved quickly as they became accustomed to the camp lifestyle.

3.5.2 Life lessons

Learning is a critical component of the camp experience and all caregivers expressed that their children acquired some form of a lesson. Lessons learned while attending camp varied from learning new camp songs and games, to physical skill development such as swimming and archery, to obtaining life lessons such as independence and ‘never giving up’. Catherine discusses the lessons her child learned while attending camp:

I think that she probably took away life lessons in that she has to take care of herself. I mean eventually yeah there’s going to be people watching for you, maybe a guidance person or something. But in the long run you’ve gotta take care of yourself. She’s the only one that can brush her teeth and get herself ready in the shower and stuff like that. So I think that that was a life lesson – she had to pack her bag and unpack it and make her bed. That’s something that I would typically probably do if we went away – I would be the one that packs the suitcase … So she said that she was the first one, she took the initiative, she unpacked the bag, she put her sleeping bag on top and put all her stuffies down and she’s the first one to have her bed ready. So yeah I think that that is a huge thing that at least to her it shows her that she can do it and for me it’s like reassuring that ‘ok that’s good, I’ve taught her something’.

Whereas Judy’s son learned how to be respectful of others, “they taught the boys to be like a gentleman [laughs] like how to treat girls, pulling out chairs and dress up.” Lastly, Alicia suggests that her daughter acquired determination to participate in activities, and skills to be self-reliant:

Oh well she did tons of new stuff while she was up there. She did the waterskiing, which she’s never done. She tried archery for the first time. She did couching [tubing] [laughs], which she loved and oh she did all sorts of arts and
crafts and pottery … I’d say there’s a difference in her determination to do it [physical activities] and feel like she can and to keep trying … I mean one of them [lesson learned] is obviously that to keep trying. I’d say that’s obviously one that she’s come out of it with. That she’s stronger than she thinks, not just physically but emotionally. … Yeah because she can actually get through that time away from me. She can self soothe if she gets upset, she can – and I think that on the whole – that she’s not the only one that has been going through things like this and that she sees role models and other kids and other girls that are obviously striving and doing well.

Although all children were able to learn new physical skill development from the camp activities offered, caregivers primarily discussed the life lessons that their children obtained from attending camp.

3.6 Psycho-social impact of camp for the caregivers

Prior to camp, participants described three central benefits that they would obtain from their child’s camp experience. Caregivers identified that Camp Oki would allow them to ‘let go’ and allow their children and themselves to be independent, receive a break from their children and gain a form of respite care, and spend more quality time with other family members and friends. As well, caregivers addressed an expectation for Camp Oki, where families of children with CHD would be able to interact and share experiences with one another. These benefits discussed during the pre camp interviews were perceived as being ‘met’ throughout the follow-up interviews. All participants expressed how their expectations of the camp experience were surpassed. However, the expectation of sharing experiences with other families was not met to its fullest potential. All participants described other ways in which they benefitted psychologically and socially from their children attending camp. These new benefits were summarized into three themes and are presented below. The majority of caregivers identified that they truly were able to let their child be independent once they returned home, and were more supportive of their children participating in new activities. In addition, these participants identified that camp temporarily alleviated their need to be caregivers, and allowed opportunities to reconnect with other family members. Lastly, all caregivers had the opportunity to interact with other families who have children with CHD. However, these caregivers were
expecting more in-depth interactions where they would be able to share knowledge and advice about caring for children with CHD.

3.6.1 Increased independence – ‘I must let them go’

Prior to Camp Oki, caregivers identified that camp would allow them the opportunity to let go, and have comfort and confidence in their children to become independent. All caregivers discussed how this benefit was met following camp attendance. Participants described how they actually had confidence in their children to be more independent and engage in new activities. Alicia describes how she has benefitted from her daughters’ camp participation:

I think it’s good for me to see that she can go away and she can do these things and she can survive and end up better for it at the end … I’d say it made me feel better and like I said it’s also encouraged me to say ‘hey you don’t have to mother her so much, she can do things on her own – so let her’.

These participants were encouraging and supportive of their children to engage in more independent behaviours following camp attendance. Additionally, the caregivers who revealed overprotective and restrictive behaviours during the pre camp interviews, acknowledged a change in their behaviours after camp. These caregivers identified that camp helped reduce their restrictive and overprotective behaviours. This was evident through caregivers providing their children with more household responsibilities, not mollycoddling their children the first time they requested help with daily activities, and by worrying less about their child. Catherine states that:

I try to think that she’s grown up and I can give her more responsibility around here. As far as taking care of herself – I have to. I’m trying to put more responsibility on her I guess because she’s done this – big feats of going away for a week. So I’m trying to get her that more responsibility and less hovering, more space – let her be herself more.

Similarly, Henry identifies how his parenting techniques have changed since camp:

But also I think when it comes to independence – go back to independence – I think I do allow him to do more things for himself and encourage him. If he’s got a question whether that be around schoolwork, whereas I might have before said
‘ok now let me just do that for you’, now it’s ‘I think you can, just think about it’. And so really encouraging him to take ownership for completion on those types of things.

Additionally, three caregivers used their children’s camp experience as a resource to reinforce good behaviours through mastery experiences. This allowed participants to connect back to what their children were able to accomplish at camp:

I’m encouraging her now, ‘Amanda you went to camp, you did this at camp you can totally do this’. And that’s helped too, having the camp experience has really helped with whenever she does feel like she can’t do something I’m like, ‘well Amanda look at all the stuff you did at camp’, she’s like ‘oh you know what, right, I did do a lot of cool stuff’. And then she’s not really afraid to try new things now’. (Julie)

Caregivers frequently used camp as a reminder for children to acknowledge their own accomplishments and the confidence they exhibited while attending camp. Not only was camp used to strengthen new behaviours but participants also used it as a tool to help reinforce within themselves that their children were able to function and be independent without their family.

All but two caregivers conveyed how camp had influenced their anxious behaviours. The majority of caregivers identified that camp had a positive impact on their anxious behaviours by allowing them to worry less about their child’s psycho-social well-being and physical capabilities, and being away from one another. Alicia conveys the various ways in which camp has changed her worry towards her daughter:

I certainly don’t worry about her as much if she goes on a sleepover somewhere or if I’m not around for her as much because I’m doing something else because I know she spent an entire week – as long as she’s got supervision … I don’t worry about her abilities anymore. Like I certainly don’t worry that she’s gonna go and be running around and have an issue with her heart while she’s in gym or anything like that.
Prior to camp, caregivers were anxious and/or nervous about how others (e.g., parents, teachers, and/or peers) would react to a heart related incident. For Sarah, this type of anxiety was alleviated following camp:

He went to my friends for the night but he had gone to her house for the night before Oki [laughs]. But I know that he happened to go to her house when he had the holter monitor on. And so I didn’t really worry about that – her having to take it off of him and how he would just respond to that, and whether he could keep it on without complaining about them [holter monitor] being on. I didn’t worry about it, I was like ‘they’ll figure it out and he’ll be ok’.

While Judy no longer worries about her son’s psycho-social well-being:

I was very encouraged and I also felt liberated when he shared that ‘I feel more brave mommy because I don’t feel like an outcast because I know they’re other kids like me’. That really made a difference for me. I don’t worry – I mean I will always worry about his health but I’m not worrying about how he feels about himself.

Similar to Judy, the majority of caregivers discussed that the worry they displayed towards their child’s heart condition itself would never be alleviated. These caregivers will always worry about their child’s uncertain future lifestyle and heart health.

3.6.2 Camp alleviated the ‘need’ to be CHD caregivers

During the pre camp interviews, participants addressed two benefits that they would obtain from Camp Oki. Camp would provide them with a form of respite care and the opportunity to spend more quality time with other family members and friends. All participants acknowledged that these two specific benefits were met, and further described how camp alleviated their need to be caregivers. For Sarah, camp provided her family with the much-needed break from her son:

We enjoyed the quiet [laughs]. We still had four children but [laughs] he sometimes really gets people going … He doesn’t always know how to entertain himself unless he has an electronic or something in his hands … So it was a nice break for us with him not being here.
Even though these participants still had other children to care for, they recognized how camp relieved them of their daily responsibilities of being a ‘cardiac’ parent. These caregivers were able to relax, have quality time to themselves, and get a break from their children. Catherine conveys what it was like to not have her child present, “so I had the afternoon to myself. It was good – it was a little stressed. But it was nice to sit back and kind of relax and not worry and know where she is and know that she’s safe.” Similarly, Judy discusses what activities she participated in while her son attended camp:

I just know one week I was meeting a friend each day for lunch. Yeah I road my bike and I just went to meet different friends each day for lunch … See that was nice, that was nice for me. My other son went to his day camp, yeah so I did my own thing.

Furthermore, the majority of caregivers identified how they were able to spend quality time with their other family members and engage in different activities. Henry conveys how camp allowed himself and his wife to spend time with their family members:

Michelle [wife] and I spent a bit more time with her own mom during that week as well … So it’s just one of those things when you don’t have to look after [him] – it just allows you to have more time to engage with other people, other family members. So that’s kind of a similar experience for myself, being able to spend more time with Neil and John [other children].

As well, Julie discusses the different activities that she participated in with her other children:

What did I do? I hungout with my other two daughters [laughs]. It was really cool; it was a different dynamic without Amanda here … So we went and got pedicures together and got our hair done and all kinds of stuff like that. But normally Amanda has no interest in that kind of stuff.

Lastly, participants expressed how camp relieved them of their parenting roles where they were able to identify as a ‘couple’ and not just ‘caregivers’:

Well it definitely helped my husband and I – have some time to talk [laughs] and opening our lines of communication and remember that we are a couple too and
it’s just not always about Chris’s health. Because it’s [child’s health] not always on the front burner but it’s always in your head. (Diana)

All caregivers were grateful for the opportunity to interact with friends and other family members on a different level. These caregivers were provided with reprieve from their parenting responsibilities and were able to have time to themselves.

3.6.3 CHD caregivers’ interactions – ‘Not what I expected’

As mentioned previously, the majority of caregivers expected camp would be a setting where families of children with CHD could interact and share experiences with one another. There were two instances where this occurred; while dropping off and picking up their children from camp. There were only two caregivers who were unable to interact with other families because, “everybody sort of disappeared and there wasn’t really a big long goodbye” (Rose). Among those who did interact with other caregivers of children with CHD, most interactions took place among families who already had past relationships. Additionally, the conversations that occurred among these caregivers were not the topics that were previously anticipated. The participants described that the conversations were ‘small talk’ or camp specific, and they were unable to share experiences and learn about other’s parenting techniques. Danielle shares her experience with meeting other families who have children with CHD:

Well some of the kids I recognized from the video from the year before so I was saying ‘oh he gets to come back this year, he looked like he really enjoyed it’. We just talked about how lucky they are, James [another camper] and other kids that’s in Christine’s karate class. Talked with his parents about them going and all of that.

Although the majority of caregivers were able to interact and connect with other families, the topic of conversation, such as sharing advice on parenting techniques or discussing life and health situations with caregivers who have older children with CHD, did not meet participants’ expectations.

Another way in which families were able to interact was through the social media website Facebook. Camp Oki has a camp specific Facebook page that is used as a platform for caregivers and campers to share experiences, comment on photos, and stay updated with camp
related activities. The majority of caregivers mentioned they were present on Facebook; however, participants were primarily active and interacting with other families only during the camp week. Unfortunately, relationships that were created in person or online, as a result of camp, were not sustained at the six to eight-week follow-up.

3.7 Perceived psycho-social impact of camp for children

Prior to camp, caregivers discussed their initial perceptions of their child’s camp experience, and identified four benefits that their children would obtain. Participants perceived that Camp Oki would provide their children with the opportunity to gain independence, be exposed to new activities, create long lasting friendships with other children with CHD, and enhance their self-confidence. Following camp attendance, caregivers identified that these anticipated benefits were ‘met’, and further described how camp equipped their children with a wide variety of psychological and social benefits. The psycho-social impact of camp for children with CHD is presented in three main themes. First, participants suggested that camp enhanced their children’s independent behaviours with respect to daily routines, and reduced caregiver attachment. Second, camp was an environment that fostered caring and fun relationships among children with CHD. These children returned home with reduced anxieties and fears of ‘being the only one’ with a heart condition. Third, caregivers described their children’s improved determination and confidence to participate in different activities.

3.7.1 Reduced parental attachment – ‘I’ve grown up’

The anticipated benefit of children obtaining new independent behaviours was perceived as being met following camp attendance. All caregivers described how their children returned home with a newfound independence. Participants acknowledged that their children were maturing and becoming more responsible; this was especially apparent when children completed daily routines without hassle or parental help. Henry conveys the changes he witnessed in his son:

Yeah I think he’s a little more independent and again it’s everything from getting up in the morning, getting dressed, brushing his teeth and those types of things. He’s really kinda accelerated on those types of things … And prior to him going [to camp] he generally would call and ask for one of us to lay down with him to
go to sleep at night … He very rarely asks anymore for us to kind of lay down with him as he’s going to sleep.

As well, four caregivers identified that camp helped their children realize they do not need to depend on their family and are able to make choices for themselves. This was evident through the way Catherine expresses how her daughter has grown up:

I think that she came back with more an idea that she could have more freedom. She came back, she’s like ‘why do I have to ask you now, I’ve done this on my own [at camp]’ … But I think it [camp] gave her just that little bit more of an independence to know that she can do these things, which is good. I mean she realizes that she can go to camp and be on her own and she doesn’t need us around to remind her to do all the things that need to be done. So I think psychologically she grew up while she was away.

Lastly, participants suggested that camp taught their children to advocate for themselves when being physically active. As well, their children were no longer using their heart disease as an excuse to not participate in activities. Catherine describes the changes she has observed in her daughter since returning home from camp:

Since going back to school – so camp, then it was school the next week – she realized that, and she knows that from camp as well, that she has to be an advocate for herself. That she’s the one that has to kind of put the foot down and say ‘this is why I need to stop and I’m going to stop’.

All caregivers described positive changes in their child’s ability to be self-reliant. Participants were happy and proud that their children were maturing and wanting to take on more responsibilities.

3.7.2 Sense of community, acceptance, and camaraderie

Prior to camp, caregivers described that creating long lasting friendships among children with CHD would be a main benefit for their children. As well, participants conveyed three additional benefits their children would obtain from interacting with other children with CHD. Following camp, all benefits surrounding friendships among children with CHD were identified as being met. All caregivers were pleased that their children were able to interact with their peers. The
first benefit caregivers addressed concerned their child’s ability to share experiences with others and feel like they ‘belong’. Camp Oki allowed children to gain a sense of community since they were immersed in an accepting and non-judgmental atmosphere:

I think it was just a really nice feeling for her to know that it wasn’t just her – I think she felt a sense of community … I think she’s not feeling as alone anymore and she feels like she has that community around her … I know this is going to sound corny but it really warmed my heart to see her kind of bloom like that while she was there. And having that connection with other kids and feeling not so alone. (Alicia)

Similarly, Diana describes how her son felt like he belonged and was able to be his ‘normal self’ at camp:

He was excited about the songs and being able to do his skits and just to be himself and not be judged … So I think it really – it helped him feel like ‘wow I’m part of something’ and no one judged him and no one said he was ‘too slow’ or ‘you can’t keep up’.

Furthermore, Julie discusses what it was like for her daughter to interact with similar children:

I think it was fantastic. She’s like ‘mom everybody has a scar like me. It was really cool and I wasn’t embarrassed about mine’ … I think it was just she felt normal and that’s a big deal. It’s good to find a group of people where you can be completely yourself around. And I think that’s what everybody strives for in life.

The second anticipated benefit involved children’s ability to understand and observe what other children with CHD can and cannot accomplish. This was especially apparent in the way that Rose acknowledges how camp helped her son understand that other children have similar limitations and health experiences:

I can say that maybe exactly what we wanted to accomplish was accomplished. And that knowing that he’s not the only one with limitations, he’s not the only one with issues like this. And he was with a whole bunch of people that had the same thing; that have these scars and whatever.
Similarly, these relationships helped participants’ children become reassured in themselves, and realize that they were ‘not the only child’ with a heart condition:

So there’s been really I think the camp really bringing him kind of full circle. And he doesn’t ask so many questions about ‘why did God make me different’. So I mean that’s a positive thing. I think he kind of got the fact that all those kids had some kind of a surgery and they were all like him. (Diana)

Lastly, caregivers described how the third benefit of children encouraging one another and improving their own self-confidence was met. Julie comments on her daughter’s improved self-confidence since returning home:

So she has so much more self-confidence since she got back. Because I think the thing is that all the other kids were doing it and when you see all these other kids that have the same issues that you have and they’re doing it, it makes it so much easier for you to say ‘oh I can totally do this’.

All caregivers were satisfied with the camaraderie and friendships that their children obtained while attending camp. However, the relationships that were formed among children with CHD have not been sustained. The majority of caregivers attributed this to the age and location of children who attended camp.

3.7.3 Improved determination to engage in activities

Prior to camp, caregivers discussed how their children would be exposed to new recreational activities, and ultimately improve their self-confidence. These two benefits were perceived as being met following camp, and were combined into a new overarching benefit. Four participants expressed changes in their children’s determination to participate in activities once they returned home. These caregivers identified that their children had enhanced confidence and willingness to engage in social, physical, and extracurricular activities, as well as took ownership in their academic achievement:

I’ve tried to encourage her [daughter] to get involved in extracurricular activities at school ... And she’s always kind of resisted and this year she decided completely on her own, she was totally excited about joining choir [after camp]
… Yeah and she’s never done that before. And I would say maybe part of it is from camp because they actually got up on stage and did things. (Alicia)

Similarly, Julie witnesses a change in her daughter’s willingness to be physically active:

Oh she tries anything now, she wants to join the running club at school and she did swimming lessons like a trooper without being nervous and jumped off the diving board at the swimming lessons – she wouldn’t do that before she went to camp, at all … She comes back from camp and she’s like ‘let’s go, let’s do this!’ … She doesn’t shy away from new experiences, which is what she used to do a lot – quite a lot.

Additionally, four caregivers perceived that their children improved their confidence while interacting with peers at school and within the community. Participants also reported that their children were less frustrated with ‘not being able to keep up’ with their peers in social and physical settings. Caregivers attributed their children’s self-efficacious behaviours to the atmosphere that Camp Oki promoted. Staff and campers encouraged all children to be physically active and socially interact with one another in a non-restricting and non-judgmental environment.

3.8 Advice for future caregivers of children going to camp

All caregivers were extremely satisfied with their child’s camp experience, and highly recommended camp to other families who have children with CHD. Participants provided recommendations and advice for future caregivers who may be hesitant to send their child to camp. Rose explains why she recommends camp to all families who have children with CHD:

It’s just a great opportunity to let your child grow – let him experience new things. And have some time for you and your significant other, whatever. You need that distance, I mean it’s almost like a – what’s that word – respite type. Because you know they’re well taken care of, there’s just no worry whatsoever there – as opposed to any other camp setting … Respite yeah oh for sure. Next we’re planning on taking the week off while they’re away [laughs] … They’re safe – it’s a safe environment.
Furthermore, all caregivers addressed topics that future first time Camp Oki caregivers should take into consideration. The advice that caregivers conveyed entailed allowing children to have this camp opportunity, as it is “an experience that their kids will grow from” (Henry). As well, participants described how other caregivers should try not to worry because their children will be in capable hands with “people who can take care of them if anything was to go wrong” (Danielle). Additionally, other families should consider the time away from their children as a gift, and make time for themselves and other family members.

3.9 Summary of results

Overall, participants and their children do experience issues relating to their psycho-social well-being. Caregivers struggled with the uncertainty of their children’s future health and psychological well-being, were overprotective of their children within physical and social contexts, and were constantly worried about their child’s medical condition. Children with CHD experienced anxiety and frustrations with daily living, especially when trying to keep up with their peers in social, academic, and physical contexts, and have reduced self-confidence. Caregivers identified several benefits that they and their children would obtain as a result of camp participation. Participants described how Camp Oki would allow them to let their child go and be independent, obtain respite care and get a break from their child, spend time with other family members and friends, and interact with other families who have children with CHD. As well, caregivers described several benefits that their children would obtain such as increased independence, exposure to new activities, friendships among children with CHD, and enhanced self-confidence.

These anticipated benefits were identified as being met at the six to eight-week follow-up interviews. Following camp participation, caregivers felt liberated because they acquired the confidence in themselves to allow their children to be independent and ‘let them go’. As well, camp temporarily alleviated their need to be caregivers for one week, allowing them to interact with other family members and friends. Although the quality of interactions among other families were less than anticipated, participants still had the opportunity to meet other families and make connections for the future. Participants were also grateful that their children were able to experience camp in a non-restricting, inclusive environment that fostered independent and confident behaviours. All caregivers were happy and proud that their children were able to spend time away from the family, function on their own, and develop friendships among their
peers who have CHD. Overall, Camp Oki is a unique environment that equips caregivers and their children with an improved psycho-social well-being and quality of life.
Chapter 4
Discussion

The experiences of caregivers suggest that they and their children have a compromised psycho-social well-being, and these caregivers described the value of a camp for both them and their children. Caregivers reflected on the various struggles they encountered while parenting a child with CHD, and identified the reduced psycho-social well-being that their children experienced. All caregivers perceived Camp Oki as a pleasurable environment that their children must experience, as it would help address the multiple issues their children faced. As well, caregivers discussed three anticipated benefits of camp for themselves where they would be able to gain independence and let their children go, obtain respite care and be relieved of daily caretaking responsibilities, and have the opportunity to spend quality time with others family members and friends. These caregivers also described an expectation of camp where they would be able to interact and share experiences with other families who have children with CHD. Additionally, caregivers described their perceived benefits for their children, which included improved independence and self-confidence, exposure to new activities, and building long lasting friendships among children with CHD. All benefits were perceived as being ‘met’ six to eight weeks after camp attendance. Following camp, caregivers reemphasized the ways in which they and their children benefitted from camp, and provided new insights into the camp experience. As the first pre post qualitative study to examine caregivers’ perceptions of the camp experience, these findings support the current literature and provide several novel insights into the camp experience.

4.1 Parenting children with CHD

Parenting a child with CHD is a constantly challenging process where caregivers encountered various struggles and issues throughout their child’s childhood. Caregivers were overwhelmed with emotions and the management of their child’s health care, and had uncertainties surrounding their child’s lifestyle and health status. These findings support Coffey’s (2006) and Kepreotes and colleagues’ (2010) systematic reviews, which reported on the struggles caregivers of children with chronic health conditions faced. Although chronic illnesses differ in medical regimens, caregivers of children with CHD displayed similar experiences that other caregivers have encountered. All participants displayed three main stages upon learning about their child’s diagnosis. First, these caregivers were shocked and frustrated with their child’s
diagnosis (Rempel, Ravindra, Rogers, & Magill-Evans, 2013). Second, similar to Coffey’s (2006) theme of ‘staying in the struggle’, participants were overwhelmed by the responsibility and amount of care that was required for their children after discharge. The autopilot mode caregivers adopted is also similar to Coffey’s (2006) theme of ‘taking charge’ and Kepreotes and associates’ (2010) theme of ‘getting a grip’ where it was essential for caregivers to “gain control of the situation” (Kepreotes et al., 2010, p. 55). All participants were resilient, and advocated for and took charge of their child’s health care (Rempel & Harrison, 2007; Rempel et al., 2013). Lastly, the immediate and future uncertainties caregivers discussed were multifaceted and confirmed reports from parents of children with CHD and other chronic illnesses (Connor et al., 2009; Rempel & Harrison, 2007; Rempel et al., 2009; Rempel et al., 2013; Sparacino et al., 1997; Coffey, 2006; Kepreotes et al., 2010). Similar to Connor and associates (2009), who interviewed 20 families on the emotional and financial costs of caring for children with CHD, participants had uncertainties or ‘unknowns’ about their children’s immediate and future health, more specifically their children’s prognosis and future psychosocial well-being.

According to Bowen (1966, 1974), social support is an essential component of family systems theory where families may encompass a ‘nuclear family’. This was apparent through the ways in which caregivers found support from other family members, friends, and members of the community to help them deal with and understand their situations. Unfortunately, there was a lack of support and information offered by health care professionals when children were discharged from the hospital. This is consistent with previous literature where the “medical model had hindered or inadequately supported parents” (Kepreotes et al., 2010, p. 57) resulting in caregivers taking matters into their own hands (Coffey, 2006; Rempel & Harrison, 2007). Participants resorted to sharing experiences with other families who have children with CHD, as these families could empathize with the feelings they experienced (Coffey, 2006).

The concept of normalization (Knafl & Deatrick, 1986) was adopted by the majority of caregivers to understand their child’s cardiac condition. Similar to Rempel and Harrison (2007), perceiving children with CHD as ‘normal’ was simple for some caregivers and difficult for others. However, all caregivers acknowledged that their children had physical, social, psychological, and/or medical differences compared to their children’s typically developing peers. As well, the majority of caregivers tried to normalize their child’s life and health
experiences as they acknowledged the existence of their child’s illness and perceived the social consequences as minimal (Knafl & Deatrick, 1986). Caregivers rarely discussed social consequences of their child’s illness and instead, emphasized how their child’s illness had strengthened their current relationships among other family members and friends. This is an interesting finding as it contradicts Coffey’s (2006) research, which concludes caregivers lose their sense of freedom and friendships with others when their child is diagnosed with a chronic illness. Furthermore, caregivers’ parenting techniques echo that of existing literature where caregivers encouraged their children to engage in social and physical activities, and did not attribute differences in their children’s development and well-being to the cardiac condition itself (Rempel et al., 2009; Sparacino et al., 1997).

Consistent with Rempel and colleagues (2013) and in contrast to previous literature (Coffey, 2006; Kepreotes et al., 2010) caregivers did not discuss feelings of constant grief. The only ‘constant’ emotion that affected caregivers’ psycho-social well-being was worry. Similar to previous research on caring for children with CHD, caregivers consistently acknowledged that their children’s cardiac condition was ‘always in the back of their minds’ (Moola, 2012; Rempel & Harrison, 2007; Rempel et al., 2013). Worry and distress were apparent in participants’ daily living, where they were anxious and fearful of their child’s health status, future lifestyle, and psycho-social well-being. These findings are consistent with existing literature that concludes caregivers of children with CHD experience constant anxiety and distress (Frank et al., 2010; Lawoko & Soares, 2003; Lawoko & Soares, 2006). Furthermore, with the “ongoing influence of uncertainty”, participants acknowledged that the ‘unknowns’ of their child’s life exacerbated their anxious behaviours (Rempel et al., 2013, p. 623). These anxious behaviours resulted in a struggle for balance and contributed to their overprotective behaviours (Rempel & Harrison, 2007).

The overprotective and restrictive behaviours exhibited by caregivers are well documented in children with CHD (Linde et al., 1966; Luychx et al., 2011; Moola, Fusco, & Kirsh, 2011b; Ong et al., 2010; Rempel & Harrison, 2007; Sparacino et al., 1997) and children with other chronic illnesses (Hullman et al., 2010). In this particular study, caregivers were overprotective of their child’s behaviours such as physical activity (Moola et al., 2011b) and general play with others. For instance, caregivers restricted their child’s participation in activities with humid environments, and when activities involved physical contact and/or increased their child’s risk
of acquiring an illness such as the common cold or flu. Furthermore, caregivers acknowledged they were more protective of their child with CHD compared to their other children (Linde et al., 1966), and perceived them as being ‘sicker’ and more vulnerable compared to their children’s typically developing peers (Thomashard & Metz, 1997). According to Linde and associates (1966) maternal anxiety is the main predictor of protective behaviours exhibited by caregivers. Therefore, it is of great importance to target caregivers’ attitudes and anxieties to simultaneously reduce their overprotective behaviours (Simons et al., 2007).

Lastly, caregivers described various ways in which their children experienced psycho-social sequelae, specifically in terms of frustrations with daily living, lack of self-confidence, and anxieties and worries. These findings are in accordance with previous literature that demonstrated children with CHD have continued psycho-social distress, specifically concerning social problems and anxiety disorders (Fredriksen et al., 2004; Spurkland et al., 1993). Participants perceived that their children were frustrated with their inability to keep up with their peers in social, physical, and academic environments (Moola, Faulkner, Kirsh, & Schneiderman, 2011a). In contrast to previous literature (Spurkland et al., 1993), caregivers consistently discussed their children’s physical activity behaviours to be influenced more by their children’s lack of self-efficacy (Bar-Mor et al., 2000; Moola et al., 2011a) and determination than to their children’s physical capacity to participate. Furthermore, caregivers perceived their children as being more anxious about psycho-social issues such as making friends and keeping up with their peers compared to concerns surrounding their medical condition. Due to the young age of first time Camp Oki campers, caregivers believed anxieties surrounding body image would arise as their children matured and became more aware of their body. These findings confirm Moola and associates’ (2011) research that concluded body image concerns, specifically scars and stature, were significant barriers to physical activity participation. In the present study, participants described how their children may begin to recognize differences among their peers that can be attributed to their heart disease, and this may further contribute to reduced engagement in activities.

Caregivers articulated the multifaceted struggles they encountered on a daily basis and provided further insights into their children’s compromised psycho-social well-being. These aforementioned findings support and contribute to existing literature on the psycho-social impact of parenting a child with a cardiac condition. As well, these findings attest to the body of
literature that advocates for the need of psycho-social programming among children and their caregivers (Coffey, 2006; Goodwin & Staples, 2005; Kepreotes et al., 2010).

4.2  Psycho-social utility of Camp Oki

As this is the first pre and post qualitative design examining caregivers’ perceptions of the camp experience, the findings presented here are novel as caregivers reflected on their perceived benefits, and discussed discrepancies between their anticipated and acquired benefits. Conducting two interviews, before and after camp attendance, allowed rapport to be established between the participants and myself. This type of interview process enabled deeper insights into the camp experience as participants clarified how their expectations translated into acquired benefits. As well, caregivers were able to describe which psycho-social factors were actually influenced by their child’s camp participation. Furthermore, all caregivers had children who were first time camp attendees at Camp Oki. These caregivers provided a ‘newness’ to the camp experience as they had no prior connections with the camp (Munhall, 2012). Within the camp literature, qualitative designs are scarce (Moola et al., 2013) and conducted either during or following camp attendance (Gillard et al., 2011; Goodwin & Staples, 2005). Moreover, within the CHD camp context, research designs are mainly quantitative in nature and from the perspectives of the children (Moons et al., 2006a; Moons et al., 2006b). This study design contributes novel findings to the body of literature surrounding camps for children with chronic illnesses, as it established the anticipated and attained psycho-social benefits for both the children and their caregivers.

4.2.1  Psycho-social utility of camp for the caregivers

Prior to camp attendance, all caregivers described the value of camp for themselves. Caregivers had mixed feelings regarding their child’s camp attendance. Participants were both anxious and excited for their children to be away from their family for an entire week. This is perhaps not surprising as I could imagine most caregivers might be anxious about their child leaving home for camp for the first time. Participants also provided initial insights into the camp experience, where having the ability to let go, obtain respite care, and spend time with others, were described as three essential benefits. Caregivers identified that Camp Oki would provide them with the ability to let their child go and have confidence in themselves and their children to do so. These caregivers hoped camp would provide their children and themselves with the chance to “explore their mutual independence” (Goodwin & Staples, 2005, p. 171). This finding is not
surprising, as the majority of caregivers described overprotective and restrictive behaviours throughout their child’s childhood. It is understandable that caregivers might want to modify their overprotective behaviours and allow opportunities for their children to be independent. A major issue that caregivers also experienced throughout their child’s life was surrounding the reactions of others and their children during a heart related incident. For instance, caregivers were anxious about others’ (e.g., extended family members, friends and/or teachers) responses and how they would take care of children with CHD when they were in distress because of a medical complication. However, participants anticipated that the provision of trained staff at Camp Oki would reduce the anxiety felt.

The ability to obtain respite care from the camp experience is well documented in camp literature for children with disabilities (Shelton & Witt, 2011), cancer (Meltzer & Johnson, 2004; Wu et al., 2011), and end-stage renal disease (Warady, 1994). Caregivers of children with CHD anticipated that getting a break from their medical obligations and children’s disruptive behaviours, and knowing that their children would be in a safe environment operated by health care professionals, would contribute to their respite benefits. These factors would also allow caregivers to “fully enjoy their respite without feeling burdened by undue worry” (Shelton & Witt, 2011, p. 26). As well, it is well established that safety is a fundamental aspect of the camp experience, and has been shown to be an essential variable in caregivers’ ability to obtain respite care (Nicholas et al., 2009; Wu et al., 2011). Lastly, participants perceived that their child’s camp attendance would provide them with the much-needed time to spend with other family members and friends. Although spending time with others during camp was an anticipated benefit, these findings support Smith’s (1987) research, which established mothers of children with cancer were able to interact significantly more with their family members and others during and two weeks post camp attendance.

Following camp attendance, all perceived benefits were obtained and caregivers discussed other factors that were critical to the psycho-social utility of camp. Participants conveyed the effectiveness of camp through three crucial components such as Camp Oki’s ability to allow caregivers to gain independence, alleviate their need to be caregivers, and interact with other families who have children with CHD. Consistent with mothers’ reports on a camp for children with disabilities, caregivers exhibited understanding and acceptance of the “process of letting go” (Goodwin & Staples, 2005, p. 171). After camp attendance, caregivers conveyed the
enhanced confidence and comfort they had in their children and themselves to be self-reliant. This is a positive finding, as camp seems to be an opportunity for short-term exposure to separation between children and their caregivers. With small doses of the camp experience, overtime caregivers may have increased confidence in letting their children leave the home for longer periods of time. Those caregivers who exhibited overprotective and restrictive behaviours prior to camp described how their parenting techniques had changed. For example, following camp attendance the majority of caregivers were providing their children with more household responsibilities, were less submissive to their children, and were trying to be less of a ‘hovering’ caregiver during physical and/or social activities. These findings provide novel insights into the camp literature as no studies have examined the specific ways in which caregivers have been less overprotective or anxious as a result of camp.

Literature surrounding changes in caregiver anxiety is well established and it has shown a reduction following camp attendance (Meltzer & Johnson, 2004; Simons et al., 2007). However, due to the nature of the previous study designs, it is hard to distinguish specifically what caregivers were anxious about prior to and following camp attendance. Thus, this study was conducted to offer novel insights into the particular anxieties and worries caregivers experienced. It is important to note that the anxieties caregivers displayed towards their child’s heart condition itself would never be alleviated. Following camp, caregivers worried less about their child’s psycho-social functioning and how others may react in a heart related incident. However, caregivers consistently expressed that their anxieties surrounding their child’s physical and cardiac health will never entirely be reduced.

Within the theme of ‘increased independence – I must let them go’ two novel findings emerged. As a result of pleasurable camp experiences and children’s accomplishments, caregivers used camp as a ‘reinforcing tool’ to reconnect back to mastery camp experiences. These caregivers used their child’s accomplishments and positive camp experiences as a resource to reinforce good behaviours or enhance their children’s self-esteem. As well, caregivers used the concept of positive camp experiences to reinforce within themselves that their children can be self-reliant when unaccompanied. This was especially apparent when caregivers started to revert back to overprotective or anxious behaviours. Participants constantly reminded themselves of what their children accomplished at camp, as well as the confident and independent behaviours their children exhibited while attending. Using Camp Oki as a mastery experience is an essential
component of caregivers’ parenting techniques, as it is an easy tool to use to help enhance independent behaviours. The second novel insight participants described within this theme related to their increased confidence in their children. Participants also exhibited caregiver proxy efficacy where they had confidence in their children to be independent, become more physically active, and socially interact with their peers once they returned home from camp. This is positive to hear as mothers’ attitudes significantly influence their children’s behaviours (Bar-Mor et al., 2000). Therefore, by positively influencing caregivers’ attitudes and behaviours through camp, children’s behaviours could potentially be enhanced. Notably, these findings suggest that the experience and benefits of camp extend temporally through its use as a resource for caregivers in reminding both their child and themselves of what was achieved.

During pre camp interviews, caregivers described the stress and overwhelming feelings they experienced while caring for their children in their daily living. Through camp, participants acquired a temporary relief from these issues as Camp Oki alleviated their need to be caregivers. Within family systems theory, an under functioning of one family member may result in an over functioning of another, which subsequently causes an imbalance within the family unit (Bowen, 1974). This becomes especially apparent among the parent’s role within a family that has a child with a chronic illness (McDaniel & Campbell, 1998). Findings from this study suggest that over the duration of camp, participants’ role within the family system changed. With the removal of medical responsibilities and daily caring for their child with CHD, participants’ role functioning changed from being a primary ‘healthcare provider’ to a ‘typical’ caregiver. This allowed participants to spend more quality time with others, participate in different activities, and appreciate the long awaited period of relaxation (Shelton & Witt, 2011). Since the roles of the participants changed throughout the duration of camp, the imbalance that usually occurs within a family was able to stabilize. This was evident through the ways in which participants were able to interact more as a family, especially with their other children. These findings support caregivers’ insights into the camp experience for children with disabilities (Smith, 1987) and cancer (Shelton & Witt, 2011), where camp allowed caregivers to interact more with other family members and friends. An essential component of this theme and a novel finding in the CHD camp literature was the ability of caregivers to once again change their roles within the family system, and reconnect with their significant other. Camp provided caregivers with the “opportunity for ‘normalcy’” where they were able to re-identify as a ‘couple’ (Shelton & Witt,
2011, p. 26). Caregivers expressed how they were thankful for the opportunity to engage in adult activities, take short vacations, and dialogue about non-health related and/or child matters.

Lastly, participants hoped that Camp Oki would provide them with a setting to connect, and share experiences and advice with other families. Caregivers were able to interact with other families at camp and through social media. However, the content of conversations did not explore others’ personal life and health experiences. As well, any relationships that were formed amongst caregivers were not sustained following camp. This may be attributed to the time constraints when meeting others families at camp. This finding provides a new insight into the camp environment for caregivers, and confirms the need for caregiver programming and support that helps connect caregivers together to share experiences and remain connected over time (Wu et al., 2011).

4.2.2 Perceived psycho-social utility of camp for children

The secondary objective of this qualitative study was to build upon the existing knowledge surrounding camps for children with chronic illnesses, and provide further insights into the values of camp for children with CHD. Prior to camp, caregivers discussed four central benefits that their children would obtain from attending Camp Oki. Caregivers were confident that camp would instill independence within their children, expose their children to new recreational activities, allow them to develop bonds with other children with CHD, and enhance their children’s self-confidence in social and physical contexts. These findings support caregivers’ follow-up reports on the camp experience for typically developing children (Henderson, Whitaker, Bialeschki, Scanlin & Thurber, 2007), and children and youth with diabetes (Hunter et al., 2006, Santiprabohb et al., 2008), asthma (Nicholas et al., 2009), cancer (Wu et al., 2010), and disabilities (Goodwin & Staples, 2005; Shelton & Witt, 2011). As well, these anticipated positive changes among some psycho-social parameters are in line with children’s perceptions of their own camp experience (Bongiovanni et al., 2010; Cushner-Weinstein et al., 2007; Devine & Dawson, 2010; Gillard et al., 2011; Goodwin & Staples, 2005; Hunter et al., 2006; Kiernan et al., 2005; Török et al., 2006). Participants also described one expectation for Camp Oki where their children would adapt fairly well if put in unfavourable situations at camp. Caregivers believed that if their children were hesitant or unable to participate in an activity because of their heart condition, they would be initially frustrated. However, participants still wanted their children to have self-confidence regardless of what would happen at camp. This is positive, as it
is essential for caregivers to have confidence in their children’s ability to participate in activities. As well, participants believed that staff, counselors, and other campers would sensitively handle their child’s attitudes towards an unfavourable situation at camp.

Following camp, all caregivers identified that Camp Oki was a pleasurable experience that allowed children to acquire new physical skills and life lessons. These findings support previous camp literature where typically developing children and children with a variety of life threatening illnesses and disabilities gained social and physical skills, and psychological benefits such as enhanced confidence following camp attendance, respectively (Henderson et al., 2007; Kiernan et al., 2005; Shelton & Witt, 2011). In addition to the acquired skills and life lessons, children’s ability to socially interact with other children with CHD and participate in recreational activities contributed to their enjoyable camp experiences. All anticipated benefits that children would obtain were perceived as being ‘met’ during the follow-up interviews. From the caregivers’ perspective, children reduced their caregiver attachment. This was apparent through the ways in which children gained independence, maturity, and responsibility in their daily living. As well, caregivers discussed improvements in their child’s self-esteem and insecurities following camp. Caregivers attributed these changes to their children’s ability to participate in new activities and witness other children with CHD participating. Children’s ability to be self-reliant at camp and discover their own physical capabilities is consistent with caregivers’ insights into the camp experience for children with disabilities (Goodwin & Staples, 2005), diabetes (Hunter et al., 2006; Santiprabhob et al., 2008), and cancer (Wu et al., 2011).

Lastly, through peer interactions at camp, children were equipped with a sense of community and belonging. Caregivers’ perceptions of peer interactions are in accordance with qualitative camp literature where caregivers discussed how their children felt a sense of inclusion and understanding within their chronic illness community, and were grateful for the camaraderie offered through the camp experience (Goodwin & Staples, 2005; Nicholas et al., 2009; Wu et al., 2011).

This study also attests to the psycho-social benefits of camp for children with CHD. Consistent with Moons and associates (2006a), caregivers discussed improvements in their children’s mental health, physical functioning, and general behaviours following camp attendance. However, in contrast to Moons and associates (2006a; 2006b), caregivers reported changes in their child’s self-esteem at the six to eight-week follow-up interview. This was especially
apparent in their children’s determination to participate in social and physical activities. Although caregivers could not comment on the actual changes observed in their children’s activity levels, they conveyed how their children had enhanced self-confidence to be more physically active once they returned home. It is important to note research conducted by Moons and associates (2006a; 2006b) was from children’s reports, whereas the current study solely examined caregivers’ perspectives. The differences seen here, within the CHD camp literature, may be attributed to Eiser and Morse’s (2001) research that determined there was better agreement between children and caregiver proxy reports on health-related quality of life domains that related to observable behaviours (e.g., physical symptoms) compared to non-observable behaviours (e.g., psychological functioning). Therefore, caregivers may have exaggerated perceptions regarding their children’s self-esteem and other non-observable health related quality of life behaviours compared to children’s perspectives.

Although samples differed, it is interesting to compare and contrast caregivers and children’s perceptions of Camp Oki. In our preliminary research within the CHD population, children expressed their camp experiences through four central orientations that related to bodily freedom, developing relationships, spatial awareness of the outdoor environment, and temporal friendships (Moola et al., 2014). Similar to children’s reports on their ‘bodily freedom’, caregivers discussed how their children were able to be physically active at camp, and realize their own physical capabilities. As well, the theme of ‘developing relationships’ described by Moola and associates (2014), is also reflected in caregivers’ reports. Camp Oki provided children with the opportunity to develop new friendships among peers where children felt a sense of inclusion, acceptance, and belonging. However, in contrast to children’s reports, caregivers were unable to discuss the dialogues that occurred at camp. Since communication is essential to forging relationships (Moola et al., 2014), this study cannot fully identify the foundations through which friendships were formed.

As well, there were some disparities concerning which camp aspects contributed to children’s pleasurable camp experiences. Within the theme of ‘spatial awareness of the outdoor environment’, being exposed to nature and surrounded by the wilderness were important factors contributing to the enjoyable camp experiences of the children. Unfortunately, caregivers did not discuss any information about the outdoor environment, but rather identified how camp specific activities and interactions among peers were essential to their children’s camp
experience. This discrepancy may be a result of caregivers not having the opportunity to explore the picturesque scenery surrounding Camp Oki. Lastly, all but one caregiver identified that their children’s friendships created at camp were not sustained since camp in August 2013. These caregivers discussed the reasons why this occurred, and attributed them to their children’s young age and inability to obtain contact information from their friends. These findings are in stark contrast to children’s reports within the theme of ‘temporal friendships’ as friendships were maintained through social media websites such as Facebook. According to O’Keeffe, Clarke-Pearson, and Council on Communication and Media (2011), the minimum age for social media website engagement is 13 years. Therefore, it becomes clear why caregivers perceived their children’s friendships as not being sustained, especially through social media websites, because of the younger age of their children (Mage = 9.4 years) compared to other children’s reports (Mage = 14.7 years). This discrepancy between temporal relationships among children with CHD as described by children and caregivers is a novel finding within the CHD camp literature. This finding supports the need for consistent camp exposure for children to obtain long-term benefits.

The perceived positive changes on some psycho-social parameters discussed by caregivers provide support for camp being an ideal psycho-social intervention for children and their caregivers. This study attests to the concept of camp being a ‘therapeutic landscape’ (Walker & Pearman, 2009) that allows children to escape from the stresses of the home life, and provides them with a safe and inclusive community (Wu et al., 2011; Gillard et al., 2011; Goodwin & Staples, 2005). As well, by understanding caregivers’ experiences and values relating to Camp Oki, this study confirms the concept of camp being a form of respite care for caregivers (Meltzer & Johnson, 2004; Warady, 1994; Wu et al., 2011). Furthermore, these findings provide five novel insights into the camp experience for the caregivers and their children, where it is essential for health care providers and parents to focus on the benefits both their children and themselves can obtain (Meltzer & Rourke, 2004; Shelton & Witt, 2011; Simons et al., 2007).

4.3 Limitations and recommendations

Despite the novel experiences addressed by caregivers, pre and post camp attendance, there are a few limitations that must be addressed. These limitations concern the interview modes, the sample of participants, potential for bias, and the long-term sustainability of changes in psycho-social well-being. Since caregivers were recruited from the Hospital for Sick children and
participated in interviews before and after camp, convenience and location were major issues. The Hospital for Sick Children is located in Southern Ontario, and supports and cares for children and their families all across Ontario. Therefore, to accommodate all participants, both in-person and telephone interviews occurred. Although this is not a major limitation to the study, issues relating to the two different interview modes must be acknowledged. Telephone interviews may allow participants to feel more relaxed in their own environment, increase rapport between participants and researchers, and give researchers “access to geographically disparate subjects” (Novick, 2008, p. 4). However, it is important to acknowledge the difficulties when conducting telephone interviews such as the potential for distractions, and the lack of visual cues given by participants resulting in a loss of nonverbal communication (Sturges & Hanrahan, 2004; Novick, 2008). Fortunately, interviews that occurred over the telephone, in the present study, had no major distractions, and ran smoothly and on time. Both telephone and in-person interviews occurred pre and post camp, and there were no issues surrounding the different interview modes.

Limitations regarding the sample of participants are also warranted for discussion. The sample of participants were primarily middle class, well-educated, Caucasian caregivers. This is a relatively privileged sample and may not accurately reflect the patient demographics of all children with CHD and their caregivers (Agha, Glazier, Moineddin, Moore, & Guttmann, 2011; Moola et al., 2014; Nembhard, Wang, Loscalzo, & Salemi, 2010). As well, due to the nature of the sample, there are generalizability issues with the findings from this study. Since first-time Camp Oki caregivers were recruited for this study, their children may not be a representative sample of all children who attend camp. These children were attending Camp Oki for their first time and were relatively younger in age. As well, these children were all diagnosed with a cardiac condition under the age of three years, and therefore, have lived with a chronic illness most of their life. Given that only 5% of children with CHD actually attend camp (J. Kirsh, personal communication, February 2011), these children may not be a representative sample of the children who have been diagnosed with a cardiac condition. Thus, future researchers need to examine strategies for making camp more accessible to more families.

Moreover, gender was not equally represented among all caregivers. Of the nine caregivers who participated in this study, only one was a father. This is consistent with research within the field of pediatric psychology and the camp literature, where fathers are an underrepresented sample
As well, for children with chronic illnesses, mothers are more likely to participate in research than fathers, and fathers are also more reluctant to engage in the therapeutic process (Phares et al., 2005). This may be attributed to the different interactions and roles mothers and fathers have with their children (Phares et al., 2005). For instance, fathers are more likely to take on a ‘playmate’ or ‘breadwinning’ role, whereas mothers establish a ‘caretaking role’ with their children (Lamb, 2000). This study attests to the gendered nature of children’s health care and research for children with chronic illnesses, where fathers are not the primary focus of observation (Peckover, 2004; Phares et al., 2005; Wysocki & Gavin, 2004). Thus, future researchers should determine the psycho-social utility of camp for both mothers and fathers, and compare and contrast the different benefits obtained.

Another issue that must be acknowledged is the potential for bias in my interpretations. However, I deliberately looked for negative instances of camp both during my work as a camp volunteer and during the interviews. In both cases, my observations and caregiver reports were consistently positive regarding the camp experience for both children and caregivers. It may be that caregivers were telling me what they thought I wanted to hear. Yet, only three caregivers were aware that I was a camp volunteer, and thus, likely positively predisposed to camp for children with CHD. The use of peer debriefing with my supervisory committee and triangulation of parent and child data (Moola et al., 2014) may also lessen the potential for such bias. I also encouraged each participant at the beginning of the interview to be honest, and I indicated that there were no right or wrong answers to the questions I was asking. In interviewing participants twice, I also believed that this would establish a greater rapport that would encourage honest appraisals of the camp experience. Thus, attempts were made to reduce this source of bias, but given my constructivist perspective where knowledge is co-created between myself and the participants, then this potential for bias can never be totally discounted.

The last limitation to consider concerns the sustainability of the psycho-social improvements derived from the camp experience. Due to the short-term length of camp and follow-up interviews, the sustainability of improvements among some of the described psycho-social parameters is unknown. This confirms Moola and associates’ (2013) research that advocates for long-term evaluations of camp for children with chronic illnesses. It may be that the perceived psycho-social changes among caregivers and their children are only short-term. Therefore, it is
essential for researchers to assess changes over multiple time points to understand if and when changes are maintained. As well, caregivers acknowledged other activities that may have had an influence on their child’s behaviours. For example, changes in social interactions with others and determination to participate in extracurricular activities may also be a result of children returning to school, and being surrounded by their peers and their influential behaviours. Although all caregivers attributed their child’s benefits to Camp Oki, in reality there are other factors that may have contributed to the benefits derived from camp. Lastly, determining the factors that influence the sustainability and the specific psycho-social benefits derived from the camp experience is warranted. It is important to understand how certain factors that are caregiver and child specific influence the types of benefits obtained. Factors such as the caregivers’ gender and previous psycho-social functioning, and their children’s age, disease type, severity of disease, time of diagnosis, and previous camp experiences need to be taken into consideration to identify how camp influences children with CHD (Moola et al., 2013).

Despite these limitations, this is the first pre and post qualitative study that examined caregivers’ perceptions of the camp experience. Participants were able to describe their expectations for camp and further explain the ways in which they and their children benefitted from the camp experience. Through this, caregivers offered five novel insights into the psycho-social value of camp for them and their children. As well, these participants were first time Camp Oki caregivers; therefore, benefits derived from camp may be different compared to returning families. In addition to longitudinal research designs and a more robust sample of participants, future researchers should examine the sustainability of the psycho-social improvements between first time and returning families. Lastly, researchers should further explore the psycho-social utility of camp for the caregivers in order for health care professionals to promote camp to other families. Health care professionals should focus not only on the benefits children can derive from the camp experience, but also how caregivers can improve their psycho-social well-being, as a result of camp.

4.4 Novel contributions and study implications

The evidence provided by the caregivers’ perceptions of their child’s camp experience contributes to the knowledge surrounding the psycho-social utility of camp for children with CHD. As well, these findings offer five novel insights into the value of camp for the caregivers and their children. For instance, participants used camp as a mastery experience to reinforce
positive behaviours among their children. Participants also described how they exhibited
caregiver proxy efficacy where they had enhanced confidence in their children to participate in
new activities and become more independent. While their children attended Camp Oki,
caregivers were able to spend more time with their significant others and reconnect as a
‘couple’. Lastly, children’s camp experiences provided participants with an environment where
families could interact, however the quality of interactions did not meet participants’
expectations. Caregivers also described a novel insight into the benefits of camp for children
with CHD. Participants described how their children’s relationships created at camp were not
maintained at the six to eight-week follow-up. This contradicts current literature where children
established temporal friendships among their peers (Moola et al., 2014). As a result of these
novel findings, three of these findings have study implications that need to be addressed.

First, caregivers’ reports on using camp as a resource to reinforce behaviours and their ability to
have confidence in their children, demonstrates how camp can have a longitudinal impact on
children and their caregivers. Caregivers can help encourage their children in their daily living
by using the camp context and experience to reinforce or establish new behaviours among their
children. This finding suggests that the benefits of camp for the caregivers may extend far
beyond the one-week experience.

Second, rather than creating new settings for caregivers to interact and share experiences with
one another, health care professionals and programmers should utilize camp as a resource for
caregivers to connect with other families who have children CHD. This is of great importance as
it is crucial for caregivers to connect with other families who have gone through similar life and
health experiences, and to maintain relationships over time (Wu et al., 2011). Through
implementing informal, voluntary programming at the camp or elsewhere, these caregivers will
be able to interact with other families. For instance, including a ‘caregiver day’ at camp would
have minimal intrusion on children’s camp experiences, and would allow caregivers to be
immersed within the camp atmosphere and have informal discussions with other families. This
type of programming may be able to get at what this study did not – the opportunity for
caregivers to share experiences and gain advice on parenting a child with CHD. This study also
has practical implications as these aforementioned findings confirm the need to expand camp
access to more families affected by CHD by way of targeting the caregivers. In support of
Shelton and Witt (2011) and Simons and associates (2007), it is essential for researchers to
explore the benefits of camp for the caregivers, and to educate and promote camp to the caregivers. For example, through programs that can influence caregivers’ poor psycho-social well-being, like camp, overprotective and restrictive behaviours exhibited by these caregivers may be reduced (Simons et al., 2007). Thus, health care professionals and camp programmers need to promote and focus on both the caregiver and child specific benefits that camp provides, as this may ultimately influence caregivers’ attitudes towards sending their child to camp.

Third, the inability of children to maintain their friendships over time has clinical and practical implications. In order to sustain the long-term changes in some psycho-social parameters, camp programmers should consider delivering the camp philosophy to patients within hospital and year round in other settings (Moola et al., 2013). As well, reinforcing the camp atmosphere within the hospital and other settings could potentially reach those children who cannot attend camp due to their health complications or younger age. For instance, by having in hospital programming, children can experience the camp atmosphere, be exposed to new activities, feel a sense of community, and develop friendships among other children with CHD. This type of programming is one way that can make the camp experience more accessible and inclusive to all children with CHD. As mentioned previously, a main concern about the camp experience is its accessibility to all children with CHD, where only a small percentage (5%) of children with CHD actually have access to camp (J. Kirsh, personal communication, February 2011). An urgent priority is examining strategies to increase the diversity of families accessing camp.

As camp seems to address the psycho-social sequelae that caregivers and children with CHD experience, it is a great opportunity to intervene. Although there are issues with interrupting the camp environment, Nicholas and colleagues (2009) found that caregivers had minimal concerns regarding the intrusiveness of conducting research at camp. Intervention development within the camp context is minimal, but does show positive improvements in some psycho-social processes such as enhanced coping skills and self-competence (Nicholas et al., 2009; Pulgaron et al., 2010). Thus, by implementing additional nighttime programming at camp, sustainable changes in psycho-social well-being could occur. For instance, including an educational program that focuses on informal or structured camper discussions could help facilitate these long-term improvements. Specifically, providing children with an opportunity to share experiences, gain knowledge about illness management, and learn different ways to cope or gain social support,
could potentially contribute towards sustainable changes in children and caregivers’ psycho-social well-being.

This is one of the first studies to solely examine the caregivers’ perceptions of their children’s health behaviours and camp attendance within the CHD context. As well, this study attests to the dilemmas and struggles caregivers encountered when caring for children with CHD. Caregivers discussed the lack of support and guidance provided by health care professionals, and subsequently took charge of their child’s care. Participants confirm the need for a stronger caregiver and health professional relationship in order to provide better care for children with CHD (Coffey, 2006; Kepreotes et al., 2010). These findings have clinical importance as maintaining the relationships between the hospital and home is essential for effective childcare (Kepreotes et al., 2010).

4.5 Conclusion

In conclusion, the experience of CHD impacts the psycho-social well-being of both children and their caregivers. As previously discussed, caregivers have encountered various dilemmas while caring for their child, and thus, demonstrate poor psycho-social functioning. Therapeutic recreation camps have been proposed to be an effective environment that is beneficial for both children with CHD and their caregivers. Results confirm that caregivers experience such benefits as the ability to let go and have confidence in their children to be independent, obtain respite care where they were relieved from their medical and caregiving responsibilities, and spend more quality time with other family members and friends. Caregivers also demonstrated how Camp Oki equipped their children with independence and self-confidence, exposed them to new recreational activities, and provided them with a community where they felt a sense of inclusion, acceptance, and camaraderie. These findings strengthen the case for therapeutic recreation camps and underscore the importance of expanding camp access to more families affected by CHD.
References


Family Review, 29, 23-42.
Moola F. (2012). “This is the best fatal illness that you can have”: Contrasting and comparing the experiences of parenting youth with cystic fibrosis and congenital heart disease. Qualitative Health Research, 22, 212-225.
Moons, P., Barrea, C., Suys, B., Ovaert, C., Boshoff, D., Eyskens, B., ... Sluysmans, T. (2006b). Improved perceived health status persists three months after a special sports


Munhall, P. *Nursing Research: A qualitative perspective* (5th Ed.). Toronto: Jones and Bartlett Learning.


SickKids. www.sickkids.ca


Hello Camp Oki Parents and/or Guardians,

Thank you for registering your child for Camp Oki 2013, we are very excited to see everyone at the end of August.

There is an opportunity to participate in a study being conducted at the Heart Centre at the Hospital for Sick Children for Camp Oki. We will be conducting 45 to 60 minute interviews and we want to know how Camp Oki impacts your child. Specifically, we want to explore how camp impacts your child’s psychological and social well-being as well as your own. In addition, we want to investigate what types of relationships exist among the caregiver population.

If you are interested and would like more information concerning this study, please email lauren.white@sickkids.ca with your name, the age of your child attending Camp Oki 2013 and a contact phone number for future contact.

Sincerely,

Camp Oki Staff
Appendix B - Consent Form

Experiencing Caregivers’ Perspectives of the Psycho-social Impact of Camp for Children with Congenital Heart Disease (CHD)

Investigator(s):
Principal Investigator: Dr. Joel. A. Kirsh, (416) 813 6140
Co-Investigator: Lauren White; MSc Student, Supervised by Dr. Guy Faulkner, Faculty of Kinesiology and Physical Education, University of Toronto (416) 946 0262
Co-Investigator: Dr. Fiona J. Moola, (204) 998 1039
Co-Investigator: Dr. Guy E. J. Faulkner, (416) 946 7949

Purpose of the Research:
Children with congenital heart disease (CHD) often experience a compromised quality of life and psychological and social problems. There is a need for health experts to develop programs to address these problems in order to help improve quality of life among this population. There is limited evidence examining the impact camp has on children with CHD, from the perspective of the caregivers. We are particularly interested in learning from caregivers about what they see are the benefits of camp for their children. This information will help inform efforts to improve the camp experience, if necessary.

Description of the Research:
This study will entail the following steps:

1) After consent forms are signed, you will fill out a short questionnaire and participate in two interviews with a member of the research team in the Labatt Family Heart Centre at the Hospital for Sick Children. The first interview will occur before your child attends Camp Oki in August 2013. The second interview will take place Fall of 2013, approximately one month after your child has attended camp. The interviews will take approximately 45 to 60 minutes to complete and will be audio-taped. A separate audio-taping consent form is provided. The interview questions will ask about your expectations towards camp and your thoughts and feelings towards your child’s camp experiences.

2) The total duration of participating in this qualitative study is two hours.

3) In total, 30 caregivers of children with CHD who will attend Camp Oki in 2013 will participate in the study.
**Potential Harms:**

The overall level of risk for participating in this qualitative interview is minimal. You may experience some emotional distress when discussing your child’s congenital heart disease and how it impacts them and yourself. However, this emotional risk is no greater than the risk that you could experience during your daily life. If any emotional distress occurs during the interview, we will manage them by skipping interview questions, stopping the interview or referring to counseling if needed.

**Potential Discomforts or Inconvenience:**

The time required to travel to the hospital and participate in the qualitative interview may be experienced as a minor inconvenience for you. You will be reimbursed for your travel expenses.

**Potential Benefits to Individuals:**

You will not benefit directly from participating in the study. Researchers will provide you with a copy of the study findings, which will be mailed to you when the study is complete.

**To society:**

There are societal benefits, as well as benefits to other children with CHD, from participating in this qualitative study. If the findings from this study suggest that your children do experience improved psychological and social well-being after attending camp, researchers and health care providers may have the opportunity to make camp more accessible to children and youth with CHD.

**Confidentiality:**

We will respect your privacy. No information about who you are or who your child is will be given to anyone or be published without your permission, unless required by law. For example, the law could make us give information about you if a child has been abused, if you have an illness that could spread to others, if you or someone else talks about suicide (killing themselves), or if the court orders us to give them the study papers.

Sick Kids Clinical Research Monitor, or the regulator of the study, may see your child’s health record to check on the study. By signing this consent form, you agree to let these people look at your child’s records. We will put a copy of this research consent form in your patient health record and give you a copy as well.

The data produced from this study will be stored in a secure, locked location. Only members of the research team (and maybe those individuals described above) will have access to the data. This could include external research team members. Following completion of the research study the data will be kept as long as required then destroyed as required by Sick Kids policy. Published study results will not reveal your identity.
Reimbursement:

We will reimburse you for all your reasonable out of pocket expenses for being in this study e.g., meals, babysitters, parking and getting you to and from Sick Kids. If you stop taking part in the study, we will pay you for your expenses for taking part in the study up until that point. You will be reimbursed $50.00 for your travel expenses.

Participation:

It is your choice to take part in this study. You can stop at any time. The care your child gets at Sick Kids or participation at Camp Oki will not be affected in any way by whether you take part in this study.

New information that we get while we are doing this study may affect your decision to take part in this study. If this happens, we will tell you about this new information. And we will ask you again if you still want to be in the study.

During this study we may create new tests, new medicines, or other things that may be worth some money. Although we may make money from these findings, we cannot give you any of this money now or in the future because you took part in this study.

If you become ill or are harmed because of study participation, we will treat you for free. Your signing this consent form does not interfere with your legal rights in any way. The staff of the study, any people who gave money for the study, or the hospital are still responsible, legally and professionally, for what they do.

Sponsorship:

This research is sponsored and funded by the Labatt Family Heart Centre at the Hospital for Sick Children.

Conflict of Interest:

Dr. Kirsh and the other research team members have no conflict of interest to declare.

Consent:

By signing this form, I agree that:
1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right not to take part in the study and the right to stop at any time. My decision about taking part in the study will not affect my child’s health care at Sick Kids or participation at Camp Oki.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my child’s medical records will be kept private except as described to me.
6) I understand that no information about who I am or who my child is will be given to anyone or be published without first asking my permission. 
7) I have read and understood pages 1 to 4 of this consent form. I agree, or consent, to take part in this study.

Printed Name of Subject & Age

Subject’s signature & date

Printed Name of person who explained consent & date

Signature of Person who explained consent

Printed Witness’ name (if the subject/legal guardian does not read English)

Witness’ signature & date

If you have questions about your rights as a subject in a study or injuries during a study, please call the Research Ethics Manager at 416-813-5718.
Appendix C - Interview Guides

Interview Guide 1

Background and Context

1) Tell me a little bit about yourself, what do you do for a living?
   a. What are your hobbies and interests?

2) How and when did you find out about Camp Oki?
   a. If you knew before this year, why did your child not attend in previous years?
   b. How did you make the decision to come to Camp Oki? Did you discuss it with your child?

Diagnosis and Understanding

1) Looking back when your child was first diagnosed with a CHD, what were your initial reactions?
   a. When did you first learn about your child’s disease and who told you?
   b. What were your thoughts and feelings towards your child being diagnosed with a chronic disease?
   c. Were there any informational guides or services recommended to help you manage the disease or your reaction to hearing about the disease?

2) How did you or your family deal with your child’s diagnosis?
   a. Were there any services provided to help you deal with the diagnosis?
   b. Did you have any support systems… who has supported you throughout these hard times

3) Is your child’s life different compared to other children?
   a. Would you consider your child “normal”? If so, in what ways are they normal?
   b. Do you have any strategies (parenting techniques) that you use to normalize your child?

4) Did you see a difference in your child’s or your own social skills and psychological behaviours after they were diagnosed?
   a. For example, did they stop hanging out with other friends, not talk to their peers as often, did they mention they were bullied? Did their grades drop in school? Were they sad or angry about what has happened to them? No longer participating in certain activities?

Independence and Protectiveness
1) What are your thoughts and feelings about letting your child attend a camp that you cannot attend with them?
   a. How do you feel about your child being away for a week?

2) How do you think your child feels being away from you for a week?

3) Do you have any concerns about your child’s safety at camp?
   a. What makes Camp Oki safe for children with CHD?
   b. What are your thoughts and feelings about the medical shed and having doctors and nurses available to the children 24/7?

4) Do you worry or are you anxious about your child’s heart condition when you are not around them?
   a. Do you restrict them from certain physical activities?

5) In your opinion, do you notice your child is anxious towards their own condition?
   a. Do they limit themselves when it comes to certain activities?
   b. Do they know when to stop any activity because it is too hard for them?

6) Is your child able to manage their illness by themselves?
   a. For example, when to take certain medications?

**Social**

1) What types of friendships does your child have?
   a. Is your child sociable?
   b. Do they have a big or small group of friends?
   c. Is it easy for your child to make friends?
   d. Do their friends treat them differently because they have a CHD?

2) In your opinion, what do you think it will be like for your child to spend time with other children that have a CHD at Camp Oki?
   a. What are the good and bad things about your child interacting with other children who have CHD?

3) In your opinion, how will your child feel knowing that other children with CHD may be able to accomplish certain activities that they may be nervous or uncomfortable to try?

**Psychological and Social Health**

1) In your opinion, does having a child with CHD impact your psychological well-being?
For example, how does living and parenting a child who has a chronic illness impact your thoughts and feelings about yourself?

2) What are the types of social relationships or social support networks that you have?
   a. In your opinion, does having a child with CHD impact your social networks?
   b. Do you socially interact with other parents from the Labatt Heart Centre or other parents that have a child with CHD?

3) In your opinion, how do you think your child feels about their self?
   a. Does their heart condition impact them psychologically?
   b. What are their thoughts and feelings about themselves?

Camp Expectations

1) What are your expectations of camp?

2) In your opinion, what will attending camps allow your child to do? What will it allow you to do?

3) Do you feel that having your child participate in Camp Oki will have any influence on your interactions with other parents whose children attend Camp Oki?

4) In your opinion, do you think your child will benefit from attending camp? How will your child benefit?
   a. Psychological benefits?
   b. Social benefits?
   c. Physical benefits?
   d. Anything else?

5) Do you think you will be benefit from your child attending camp? If so, how?
   a. Psychological benefits?
   b. Social benefits?
   c. Physical benefits?
   d. Anything else?

Is there anything else you think is important that we haven’t discussed about your child and Camp Oki?
Interview Guide 2

General

1) What did your child tell you about their camp experience?
   a. In your opinion, what were the good things about your child attending Camp Oki?
   b. In your opinion, what were the bad things about your child attending Camp Oki?
   c. In your opinion, what was your child’s favourite and least favourite part about camp?

2) In your opinion, what was it like for your child to share a cabin with other campers and eat meals with all campers and staff?
   a. What are the good and bad things about this?

3) Did your child learn any lessons at camp?
   a. Any new skill development for certain activities? Any life lessons?

4) Were there any instances where your child wasn’t able to engage in an activity or not complete something while other children could?

5) What did you do while your child attended camp?

Independence

1) Are you still worried about your child’s heart condition after they attended camp?

2) Have you been able to ‘let your child go’?
   a. Realize that they can do tasks on their own?
   b. It’s ok for them to be alone and away from the family – they will be fine.

3) Are they still worried about their own health?

4) After attending Camp Oki did you notice a change in what activities your child and yourself engaged in? (less restrictive of activities?)
   a. At home?
   b. At school?
   c. Within the community?
   d. Are they able to complete tasks on their own?
**Social**

1) Did your child make any friends at Camp Oki?
   a. Did they explain their friendships to you?
   b. How does your child stay connected with their friends?
   c. Older vs. younger friends?

2) Do you see a change in the way others interact with your child?
   a. Friends treating them the same or differently?
   b. Branching away from family members/siblings?

3) What was it like for your child to spend time with other children with a heart condition?
   a. What kind of conversation did they have?
   b. What did they discuss at camp?

4) As a result of camp, has your social network among parents with CHD changed?
   a. Have you met any other parents from Camp Oki?
      i. If so, how do you stay connected with these parents?
      ii. What kinds of conversations do you have?
   b. Did you have any social interactions at camp, with other families of children with CHD?
   c. Other individuals in general while your child attended camp? – spend more time with family or friends?

**Psychological and Social Health**

1) How has camp impacted your child’s psycho-social well-being?
   a. Has attending camp changed the way your child feels about themselves as a person?
   b. Add in any issues from first interview (lack of self confidence, independence etc.)

2) As a result of camp, has your psychological health increased, decreased or stayed the same?
   a. Have your thoughts and feeling about you as a person changed?
   b. Less restricting, overprotective etc?

**Overall Benefits**

1) Has your child benefited from attending Camp Oki? (talk about how they thought they could benefit)
   a. Psychological benefits?
b. Social benefits?
c. Physical benefits?
d. Anything else?

2) Have you benefited from your child attending camp? (talk about how they thought they could benefit)
   a. Psychological benefits?
   b. Social benefits?
   c. Physical benefits?
   d. Anything else?

Future recommendations

1) Do you have any suggestions on how to make camp more accessible to children with CHD?

2) What are your thoughts on bringing some of the camp activities and life lessons to the hospital setting?

3) Are there anyways in which Camp Oki can be improved?

4) What advice would you give to other caregivers who are in similar situations as yourself?
   a. Would you recommend Camp Oki to other caregivers?

Is there anything else you think is important that we haven’t discussed about your child and Camp Oki?
Appendix D - Demographic Questionnaire

Please check or fill in the following for each question.

Are you male or female?
   Male
   Female

How old are you? ____

What is the highest level of education that you have completed?
   High school
   College
   University
   Post graduate education
   I prefer not to answer

What is the ethnic group you identify with?
   Aboriginal
   African American
   Caucasian
   Caribbean
   East Asian
   Latin American
   Middle Eastern
   South Asian
   Other (please specify) _______________
   I prefer not to answer

What is your marital status?
   Single
   Married or Common Law
   Divorced or Separated
   Widowed

How many children do you have in your household? ____

How many children within your household are diagnosed with a congenital heart disease? ____

During a typical **7-day period** (a week), how many times on the average do you do the following kinds of exercise for **more than 15 minutes** during your free time?

   a) **Strenuous exercise (heart beats rapidly)**
      (e.g., running, jogging, hockey, football, soccer, squash, basketball, cross country skiing, judo, roller skating, vigorous swimming and vigorous long distance bicycling)
Times per week _____

b) **Moderate exercise (not exhausting)**
   (e.g., fast walking, baseball, tennis, easy bicycling, volleyball, badminton, easy swimming, alpine skiing and folk dancing)

   Times per week _____

c) **Mild exercise (minimal effort)**
   (e.g., yoga, archery, fishing from the river bank, bowling, horseshoes, golf, snowmobiling, easy walking)

   Times per week _____

---

For the child who has a congenital heart disease and will be attending Camp Oki 2013, please complete the following questions.

Is your child male or female?
   Male
   Female

How old is your child? _____

At what age was your child diagnosed with a congenital heart disease? _____

What form of congenital heart disease was your child diagnosed with?

_________________________________________________________

At what age(s) did your child undergo surgery? _____

Please rate your child’s current health status
   Excellent
   Good
   Fair
   Poor