Investigating Supportive Care Needs of Parents of Children with Cancer:
Is a Parent Support Group Intervention a Feasible Solution?

by

Kristen Maunder

A thesis submitted in conformity with the requirements
for the degree of Master of Science
Institute of Medical Sciences
University of Toronto

© Copyright by Kristen Maunder 2012
Investigating Supportive Care Needs of Parents of Children with Cancer: Is a Support Group Intervention a Feasible Solution?

Kristen Maunder

Master of Science

Institute of Medical Sciences
University of Toronto

2012

Abstract

PURPOSE: (1) Investigate supportive care needs and preferences of parents of children with cancer (2) Assess the feasibility and preliminary outcomes of a Parent Support Group Intervention (PSGI). METHODS: One-hundred and eight parents completed the Parent Support Survey (PSS). Data were utilized in the creation of a PSGI. The PSGI consisted of eight 1.5-hour sessions encompassing guided group discussion. As part of feasibility, acceptability, recruitment/retention and preliminary outcomes were assessed. Parents completed outcome measures assessing knowledge of disease/treatment management, community/hospital/family resources, perception of social support and feelings of distress/anxiety. RESULTS: From the PSS, 86/108 (80%) of parents expressed interest in a PSGI. Fourteen parents attended the PSGI only once and 14 parents attended the PSGI more than once. Outcome measure results depict favourable changes after group attendance. Recruitment and retention data highlight challenges. CONCLUSIONS: Information gained from this study will be used to improve planning and delivery of future PSGI’s.

Word Count: 150
Acknowledgments

First, I would like to thank all parents that took part in this study. Without your time, strength and participation this research project would not have been possible.

I would also like to express my most sincere gratitude to my thesis supervisor, Dr. Maru Barrera. Your encouragement, patience and support have been greatly appreciated. Being able to work alongside you has not only been enjoyable but also inspirational. I truly admire your dedication to your patients, students and colleagues and feel very fortunate to have had the opportunity to learn from you.

I would also like to extend my appreciation to Ontario Parent’s Advocating for Children with Cancer. In particular, parent representatives Susan Kuczynski and James Thomson for having the courage to share their stories and offer support to other parents going through a similar experience. In addition, I would like to thank Deborah Berlin Romalis, Karen Drybrough, Sonia Lucchetta and Sandra Doyle. Your involvement with both the Parent Support Survey and Parent Support Group Intervention helped to make this project a success. Also, I would like to thank Judy Van Clieaf for aiding in the timely implementation of this study within the Hematology/Oncology department.

I appreciate the feedback and continual support I have received from my committee members Dr. Bonnie Stevens and Dr. Katherine Boydell. You have both taught me a great deal about research methodology and it has been an absolute pleasure working with you.

Finally, I would like to thank my friends and family. To my closest friends, Becky McEvilly and Ashley Pacht, I appreciate your encouragement and belief in me. To my parents Robin Maunder and David Maunder thank you for encouraging me to always do my best, think positively and for being such powerful role models.
Table of Contents

CHAPTER 1: Introduction
1.1 Introduction 1
1.2 Literature Review 2-28
   1.2.1 Childhood Cancer 2-5
   1.2.2 Parental Distress When Faced With a Child Having Cancer 5-14
       1.2.2.1 Uncertainty 5-7
       1.2.2.2 Depressive Symptoms 7-9
       1.2.2.3 Post-Traumatic Stress Symptoms (PTSS)/Post-Traumatic Stress Disorder (PTSD) 9-12
   1.2.4 Gender Differences 12-14
   1.2.3 The Importance of Family Relationships, Coping Strategies and Social Support for Parents of Children Having Cancer 14-22
       1.2.3.1 Family Relationships 14-17
       1.2.3.2 Coping Strategies 17-19
       1.2.3.3 Social Support 19-22
   1.2.4 Support Groups for Parents of Children Having Cancer 22-26
   1.2.5 The Pediatric Psychosocial Preventative Health Model (PPPHM) 26-28
   1.2.6 Goals of the Current Study 28

CHAPTER 2: Objectives and Hypotheses
2.1 Phase I: The Parent Support Survey 29
   2.1.1 Specific Objectives of Phase I 29
   2.1.2 Hypotheses 29
2.2 Phase II: The Parent Support Group Intervention 30-31
   2.2.1 Specific Objectives of Phase II 30-31
   2.2.2 Hypotheses 31

CHAPTER 3: Methods
3.1 Phase I: The Parent Support Survey 32-36
   3.1.1 Participants: Inclusion Criteria 32
   3.1.2 Instrument and its Development 33
   3.1.3 Procedures 34
   3.1.4 Data Management and Statistical Analysis 35-36
   3.1.5 Confidentiality 36
3.2 Phase II: The Parent Support Group Intervention 36-47
   3.2.1 Participants: Inclusion Criteria 36
   3.2.2 Recruitment 36-38
   3.2.3 Description of Parent Support Group Intervention 38-39
   3.2.4 Roles of Parent Support Group Intervention Participants 39-41
   3.2.5 Assessment 41-43
   3.2.6 Information Form 43-44
   3.2.7 Visual Analogue Scale (VAS) Questions 44
   3.2.8 Acceptability Questionnaire 45
   3.2.9 Statistical Analysis 45
   3.2.10 Dissemination of Results 45-46
   3.2.11 Confidentiality 46
   3.2.12 Budget 46
CHAPTER 4: Results
4.1 Phase I: The Parent Support Survey
   4.1.1 Demographic Characteristics of Sample
   4.1.2 Overall Support Needs and Preferences
   4.1.3 Gender Differences
   4.1.4 Other Demographic and Clinical Variables
4.2 Phase II: The Parent Support Group Intervention
   4.2.1 Demographic Characteristics of Sample
   4.2.2 Acceptability
   4.2.3 Recruitment and Retention
   4.2.4 Preliminary Outcomes
      4.2.4a Assessment of Outcome Measures
      4.2.4b VAS Results
CHAPTER 5: Discussion
   5.1 Phase I: The Parent Support Survey
   5.2 Phase II: The Parent Support Group Intervention
CHAPTER 6: Conclusion
CHAPTER 7: Future Directions
References
Appendices
   Appendix 1: Parent Support Survey
   Appendix 2: Consent Form
   Appendix 3: Parent Support Group Information Form: Demographics
   Appendix 4: Parent Support Group Information Form: Resources Information
   Appendix 5: Visual Analogue Scale (VAS) Questions (Pre/Post)
   Appendix 6: Acceptability Questionnaire
Contributions

Dr. Maru Barrera: MSc. supervisor. Health care professional who acted as a co-facilitator for the Parent Support Group Intervention. As well, aided in the creation of the Parent Support Survey and outcome measures used in the Parent Support Group Intervention.

Ontario Parents Advocating for Children with Cancer (OPACC): Funding support for the Parent Support Group Intervention weekly meetings.

Susan Kuczynski: OPACC parent representative who acted as a co-facilitator for the Parent Support Group Intervention.

James Thomson: OPACC parent representative who acted as a co-facilitator for the Parent Support Group Intervention.

Deborah Berlin Romalis: Health care professional who acted as a co-facilitator for the Parent Support Group Intervention.

Karen Drybrough: Health care professional who acted as a co-facilitator for the Parent Support Group Intervention.

Sonia Lucchetta: Health care professional who acted as a co-facilitator for the Parent Support Group Intervention.

Sandra Doyle: Health care professional who aided in the recruitment of parents for the Parent Support Survey.

Judy Van Clieaf: Director of Child Health Services with the Haematology/Oncology program at SickKids. Aided in the timely implementation of the Parent Support Survey and Parent Support Group Intervention within the department.

Dr. Bonnie Stevens: Senior Scientist Child Health Evaluative Sciences. Acted as a Program Advisory Committee member.

Dr. Kathryn Boydell: Senior Scientist Child Health Evaluative Sciences. Acted as a Program Advisory Committee member.

Eshetu Atenafu: Statistician who aided with statistical analysis of the Parent Support Survey results.

Social Sciences and Humanities Research Council (SSHRC): helped to fund the present study.

National Institute of Health: helped to fund the present study.

Pediatric Oncology Group of Ontario (POGO): helped to fund the present study.
List of Tables

Table 1  Phase I: Demographic Characteristics of the Parents  48
Table 2  Phase I: Demographic and Medical Characteristics of the Participants’ Children Having Cancer  49
Table 3  Phase II: Demographic Characteristics of the Parents  52
Table 4  Phase II: Demographic and Medical Characteristics of the Participants’ Children who were Diagnosed with Cancer  53
Table 5  Attendance Record  56
Table 6  How Parents Found out About the Parent Support Group Intervention  58
Table 7  Paired Sample T-Test Comparison of Pre- and Post- VAS Scores for Each Parents First Time Attending the Parent Support Group Intervention  64
Table 8  Pre- and Post- VAS Score Differences for Parents Attending the Parent Support Group Intervention Only Once vs. Those Attending More Than Once  66
Table 9  Comparison of Pre- and Post- VAS Scores for Each Parent’s First Time Attending the Parent Support Group Intervention  67-68
List of Figures

Figure 1: Flow Diagram of Phase I Progression 35

Figure 2: The Number of Times Each Participant Attended the Parent Support Group Intervention 57

Figure 3: Parental Attendance 59

Figure 4: Gender and Frequency of Attendance 60

Figure 5: Comparison of Pre- and Post- VAS Scores for Each Parent’s First Time Attending the Parent Support Group Intervention 63
List of Appendices

Appendix 1: Parent Support Survey 102-106
Appendix 2: Consent Form 107-109
Appendix 3: Parent Support Group Information Form: Demographics 110-111
Appendix 4: Parent Support Group Information Form: Resource Information 112
Appendix 5: Visual Analogue Scale (VAS) Questions (Pre/Post) 113-116
Appendix 6: Acceptability Questionnaire 117
CHAPTER 1

Introduction

1.1 Introduction

Due to advances in cancer treatment, children can now envision a more promising prognosis. Although rates of death amongst children with cancer have decreased substantially, children are likely to experience late-effects as a result of aggressive treatment. Late-effects not only affect the child-patient but also the family as a whole. There has been growing interest in the provision of supportive services to families during their child’s cancer trajectory. However, definitive evidence has not yet been established to confirm how to best meet the unique supportive care needs of families, in particular parents of children having cancer. Given the importance of this area, the current study involved ascertaining parental preferences in terms of supportive care needs of parents. Furthermore, the current study sought to assess the feasibility and preliminary outcomes of a Parent Support Group Intervention.

1.2 Literature Review

A literature search was conducted in order to find relevant articles in the field pertaining to childhood cancer and its impact on parental psychosocial adjustment, as well as to identify areas for further research. Studies that described support or psychosocial intervention programs for families, in particular for parents, were searched in order to provide an academic basis to the current study. Firstly, key themes were formulated through discussion with Dr. Maru Barrera who has had experience working with our population of interest, parents of children having cancer. In order to perform an adequate literature search, key words were extracted from the themes postulated. For example, key search words included childhood cancer, parental distress and
Various approaches were utilized in order to conduct the literature search. Primarily, a retrospective approach was utilized whereby the most recent materials focusing on the topic of interest were reviewed first. As well, citations from articles of value were used to follow leads to other useful articles and books. Inclusion criteria consisted of qualitative and quantitative studies that described the effect of childhood cancer on the family at any stage of the cancer trajectory as well as studies that described and evaluated supportive programs for families, in particular parents of children having cancer. Given the interest in using quantitative instruments for pursuing my research interest, the focus of the literature search was primarily on studies that used quantifiable methods. The search engines PubMed and MEDLINE were used to search for articles and the University of Toronto library catalogue was also used to search for books highlighting the topic of interest. Articles and books found were read and reviewed critically in order to ensure that each study followed sound research methodology. For example, studies that had small sample sizes as well as studies describing programs that did not conduct a systematic evaluation were excluded.

1.2.1 Childhood Cancer

Between 2003 and 2007, there were 6,550 children and youth aged 0-19 years (on average 1,310 a year) diagnosed with cancer in Canada and between 2002 and 2006, 962 died from their disease (Canadian Cancer Society, 2011). There has been little change in age-standardized incidence rate for all childhood and youth cancers since 1985 (Canadian Cancer Society, 2011). Highest incidence rates generally occur during the first five years of life and then show decreasing trends with age. Childhood cancer shows no racial, ethnic or socio-economic boundaries. However, cancer is slightly more common in boys than in girls and the type of cancer diagnosed can vary with age (Canadian Cancer Society, 2008).
A distinctive feature seen between adult versus childhood cancers is that tumors present in children tend to grow more rapidly, aggressively, invasively and metastasize more frequently (Pizzo & Poplack, 2005). The *International Classification of Childhood Cancer* was developed to highlight important differences between adult and child cancers and has organized childhood cancers into 12 distinct diagnostic groups: Leukemias, Lymphomas, CNS, Neuroblastoma & PNS Tumors, Retinoblastoma, Renal Tumors, Hepatic Tumors, Malignant Bone Tumors, Soft Tissue Sarcomas, Germ Cell Tumors, Malignant Epithelial Neoplasms and Unspecified Malignant Neoplasms (Ellison, De, Mery, & Grundy, 2009). Children tend to present with a higher proportion of blood and lymphatic cancer, most commonly leukemia and cancers of the nervous system compared to adults (Canadian Cancer Society, 2008).

Since 1985, incidence rates of childhood cancers have remained stable; however rates of death amongst children with cancer have decreased substantially (Ellison et al., 2009). Fortunately, because of improvements in cancer treatments, children diagnosed with cancer can now envision a more promising prognosis. Overall, five-year survival rates have significantly improved for childhood cancers from 71% in the late 1980’s, to 82% in the early 2000’s (Villeneuve et al., 1998). Cancer survival rates depend on the histology, site of origin and behavior of the tumor expressed by the patient. Five-year survival rates have been shown to be highest amongst children diagnosed with retinoblastoma (99%) and lowest amongst those diagnosed with malignant bone tumors (66%) (Ellison, Pogany and Mery, 2007). Brain tumors may show a grimmer prognosis. Brain tumors such as atypical teratoid/rhaboid tumors and some brain stem gliomas have survival rates of less then 20% (Pediatric Brain Tumor Foundation, 2012). As well, brain tumor survivors often suffer from lifelong side effects as a result of aggressive treatment including surgery, chemotherapy and radiation. Brain tumour survivors may present with more physical, learning and emotional challenges compared to other childhood
cancer survivors, which can place limits on their future quality of life (Pediatric Brain Tumour Foundation, 2012).

As the likelihood of childhood cancer survival is increasing, the possibility of late effects from cancer and its treatment has become a serious concern (Ellison, De, Mery & Grundy, 2009). The use of cancer therapy at an early age can have significant adverse effects on the health of the child later in life. It has been demonstrated that approximately two-thirds of childhood cancer survivors will experience at least one late effect and about one third will experience a late effect that is severe or life threatening (Landier & Bhatia, 2008). As a result of cancer and its treatment, children may experience long term sequelae such as secondary neoplasm, cardiac dysfunction, pulmonary dysfunction, impaired neuro-cognitive function, impaired intellectual function, various endocrine problems, gonadal dysfunction, decreased fertility and reduced growth (Maeda, 2008). These long-term sequelae can have a negative impact on the survivor’s overall quality of life.

Researchers have attempted to estimate the problem of morbidity by quantifying the chronic health conditions inflicted on the population of childhood cancer survivors (Landier & Bhatia, 2008). Chronic medical problems have been defined as health problems that cause physical, psychological, or social difficulty and therefore justify ongoing medical intervention (Landier & Bhatia, 2008). In a recent study, Oeffinger et al. (2006) confirmed that out of 10,397 adult survivors of childhood cancer, those children identified to be at highest risk were children treated for Hodgkin’s disease or brain tumors, as well as children who had received chest radiation and anthracyclines, a chemotherapeutic drug. Overall, survivors are at an eightfold higher risk of presenting with severe chronic health conditions, when compared with age and gender matched siblings (Oeffinger et al., 2006).
Studies have shown that even though the population of childhood cancer survivors is growing, the burden of late-effects faced by this population is considerable. As a consequence of cancer and treatment, the burden or late-effects not only affects the child patient but also the family as a whole. The stress of having a child with chronic health problems can cause psychological and physical strain on parents and siblings.

In order to reduce child morbidity and strain on the family system, a preventative approach may be applied from the time of diagnosis, throughout treatment and into remission. This approach would involve closely monitoring childhood cancer survivors and anticipating future chronic health conditions before they are encountered. As well, supportive resources such as individual support and/or support groups for parents may be created, implemented, and evaluated throughout the cancer trajectory. Supportive resources may help parents cope with enduring stresses, improve their adjustment to their child’s cancer and support the family as a whole (Hoekstra-Weebers, Heuvel, Jaspers, Kamps, & Klip, 1998)

1.2.2 Parental Distress when faced with a Child having Cancer

1.2.2.1 Uncertainty

Uncertainty is the single greatest source of psychosocial stress for persons affected by life-threatening illness and their loved ones (Koocher, 1985). Parents of children with cancer present with varying levels of uncertainty throughout their child’s diagnostic and treatment trajectory. Parental uncertainty surrounding childhood cancer relates to both acute and ongoing pervasive fear of possible disease related consequences (Stewart & Mishel, 2000). These consequences may include physical and psychosocial late-effects, relapse or death.

When a family is confronted with the news of their child’s cancer diagnosis and treatment plan, this can precipitate the development of a family crisis (Barrera et al., 2004).
Families encounter long periods of intensive treatment, distressing side effects and the uncertainty of child survival (Hoekstra-Weebers, Heuvel, Jaspers, Kamps, & Klip, 1998).

In a study completed by Boman, Lindhal and Bjork (2003), investigators used a cross-sectional design to evaluate levels of parental uncertainty. Mothers and fathers of children with cancer (n=264), whose children had been diagnosed 4 weeks to 14 years prior to the commencement of the study, completed a questionnaire. The questionnaire investigated parental uncertainty concerning the future and their child’s long-term physical and psychological health and development. Approximately two-thirds of all parents responded at the higher end of the severity span with respect to levels of uncertainty. Time elapsed since diagnosis did not significantly predict the severity of uncertainty, suggesting that most parents reported elevated levels of uncertainty regardless of how long they had been dealing with their child’s disease and treatment.

In another study, Stam, Grootenhuis, Brons, Caron & Last, (2006) investigated health-related quality of life (HRQL) of pediatric cancer patients and emotional reactions of their parents, shortly after the end of successful treatment. A few months after the end of successful cancer treatment, both patients and parents appeared to experience a lower quality of life compared to normative values. Specifically, parents suffered more from feelings of loneliness, helplessness and uncertainty. The investigators interpreted these results as being related to the fact that parents were no longer protected by medical treatment and support from the hospital (Stam et al., 2006).

In the short term, high levels of parental uncertainty may interfere with making health decisions or remembering important appointments concerning their child with cancer (Vrijmoet-Wiersma, Van Klink, Kolk, & Koopman, 2008). In the long term, chronic uncertainty may permeate the illness trajectory and become debilitating (Cohen & Martinson, 1988). Alarmingl
parents who suffer chronic uncertainty may go on to develop symptoms similar to those seen in persons with posttraumatic stress disorder (PTSD) (Mishel, 1990).

1.2.2.2 Depressive Symptoms

Due to the life-threatening nature of childhood cancer, the stress of having a child with cancer is associated with an increased risk for the development of depressive symptoms in parents. Depressive symptoms may include but are not limited to, feelings of hopelessness, loss of interest in daily activities, appetite or weight changes, sleep changes, irritability, and loss of energy or concentration problems (Helpguide, 2011). Depressive symptoms can remain high a year or more following diagnosis (Brown et al., 1992). When parents are depressed this may impede their ability to remain responsive to their children (Jobe-Shields et al., 2009). Additionally, children of depressed parents have been shown to be at a higher risk for a range of social and psychological difficulties (Jobe-Shields et al., 2009).

In a study by Manne et al., (1996), fifty-five parents of children with cancer were assessed for depressive symptomatology at three time points: shortly after diagnosis (T1), 3 months post diagnosis (T2) and 6 months post diagnosis (T3). The Beck Depression Inventory (BDI), a commonly used 21-item scale instrument that measures the severity of depressive symptomatology, was used to assess depressive symptoms amongst parents. At T1, 65% of parents showed symptoms of depression, T2 58%, and finally at T3 40% of parents showed depressive symptomatology.

Hierarchical regression analysis was conducted in order to examine the contribution of variables to parents’ depressive symptoms. The equation included parents’ average BDI score across T1-T3 and four factors, including: (1) prior parental depressive symptoms, (2) child functional status, (3) child behavior problems and (4) spousal assistance. Prior depressive symptoms accounted for the majority of the explained variance (68%) and general child
behavioral problems accounted for 4% of the variance (p < 0.05). The other predictors did not account for a significant amount of the variance. Parents who were moderately or severely depressed shortly after a child’s diagnoses were likely to be symptomatic at the 6-month follow up (Manne et al., 1996).

Barrera et al., (2004) examined early psychological adjustment of mothers of children with cancer (MCC) and mothers of children with acute illnesses (MCA). Sixty-nine MCC and twenty-two MCA completed standardized measures of depression, anxiety, global mental health, concurrent stress and strains, social support, coping strategies and child behavior. MCC reported greater depressive symptomatology and emotion-focused coping than did MCA. It can be a challenge for mothers of children having cancer to manage their own emotional response to their child’s illness, which may contribute to depressive symptomatology.

Barrera, Atenafu, Doyle, Berlin-Romalis & Hancock, (2011) carried out a longitudinal study investigating differences in mothers’ and fathers’ psychological distress after pediatric stem cell transplant (SCT). Parents completed standardized measures of depression and anxiety symptoms at pre-SCT (n=111), 1 year (n=85) and 2 years post SCT (n=81). Depression and anxiety scores significantly decreased by 2 years post SCT. Interestingly, at all time intervals, mothers reported significantly higher depressive symptoms when compared to fathers. In particular, mothers’ scores at pre-SCT were comparable to those of mothers of children newly diagnosed with cancer (Barrera et al., 2011). However, only a small percentage of mothers and no fathers presented with clinical levels of depression at all time points.

The study conducted by Barrera et al., (2011) also examined the association between parental psychological distress and parental age, child diagnosis, treatment variables (radiation history) and child’s age, health status and behavior. Pre-SCT depression and anxiety scores, mother’s age (younger), child’s behavior problems, radiation history and diagnosis of
neuroblastoma predicted maternal distress 2 years post-SCT (Barrera et al., 2011). In contrast to mothers, fathers’ pre-SCT depression and anxiety scores, father’s age (older) and child’s diagnosis predicted father’s distress (Barrera et al., 2011).

Both Manne et al., (1996) and Barrera et al.’s (2011) results demonstrate that early depressive symptoms displayed at the beginning of the treatment trajectory as well as child behavioral problems could put parents at risk for the development of future depressive symptoms. Manne et al., (1996) also highlighted that because it is generally impossible to assess parents prior to their child’s cancer diagnosis, we cannot rule out the possibility that the depressive symptoms seen in parents represent a preexisting state. Regardless, when parents display depressive symptoms, this can negatively impact the care they are able to provide to both their child and family. It should be stated that much of this research was conducted with mothers who were typically the primary caregiver of the child. Assessing parents at an early stage for depressive symptomatology, may allow for the timely provision of clinical support and interventions when required.

1.2.2.3 Post-Traumatic Stress Symptoms (PTSS) & Post-Traumatic Stress Disorder (PTSD)

During the first months after a diagnosis of a life-threatening illness, such as pediatric cancer, family members may experience their first episode of acute stress over the extended period of treatment and chronic illness (Barrera et al., 2004). Research supports the notion that the period following the child’s diagnosis and the initiation of treatment may be particularly stressful and traumatic for parents (Sawyer, Antoniou, Toogood, Rice & Baghurst, 2000). Empirical studies have documented elevated levels of psychological distress, most often in the form of anxiety and depressive symptoms, amongst parents adjusting to their child having cancer (Barrera et al., 2004). Psychosomatic complaints and detrimental health effects such as sleep disturbances, poor nutritional intake, and inadequate time to attend to one’s own needs and well-
being are commonly reported amongst parents as their child is undergoing treatment (Sawyer et al., 2000).

Posttraumatic stress disorder (PTSD) is an emotional illness that is classified as an anxiety disorder. The DSM-IV-TR (American Psychiatric Association, 1994, 463-468), defines PTSD as a serious mental condition following “an individual experiencing, witnessing, or being confronted with a traumatic event/s that involved actual death or threatened death or serious injury; or a threat to the physical integrity of himself or herself or others.”

Finding out that one’s child has a life-threatening disease is a qualifying event for Post-Traumatic Stress Symptoms (PTSS) or PTSD (American Psychiatric Association, 1994, 463-468). PTSS may include the presence of re-experiencing (e.g., recurrent or distressing memories), avoidance/numbing (e.g., avoiding reminders, inability to recall moment of diagnosis or specifics of treatment), and persistent arousal (e.g., concentration difficulties, irritability or insomnia) (Bruce, 2006).

Acute Stress Disorder (ASD) is characterized by the development of severe PTSS within one month after exposure to an extremely traumatic stressor (e.g., the diagnosis of a child with cancer) (PsychCentral, 2011). Individuals exhibiting signs of ASD generally find it difficult to engage in daily activities and often lose interest in previously pleasurable activities. If the PTSS persist over a month, the person is likely to meet the criteria for diagnosis of PTSD.

Caregivers of children with cancer have been labeled as “hidden sufferers” because they must face their child’s emotional reaction as well as their own (Chesler & Barbarin, 1984). Rates of PTSS, ASD and PTSD tend to be higher in parents of cancer survivors than in the survivors themselves (Best, Streisand, Catania, & Kazak, 2001; McGrath, 2001). As well, parental distress can have a reciprocal influence on spousal, child-patient, and sibling adaptation and functioning within the dynamic family system (Dolgin et al. 2007).
A meta-analysis (Bruce, 2006) examined posttraumatic stress in childhood cancer survivors and their parents. Bruce (2006) concluded that a number of factors (e.g. female gender, greater physical late effects, prior stressful life events, severity of cancer and treatment, family conflict, poor social support, and emotional focused coping) could contribute to the development of PTSD and PTSS in parents of childhood cancer survivors.

Poder, Ljungman and Von Essen (2008), investigated ASD and PTSD amongst parents of children on cancer treatment one week (T1), two months (T2), and four months (T3) after the child’s cancer diagnosis. PTSS showed a linear, descending pattern over time with mothers reporting higher levels then fathers at all assessments periods. 33% of parents showed signs ASD at T1. At T2, 28% of parents were PTSD positive and 22% at T3. Even though PTSS showed a descending pattern with time, the decline was minor and PTSD still had a substantial effect on a subset of parents.

In a cross-sectional study conducted by Barakat et al. (1997), researchers compared PTSS in 309 8-20 year old survivors of childhood cancer (50% male, 50% female) and their parents (309 mothers and 213 fathers) with 219 healthy children (44% male, 56% female) and their parents (211 mothers and 114 fathers) who responded to child-related stressors. Study participants were recruited from two large teaching hospitals in urban areas on the East and West coasts of the United States. Survivors of childhood cancer had completed treatment a mean of 5.86 years prior to participation in the study. Mothers and fathers of childhood cancer survivors showed significantly higher levels of PTSS than comparison parents despite the fact that their children had now entered remission. These results are similar to those found in other studies showing that PTSD and PTSS have been seen in parents for five or more years after treatment, making these parents at risk for future mental health problems (Alderfer, Cnaan Annunziato & Kazak, 2005; Boman, Lindahl & Bjork, 2003; Wijnberg-Williams, Kamps, Klip, Hoekstra-
In the study conducted by Barakat et al. (1997), survivor mother and child and survivor father and child PTSS were associated. Specifically, when mothers or fathers showed PTSS it was likely that their children would also show signs of PTSS. Therefore, PTSS, ASD and PTSD can impact the entire family and have a significant influence on the child-parent relationship, spousal relationship, and the child’s well being. Assessing parents for PTSS early on (e.g. at the time of their child’s diagnosis), as well as offering appropriate resources when needed, may help to decrease the likelihood of parents developing ASD and PTSD.

1.2.2.4 Gender Differences

Research published over the past few decades highlight the contradictory findings concerning gender differences and levels of parental distress. Most research has focused on mothers. As a result, conclusive evidence concerning gender differences has not yet been well established.

Mothers play a pivotal role within the family system. Mothers are more likely to act as the primary caregiver when their child is diagnosed with cancer (Yeh, 2002). Acting as the primary caregiver, mothers generally stay with their child during hospitalizations, have to learn treatment protocols, take care of medications as well as continue to perform previous household and family responsibilities (Yeh, 2002). The multiple obligations that mothers have to deal with on a daily basis may contribute to elevated levels of maternal distress seen amongst this population.

Because it is common for mothers to have to put their jobs on hold to act as the primary caregiver, fathers may have to increase their hours of work to support their families (Yeh, 2002). Fathers may also feel uninvolved and uncertain about their child’s care and prognosis because they are not able to attend clinic appointments or be present as much as mothers at the hospital.
(Pei-Fan, Fung-Chi, Beau Hwang & Yu-Mei Chao, 2002). These factors may contribute to increased levels of paternal distress.

Mothers and fathers respond differently to stressful events, including those pertaining to caring for a child with a chronic illness (Conger, Lorenz, Elder, Simons, & Ge, 1993). These differences are likely a result of societal expectations, care giving roles and biological mechanisms (Clarke et al., 2009).

According to a review by Clarke et al. (2009), mothers of children having cancer report more suffering than fathers from symptoms of depression, anxiety, and decreased general well being. These studies focused mainly on parents during the initial stages of their child’s illness.

Dolgin et al. (2007) investigated the trajectories of adjustment in mothers of children with newly diagnosed cancer. Two hundred and twelve mothers at seven sites were assessed at three time points: following their child’s diagnosis (T1), three months later (T2), and six months later (T3). Questionnaires were used to measure mood disturbances, depressive symptoms, and symptoms of posttraumatic stress. Mothers were found to display moderate elevations in PTSS during the period following diagnosis but distress declined steadily at three and six months follow up. Depressive symptoms and mood disturbances also showed improvements with time. These results are consistent with research carried out by both Manne et al., (1996) and Barrera et al., (2011) showing a decline in symptoms of parental depression and anxiety as time passed since their child’s diagnosis.

Ribi et al. (2007) compared the prevalence of PTSS and PTSD in 69 fathers of children with chronic diseases (cancer, type 1 diabetes, epilepsy) to those seen in 70 fathers of children with acute unintentional injuries. Questionnaires were disseminated to both groups at 4-6 weeks (T1) and 6 months (T2) after diagnosis or injury. PTSD rates were higher amongst fathers having children with chronic diseases (26% at T1 and 21% at T2) compared to those with
unintentional injuries (12% at T1 and 6% at T2). However, within 6 months after the child’s
diagnosis or unintentional injury, PTSS declined significantly in both groups.

The majority of studies published have focused on maternal distress as mothers are more
likely to act as the primary caregiver of their child diagnosed with cancer. Alternatively, elevated
levels of maternal distress when compared to fathers may be due to differences in reporting style
(Yeh, 2002). Research by Wool and Barsky (1994) suggests that mothers are more willing to
admit discomfort than fathers. Men are expected to act ‘strong’ and this may interfere with their
ability to report feelings of uncertainty, depression, PTSS and PTSD. Thus, true levels of
paternal distress may be higher than current literature suggests.

Clinicians must be sensitive to parental distress by assessing and identifying both mothers
and fathers early on in their child’s treatment trajectory. By identifying distressed parents early
on, appropriate care can be provided to prevent future mental health problems and preserve
healthy functioning of the family system. Preventative interventions and support groups could
also be created and implemented to address the specific and unique needs of both mothers and
fathers who are distressed.

1.2.3 The Importance of Family Relationships, Coping Strategies and Social Support for
Parents of Children with Cancer

1.2.3.1 Family Relationships

The diagnosis of cancer requires families to make adjustments to their daily life, which
can cause not only strain on each individual but on the family system as a whole. When viewed
from a family systems perspective, what happens to one family member affects the other
members (Patterson, Holm & Gurney, 2004). Poor family functioning and relationships can have
a negative impact on the quality of life of the child-patient, siblings and parents.
Researchers have documented both positive and negative changes in parents’ marital relationships after the diagnosis of childhood cancer. An integrative review conducted by Machado da Silva, Jacob and Nascimento (2010), included 14 articles and investigated the question, “How does childhood cancer affect parents’ marital relationships?” Studies reviewed were descriptive in nature and included both quantitative and qualitative research methodology. A number of articles revealed that there were both negative and positive changes in parent’s marital relationships over time and throughout their child’s treatment trajectory. Positive changes included but were not limited to, an increased ability to solve conflict, greater flexibility in the relationship and a better perception of partner’s personal and behavioral traits. Negatives changes included a weakened connection between partners and a negative impact on their sexual life and feelings of intimacy.

Interestingly, most positive and negative changes in marital relationships were seen within a few weeks to four months after diagnosis. When a child had been sick for up to one year, less change in the marital relationship was seen. As children entered remission, it was common for parents to report that their marital relationship had been strengthened because of the crisis they had previously overcome (Machado da Silva, Jacob & Nascimento, 2010). When parents experienced the relapse of their child this seemed to result in two different reactions. Some parents reported the relapse brought greater emotional closeness between them and their partner while others reported it caused a strain on the marital relationships (Lavee & May-Dan, 2003; Leavitt et al., 1999; McGrath, 2001).

Established patterns of communication between partners appeared to be an important factor in whether or not childhood cancer had a positive or negative impact on parents’ marital relationship (Machado da Silva, Jacob & Nascimento, 2010). It is common for one parent, usually the mother, to be with the sick child at the hospital when he/she is undergoing treatment
As a result, fathers generally have to take on the added responsibility of taking care of the family within the home as well as working to provide financially for the family. The separation between the spouses can impede their ability to communicate which can cause strain on the marital relationship and a sense of emotional disconnect between partners (Machado da Silva, Jacob & Nascimento, 2010). Communication problems, both verbal and non-verbal, have been reported in parents with higher stress levels (Steffen & Castoldi, 2006).

Dahlquist, Czyzewski, & Jones (1996), carried out a longitudinal study including 84 parents (42 couples), to investigate marital adjustment of parents two and 20 months after their child’s cancer diagnosis. Questionnaires were administered to parents at both time intervals to investigate if emotional distress had an effect on marital adjustment. Hierarchical multiple regression analyses were conducted separately for mothers and fathers. For mothers, less depressive symptomatology and greater marital satisfaction predicted positive marital adjustment. For fathers, less depressive symptomatology, greater marital satisfaction and poor child health status predicted positive marital adjustment. Dahlquist et al. (1996) speculated that having a sick child might encourage fathers to seek emotional support from their partner and thus build a stronger partnership between the two spouses. Women generally have a larger social network when compared to men. Therefore, in times of crisis, fathers may rely more on their partners for social support. This can have a positive influence on the relationship yet may also add to the emotional strain experienced by mothers.

As suggested by Machado da Silva, Jacob and Nascimento (2010), the implementation of interventions that promote dialogue between spouses may help parents to recognize each other’s strengths and encourage them to support each other through their period of crisis. As well, encouraging parents to interact with other parents’ going through a similar life event, may
provide mutually supportive interactions and may help to normalize the similar difficulties parents are experiencing.

1.2.3.2 Coping Strategies

Dealing with childhood cancer can be an enduring, draining and painful experience for parents. The use of avoidant behaviors, as a way of coping, seems to be functional in the early phase of childhood cancer when parents are overwhelmed with stressors (Vrijmoet-Wiersma et al., 2008). However, during the active phase of treatment, avoidant behaviors have been related to increased levels of anxiety and depression (Hoekstra-Weebers et al., 1999; Lindahl-Norberg, Lindblad & Boman, 2005).

Coping is defined by Lazarus and Folkman (1994) as constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person. Coping involves efforts to manage stressful demands regardless of their outcome (Lazarus and Folkman, 2004).

Research on coping commonly groups coping strategies into three main domains: appraisal-focused coping, problem-focused coping, and emotion focused coping behaviours. Appraisal-focused coping refers to the way a person thinks about the stressors or circumstances they are experiencing (Patterson, Holm and Gurney, 2004). Each individual appraises a situation in a different way based on their past life experience, which then impacts the way the individual reacts to the circumstance. An example of appraisal-focused coping could be believing and trusting in God in order to help a parent cope with the stress of having a child diagnosed with cancer. In this case, a belief in God helps the parent cope in a previously stressful circumstance therefore the parent turns to this belief in order to cope with their current stressful situation. Problem-focused coping refers to the use of strategies directed at changing the environment or changing one’s own behavior or thoughts regarding the stressor. This is in contrast to emotion-
focused coping which aims to regulate emotional states that are caused by or related to stressful events in order to cope with the situation (Barrera et al., 2004). Using emotion-focused coping strategies has been linked to problematic functioning and increased levels of distress (Miller, Gordon & Daniele, 1992).

Patterson, Holm and Gurney (2004), carried out seven focus groups to qualitatively analyze 45 parents of children who were a year or more out of cancer treatment. The goal of the study was to report on resources and coping behaviors parents perceived as helpful to their family in dealing with and managing the cancer experience. Through focus group discussion, appraisal-focused coping was the most frequently used coping behavior amongst parents. The most frequently utilized appraisal-focused coping behavior used by parents was trying to be positive and maintain hope. These findings were consistent with other studies examining coping behaviors of parents dealing with other chronic health conditions. Appraisal-focused coping seems to allow parents to maintain their emotional energy (Patterson, Holm and Gurney, 2004).

Focus group discussion amongst parents highlighted the importance of actively seeking information about childhood cancer as a commonly utilized problem-focused coping strategy (Patterson, Holm and Gurney, 2004). For example, in order to reduce parental distress, parents may search the Internet or talk to other parents having gone through the experience of having a child with cancer in order to seek more information. To further cope, parents may advocate for their children both within the hospital setting and within the school environment using problem-focused coping strategies (Patterson, Holm and Gurney, 2004). For example, parents may advocate that their child be allowed to go to school while undergoing treatment versus being isolated from the school environment and having a tutor at home. Problem-focused coping strategies may help parents proactively feel a sense of control over their situation and subsequently reduce feelings of distress.
Emotion-focused coping may help to regulate overwhelming emotions (Lazarus and Folkman, 1983). However, research shows that it is generally the least helpful coping strategy that parents can utilize. Interestingly, Baskin, Forehand & Saylor (1985), showed that mothers with lower socio-economic status (SES) reported higher degrees of emotion-focused coping and this coping style was associated with increased maladjustment. Examples of emotion-focused coping behavior used amongst parents of children having cancer may include crying, hiding difficult feelings from other family members, outwardly being strong as a way to support their child, and writing in a journal to sort out difficult feelings (Patterson, Holms and Gurney, 2004). In an earlier study, increased depression and anxiety have been correlated with emotion-focused coping (Baskin, Forehand and Saylor, 1985).

Effective parental coping, was found to protect children from feeling hopeless following their treatment for cancer (Blotcky, Raczynski, Gurwitch & Smith, 1985). The ability of parents to deal with the multiple sources of stress that having a child with cancer brings can have a direct influence on the quality of life of all family members. From a family systems perspective, how one family member copes and responds to the diagnosis and treatment of the child with cancer directly effects the functioning of other family members.

1.2.3.3 Social Support

Social support refers to the perceived availability of friends and family to help a person cope with a stressful situation (Overholser & Fritz, 1990). Research suggests that support from family and friends can have a positive impact on the ability of parents to cope with the stress of having a child with cancer (Grootenhuis, Last & Kinderziekenhuis, 1997). Social support is one variable that may help to explain why some parents adjust well to the experience of having a child with cancer while others do not.
Lindahl-Norberg, Lindblad and Boman (2006) proposed three modes of social support: (1) Network resources; (2) Social behaviors and (3) Subjective appraisal of support. *Network resources* refer to the actual number of persons available to provide supportive care to parents. *Social behaviors* refer to the use of support seeking behaviors as a form of coping. Parental *subjective appraisal of support* refers to how satisfied parents are with the amount of support they are receiving. Lindahl-Norberg et al.’s (2006) results were consistent with previous findings showing that satisfaction with support was similar amongst both men and women while support-seeking behavior was used more frequently as a coping strategy amongst women.

In a meta-analysis conducted by Clarke et al. (2009), not only did mothers use social support seeking behaviors more frequently than fathers, but mothers actually received more social support - in particular emotional support - from their family and extended networks. Social support seems to have a buffering effect on the severity of depressive and anxiety symptoms in parents (Vrijmoet-Wiersma et al., 2008). After the meta-analysis Clarke et al. (2009), concluded that social support could be more important for mothers than fathers in terms of decreasing symptoms of anxiety and depression (Clarke et al., 2009). Consequently, mothers may be more apt to engage in support seeking behaviors compared to fathers. Furthermore, women commonly have larger and closer social networks than men and are more able to mobilize support when needed (Hoekstra-Weebers, Jaspers, Kamps & Klip, 2001).

Using a longitudinal study design, Hoekstra-Weebers et al., (2001), investigated parent’s psychological distress, quantity of social support and satisfaction/dissatisfaction with support at diagnosis, 6 and 12 months post-diagnosis. Both fathers and mothers reported that they received significantly less social support with time. The amount of received support diminished mainly during the first 6 months following the diagnosis. These results are consistent with past literature showing that during the acute crisis phase of cancer diagnosis, parental distress is
highest and this coincides with a high need and receipt of social support (Hoekstra-Weebers, Jaspers, Kamps and Klip, 2001; Wortman, 1984; Van Sonderen, 1993). As the child undergoes treatment, stress becomes more chronic, parental distress may decrease and thus the need for social support may diminish. Social, hospital and family networks may perceive less of a need from parents for social support during the time of treatment compared to the time of diagnosis. As a result, less social support may be delivered to parents post-diagnosis.

A majority of studies suggest beneficial effects of social support (Kupst & Shulman, 1988; Magni, Sylvestro, Tamiello, Zanesco & Carli, 1988, Sarason, Sarason, & Pierce, 1990). However, childhood cancer, because of its life threatening nature, may cause parents to remove themselves from social networks. Parents may not perceive social interaction as a beneficial form of support (Chesler & Barbarin, 1984). Therefore, social interaction is only supportive to parents if they perceive it as meeting their specific need to better cope with their situation versus causing added stress (Lindahl-Norberg et al., 2006).

Beltrao, Vasconcelos, Pontes & Albuquerque (2007), investigated maternal perceptions of childhood cancer and strategies for coping in a pediatric unit in Recife, Brazil. Ten mothers of pediatric cancer patients were interviewed and qualitative analyses were used to extract recurrent themes. Mothers stated that social support helped them to cope with the situation they were confronted with. In particular, mothers relied most heavily on family support to share difficult moments, offer compassion and help maintain family responsibilities. As well, everyday contact with other people in the hospital, other mothers in particular, was perceived as beneficial. Finally, professionalism, dedication and attention from the healthcare team including doctors, nurses and psychologists, was also deemed as an important source of social support.

Treatment protocols establish a large variety of medical procedures for the child-patient, but often do not provide guidelines concerning the provision of support for the caregivers.
(Beltrao, Vasconcelos, Pontes & Albuquerque, 2007). The degree to which parents identify family and extended social systems as supportive can influence parent’s psychological well-being as well as the psychological and physical outcomes of their child with cancer (Morrow, Hoagland, & Carnrike, 1981). Understanding each parent’s specific and unique needs for social support is an essential step in providing family centered care.

1.2.4 Support Groups for Parents of Children Having Cancer

There is growing empirical support for interventions for parents of children with cancer (Foreman, Willis, & Goodenough, 2005). A meta-analysis of 12 psychological intervention studies reviewed psychological distress and adjustment of children with cancer and their parents as the primary outcomes (Pai, Drotar, Zebracki, Moore & Youngstrom, 2006). Parental distress was measured using standardized measures of depression, anxiety and posttraumatic stress symptomatology. Parent adjustment measures included parenting competence, problem-solving skills and positive affect. Five of the intervention studies were delivered to parents only, five delivered to children, and two were delivered to caregivers and children. The interventions ranged from 1-8 sessions, each lasting for an average of 66 minutes. Interventions were eclectic in nature, employing a variety of modalities within the same intervention (cognitive behavioral techniques, education, support, etc.). There was a significant improvement in parental adjustment and a decrease in distress after parents had participated in the interventions (Pai et al., 2006). Unfortunately, from this meta-analysis we cannot determine which type of intervention was most effective for parents (i.e. those delivered exclusively to parents vs. parents and children), or the minimum duration by which the intervention should be carried out.

Support groups allow parents to discuss shared experiences, provide examples of coping behaviors they have used to manage their situation and also give parents hope that solutions are attainable (Monaco, 1988). Support groups may also provide a safe environment whereby
parents feel as though other group members can relate to what they are going through having gone through the experience themselves (Monaco, 1988).

Some health-care professionals fear that parental participation in support groups may promote negative attitudes towards treatment and doctors, may interfere with the patient-physician relationship or may introduce more of an emotional burden on parents (Monaco, 1988). However, research by Chelser & Barbarin (1984), provided contrary evidence to the above speculation when they validated that parents who participated in support groups were more positive towards medical staff versus those parents who did not participate. As well, the study showed that parents actively sought participation in support groups to satisfy their need for support and information and were not motivated by hostility towards other health-care professionals or treatment plans. Instead of placing an emotional burden on parents, support groups may act as direct reducers of stress helping parents to advocate for their children and promote their child’s well-being as well as their own (Nathanson & Monaco, 1984).

Time constraints, child-care and in some cases far travel distances may impede parents ability to participate in face-to-face mutual support groups. In order to alleviate the stress these factors may place on parents, and to increase the accessibility of valuable supportive services catered towards parents, computer-mediated support group interventions have been tested. A study by Bragadottir (2008) followed an evaluative one-group, before-and-after research design, which assessed the feasibility of a computer mediated support group (CMSG). The CMSG included 21 parents of children having cancer living in Iceland. Outcome measures were delivered before the intervention (T1), after 2 months of intervention (T2), and 4 months post intervention (T3). Results indicated statistically and clinically significant improvements in mothers’ depression and in fathers’ anxiety during the time period of participation in the CMSG and following the intervention. Interestingly, mothers seemed to be more engaged in the CMSG
writing more online messages compared to fathers. Overall, evidence from the study supports CMSGs as a valuable addition to face-to-face support groups or as a substitute for parent support groups when factors impede on parental participation.

Research conducted by Lindahl-Norberg et al., (2005) has shown that parents, who use problem-focused behaviors to solve problems pertaining to having a child with cancer, show fewer symptoms of anxiety and depression. Problem Solving Therapy (PST) has become a popular cognitive behavioral intervention used amongst individuals showing symptoms of negative affectivity (i.e. depression, anxiety) and reduced well being (Sahler et al., 2002). Sahler and colleagues (2002) created the Problem-Solving Skills Training (PSST) intervention specifically for parents of children having cancer. The main purpose of the intervention was to improve problem-solving skills and to decrease negative affectivity in parents.

The PSST intervention was first pilot tested amongst a population of 92 mothers who were randomly assigned to receive PSST (treatment group) or to receive standard psychosocial care (control group) (Sahler et al., 2002). Researchers hypothesized that the primary effect of the PSST would be to increase problem solving skills with a secondary effect of decreasing negative affectivity. The intervention consisted of eight 1-hour individual sessions including either PSST for the treatment group or standard psychosocial care for the control group. Mothers were assessed prior to the intervention (T1), immediately following the intervention (T2) and 3 months post intervention (T3). After the 8-week intervention mothers who had engaged in PSST showed a significant improvement in problem-solving skills and significantly decreased negative affectivity compared to the control group.

Askins et al., (2009), evaluated the feasibility and efficacy of a handheld personal digital assistant (PDA) which delivered PSST. The PDA based intervention was created based on the fact that communication technology is a cost-effective, sophisticated and an easily attainable way
to deliver behavioral healthcare (Taylor & Luce, 2003). A total of 197 mothers of children with cancer were randomized to either an 8 week program incorporating traditional PSST or PSST + PDA. The primary purpose of the study was to examine the potential benefits of computer-assisted therapist based training for mothers of children newly diagnosed with cancer (Askins et al., 2009). Researchers hypothesized that mothers receiving PSST + PDA would show a larger decrease in negative affectivity then those receiving PSST alone. Participants in both groups completed the Social Problem Solving Inventory Revised, Beck Depression Inventory-II, Profile of Mood States, and Impact of Event Scale Revised pre-, post-treatment, and three months after completion of the intervention. The PSST intervention consisted of eight in person 1 hour sessions following a strict protocol. The PSST + PDA intervention consisted of eight 1 hour in person sessions supplemented by a PDA device created to review the problem solving skills that has been taught in the PSST session. For the PSST + PDA arm of the study, the traditional eight session PSST delivery format was altered slightly. Both groups showed significant improvements over time on all psychosocial measures. No outcome measures showed the emergence of between group differences, meaning PSST + PDA showed no additional value compared to the traditional PSST. However, mothers rated the PSST + PDA based program favorably (Askins et al., 2009).

Support and resources available to parents may help to offset the stress of having a child diagnosed with cancer (Morrow, Hoagland & Carnrike, 1981; Vrijmoet-Wiersma et al., 2008;). Psychological interventions for children with cancer and their families can help to strengthen and mediate the process of moving forward from the cancer experience (Barakat et al., 2003; Kazak et al., 2004; Sahler et al., 2005). Support programs are becoming increasingly more widespread in clinical practice for parents of pediatric cancer patients. The American Academy of Pediatrics has recommended the incorporation of “family support group services” as an essential part of
comprehensive oncology care (American Academy of Pediatrics, 1997). There is however great
diversity in the type of support group interventions documented in the literature regarding
beneficial results (Foreman et al., 2005; Kazak et al., 2005). Furthermore, little is known
regarding what parents of children with cancer perceive as their needs for support and the
characteristics of their preferred support activities. Although younger parental age, being a
mother and a short time since diagnosis have been found to be associated with psychological
distress among parents of children with cancer, the relationship between these factors and
parental perception of support needs and preferences are unknown (Clarke et al., 2009; Dolgin et
al., 2007;)

To date, conclusive evidence has yet to be established as to the feasibility and
effectiveness of support groups to meet the supportive care needs and preferences of parents of
children with cancer. Support groups may be a beneficial addition in the provision of
comprehensive care to families. However, in order to validate the addition of support groups to
the treatment plan, support groups must be further pilot tested and assessed for feasibility and
efficacy.

1.2.5 The Pediatric Psychosocial Preventative Health Model (PPPHM)

The PPPHM developed by Kazak (2006), was utilized as a theoretical framework to guide
the current research. The PPHM is a biopsychosocial framework for assessing and treating families
of children in pediatric health care settings (Kazak, 2006). This model was evidence based
considering findings in the field that identify biomedical factors (e.g. patient diagnosis),
psychological factors (e.g. anxiety or depressive symptoms) and social factors (e.g. cultural
background) as risk factors that influence the health of the child. The PPHM model views the child
in the context of the family. Therefore, families can influence the biopsychosocial health of the
child. The goal of the PPPHM is to conceptualize how parents of children having either an acute or
chronic illness might be provided psychosocial support based on level of need and risk (Kazak, 2006). The PPPHM model groups families into three groups when confronting health related stressors: Universal, Target and Clinical. The Universal group constitutes the largest group of families entering the pediatric health care system and consists of competent and adaptive families. Applying a preventative approach by supporting the competence of these families and identifying future difficulties before they are encountered is essential. The Targeted group of families display factors that predispose them to ongoing difficulties (i.e. family conflict) that may interfere with their ability to cope with their child’s illness. This group constitutes a smaller number of families and necessitates more specific, targeted care. The Clinical group constitutes the smallest group of families and has several factors that predispose them to a high risk of ongoing distress. This group of families, while small, requires the most labor intensive care and greatest number of resources.

The PPPHM involves three main stages: (1) Evidence based assessment of families; (2) Classification of families into Universal, Targeted or Clinical groups based on level of need and risk; and (3) Allocation of appropriate supportive services to meet family needs. The underpinning assumption of the PPPHM is that rather than assuming that families have adequate support needs, of these needs it is necessary to tailor intervention approaches that support families to such needs in order to facilitate adjustment over time (Kazak, 2006). Based on the PPPHM, very few families will require traditional mental health services. However, parental views of their needs will complement the model for better allocation of how many will need support regarding issues pertaining to diagnosis and treatment, resource availability, and tools for coping with their own personal feelings of distress and anxiety.
1.2.6 Goals of the Current Study

Utilizing the PPPHM model as a theoretical framework, the goal of this project was two-fold. To assess parental perspectives of their supportive care needs using the Parent Support Survey. This goal was examined in Phase I of this study. Using data collected from the Parent Support Survey, a Parent Support Group Intervention was created. Parents who voiced interest in joining a Parent Support Group Intervention from the Parent Support Survey or those identified as being in need of supportive services by health care professionals were invited to partake in the group. The Parent Support Group intervention was then pilot tested for feasibility and preliminary outcomes. This goal was pursued in Phase II of this study. This feasibility and pilot study was based on quantitative data (e.g. pre/post Visual Analogue Scale questions) but incorporated anecdotal information (e.g. feedback from parents and healthcare professionals) to help explain why the effects were observed. Information gained from this pilot study will aid in the creation and refinement of supportive services offered to parents of children with cancer within the pediatric oncology health care setting.
CHAPTER 2

Objectives and Hypotheses

This chapter will begin by outlining specific objectives and hypotheses investigated in Phase I of the current research project. To follow, specific objectives and hypotheses addressed in Phase II will be summarized.

2.1 Phase I: The Parent Support Survey

Phase I of the current study aimed to capture what parents of children with cancer viewed to be the needs for support in general and specifically the preferred content, process, and structure for a parent support group.

2.1.1 Specific Objectives of Phase I

1. To investigate parental views regarding supportive services for parents of children with cancer using both close-ended and open-ended questions.

2. Guided by the PPPHM which identifies biomedical, psychological and social risk factors, the second objective is to examine relationships between parental characteristics (e.g., age, gender, socioeconomic status defined by education, employment and marital status), social factors (e.g., cultural background), and biomedical factors (e.g., child’s diagnosis and stage of child’s treatment) with respect to the need for support

2.1.2 Hypotheses

Based on current evidence, we hypothesized that parents would communicate an interest in participating in a support group to fulfill their informational and emotional needs. We also hypothesized that there would be a higher need for support amongst mothers, younger parents, parents with less education and parents who were unemployed. These hypotheses would be tested based on quantitative data collected from the Parent Support Survey close-ended questions.

29
2.2  *Phase II: The Parent Support Group Intervention*

Based on results obtained from Phase I, a Parent Support Group Intervention was designed to address the following parental needs: 1) Knowledge of diagnosis and treatment; 2) Knowledge of community, hospital and family resources; 3) Social support to parents; and, 4) Parental distress and anxiety. Thus, Phase II aimed to test the feasibility of the Parent Support Group Intervention and to pilot test preliminary outcomes of this group intervention.

2.2.1  *Specific Objectives of Phase II*

1. To create a Parent Support Group Intervention based on results from Phase I
2. Based on the definition of feasibility established by Kazak et al. (2005), the following components of feasibility were assessed:
   A. Acceptability of the group, including:
      a. Measuring the willingness of parents to attend the group each week
      b. Facilitators views in terms of the impact the group sessions had on parents
      c. Parents’ satisfaction with the group
   B. Recruitment and retention
      a. The number of parents who attended each week and over the course of the 8-weeks
      b. The number of parents who attended one versus two, three, four or more group sessions
      c. Reasons provided for not attending
   C. Preliminary Outcomes
      a. To determine whether the outcome measures (i.e. Visual Analogue Scales) were easy to use, easy to understand and the duration of time it took to complete them.

2.2.2 Hypotheses

Based on the preliminary literature regarding parental distress, we hypothesized that:

1. Parents would be interested in attending a co-facilitated support group, offered during a weekday afternoon or evening and led by both a parent and a health-care professional.

2. Mothers would be more likely to participate in the parent support group versus fathers.

3. Based on the VAS results, parents will report increases in: a) Knowledge of diagnosis and treatment, b) Knowledge of community, hospital and family resource availability c) Perception of social support and d) Decreases in distress and anxiety.

4. Improvements in the outcomes will be even more pronounced when parents attend the Parent Support Group Intervention more than once.
CHAPTER 3

Methods

This chapter will begin by describing the research methodology utilized for Phase I: The Parent Support Survey. Participant inclusion criteria, development of the Parent Support Survey, study procedures, data management and confidentiality will be described. Next, the research methodology utilized for Phase II: The Parent Support Group Intervention will be described. This will include participant inclusion criteria, recruitment, a description of the Parent Support Group Intervention, roles of participants, assessment measures, how confidentiality will be maximized as well as the budget for the intervention.

3.1 - Phase I: The Parent Support Survey

3.1.1 - Participants

Inclusion Criteria:

- Parents of children under 18 years of age who were currently on treatment or had been treated for cancer in the past, within the Hematology/Oncology at a pediatric tertiary care center, which serves metropolitan Toronto were eligible to participate. In addition to biological parents, adopted, and stepparents who were the primary caregivers for the child's care, were eligible so as not to systematically exclude non-traditional families. The intention was that this inclusion of a range of caregivers would represent the uniquely diverse population served at the pediatric tertiary care center. Targeted sampling was utilized in order to select individuals for the study.

- Parents were required to have sufficient verbal fluency in the English language in order to participate in group activities and complete evaluations. Parents speaking English as a second language were offered assistance by a research assistant with the completion of assessment forms if needed.
The study aimed to capture what parents of children with cancer viewed to be their needs for support and preferred content, process, and structure for a parent support group. Since no validated survey with this focus existed, the Parent Support Survey (Appendix 1) was developed specifically for this study. This study followed a descriptive survey design whereby initial items were based on prevailing themes from past literature. An expert in instrument development at the University of Toronto was consulted in order to provide input into the creation of the Parent Support Survey. Items were further developed based on the clinical experiences by the study clinicians. Item reduction and refinement was achieved by extensive input from nurses, social workers, and parents of children with cancer on early revisions of the survey. Face validity was achieved by obtaining parental input on the readability of the survey and cognitive testing of the items. Thus, the survey underwent numerous iterations to increase its readability and to minimize the burden for parents. The final revision of the survey consists of 22 items, which were predominantly multiple-choice. The survey was organized into two parts, demographic (parental age and gender, marital status, having other children, language spoken at home, highest educational level attained, employment status, and ecological factors such as travel distance and place of birth) and clinical information (child’s diagnosis, date of diagnosis, and whether child was on or off treatment) and parents’ support group interest and preferences. For questions pertaining to individual and support group preferences, parents were asked to rate on a Likert scale how useful they would find various types of support groups (e.g. online, drop-in, informal, speaker series, family activities group, yoga-based). Parents were also asked to share their reasons for deciding to participate in a support group (e.g. meet other parents with similar experiences, learn more about treatment side effects, express their frustration and fears, get advice on relationship or family issues).
3.1.3 - Procedures

After receiving institutional Research Ethics Board approval and University of Toronto Ethics Approval, parents were recruited from the ambulatory clinics of the oncology program. Health care professionals within the program were informed of the study, and the primary nurse for each patient initially approached parents during their regular outpatient clinic visit to inform them about the study. During a three-month enrollment, a total, 127 parents were identified as eligible for the Parent Support Survey. A research assistant then approached these parents, explained the study objectives and procedures in detail, including the time required to complete the survey, confidentiality, and the risks and benefits of participation. 108 parents completed the survey. Parents were asked to complete the surveys anonymously and return the completed survey to a collection box in the clinic’s waiting room. Of the Parent Support Survey participants, 66 parents provided contact information and consent to be contacted if future parent support groups were delivered. In total, 19 parents refused to participate for reasons such as a lack of child care availability.
3.1.4 – Data Management and Statistical Analyses

A research assistant entered data after each survey was checked and verified for accuracy of values. Analyses were conducted using the SAS statistical package version 9.1 (SAS Institute Inc. SAS/SASS User’s Guide, 2003). Initially, data entry was checked for errors and tested for normality. Subsequently, descriptive statistics were conducted to obtain an overall profile of the study sample. Likert scale results were analyzed to investigate need for support as well as individual and support group preferences. Several continuous variables (age and travel distance) were converted into categorical variables for ease of interpretation. Chi-square tests were used for
assessing the association of the outcome (support group needs) with the categorical variables such as demographic (age, gender, marital status, employment status, and having other children), ecological (travel distance), and clinical variables (diagnosis) and the dependent variable, support group need. Factors considered as potential predictors of parent support group interest and preferences were tested using logistic regression. To build the final regression models, variables \( (p \leq .20) \), at univariate analyses were selected. Using this criterion, potential predictor variables included age, gender, marital status, employment status, and having other children. Odds ratios (OR) and confidence intervals (CI) were calculated for each variable that were found to be statistically significant \( (p \leq .05) \).

3.1.5 Confidentiality

To respect the anonymity of parents, participants were not required to provide their name and were given a number for identification. Privacy of program participants was respected. No information about who the participant was or his or her child was given to anyone or published without the participant’s permission.

3.2 - Phase II: The Parent Support Group Intervention

3.2.1 - Participants

Inclusion Criteria:

- Inclusion criteria were the same as in Phase I.

1.2.2 – Recruitment

It was difficult to estimate the exact number of parents who would attend each weekly session due to the very nature of the groups (see description of the group format and structure below). Based on previous experience running parent groups in the bone marrow transplant unit, we decided that a minimum of two parents was necessary to run a parent support group, however, for the group to work well and develop harmonious interactions, a size of five to six parents was
considered ideal. This number would allow for individual participation and diversity of parental experiences, which enhances the group experience. Based on previous experience, it would be unlikely that more than eight parents would attend a session at any given time. We did however accommodate all parents who attended.

Four approaches were utilized to recruit participants for the Parent Support Group Intervention: (1) Parents who completed the Parent Support Survey providing consent and contact information indicating interest in joining a parent support group were contacted by Kristen Maunder (KM) after clinical teams agreed that they could be contacted. KM also provided parents with more information pertaining to the group intervention and invited them to participate. (2) KM and Dr. Maru Barrera (MB) met with staff from the Hematology/Oncology program at SickKids, including contact nurses, social workers, psychologists and oncologists to explain the Parent Support Group Intervention. Staff were asked to identify potential participants. Subsequently, an information letter was sent to families followed by a phone call by KM, to provide additional information about the group and to invite them to participate. (3) A poster was displayed on the television screen within the Haematology/Oncology clinic, providing more information about the Parent Support Group Intervention and was used as a recruitment tool. This poster invited parents to contact KM if they were interested in participating in the group. As well, information on the Parent Support Group Intervention was posted in the parent’s newsletters, Ontario Parents Advocating for Children with Cancer (OPACC) and Brainchild. (4) Finally, in order to enhance recruitment each week, our parent representative provided information pertaining to the Parent Support Group Intervention and personally invited parents in the waiting room of the Hematology/Oncology clinic to participate in the group. Announcements were made on the over-head speaker within the Hematology/Oncology clinic approximately a
half an hour before the commencement of the group inviting parents to join. Recruitment took place over a one month time period utilizing the strategies listed above.

3.2.3 - Description of Parent Support Group Intervention

General structure of the parent support group intervention was as follows:

1. Sign-in and completion of consent (only done first time parents attended a meeting), information forms and pre-session measure (10 minutes)
2. Refreshments, introductions and group rules including confidentiality (5 minutes)
3. Informal Group Discussion co-facilitated by a health care professional (Dr. Maru Barrera or Debbie Berlin Romalis or Karen Drybrough) and a parent (60 minutes)
   - Discussed with group how a parent support group intervention can be helpful
   - There were no set topics covered each week. Parents were given the opportunity to decide what issues were discussed each week based on their needs.
   - Prompts were offered by the co-facilitator to stimulate discussion:
      - For example;
        i) Does anyone want to share any particular experience? What made it more difficult? What made it easier? Does anyone have any suggestions that might help?
   - Co-facilitators: Healthcare professional co-facilitators rotated each week from a pool of three (a psychologist, a social worker and an inter link nurse). Similarly, parent co-facilitator rotated from a pool of two parents.
   - Encouraged parents to express interests and concerns regarding issues such as their child’s treatment and side effects, resources available in the hospital and their community to assist them with practical matters, personal health, family relations, fears
regarding treatment, difficulties dealing with child’s behaviour and any other concerns regarding their child’s care.

- Listened to concerns and provided a forum to discuss relevant issues
- Promoted problem solving for potential solutions
- Offered practical suggestions in dealing with problems common to members

(4) Closing Remarks (5 minutes)

- Encouraged parents to ask questions regarding child’s treatment amongst their child’s healthcare team
- Encouraged parents to seek help when needed
- Empowered participants to establish connections with other parents in group
- Encouraged parents to attend future parent support group meetings

(5) Completion of post-session measure (5 minutes)

Each parent support group session was offered once a week, in the afternoon and evening, was based on the specific parental preferences of interested parents and was 1.5 hours in length. The Parent Support Group Intervention was held in a conference room, within the Hematology/Oncology Department. Each week, the same process and format for the group was followed. For each parent support group session, parents completed pre- and post- measures and a brief satisfaction questionnaire. During the initial session for each parent, they completed the consent and information forms.

3.2.4 - Roles of Parent Support Group Intervention Participants

(1) Healthcare Professional Co-Facilitator:

- Discussed group rules
- Guided introduction of group members
• Facilitated informal group discussion by probing into issues that may be of concern to parents.
• Listened to concerns of parents and their unique circumstances.
• Created and maintained a positive and trusting environment.
• Made parents feel welcome and valued by listening to their views and concerns empathetically.
• Helped to keep the progress of the group on track, paying special attention to adherence of time limits.
• Promoted balanced participation by all group members.
• Invited parents to candidly share feelings, frustrations and solutions
  o Promoted problem solving of potential solutions based on each parent’s unique circumstances.
• Empowered parents to become an active partner alongside their child’s healthcare team.
• Highlighted the importance of parental self-care and well-being
  o Encouraged parents to ensure that their emotional, psychosocial and physical needs were taken care of as well.
• Offered professional advice to parental concerns, when appropriate
• Did not assess pathology, degree of symptomatology, nor did she provide therapy in the drop-in group setting (but could offer individual sessions if required or referral to other professionals).

(2) Parent Co-Facilitator: OPACC Parent
• Facilitated informal group discussion
• Listened to concerns of parents and their unique circumstances
• Contributed advice and guidance providing parental perspective on how to utilize appropriate resources within the hospital and community.

• Contributed ideas towards problem solving and solutions based on his/her parental perspective.
  
  o Informed parents as to what ‘may’ work with respect to their situation however realized that each parent’s circumstances were different

(3) Graduate Student Researcher: Kristen Maunder

• Recruitment of parents for Parent Support Group
  
  o Informed contact nurses, social workers, psychologists and oncologists within the Haematology/Oncology program at SickKids about the parent support group intervention. Individuals within the department were asked to identify potential participants. Participants were contacted and invited to participate in the support group intervention.
  
  o Contacted parents who completed the Parent Support Survey and provided contact information indicating interest in joining a parent support group intervention, and invited them to participate in the co-facilitated group.
  
  o Maintained documentation of group recruitment, start and stop time of each group, attendance and participation in order to assess feasibility of the parent support group.

• Dissemination, collection and analysis of pre and post session forms

3.2.5 - Assessment

The feasibility of a Parent Support Group Intervention particularly catered towards the needs of parents of children recently diagnosed with cancer, was assessed using three
components of the model of feasibility proposed by Kazak and colleagues (Kazak et al., 2005): program acceptance, recruitment and retention and preliminary outcomes.

A. Acceptability of the group, including:

(1) Measuring the willingness of parents to attend the group each week

(2) Comments and concerns voiced by group facilitators carrying out the group

(3) Parents’ satisfaction with the group.

- These questions were answered based on whether we were able to carry out the Parent Support Group Intervention which was offered over an eight week period. Also, by reflecting on concerns expressed by healthcare professionals within the Hematology/Oncology program, and co-facilitators during recruitment. As well, results from the brief one-page Acceptability Questionnaire (Figure 6), developed to assess parent’s perceptions regarding the support group, were used to evaluate parents’ satisfaction with the group. For example, parent’s were asked what they liked/disliked about the group, what they would change and whether or not they would recommend the group to another family. The Acceptability Questionnaire was pilot tested and discussed with an OPACC parent representative as well as with health care professionals within the Hematology/Oncology program. Comments and concerns were reviewed and addressed before the Acceptability Questionnaire was disseminated amongst parents participating in the Parent Support Group Intervention.

B. Recruitment and Retention. This was assessed by:

(1) The number of parents who attended each week and over the course of 8-weeks.

(2) The number of parents who attended one versus two or more of the drop in sessions (this split was determined based on frequency of attendance amongst parents).
(3) The number of times each parent attended.

(4) Reasons provided for not attending

• These questions were answered based on assessing participant attendance records, attendance rates, and reasons parents shared with researchers prior to enrolment and during their group attendance.

C. Preliminary Outcomes:

a. Whether the outcome measures (i.e. VAS, Acceptability Questionnaire etc.) were easy to use, easy to understand and the duration it took to complete them.

b. To obtain estimates of the support group effect on primary outcomes measured by Visual Analog Scales of 1. Knowledge of diagnosis and treatment, 2. Knowledge of community, hospital and family resource availability; 3. Perception of social support; and 4. Personal feelings of distress and anxiety. These are described below.

• Parents were asked whether the measures were easy to use, easy to understand and the duration it took parents to complete the measures was recorded each session. As well, parents were asked if they had any questions concerning the measures as they were completing them. Primary outcomes were obtained via the VAS to pilot test the effect of the support group.

3.2.6 - Information Form

The information form consisted of questions pertaining to demographic, disease/treatment and resource information (Appendix 3 and Appendix 4). Demographics included: gender, age, marital status, highest level of education attained, employment status, languages spoken at home, country of origin, English fluency and travel distance to hospital. Disease/treatment information included: child’s diagnosis, age when diagnosed, time since diagnosis at participation, status of
their child’s treatment status, and side effects their child had experienced as a result of treatment. Finally, participants were asked about community, hospital and family resources they had utilized.

3.2.7 - Visual Analogue Scale (VAS) Questions

VAS Questions were developed by the project investigators, to be completed by parents at the beginning and end of each session. The following questions were assessed as parents indicated their level of agreement to a statement by indicating a position along the continuous line between two end points: 1. Knowledge of diagnosis and treatment; 2. Knowledge of community, hospital and family resource availability; 3. Perception of social support; and, 4. Personal feelings of distress and anxiety.

The VAS questions were developed with sensitivity to the time constraints parents of children having cancer face and after considering existing standardized measures of parental distress. VAS questions are widely used in health psychology. Although there are standardized measures of distress and social support (e.g., the State Trait Anxiety Inventory (STAI), and Harter’s Social Support Scale (HSSS)), they are lengthy and may not be sensitive to changes that may occur before and after a group session. Based on their brevity and given the nature of the group (open), it was deemed that brief VAS questions before and after each group session, would be sensitive to changes after a group session. VAS questions were pilot tested and discussed with an OPACC parent representative as well as with health care professionals within the Hematology/Oncology program. Comments and concerns were reviewed and addressed before the VAS was disseminated amongst parents participating in the Parent Support Group Intervention. Pre-session and post-session VAS questions are presented in Appendix 5.
3.2.8 - Acceptability Questionnaire

A brief one-page acceptability questionnaire (Appendix 6) was created to assess parent’s perceptions concerning the support group. For example, parents were asked what they liked/disliked about the group, what they would change and whether or not they would recommend the group to another family.

3.2.9 - Statistical Analysis

Data from the VAS was entered and processed using the Statistical Package for the Social Sciences (SPSS) software, English Version 15.0. Descriptive statistical analyses such as means, standard deviations, and proportions were performed, to describe the sample. In addition, descriptive statistics were calculated for each construct of interest assessed with pre- and post session VAS. Depending on the data available, appropriate statistics, were utilized. For example, in order to compare the pre- and post- VAS scores of parents who attended the Parent Support Group Intervention only once, a Paired Sample T-Test was used. As well, an Independent Samples T-Test was conducted to compare the difference in pre- and post- VAS scores of parents who attended the Parent Support Group Intervention only once and the average difference in pre- and post-VAS scores of parents who attended the group more then once.

3.2.10 - Dissemination of Results

Results obtained from this research study were summarized for dissemination to a number of different audiences including the Ontario Parents Advocating for Children with Cancer (OPACC) and Brain Child newsletters. Special attention was paid to the language and literacy needs of readers. The summary was also available to all families within the Hematology/Oncology clinic, regardless of Parent Support Group Intervention participation. As well, findings were communicated back to healthcare practitioners at SickKids. Results will also be presented at appropriate local, national and international scientific meetings by co-facilitators.
3.2.11 - Confidentiality

Privacy of program participants was respected. Due to the nature of the Parent Support Group Intervention, which included open discussion amongst parents, it was impossible to offer complete anonymity to participants. However, stressing to parents that information discussed amongst group members was not discussed outside of the group minimized threats to confidentiality. Furthermore, information about who the participant was or his or her child was not given to anyone or published without the participants’ permission. SickKids Clinical Research Monitors or the regulator of the study could see the program participant or child’s health record to check on the study. The data produced from the study was stored in a secure, locked location. Only members of the research team had access to the data. Following completion of the research study, the data was kept as long as required and eventually will be destroyed as required by Sick Kids policy. Published study results will not reveal the identity of participants. The results of measures will be used only for this study. If parents became emotionally upset during a session and required additional assistance after the session was over, they were referred to the care team and followed up by phone by the healthcare co-facilitator. However, over the eight week period that the Parent Support Group Intervention was carried out there were no parents who required additional assistance.

3.2.12 - Budget

At each session, OPACC provided funds allocated towards coffee and snacks for parents. The parent co-facilitator was paid by OPACC; KM was supported by a scholarship from the Social Sciences and Humanities Research Council (SSHRC) and by Dr. Barrera’s grants from the National Institute of Health and Pediatric Oncology Group of Ontario (POGO). The health professionals conducted this work in kind and partly supported by the H/O program.
CHAPTER 4

Results

This chapter is divided into results from Phase I: The Parent Support Survey and Phase II: The Parent Support Group Intervention. Results from Phase I begin with demographic characteristics of the sample followed by overall parental support needs and preferences. Results from Phase II begin with demographic characteristics of the sample followed by results pertaining to acceptability, recruitment and retention of parents participating in the Parent Support Group Intervention. Finally, primary outcome results are depicted based on findings from the VAS scales.

4.1 Phase I: The Parent Support Survey

4.1.1 Demographic Characteristics of Sample

One hundred and twenty seven surveys were disseminated to parents from January to March 2009 and 108 were returned (a response rate of 85%). Of the participants, there were 83 (76.85%) mothers and 23 (21.30%) fathers. Demographic characteristics of the parents who participated in the study and their children with cancer are presented in Tables 1 and 2. The average age (± Standard Deviation) was 38.9 years (± 8.46) and ranged from 22 years to 71 years. Ninety-four (87.03%) of the participants were married or partnered, and 62 (57.41%) had attained some post-secondary education. The majority (56.48%) were not born in Canada and a minority of the parents (12.04%) resided at a distance from the inner-city institution (>100 km). More than half (57.41%) of the children of participating parents were female. The majority of the children were between the ages of 2 and 7 (50.93%), diagnosed with leukemia/lymphoma (58.33%), and on active cancer treatment (69.44%).
Table 1

*Phase I: Demographic Characteristics of the Parents (n = 108)*

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>83</td>
<td>76.85</td>
</tr>
<tr>
<td>Male</td>
<td>23</td>
<td>21.30</td>
</tr>
<tr>
<td>Missing data</td>
<td>2</td>
<td>1.85</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20 to 29 years</td>
<td>13</td>
<td>12.04</td>
</tr>
<tr>
<td>30 to 39 years</td>
<td>45</td>
<td>41.67</td>
</tr>
<tr>
<td>40 years and up</td>
<td>49</td>
<td>45.37</td>
</tr>
<tr>
<td>Missing data</td>
<td>1</td>
<td>0.92</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single caregiver / separated / divorced</td>
<td>13</td>
<td>12.04</td>
</tr>
<tr>
<td>Married / partnered</td>
<td>94</td>
<td>87.04</td>
</tr>
<tr>
<td>Missing data</td>
<td>1</td>
<td>0.92</td>
</tr>
<tr>
<td><strong>Other Children</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>79</td>
<td>73.15</td>
</tr>
<tr>
<td>No</td>
<td>27</td>
<td>25.00</td>
</tr>
<tr>
<td>Missing data</td>
<td>2</td>
<td>1.85</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school diploma and below</td>
<td>40</td>
<td>37.03</td>
</tr>
<tr>
<td>Some post-secondary education</td>
<td>62</td>
<td>57.41</td>
</tr>
<tr>
<td>Missing data</td>
<td>6</td>
<td>5.56</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working</td>
<td>38</td>
<td>35.19</td>
</tr>
<tr>
<td>On leave because of child’s illness</td>
<td>28</td>
<td>25.93</td>
</tr>
<tr>
<td>Unemployed</td>
<td>9</td>
<td>8.33</td>
</tr>
<tr>
<td>Homemaker</td>
<td>15</td>
<td>13.89</td>
</tr>
<tr>
<td>Retired/On disability/Other</td>
<td>17</td>
<td>15.74</td>
</tr>
<tr>
<td>Missing data</td>
<td>1</td>
<td>0.93</td>
</tr>
<tr>
<td><strong>Travel distance to Sick Kids</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 30 km</td>
<td>30</td>
<td>27.78</td>
</tr>
<tr>
<td>30 – 100 km</td>
<td>39</td>
<td>36.11</td>
</tr>
<tr>
<td>&gt; 100 km</td>
<td>13</td>
<td>12.04</td>
</tr>
<tr>
<td>Missing data</td>
<td>26</td>
<td>24.07</td>
</tr>
<tr>
<td><strong>Born in Canada</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>45</td>
<td>41.67</td>
</tr>
<tr>
<td>No</td>
<td>61</td>
<td>56.48</td>
</tr>
<tr>
<td>Missing data</td>
<td>2</td>
<td>1.85</td>
</tr>
</tbody>
</table>
Table 2

**Phase I: Demographic and Medical Characteristics of the Participants’ Children Having Cancer**

(n = 108)

<table>
<thead>
<tr>
<th></th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>62</td>
<td>57.41</td>
</tr>
<tr>
<td>Male</td>
<td>41</td>
<td>37.96</td>
</tr>
<tr>
<td>Missing data</td>
<td>5</td>
<td>4.63</td>
</tr>
<tr>
<td><strong>Age (year)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 2</td>
<td>8</td>
<td>7.41</td>
</tr>
<tr>
<td>2 – 7</td>
<td>55</td>
<td>50.93</td>
</tr>
<tr>
<td>8 – 12</td>
<td>25</td>
<td>23.15</td>
</tr>
<tr>
<td>12 – 17</td>
<td>20</td>
<td>18.52</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leukemia/lymphoma</td>
<td>63</td>
<td>58.33</td>
</tr>
<tr>
<td>Solid tumors</td>
<td>26</td>
<td>24.08</td>
</tr>
<tr>
<td>Brain tumors</td>
<td>9</td>
<td>8.33</td>
</tr>
<tr>
<td>Missing data</td>
<td>10</td>
<td>9.26</td>
</tr>
<tr>
<td><strong>Treatment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Active cancer treatment</td>
<td>75</td>
<td>69.44</td>
</tr>
<tr>
<td>Cancer treatment terminated</td>
<td>25</td>
<td>23.15</td>
</tr>
<tr>
<td>Missing data</td>
<td>8</td>
<td>7.41</td>
</tr>
</tbody>
</table>
4.1.2 - Overall Support Needs and Preferences

The majority of parents (73.15%) expressed some interest in receiving individual support, and an even greater majority (75%) of parents stated they were interested in attending a support group for parents of children with cancer. Only 15 (14.4%) had experience participating in a support group in the past.

In terms of the ideal characteristics of a support group, most parents (70.3%) were in favor of a casual open style support group setting over having a pre-set organized number of sessions. The majority of parents favored a support group led by both parent and health-care professional (71.7%) over solely a health care professional (16.67%) or a parent (7.41%). The preferred timing appeared to be weekday evenings on a monthly basis (as opposed to weekly or bi-weekly).

4.1.3 - Gender Differences

Of the demographic variables, parent gender was found to be the only significant predictor of need for supportive group services and preferences. Mothers expressed a greater interest in attending a support group in general when compared to fathers (OR = 3.6, 95% CI = 1.15 to 11.49, \( p = 0.0283 \)). When asked to rank how useful they would find various support group models, mothers were more likely than fathers to express an interest in online support groups (OR = 7.14, 95% CI = 2.42 to 21.28, \( p = 0.0004 \)), informal support groups (OR = 3.23, 95% CI = 1.19 to 8.85, \( p = 0.0217 \)), yoga support groups (OR = 3.42, 95% CI = 1.25 to 10.20, \( p = 0.02667 \)), and family activities support group (OR = 3.05, 95% CI = 1.09 to 8.55, \( p = 0.0343 \)). The most popular choice amongst fathers was support groups featuring guest speakers, where no gender differences were found.

When parents were asked to rank their reasons for choosing to attend a support group, mothers ranked certain factors significantly more important than fathers: to express their
frustration and fears (OR = 4.06, 95% CI = 1.32 to 12.50, p = 0.0143) and get advice on how to deal with family or relationship issues (OR = 3.18, 95% CI = 1.03 to 9.90, p = 0.0451).

4.1.4 - Other Demographic or Clinical Variables

No other demographic variables (age, marital status, or educational level) or clinical variable (diagnosis, treatment status) were found to be significant predictors of supportive group need and preferences.

4.2 - Phase II: The Parent Support Group Intervention

4.2.1 Demographic Characteristics of Sample

Twenty-eight parents (20 mothers and 8 fathers) completed the Demographic Information Form. Demographic characteristics of the parents who participated in the study and their children with cancer are presented in Tables 3 and 4. Of the mothers and fathers who participated in the study, the average age was 42.6 (range = 30 to 59 years). 96.43% of the participants were married or partnered and 82.14% had attained some degree of post-secondary education. The majority of parents were working full-time (53.57%) or on leave from work because of their child’s illness (25.00%). Over half (57.14%) of the parents in the sample resided in the nearby Toronto area (<30km) and the majority were born in Canada (71.43%).

The majority of the children were female (71.43%), between the ages of 5 and 10 years (53.57%), diagnosed with leukemia/lymphoma (75%) and 46.42% of children were on active treatment.
Table 3

*Phase II: Demographic Characteristics of the Parents (n=28)*

<table>
<thead>
<tr>
<th>Descriptive Characteristics (n=28)</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;35 years</td>
<td>5</td>
<td>17.86</td>
</tr>
<tr>
<td>35-45 years</td>
<td>16</td>
<td>57.14</td>
</tr>
<tr>
<td>&gt;45 years</td>
<td>7</td>
<td>25.00</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
<td>28.57</td>
</tr>
<tr>
<td>Female</td>
<td>20</td>
<td>71.43</td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/Partnered</td>
<td>27</td>
<td>96.43</td>
</tr>
<tr>
<td>Divorced/Separated</td>
<td>1</td>
<td>3.57</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>High School Diploma</td>
<td>5</td>
<td>17.85</td>
</tr>
<tr>
<td>Post Secondary &amp; Above</td>
<td>23</td>
<td>82.14</td>
</tr>
<tr>
<td><strong>Employment Status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Working Now (Part-Time)</td>
<td>2</td>
<td>7.14</td>
</tr>
<tr>
<td>Working Now (Full-Time)</td>
<td>15</td>
<td>53.57</td>
</tr>
<tr>
<td>Unemployed (Looking for Work)</td>
<td>2</td>
<td>7.14</td>
</tr>
<tr>
<td>On Leave Because of Child’s Illness</td>
<td>7</td>
<td>25.00</td>
</tr>
<tr>
<td>Homemaker</td>
<td>1</td>
<td>3.57</td>
</tr>
<tr>
<td>Missing Data</td>
<td>1</td>
<td>3.57</td>
</tr>
<tr>
<td><strong>Born in Canada</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>20</td>
<td>71.43</td>
</tr>
<tr>
<td>No</td>
<td>8</td>
<td>28.57</td>
</tr>
<tr>
<td><strong>Travel Distance</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 30km</td>
<td>16</td>
<td>57.14</td>
</tr>
<tr>
<td>30-1000km</td>
<td>11</td>
<td>39.29</td>
</tr>
<tr>
<td>&gt;100km</td>
<td>1</td>
<td>3.57</td>
</tr>
</tbody>
</table>
Table 4

**Phase II: Demographic and Medical Characteristics of the Participants’ Children who were diagnosed with Cancer**


table:

<table>
<thead>
<tr>
<th>Descriptive Characteristics (n=28)</th>
<th>n</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Child’s Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>8</td>
<td>28.57</td>
</tr>
<tr>
<td>Female</td>
<td>20</td>
<td>71.43</td>
</tr>
<tr>
<td><strong>Child’s Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 5 years</td>
<td>9</td>
<td>32.14</td>
</tr>
<tr>
<td>5-10 years</td>
<td>15</td>
<td>53.57</td>
</tr>
<tr>
<td>&gt;10 years</td>
<td>4</td>
<td>14.29</td>
</tr>
<tr>
<td><strong>Diagnosis</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leukemia/Lymphoma</td>
<td>21</td>
<td>75.00</td>
</tr>
<tr>
<td>Solid Tumour</td>
<td>4</td>
<td>14.29</td>
</tr>
<tr>
<td>Blood Disorder</td>
<td>3</td>
<td>10.71</td>
</tr>
<tr>
<td><strong>Child on Treatment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>13</td>
<td>46.42</td>
</tr>
<tr>
<td>No</td>
<td>14</td>
<td>50.00</td>
</tr>
<tr>
<td>Missing Data</td>
<td>1</td>
<td>3.57</td>
</tr>
</tbody>
</table>
2.2 - Acceptability

The Parent Support Group Intervention was implemented and carried out over the 8-week time period as planned. The process of carrying out the intervention was viewed positively by the co-facilitators and parents involved with the group each week. Co-facilitators met weekly to discuss and review the sessions and to make suggestions for future sessions. Some personal concerns brought up by co-facilitators carrying out the group each week were as follows.

i) Time Commitment
   a. Being the summer, it was difficult at times for both the co-facilitators and parents to commit their consistent involvement with the group.

ii) Group Participation
   b. Co-facilitators found that during the initial sessions, particular parents tended to dominate the conversation. In order to address this concern, co-facilitator Dr. Maru Barrera, who has had considerable experience carrying out support groups specifically for parents of children having cancer, described techniques she had used in the past to re-direct and re-focus groups to allow for equal participation amongst members. These techniques were integrated into later sessions as well.

Overall, facilitators and healthcare professionals deemed the group to be clinically relevant, beneficial and doable.

Data from the brief one-page Acceptability Questionnaire indicated that parents participating in the group viewed the Parent Support Group Intervention positively. For example, one parent stated, “It was nice to share experiences with other parents who had been through what I had been through.” Another parent said, “The support group was both informative and enjoyable and it was good to talk to other parents.”
Other comments and suggestions by parents included: “The Parent Support Group Intervention should be held throughout the year in order to spread the time for discussion more evenly.” As well, another parent stated that, “it would be good if more parents would take part in the group.” A number of parents also commented that they would like to spend more time discussing treatment and side effect management. One parent suggested that a certain time during each session should be specifically allocated to discussion pertaining to treatment and side effect management. This seems to be a popular theme amongst parents.

4.2.3 - Recruitment & Retention

Recruitment and retention of a sample that is representative of the population of interest, in this case parent of children with cancer, can be a challenge in intervention studies. Because caring for a child undergoing cancer treatment can be emotionally and physical draining, parents may find it difficult to commit their time to a set number of sessions focusing on their supportive needs. For the Parent Support Group Intervention evaluated by this study, parents could attend as many sessions as they could and did not have to commit their attendance to the 8-week intervention. To attend the Parent Support Group Intervention, parents could come for as many as the eight sessions offered or any number of sessions. Although the actual sessions were relatively informal, the group had some structure and therefore drop-in was discouraged as this disrupted the flow of the discussions. Table 5 below represents the weekly afternoon and evening attendance record over the course of the eight-week intervention. Figure 2 represents the number of times each participant attended the Parent Support Group Intervention. The mean number of times parents attended the Parent Support Group Intervention was 2 times.

Reasons why parents decided not to participate in the Parent Support Group Intervention when contacted were as follows: child-care for children was unavailable, they were feeling too overwhelmed to participate, they were not interested, the hospital brought back painful memories.
or other commitments (i.e. family vacation, working) impeded their ability to participate. Table 7 depicts which recruitment tool was utilized by parents in order to facilitate their participation in the Parent Support Group Intervention.

Table 5

Attendance Record

<table>
<thead>
<tr>
<th>Session</th>
<th>Number of Parents Attending (Afternoon)</th>
<th>Number of Parents Attending (Evening)</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week 1</td>
<td>5</td>
<td>4</td>
<td>9</td>
</tr>
<tr>
<td>Week 2</td>
<td>6</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Week 3</td>
<td>2</td>
<td>7</td>
<td>9</td>
</tr>
<tr>
<td>Week 4</td>
<td>3</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>Week 5</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Week 6</td>
<td>3</td>
<td>0</td>
<td>3</td>
</tr>
<tr>
<td>Week 7</td>
<td>1</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Week 8</td>
<td>3</td>
<td>7</td>
<td>10</td>
</tr>
<tr>
<td>TOTAL</td>
<td>23</td>
<td>35</td>
<td>60</td>
</tr>
</tbody>
</table>
Figure 2.

The number of times each participant attended the Parent Support Group Intervention
Table 6

*How Parents found out about the Parent Support Group Intervention*

<table>
<thead>
<tr>
<th>How Parents Found out about the Parent Support Group Intervention (Recruitment Tool Used)</th>
<th>Number of Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent Support Survey</td>
<td>47</td>
</tr>
<tr>
<td>Overhead Announcement</td>
<td>11</td>
</tr>
<tr>
<td>Poster</td>
<td>0</td>
</tr>
<tr>
<td>Brainchild/OPACC Newsletter</td>
<td>0</td>
</tr>
<tr>
<td>Referred by Staff from the Hem/Onc Dept.</td>
<td>0</td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>60</strong></td>
</tr>
</tbody>
</table>
Some parents participated in the parent support group for only one session, while others attended multiple sessions. Figure 3 represents how many parents attended one, two, three or more sessions.

Figure 3.

*Parental Attendance*
Results pertaining to gender and whether or not parents attended the Parent Support Group Intervention once vs. more than once can be seen below in Figure 4. In total, five males attended the Parent Support Group Intervention once and four attended more than once. Eight females attended the Parent Support Group Intervention once and eleven attended the more than once.

Figure 4.

*Gender and Frequency of Attendance*
4.2.4 - Preliminary Outcomes

4.2.4a Assessment of Outcome Measures

Parents described the outcome measures as easy to use and understand. For some parents, English was not their primary language and minor assistance was required by KM to clarify terms. Parents seemed to be comfortable filling out the other measures but asked the most questions when completing the VAS scales. As a result, KM ensured that an adequate amount of time was spent with each parent to explain how to properly fill out the VAS forms.

For parents who had not previously attended a session of the Parent Support Group Intervention, the complete package of pre-session measures took approximately 15 minutes at the beginning of the session. For parents who were returning to the support group, the pre-session measures only included the VAS scales and took approximately 5 minutes to complete. All parents regardless of whether or not they had attended the Parent Support Group Intervention previously, completed the same post-session measures.

4.2.4b VAS Results

a) Pre- and Post- VAS Results for Each Parent’s First Time Attending a Parent Support Group Intervention Session

In total, 28 parents completed pre-VAS and post-VAS measures during the first parent support group they attended. A paired sample T-Test was used to compare the pre-VAS and post-VAS scores of these parents. Results are presented below in Figure 5 and Table 7. There was a significant increase from pre- to post-VAS scores for Knowledge of How Other Parents of Children Having Cancer Cope (t=4.824, p=0.000); Knowledge of Resource Availability (t=4.818, p=0.000); Knowledge of Family Support Management (t=2.700, p=0.000); Perception of Receipt of Social Support (t=5.359, p=0.000); and Future concerns regarding diagnosis and treatment (t=3.989; p=0.000). In addition, there was a significant decrease from pre- and post- VAS scores
for Feeling tense/ ‘wound up’ (t=2.693, p=0.012) and Feeling tired/without energy (t=3.240, p=0.003). However, there was not a significant difference in the pre- and post-VAS scores for Current concerns regarding treatment and side-effect management (t=1.053, p=0.302).

These results suggest that, parents generally benefited from attending the Parent Support Group Intervention after attending one or more group sessions. Specifically, parents gained more information regarding how other parents cope with childhood cancer, community, hospital and family resource availability, showed a reduction in personal feelings of distress and anxiety, perceived an increase in social support and showed a decrease in future concerns regarding their child’s diagnosis and treatment.
Figure 5
Comparison of Pre- and Post- VAS Scores for Each Parent’s First Time Attending the Parent Support Group Intervention

Legend

Q #1 Knowledge of Dx and Tx - Current concerns regarding treatment and side-effect management
Q #2 Hospital/Community/ Family Resources – Knowledge of How Other Parents of Children Having Cancer Cope
Q #3 Hospital/Community/ Family Resources – Knowledge of Resource Availability
Q #4 Perception of Social Support - Knowledge of Family Support Management
Q #5 Perception of Social Support – Perception of Receipt of Social Support
Q #6 Personal Feelings of Distress & Anxiety – Feeling tense/ ‘wound up’
Q #7 Personal Feelings of Distress & Anxiety – Feeling tired/without energy
Q #8 Knowledge of Dx/Tx – Future concerns regarding diagnosis and treatment

*p < 0.05
### Table 7

Paired Sample T-Test Comparison of Pre- and Post- VAS Scores for Each Parent’s First Time Attending the Parent Support Group Intervention

<table>
<thead>
<tr>
<th>Q #1 Knowledge of Dx and Tx</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
<th>95% Confidence Interval of the Difference</th>
<th>t</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current concerns regarding treatment and side-effect management</td>
<td>0.2921</td>
<td>1.468</td>
<td>0.277</td>
<td>-0.277</td>
<td>0.862</td>
<td>1.053</td>
<td>27</td>
</tr>
<tr>
<td>Q #2 Hospital/Community/ Family Resources – Knowledge of How Other Parents of Children Having Cancer Cope</td>
<td>2.942</td>
<td>3.227</td>
<td>0.610</td>
<td>1.691</td>
<td>4.193</td>
<td>4.824</td>
<td>27</td>
</tr>
<tr>
<td>Q #3 Hospital/Community/ Family Resources – Knowledge of Resource Availability</td>
<td>3.627</td>
<td>3.984</td>
<td>0.753</td>
<td>2.082</td>
<td>5.172</td>
<td>4.818</td>
<td>27</td>
</tr>
<tr>
<td>Q #4 Perception of Social Support – Knowledge of Family Support Management</td>
<td>1.317</td>
<td>2.581</td>
<td>0.488</td>
<td>0.316</td>
<td>2.318</td>
<td>2.700</td>
<td>27</td>
</tr>
<tr>
<td>Q #5 Perception of Social Support – Perception of Receipt of Social Support</td>
<td>2.475</td>
<td>2.444</td>
<td>0.462</td>
<td>1.527</td>
<td>3.423</td>
<td>5.359</td>
<td>27</td>
</tr>
<tr>
<td>Q #6 Personal Feelings of Distress &amp; Anxiety – Feeling tense/ ‘wound up’</td>
<td>1.591</td>
<td>3.127</td>
<td>0.591</td>
<td>0.380</td>
<td>2.804</td>
<td>2.693</td>
<td>27</td>
</tr>
<tr>
<td>Q #7 Personal Feelings of Distress &amp; Anxiety – Feeling tired/without energy</td>
<td>1.512</td>
<td>2.469</td>
<td>0.467</td>
<td>0.555</td>
<td>2.469</td>
<td>3.240</td>
<td>27</td>
</tr>
<tr>
<td>Q #8 Knowledge of Dx/Tx – Future concerns regarding diagnosis and treatment</td>
<td>2.311</td>
<td>3.074</td>
<td>0.581</td>
<td>1.119</td>
<td>3.504</td>
<td>3.979</td>
<td>27</td>
</tr>
</tbody>
</table>

*p<0.05
b) Pre- and Post- VAS Results for Parents Attending the Parent Support Group Intervention Only Once vs. those Attending More than Once

In total, 14 parents attended the Parent Support Group Intervention only once and 14 parents attended the group more than once. For each group (attended once vs. attended more than once) the difference between pre- and post- VAS scores were calculated for each question and then an average difference was calculated for each question across parents. Descriptive statistics are presented in Table 8.

An independent-samples t-test was conducted to compare the mean difference in pre- and post- VAS scores of the two groups. Results are presented below in Table 9. There was a significant difference between the groups for Question #3: Hospital/Community/Family Resources – *Knowledge of Resource Availability*. Thus, parents who attended the support group only once (M=5.448, SD=3.423) had a larger pre-post difference than those who attended the support group more than once (M=1.530, SD=2.390); t (26)=3.511, p =0.002. Other VAS questions showed no significant difference between pre- and post VAS scores between both groups. These results suggest that the greatest improvement for parents occurred after attending the first session.
Table 8

Pre- and Post- VAS Score Differences for Parents Attending the Parent Support Group Intervention Only Once vs. Those Attending More than Once

<table>
<thead>
<tr>
<th>Q #1 (Difference) Knowledge of Dx and Tx</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current concerns regarding treatment and side-effect management</td>
<td>Once</td>
<td>14</td>
<td>0.175</td>
<td>1.672</td>
</tr>
<tr>
<td>More than Once</td>
<td>14</td>
<td>1.980</td>
<td>3.426</td>
<td>0.916</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q #2 (Difference) Hospital/Community/Family Resources – Knowledge of How Other Parents of Children Having Cancer Cope</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td>14</td>
<td>3.686</td>
<td>2.845</td>
<td>0.760</td>
</tr>
<tr>
<td>More than Once</td>
<td>14</td>
<td>2.031</td>
<td>1.854</td>
<td>0.496</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q #3 Hospital/Community/Family Resources – Knowledge of Resource Availability</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td>14</td>
<td>5.448*</td>
<td>3.423</td>
<td>0.915</td>
</tr>
<tr>
<td>More than Once</td>
<td>14</td>
<td>1.530</td>
<td>2.390</td>
<td>0.639</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q #4 Perception of Social Support - Knowledge of Family Support Management</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td>14</td>
<td>1.325</td>
<td>3.234</td>
<td>0.864</td>
</tr>
<tr>
<td>More than Once</td>
<td>14</td>
<td>1.784</td>
<td>1.845</td>
<td>0.493</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q #5 Perception of Social Support – Perception of Receipt of Social Support</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td>14</td>
<td>1.849</td>
<td>2.410</td>
<td>0.644</td>
</tr>
<tr>
<td>More than Once</td>
<td>14</td>
<td>2.294</td>
<td>2.783</td>
<td>0.744</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q #6 Personal Feelings of Distress &amp; Anxiety – Feeling tense/‘wound up’</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td>14</td>
<td>2.337</td>
<td>3.270</td>
<td>0.874</td>
</tr>
<tr>
<td>More than Once</td>
<td>14</td>
<td>2.031</td>
<td>1.903</td>
<td>0.509</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q #7 Personal Feelings of Distress &amp; Anxiety – Feeling tired/without energy</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td>14</td>
<td>0.969</td>
<td>1.637</td>
<td>0.438</td>
</tr>
<tr>
<td>More than Once</td>
<td>14</td>
<td>0.949</td>
<td>3.120</td>
<td>0.834</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q #8 Knowledge of Dx/Tx – Future concerns regarding diagnosis and treatment</th>
<th>N</th>
<th>Mean</th>
<th>Std. Deviation</th>
<th>Std. Error Mean</th>
</tr>
</thead>
<tbody>
<tr>
<td>Once</td>
<td>14</td>
<td>1.718</td>
<td>2.344</td>
<td>0.626</td>
</tr>
<tr>
<td>More than Once</td>
<td>14</td>
<td>2.363</td>
<td>2.402</td>
<td>0.642</td>
</tr>
</tbody>
</table>

*p<0.05
Table 9

Comparisons of Pre- and Post- VAS Score Differences for Parents Attending the Parent Support Group Intervention Only Once vs. Those Attending More than Once

**Independent Samples T-Test**

<table>
<thead>
<tr>
<th>Q #1 (Difference) Knowledge of Dx and Tx</th>
<th>Equal Variances Assumed</th>
<th>Equal Variances Not Assumed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge of Dx and Tx</td>
<td>F = 4.961, Sig. = 0.035</td>
<td>F = 4.961, Sig. = 0.035</td>
</tr>
<tr>
<td>Current concerns regarding treatment and side-effect management</td>
<td>t = -1.772, df = 26, Sig. (2-tailed) = 0.88</td>
<td>t = -1.772, df = 18.853, Sig. (2-tailed) = 0.093</td>
</tr>
<tr>
<td>Mean Difference</td>
<td>-1.806</td>
<td>-1.806</td>
</tr>
<tr>
<td>St. Error Difference</td>
<td>1.020</td>
<td>1.020</td>
</tr>
<tr>
<td>95% Confidence Interval</td>
<td>Lower</td>
<td>Upper</td>
</tr>
<tr>
<td>Q #2 (Difference) Hospital/Community/Family Resources – Knowledge of How Other Parents of Children Having Cancer Cope</td>
<td>Equal Variances Assumed</td>
<td>Equal Variances Not Assumed</td>
</tr>
<tr>
<td>Equal Variances Assumed</td>
<td>F = 3.317, Sig. = 0.080</td>
<td>F = 3.317, Sig. = 0.080</td>
</tr>
<tr>
<td>Equal Variances Not Assumed</td>
<td>t = 1.824, df = 26, Sig. (2-tailed) = 0.080</td>
<td>t = 1.824, df = 22.355, Sig. (2-tailed) = 0.082</td>
</tr>
<tr>
<td>Mean Difference</td>
<td>1.656</td>
<td>1.656</td>
</tr>
<tr>
<td>St. Error Difference</td>
<td>0.908</td>
<td>0.908</td>
</tr>
<tr>
<td>95% Confidence Interval</td>
<td>Lower</td>
<td>Upper</td>
</tr>
<tr>
<td>Q #3 (Difference) Hospital/Community/Family Resources – Knowledge of Resource Availability</td>
<td>Equal Variances Assumed</td>
<td>Equal Variances Not Assumed</td>
</tr>
<tr>
<td>Equal Variances Assumed</td>
<td>F = 1.564, Sig. = 0.222</td>
<td>F = 1.564, Sig. = 0.222</td>
</tr>
<tr>
<td>Equal Variances Not Assumed</td>
<td>t = 3.511, df = 26, Sig. (2-tailed) = 0.002</td>
<td>t = 3.511, df = 23.241, Sig. (2-tailed) = 0.002</td>
</tr>
<tr>
<td>Mean Difference</td>
<td>3.917</td>
<td>3.917</td>
</tr>
<tr>
<td>St. Error Difference</td>
<td>1.116</td>
<td>1.116</td>
</tr>
<tr>
<td>95% Confidence Interval</td>
<td>Lower</td>
<td>Upper</td>
</tr>
<tr>
<td>Q #4 Social</td>
<td>Equal Variances</td>
<td>Equal Variances</td>
</tr>
<tr>
<td>Equal Variances</td>
<td>F = 2.717, Sig. = 0.111</td>
<td>F = 2.717, Sig. = 0.111</td>
</tr>
<tr>
<td>t = -0.462, df = 26, Sig. (2-tailed) = 0.648</td>
<td>t = -0.462, df = 26, Sig. (2-tailed) = 0.648</td>
<td></td>
</tr>
<tr>
<td>Mean Difference</td>
<td>-0.459</td>
<td>-0.459</td>
</tr>
<tr>
<td>St. Error Difference</td>
<td>0.995</td>
<td>0.995</td>
</tr>
<tr>
<td>95% Confidence Interval</td>
<td>Lower</td>
<td>Upper</td>
</tr>
</tbody>
</table>

67
<table>
<thead>
<tr>
<th>Question</th>
<th>Type</th>
<th>N</th>
<th>Mean 1</th>
<th>SD 1</th>
<th>Mean 2</th>
<th>SD 2</th>
<th>t</th>
<th>df</th>
<th>p</th>
</tr>
</thead>
<tbody>
<tr>
<td>Support - Knowledge of Family Support Management</td>
<td>Assumed Equal Variances</td>
<td>0.004</td>
<td>0.951</td>
<td>-0.453</td>
<td>26</td>
<td>0.654</td>
<td>-0.446</td>
<td>0.984</td>
<td>-2.468</td>
</tr>
<tr>
<td></td>
<td>Not Assumed Equal Variances</td>
<td>0.004</td>
<td>0.951</td>
<td>-0.453</td>
<td>26</td>
<td>0.654</td>
<td>-0.446</td>
<td>0.984</td>
<td>-2.468</td>
</tr>
<tr>
<td>Q #5 Social Support – Perception of Receipt of Social Support</td>
<td>Assumed Equal Variances</td>
<td>3.100</td>
<td>0.090</td>
<td>0.302</td>
<td>26</td>
<td>0.765</td>
<td>0.306</td>
<td>1.011</td>
<td>-1.773</td>
</tr>
<tr>
<td></td>
<td>Not Assumed Equal Variances</td>
<td>3.100</td>
<td>0.090</td>
<td>0.302</td>
<td>26</td>
<td>0.765</td>
<td>0.306</td>
<td>1.011</td>
<td>-1.798</td>
</tr>
<tr>
<td>Q #6 Parental Stress/Anxiety – Feeling tense/‘wound up’</td>
<td>Assumed Equal Variances</td>
<td>3.183</td>
<td>0.086</td>
<td>0.020</td>
<td>26</td>
<td>0.984</td>
<td>0.193</td>
<td>0.942</td>
<td>-1.917</td>
</tr>
<tr>
<td></td>
<td>Not Assumed Equal Variances</td>
<td>3.183</td>
<td>0.086</td>
<td>0.020</td>
<td>26</td>
<td>0.984</td>
<td>0.193</td>
<td>0.942</td>
<td>-1.947</td>
</tr>
<tr>
<td>Q #7 Parental Stress/Anxiety – Feeling tired/without energy</td>
<td>Assumed Equal Variances</td>
<td>0.059</td>
<td>0.810</td>
<td>-0.719</td>
<td>26</td>
<td>0.478</td>
<td>-0.645</td>
<td>0.897</td>
<td>-2.489</td>
</tr>
<tr>
<td></td>
<td>Not Assumed Equal Variances</td>
<td>0.059</td>
<td>0.810</td>
<td>-0.719</td>
<td>26</td>
<td>0.478</td>
<td>-0.645</td>
<td>0.897</td>
<td>-2.489</td>
</tr>
</tbody>
</table>

*p < 0.05
CHAPTER 5

Discussion

This section will begin with a discussion pertaining to Phase 1: The Parent Support Survey. In particular, advantages and limitations relating to Phase 1 will be highlighted. To follow, Phase II: The Parent Support Group Intervention will be reflected upon. As well, advantages and limitations of Phase II will be highlighted.

5.1 Phase I: The Parent Support Survey

As hypothesized, parents of children with cancer expressed a high degree of interest in support groups. They also expressed high interest in individual support as well as other forms of support such as family activity groups. This finding suggests that parents had diverse needs for support. Given the cost-effective nature of group intervention it was important to explore parental preferences for this format.

Parents’ preferences for an open format support group co-facilitated by both a parent and a health care professional versus the traditional group that is run by a parent or a health professional on their own was an important finding. This preference may reflect parental acknowledgment of wanting information and support that can address caring for the child with cancer and concerns about the family that included both professional knowledge and parental experience. Furthermore, parents preferred a support group where they could attend as many (or as few) sessions as they could. This preference likely reflects parental acknowledgement of wanting support that can reasonably accommodate their busy schedule caring for their child with cancer. This information formed the basis for the development of a new model of parent support group, which was informal and facilitated by both a healthcare professional and parent.

As hypothesized, mothers appeared to be more motivated than fathers to join support groups, even in the form of online groups, previously reported to be preferred by fathers.
(Nicholas et al., 2009). Fulfilling emotional needs and obtaining guidance for family or relationship issues were the main maternal reasons for wanting to join groups, whereas getting information was the main paternal reason. Moreover, mothers were also more likely than fathers to favor supports such as family activities and yoga-based groups. This finding suggests that mothers may be more likely to consider resources that reflect their need to balance family obligations in addition to maintaining their personal health and well being.

The gender differences in preferences for support group participation found in this study are consistent with the literature documenting that mothers engage in more support-seeking behaviours and health system usage than fathers (Hoekstra-Weebers et al., 1998; Yeh, 2002; Tamres, Janicki & Helgeson, 2002). The difference in support group need may be explained partly by the fact that mothers in this study were the primary caregivers, which is also commonly reported in other studies (Yeh, 2002). As the primary caregiver, in addition to holding the main responsibility to care for the child with cancer, facing daily treatment decisions and witnessing the child suffering, mothers must ensure that care for other children, if they have them, is in place (Barrera et al., 2008). Furthermore, the parent acting as the primary caregiver may remain with the hospitalized child for long periods of time, often away from their hometown. Thus, the caregiver role may require being separated from the other children, partner, and personal sources of emotional, mental, and social support (James et al., 2002). Moreover, fathers’ preferred choice for support, which was to receive information from guest speakers regarding treatment, may reflect the fact that mothers served as the source of information for fathers who did not always have the opportunity to interact with the medical team regarding the child’s treatment. This interpretation is supported by a study comparing the psychological distress of mothers and fathers who were the primary caregivers of a child with cancer in which no differences were found.
between the groups on measures of distress or illness-related parenting distress (Bonner et al., 2007).

Contrary to our hypotheses, parental age, educational level, employment status, and child’s diagnosis and treatment variables have no effect on parental preferences for support groups, even when some of these factors (parental age and child’s diagnosis) have been found to be associated with psychological distress in the past (Barrera et al., 2011; Vrijmoet-Wiersma et al., 2008; Sloper, 2000). Thus, it is possible that, except for gender differences, parental perception of their needs for support and preferred form for support may be common to parents of children with cancer in general.

Phase I of this study presents with potential limitations. Parents of children with brain tumours were underrepresented in this study. This is unfortunate, given that these parents are known to experience high levels of distress related to the adverse effects of brain tumour diagnosis and treatment and may show distinctive needs for supportive services (Anclair, Hoven, Lanning & Boman, 2009). Thus, it is possible that parents of children with brain tumors were underrepresented because they may have been too overwhelmed with the demands of their child’s treatment during clinic visits. A low participation rate by fathers is another limitation of Phase I of this study. Although this pattern is common in the literature, it is possible that the low response rate for fathers simply reflects the fact that more mothers than fathers attend out-patient clinic appointments. Greater efforts should be made in future studies to facilitate fathers’ participation in research in general and to determine paternal views of their supportive needs.

A possible advantage to this study is that although parents were recruited from a single institution, this site is one of the largest pediatric cancer centers in North America, and serves a large ethno-culturally diverse population. Unlike previous studies, which typically included predominantly middle-class white participants (Dahlquist, Czyzewski, & Copeland 1993;
Greening, 1999), this sample has a larger portion of participants born outside of Canada. Thus, the sample is likely to be representative of the wider perspective of parents of children with cancer in the population.

This study represents one of the first efforts to undertake an evaluation of parents’ perspectives on their needs and preferences for support groups in particular and highlights important gender differences in the information obtained. The findings of this study suggest that the supportive needs of mothers and fathers of children with cancer may be best met in different ways. Mothers have a stronger preference for support groups that are open and flexible (e.g. attend any session, online), and that are directed to their emotional and relational needs (e.g. expressing frustration, involving family activities), and their physical and mental well-being (e.g. practicing yoga). Although the number of fathers in our sample was limited, it appears that fathers have unmet information needs which must be addressed. These findings are the basis for the development and evaluation of a co-facilitated parent and health professional support group. The limited research in this area suggests that support group needs and the efficacy of such groups require further investigation. Developing interventions to address the unique needs of mothers and fathers of children with cancer is crucial to improving the quality of pediatric oncology care for patients and their families.
5.2 **Phase II: The Parent Support Group Intervention**

The Parent Support Group Intervention was created based on results from the Parent Support Survey to meet some of the unique supportive care needs of caregivers during their child’s cancer trajectory. The development of the Parent Support Group Intervention had the broad goal of addressing the following parental concerns: 1) Knowledge of Diagnosis and Treatment; 2) Knowledge of Community, Hospital and Family Resource Availability; 3) Perception of Social support; and, 4) Personal Feelings of Distress and Anxiety. Through conducting this pilot study, the feasibility of the Parent Support Group Intervention was assessed by examining program acceptability, recruitment and retention and preliminary outcomes. As well, unique features and challenges pertaining to the delivery of family interventions in the pediatric oncology setting were highlighted.

As hypothesized, mothers were more likely to participate in the co-facilitated Parent Support Group Intervention versus fathers. This trend was not surprising given the results of Phase I, and past research that has shown women to be more reliant on social support, as a form of coping with their child’s diagnosis and treatment, compared to men (Verbrugge, 1985). As well, as indicated above, literature shows that mothers are more likely to act as the primary caregiver to their child having cancer (Yeh, 2002). Multiple obligations including caring for their sick child as well as trying to support the family emotionally as a whole, may contribute to mothers showing elevated levels of distress compared to fathers. Feelings of distress, a gender preference for social support as well as the fact that mothers were more likely to already be with their child at the hospital may have contributed to a higher support group participation rate amongst mothers compared to fathers.

Demographic characteristics of parents attending the Parent Support Group Intervention were quite similar to parents who had completed the Parent Support Survey. Amongst both the
Parent Support Group Intervention and the Parent Support Survey, mothers were more likely then fathers to participate based on the fact that they were more likely to act as the primary caregiver. As well, in both the Parent Support Survey and the Parent Support Group Intervention, the average age of participants was between 35-45 years of age and the majority were married or partnered. Parents in both groups were also more likely to be working full time or on leave from work because of their child’s illness. Furthermore, the majority lived <100km away from the hospital. Similarities in demographic characteristics of participating parents in Phase I and Phase II suggest that both phases attracted middle aged mothers, living nearby, who were currently or had been employed.

A higher percentage of parents participating in the Parent Support Group Intervention (82.14%) had attained some degree of post-secondary education compared to parents who completed the Parent Support Survey (57.41%). As well, parents participating in the Parent Support Group Intervention (71.43%) were more likely to be born in Canada versus parents participating in the Parent Support Survey where only 41.67% of parents were born in Canada. Due to possible language barriers, we postulate that parents born outside of Canada may have been reluctant to participate in an English-speaking support group. In the future, options such as arranging a translator for non-English speaking parents attending sessions may be an idea further explored. Alternatively, perhaps parents who were born in Canada had more personal and social resources such as supports for child care then parents who were not born in Canada, which could have influenced their higher participation rate. The above findings suggest that the Parent Support Group Intervention tended to attract parents who were educated and non-immigrants, which is consistent with past literature focusing on support group participation.

To this date, few studies have investigated socio-demographic differences between parents of children having cancer who attend support groups versus those who do not. However,
Heller, Roccoforte & Cook (1997), investigated unique socio-demographic characteristics of family members who participated in a support group for individuals having a relative with mental illness. Group participants were more likely to be white, educated, middle-aged and middle income (Heller, Roccoforte & Cook, 1997). As well, parents of children with cancer who participated in the Computer Mediated Support Group carried out by Bragadottir (2008) showed distinct socio-demographic characteristics. For example, the majority of parents were middle aged and had formal education beyond high school. These findings are comparable to the socio-demographic characteristics of parents who participated in the Parent Support Group Intervention suggesting that individuals participating in support groups may be more likely to be white, middle aged and educated. Meaning, parents that may need support the most may be unable to attend due to their lack of resources (e.g. child care) and inability to commit time to their personal needs. Greater efforts need to be made to engage these parents that may need the most support.

Demographic and medical characteristics of Parent Support Group Intervention and Parent Support Survey participants’ children with cancer showed both similarities and differences. The majority of the children in both groups were female and diagnosed with leukemia/lymphoma. It was not surprising that the majority of children were diagnosed with leukemia/lymphoma as leukemia is the most common childhood cancer affecting children (American Cancer Society, 2011). According to the literature, leukemia accounts for 34% of all cancers in children (American Cancer Society, 2011). Just as with the Parent Support Survey, only a small percentage of parents of children with brain tumours participated in the Parent Support Group Intervention. This may be due to the fact that brain tumour patients often require the most aggressive and time intensive treatments. Parents may feel as though they do not have the time to attend to their own needs. However, the low participation rate amongst parents of children having brain tumours was surprising based on the fact that brain tumours are the second
most common cancers to affect children (American Cancer Society, 2011). It is unfortunate that so few parents having a child diagnosed with brain tumours participated in both the Parent Support Group Intervention and Parent Support Survey. Children with brain tumours show a high risk for permanent late sequelae (Pediatric Brain Tumour Foundation, 2012), as well as a high degree of associated parental distress as a result of the child’s diagnosis and treatment (Anclair et al., 2009; Van Donge-Melman et al., 1995;). Parents of children having brain tumours may have greatly benefited from supportive services such as the Parent Support Group Intervention based on their unique supportive care needs. Greater effort needs to be made in the future to recruit parents of children having brain tumors. Two recruitment strategies that may be beneficial include spending two consecutive weeks in the brain tumour clinic recruiting parents as well as obtaining contact information for these parents and personally inviting them to participate in future Parent Support Group Interventions.

Parents participating in the Parent Support Group Intervention were less likely to have a child on active treatment (46.42%) compared to parents participating in the Parent Support Survey where 69.44% of children were on active treatment. This may be due to the fact that participation in the Parent Support Survey required less of a time commitment (approximately 10-15 minutes), compared to participation in the Parent Support Group Intervention which required more of a time commitment (1.5 hours). Because of the multiple demands placed on caregivers caring for a child with cancer, parents having a child on active treatment may have felt that they did not have the time to take care of their own supportive care needs by participating in the Parent Support Group Intervention. Consequently, they did not consider their own needs a priority. This is unfortunate as parents having a child on active treatment may benefit the most from supportive services. Parents of children on active treatment are more likely to report symptoms of distress compared to parents who have finished treatment (Sawyer et al., 2000). It
is hypothesized that once the child finished active treatment, parents then allowed themselves to focus on their own needs. This may be why a higher percentage of parents having a child not on active treatment participated in the Parent Support Group Intervention.

Based on feedback from parents and co-facilitators (health care professional and an experienced parent), participating in the Parent Support Group Intervention, the support group was viewed positively and appears to be an acceptable mode of delivery of supportive care. Despite results from the Parent Support Survey showing a keen interest amongst parents to attend a face-to-face based support group, certain barriers seemed to impede parent’s ability to participate. A common concern voiced by both co-facilitators and parents was that groups were run during the summer when it was difficult at times for participants to commit their consistent involvement with the group. A lower participation rate than expected may have been due to the seasonal effect of parent’s having to arrange more child care during the summer months or because of other commitments such as family vacation. This was not surprising as time commitment seems to be a common barrier in the delivery of support groups (Baum, 2004; Chesler & Chesney, 1995;). Based on past research, other reasons for support group nonparticipation include distance to meeting site and parents discomfort with expressing themselves in a group (Chesler & Chesney, 1995; Bragadottir, 2008). As a result, support groups that are sensitive to the time constraints faced by parents and allow parents to engage with other parents in a more anonymous fashion may be an alternative form of support for parents.

Online support groups such as the Computer Mediated Support Group (CMSG) for parents (Bragadottir, 2008) may be a viable alternative to face-to-face support groups catered to parents of children having cancer. The unique and beneficial feature of an online support group is that parents have the ability to log onto the support group during a time that best fits with their schedule. As well, parents are able to communicate with other parents undergoing a similar
situation in an anonymous fashion versus through face-to-face communication. Interestingly, the CMSG study completed by Bragadottir (2008) had an almost equal participation rate amongst both mothers and fathers. Fathers may be more likely to join an online-based support group because they find it less intimating then a face-to-face based support group. Because fathers tend to be less likely to communicate their discomfort and talk about their feelings compared to mothers (Wool and Barsky, 1994), logging onto an online support group and being able to speak anonymously may encourage fathers to participate in support groups. A clear gender difference was seen in CMSG use amongst both mothers and fathers. Mothers wrote and read messages while fathers primarily read messages. Despite the fact that fathers were less likely to write messages, mean scores for the health-related variables indicated statistically significant improvement in fathers’ anxiety and stress during the time of the CMSG. Despite differences in communication styles between both mothers and fathers, online support groups seem to attract equal participation amongst both genders with resulting improvements in health related outcomes amongst both groups. Pilot testing a co-facilitated online Parent Support Group Intervention may be a feasible option to consider in the future enhancing group participation amongst both genders.

Results from the Acceptability Questionnaire showed a keen interest amongst parents to spend more time discussing treatment and side effect management during the parent support group sessions. These findings are consistent with results from Kerr, Harrison, Medvews, Tranmer & Fitch, (2007), who assessed supportive care needs from the perspective of parents of children diagnosed with cancer within an urban region of Ontario. In this study, informational needs were one of the most frequently acknowledged categories of need amongst parents. As well, these results are consistent with a review of 49 studies outlining supportive care needs amongst parents of children having cancer (Kerr, Harrison, Medvews & Tranmer, 2004). Kerr et al., (2004), showed that based on previous studies, informational needs were cited 88% of the
time as a category of need amongst parents. The most essential information need cited was “general medical information about the child’s illness” (Kerr et al., 2004). Meaning, parents seem to have a range of supportive care needs including a clear need for more information concerning their child’s diagnosis, treatment and side effect management. Attempts to ensure that this need amongst others is met when future parents support groups are executed is of paramount importance.

Carrying out interventions in the pediatric oncology setting can present with unique challenges. Apprehension surrounding the complexity of working with parents of children having cancer and inherent suggestions that parents are difficult to recruit and retain has deterred past intervention studies from being created and executed (Kazak et al., 1995). The recruitment and retention of participants in any intervention study is essential in order to demonstrate program feasibility. Our data on recruitment and retention illustrates factors that may facilitate recruitment as well as other factors that may impede recruitment and retention amongst parents participating in a Parent Support Group Intervention.

Our results showed that 38% of parents who participated in the Parent Support Group Intervention attended afternoon sessions versus 58% of parents who attended evening sessions. We speculate that parents may have been more likely to attend evening sessions because the majority of parents were working full time. As well, competition with childcare during afternoon sessions may have impeded parent’s ability to participate. There was variability in how many parents participated in the Parent Support Group Intervention each week. Since the support group was carried out during the summer months, and many families may have been vacation this interfered with recruitment and consistent involvement with the group. In fact, when the support group was carried out during the end of the summer (Weeks 5, 6 & 7), the least number of parents participated. This may be because this period of time may have been considerably busy
for families, as children were getting ready to go back to school. Carrying out the Parent Support Group Intervention during a time other than the summer season may aid in the recruitment and retention of parents.

With regards to gender, females were more likely to participate in the Parent Support Group Intervention more than once vs. only once compared to males. Once again, this may be because women have been shown to rely more on social support as a way of coping with their child’s diagnosis, treatment and possibility of relapse. As well, because of the intimate nature and lack of anonymity characteristic of the face-to-face support group, fathers may have been more reluctant to commit their consistent involvement with the group (Verbrugge, 1985).

Parents who did not participate in the Parent Support Group Intervention identified common concerns, including unavailability of child-care, other commitments (i.e. family vacation, working), too overwhelmed to participate, disinterested, and the fact that the hospital brought back painful memories. The unavailability of child-care, however, seemed to be one of the most commonly voiced concerns regarding non-participation. Adding the provision of child card as an adjunct to the Parent Support Group Intervention may be a wise idea in order to enhance the recruitment and retention of parents in the future.

With regards to how parents found out about the Parent Support Group Intervention, the most powerful recruitment tool seemed to be contacting parents who had completed the Parent Support Survey (78% of parents recruited using this strategy). Each week, parents who had provided contact information on the Parent Support Survey were personally contacted and invited to participate in the Parent Support Group Intervention. As well, parents who had expressed interest were contacted the day before the support group session to confirm their attendance once again. Personally communicating with parents over the phone seemed to be particularly beneficial. Parents may feel as though a personal invitation to participate is attractive.
versus a more general invitation (e.g. our attempt to recruit parents using a poster). Eighteen percent of parents were also recruited via an overhead announcement made approximately an hour before the commencement of the group session each week. This recruitment strategy seemed to attract parents who had not previously heard of the Parent Support Group Intervention and had time available to spare as they were waiting for their child’s treatment. Overhead announcements, however, seemed to alert parents to the group but their attendance was secondary to their child’s treatment and consequently often they either came late or left early depending on the child’s treatment. Personally contacting parents seems to be a powerful recruitment tool that should be further utilized in order to facilitate recruitment and retention of support group participants in the future.

Our data shows that the majority of parents participating in the Parent Support Group Intervention attended once (46%) versus attending two sessions (27%) or more then three sessions (27%). Once again, we speculate that due to the fact that the sessions were carried out during the summer months it may have been difficult for parents to commit their consistent involvement with the group. Based on the positive feedback we received from the Acceptability Questionnaire it can be concluded that parents felt the Parent Support Group Intervention was perceived as beneficial by parents. We speculate that time availability was the main barrier impeding parents from participating versus the fact that they did not find the first session they attended to be useful.

Overall, the outcome measures utilized in this study seemed to be easy to use and understand based on feedback from parents. Because of the time constraints unique to our population of parents, a strong effort was made to create measures that were brief yet still captured changes in the primary outcomes we were interested in investigating. Being a pilot test, VAS measured were created based on the fact that no previous measures had been developed that
captured all of the primary outcomes we were interested in investigating (1) Knowledge of Diagnosis and Treatment; 2) Knowledge of Community, Hospital and Family Resource Availability; 3) Perception of Social support; and, 4) Personal Feelings of Distress and Anxiety) and could be carried out in a short amount of time. Standardized measures of anxiety and social support (e.g., the State Trait Anxiety Inventory (STAI) and Harter’s Social Support Scale (HSSS)) were reviewed and question themes were extracted in order to create VAS questions. Face validity was achieved by pilot testing the VAS amongst health care professionals and a parent representative from OPACC. In the future, established measures of distress used with adults treated for cancer may be useful to test distress amongst parents of children having cancer. Vodermaier, Linden & Siu (2009), performed a systematic review examining the psychometric properties of existing tools used to screen cancer patients for emotional distress. Among the short measures (those containing five to 20 items), the Center for Epidemiologic Studies-Depression Scale and the Hospital Anxiety and Depression Scale demonstrated good psychometric properties (Vodermaier, Linden & Siu 2009). Based on their brevity and sound psychometric properties, the standardized measures mentioned above may be useful in the implementation of future Parent Support Group Interventions.

As hypothesized, pre- and post- VAS results for each parent’s first time attending the Parent Support Group Intervention suggest that parents generally benefited from attending the group after attending one group session. Overall, parents gained more information pertaining to community, hospital and family resource availability, showed a reduction in personal feelings of distress and anxiety, perceived an increase in social support and showed a decrease in future concerns regarding their child’s diagnosis and treatment. The only specific outcome measured whereby parents did not seem to show an improvement in VAS scores after attending just on group session was regarding treatment and side effect management, suggesting that these
concerns were likely being addressed by the child’s treating team. Alternatively, it is possible that parents did not generally raise these concerns during the first time they attended the group. Interestingly, based on feedback from parents on the Acceptability Questionnaire, parents suggested that future Parent Support Group Intervention sessions place a greater emphasis on spending more time discussing treatment and side effect management. Allocating more time towards this topic seems to be of particular importance when planning and executing future Parent Support Groups.

Pre- and post- VAS comparison for parents attending the Parent Support Group only once versus those attending more than once, provided some surprising results. First, a significant difference was seen between the two groups of parents on a question pertaining to knowledge of resource availability with the difference being larger for the parents who attended the group only once. At first glance, it would appear that based on VAS results, parents did not seem to benefit much more from attending the Parent Support Group Intervention more than once. One possibility is that the range of the choices for the parental response reached a ceiling effect at session one with little information in terms of family resources obtained in subsequent sessions. After carrying out the support group, anecdotal information obtained by informal verbal communication with parents suggested that parents who attended the support group more than once seemed to adopt a sense of ‘social connectedness’ through regular engagement with other group members. This sense of ‘social connectedness’ parents demonstrated with other members of the group was not measured empirically by any of our objective measures yet was observed by co-facilitators carrying out the Parent Support Group Intervention and documented in the minutes of debriefing session. For example, parents were noted to engage in informal conversations with group members long after the session “officially” finished. This should be the focus of future investigation.
Social connectedness is a psychological term used to describe the quality and number of relationships people have with others (Ministry of Social Development, 2005). Social connectedness encompasses people joining together to achieve shared goals, which can benefit each other and society as a whole (Ministry of Social Development, 2005). Public Health Canada (2011), has stated that when individuals feel a sense a social connectedness, this can have a positive effect on their health and well-being. Individuals who feel connected to those around them are generally happier, in better physical and mental health and are more empowered to cope with changes and life transitions (Public Health Canada, 2011).

Social connectedness is a rather abstract term, which makes it difficult to measure objectively. However, through observation and interviews with group members this construct could be examined and researched in the future to determine whether social connectedness and consistent group involvement has a positive effect on the health and well being of parents.

In conducting this feasibility study, key hypotheses and research questions were answered. In Phase I, based on parental response, it was concluded that parents were interested in utilizing supportive services to fulfill their informational and emotional needs. Parents showed a ranged of supportive care needs as well as preferences as to how there needs could best be met (e.g. family activity groups, support groups featuring a guest speaker). As well, a clear gender difference was seen between mothers and fathers in terms of expressed need for support. This finding was not surprising based on past literature showing mothers to be more interested in engaging in supportive services compared to fathers (Hoekstra-Weebers et al., 1998; Yeh, 2002; Tamres, Janicki & Helgeson, 2002). However, it was surprising to find that younger parents, parents with less education and parents who were unemployed did not seem to show a higher need for support.

In Phase II, the goal of the current study was to assess the face validity and clinical
relevance of a PSGI. It was concluded that parents were interested in attending the PSGI and that mother’s were more likely then father’s to attend. This finding was not surprising based on our results from Phase I. Improvements in the majority of primary outcomes assessed by the VAS questions were seen after parents attended the PSGI once. Improvements in primary outcomes did not appear as pronounced as we had expected when a parent attended the PSGI more than once. It is speculated that this may be a result of both what was measured and how it was measured (VAS). Overall, healthcare professionals and parents deemed the Parent Support Group Intervention to be clinically relevant and doable. However, certain barriers such as childcare and the fact that the PSGI was carried out during the summer months did seem to impede parent’s ability to participate. Furthermore, healthcare professional and parents communicated constructive advice with regards to how to improve the implementation of Parent Support Group Interventions in the future.

In the future, measuring social connectedness may be important to assess as a construct that may change over time after attending frequent sessions. Finding a measure that is brief and valid (eliminating possible ceiling effects, which might have contributed to the limited differences between attending PSGI once and more than once), is appealing in order to adequately assess changes in the primary outcomes of interest.

The Pediatric Psychosocial Preventative Health Model (PPPHM) was utilized as a theoretical framework to guide the current research. This model was used as a biopsychosocial framework for assessing parents of children with cancer based on the fact that it was evidence based and considered findings in the pediatric health care setting. Just as the PPPHM had portrayed, the majority of parents who participated in both Phase I and Phase II of the current study could be classified into the Universal Group of families who appeared to be competent and fairly well adapted to their circumstances. By applying a preventative approach, it was important
to identify these families in order to support their inherent competence before future difficulties were encountered. A small minority of families who participated in both phases of the study could be classified into the Target and clinical groups of families who displayed risk factors (e.g. parent divorce, poverty, symptoms of depression) that predisposed them to difficulties that had the possibility of interfering with their ability to cope with their child’s illness. These groups of families may have benefited from the PSGI but may have needed more specific and targeted care, which needs to be considered in the future.

By identifying supportive care needs of families early on in the patient’s treatment trajectory interventions can be tailored to best meet the supportive care needs of each unique family. Overall, the PPPHM seemed to be useful evidence based model when applied to the current study. Based on results from this pilot study, the co-facilitated Parent Support Group Intervention may be a beneficial addition to the comprehensive treatment plan provided to families having a child with cancer. Although most families having a child with cancer seem to adjust quite well, supportive services provided throughout the patient’s treatment trajectory represents an area of keen interest. In the future, further implementation and evaluation of Parent Support Group Interventions will add to the provision of evidence-based interventions provided to families.
CHAPTER 6

Conclusion

The Parent Support Survey contributes to a growing body of research allowing parents of children with cancer to voice their unique supportive care needs and preferences. It is hoped that results from the Parent Support Survey will add further knowledge to the area of supportive care needs of parents of children with cancer both theoretically and empirically. Survey results showed a keen interest amongst parents in the creation of a future Parent Support Group Intervention. As well, the Parent Support Survey highlighted important gender differences in terms of how parents prefer their supportive care needs to be addressed. Findings were taken into consideration to create the co-facilitated Parent Support Group Intervention that would cater towards the distinct supportive care needs of this population.

The Parent Support Group Intervention was viewed positively by both parents and co-facilitators involved. We can conclude based on the findings from Phase II that demographic characteristics of parents involved in the Parent Support Group Intervention seem to be consistent with previous support group intervention studies. For example, parents tended to be white, middle aged and educated. Unfortunately, parents who may have needed support the most may have been unable to participate due to lack of time and/or resource availability (e.g. child care).

Parents who attended the support group more than once did not seem to show more improvement in constructs of interest measured by the VAS scales compared to parents who attended the support group only once. However, parents may have benefited from attending the Parent Support Group Intervention more than once yet our outcome measures may not have adequately captured these changes. A sense of social connectedness seemed to develop between parents who attended the support group more than once, as noted by co-facilitators’ observations. Other positive effects on parent’s outlook regarding their current situation, as a result of their
participation in the groups such as greater confidence in their role parenting a sick child may need to be investigated in future research.

The implementation and evaluation of this pilot study has left us with key research questions, which we plan on addressing in the future. For example, theoretically, is the Pediatric Psychosocial Preventative Health Model the best model we can use to identify parents in need of supportive services in order to provide them with the most adequate care? Clinically, should parents be offered supportive resources based on their initial psychosocial needs? Pertaining to future research, is there a standardized measure we could use in the future that would adequately capture changes in our primary outcomes of interest? As well, can we refine questions assessing knowledge of resource availability?

Information gained from the Parent Support Survey as well as the Parent Support Group Intervention will aid in the allocation of supportive services for parents of children having cancer both theoretically and empirically. With more work allocated towards the creation of a Parent Support Group Intervention to best meet the supportive needs of this subset of parents it is expected to be a useful addition to preventative family centered care. Support groups have the opportunity to provide a plethora of information and support to parents going through such a difficult time. Finally, it is hoped that this study will encourage other researchers to focus on supportive care needs of parents of children with cancer as well as the creation of future interventions in order to improve the quality of pediatric oncology care for both patients and their families.
CHAPTER 7

Future Directions

There are several directions guided by the results of this investigation. These include: (1) enhancing recruitment and retention of participants by offering the Parent Support Group Intervention during the school year, (2) offering a co-facilitated online based Parent Support Group Intervention, (3) finding a brief validated measure to capture constructs of interest, (4) finding a way to measure the construct of social connectedness, (5) introducing a yoga based support group intervention and finally, (6) encouraging funding for the implementation of future Parent Support Group Interventions, (7) exploring more directly why parents attend a Parent Support Group Intervention. This could be simply implemented by asking parents who have attended the Parent Support Group Intervention more frequently why they came.

(1) In order to enhance recruitment and retention of parents in the future, offering the Parent Support Group Intervention during the school year when children are back at school may be a viable alternative to our pilot test of the Parent Support Group Intervention during the summer season. (2) As well, offering a co-facilitated online-based Parent Support Group Intervention may attract more fathers and encourage their participation in the future.

(3) Finding a brief, validated outcome measure that more adequately captures the constructs of interest investigated in this study is of interest. (4) Furthermore, future effort will be devoted to finding a way to measure the construct social connectedness, to determine whether or not parents who attend the Parent Support Group Intervention session more consistently show an improvement in personal well-being through building relationships with other parents.

(5) It was interesting how mothers communicated through the Parent Support Survey a keen interest in attending a future yoga based support group intervention. Yoga, a complementary alternative medicine (CAM) based therapy, is traditionally believed to have beneficial effects on
both physical and emotional health (Iyengar & Razazan, 2001). The ancient Hindu language, defines \textit{yoga} to mean the union of the individual self with the universal self (Iyengar & Razazan, 2001). Even though yoga has been practiced for thousands of years, it has only been recently that empirical research has begun to emerge proving the value of the practice. Yoga has been shown to foster the development of a healthy body and a strong breath, which can lead to a deeper mastery of the mind and awareness to oneself and others (Bower et al., 2005). The effects of yoga have been explored amongst a number of patient populations including those with cardiac conditions, pain disorders, depression, anxiety, as well as healthy individuals (Bower et al., 2005). Several studies have documented some support for the feasibility and efficacy of yoga for these populations although controlled trials are lacking (Bower et al., 2005). To this date, the feasibility of a yoga based support group intervention particularly for parents of children with cancer has yet to be examined. Thus, pilot testing a yoga based support group intervention particularly for mothers and testing its feasibility is of future interest. This future study would aim to create a yoga based support group intervention that specifically targets the reduction of maternal distress, measured by symptoms of depression and anxiety, and promotes adaptive coping skills. That rationale behind this study being, if the mother’s health and well-being are addressed through her participation in a yoga intervention, this may have a positive effect on the functioning of the family as a whole, as well as the child with cancer.

(6) In order to pilot test future parent support group interventions funding is essential. Based on the results communicated by parents through the Parent Support Survey, there is a definite need for supportive services within the hospital setting. In particular, parents showed a clear interest in joining a support group to help meet their supportive care needs. Results from the execution of the Parent Support Group Intervention showed that parents benefited through participation. In an effort to reduce healthcare spending within the hospital setting, the
importance of establishing evidence based psychological interventions that help families having a child with cancer has been established (Kazak et al., 2005). Effective psychological interventions at diagnosis could contribute to lower expenses and overall spending on psychosocial care (Kazak et al., 2005).

(7) Finally, it would be advantageous to ask parents who attended the Parent Support Group Intervention more frequently what benefit they felt they were attaining from attending multiple sessions. Gaining this information may aid in the creation and recruitment for future support groups.

In summary, the present study helped to address important processes in the development and execution of interventions amongst parents of children with cancer. In the future, comments and suggestions communicated by parents and health-care professionals will be taken into account when creating support group interventions.
References


The Hematology/Oncology Department at SickKids in collaboration with Ontario Parents Advocating for Children with Cancer (www.OPACC.com) is considering offering parent support groups to families who have a child with cancer. We would like to better understand your needs as you cope with your child’s cancer treatment. To offer the best possible support, we are asking your help to complete this survey. This information is anonymous and does NOT require your name or your child’s name. Thank you very much for your time and input!

GENERAL INFORMATION ABOUT YOU AND YOUR FAMILY

1) Your age: _______  
2) Gender: □ Male □ Female
3) Marital status: □ Single □ Married/Partnered □ Divorced/Separated □ Widowed
4) Education: □ Less than high school □ High school diploma □ Post-secondary & above

5) Please check the box that best describes your (and/or your partner’s) employment status:

• Working now □ □
• Unemployed and looking for work □ □
• On leave because of child’s illness □ □
• On disability □ □
• Retired □ □
• Homemaker □ □
• Other (please specify): ____________________________ □ □

6) Were you born in Canada? □ YES □ NO and if not, what is your country of birth? _________
and in what year did you first come to Canada?
__________________________________________
7) Language(s) spoken at home

8) How comfortable are you with the English language?
   - Speak
     □ Not at all □ Very Little □ Somewhat □ Completely Fluent
   - Write
     □ Not at all □ Very Little □ Somewhat □ Completely Fluent

9) Where do you live (city/town)?

10) Travel distance from home to Sick Kids hospital: _____ km

11) How do you get to Sick Kids hospital?
    □ Personal car □ Transportation by Canadian Cancer Society □ Public transportation □ Taxi □ Other (please state):

12) Child’s age: _______    Child’s gender: □ Male □ Female
    Diagnosis: __________________________
    Date of diagnosis (mm/dd/yy):

13) Is your child:
    □ On Treatment or □ Finished Treatment, and if so, date treatment ended (mm/dd/yy):

14) Where does (did) your child receive treatment? (Please check all that apply.)
    □ Sick Kids Hospital and/or □ Another health care centre: __________________________

15) Do you have other children? □ YES □ NO. If yes, please state their age & gender:
    Child 1: □ Male □ Female    Age: ______    Child 3: □ Male □ Female    Age:
    __
    Child 2: □ Male □ Female    Age: ______    Child 4: □ Male □ Female    Age:
    __

ABOUT SUPPORT FOR PARENTS

1) Would you be interested in individual support to help you deal with stress related to your child’s illness? □ YES □ MAYBE □ NO
2) Have you ever participated in a support group for parents of children with cancer?

☐ YES  ☐ NO

3) Would you be interested, at some point, in attending such a group?  ☐ YES  ☐ MAYBE  ☐ NO

4) If you do NOT wish to attend such a group, why not? (Please check all that apply)
   i) Do not have time to attend  ☐
   ii) Are not interested/do not feel the need  ☐
   iii) Would need child care to attend  ☐
   iv) Feel uncomfortable with people you don’t know  ☐
   v) Other (please explain): ____________________________________________________________

6) Please mark your preferences if we developed a support group for parents: (Please check all that apply)

a) Best time for you to attend the group:
   ☐ Shortly after diagnosis   ☐ During treatment   ☐ After treatment
   ☐ Other (please describe) ____________________________________________________________

b) Meeting Format:  ☐ Set number of sessions   ☐ Drop-in basis

c) Day and time of meetings:   ☐ WEEKDAY and if so, time of day:  ☐ Morning  ☐ Afternoon  ☐ Evening
   ☐ WEEKEND and if so, time of day:  ☐ Morning  ☐ Afternoon  ☐ Evening

d) Meeting Timing:  ☐ WEEKLY  ☐ ONCE EVERY 2 WEEKS  ☐ MONTHLY  ☐ LESS OFTEN

e) Group leader:  ☐ PARENT  ☐ HEALTH PROFESSIONAL  ☐ BOTH

7) How useful would you find the following support groups? Please mark a “X” in the appropriate box.

<table>
<thead>
<tr>
<th></th>
<th>Very useful</th>
<th>Useful</th>
<th>Neutral</th>
<th>Not useful</th>
<th>Very not useful</th>
</tr>
</thead>
<tbody>
<tr>
<td>a) Online support group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e.g. chat room, forum, or mailing list)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>b) Informal support group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e.g. no pre-planned topic, open discussion)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>c) Semi-formal support group</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(e.g. open discussion with specific topics chosen in advance)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
d) Support group with guest speakers
(e.g. question & answer sessions, training)

<table>
<thead>
<tr>
<th>Very important</th>
<th>Important</th>
<th>Neutral</th>
<th>Unimportant</th>
<th>Very Unimportant</th>
</tr>
</thead>
</table>

| e) Family activities support group
(e.g. with children, special events) |
|-------------------------------------|

☐ Other (please describe)

8) How important do you feel the following statements are in your decision to attend a support group for parents? Please mark a “X” in the appropriate box.

<table>
<thead>
<tr>
<th>a) Meet other people who are going through a similar experience</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>b) Become more informed about treatment options &amp; side-effect management</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>c) Have a place to express frustration and fears</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>d) Learn about how other parents cope with stress and anxiety</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>e) Get advice on how to deal with family or relationship issues (e.g. parenting skills, communication)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>f) Find out about services and supports in the community for your child/yourself (e.g. respite care)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
</tbody>
</table>

☐ Other (please describe)

9) Would you be interested in participating in an 8-week yoga support group, at the Hospital for Sick Children, while your child is receiving treatment? ☐ YES ☐ MAYBE ☐ NO
10) Are you satisfied with the help you are currently receiving from Sick Kids Hospital?

☐ Very dissatisfied ☐ Dissatisfied ☐ Neutral ☐ Satisfied ☐ Very satisfied

11) Are there other ways that Sick Kids and OPACC can help you and your family?

__________________________________________________________

12) Do you have any additional comments or suggestions?

__________________________________________________________

__________________________________________________________

THANK YOU VERY MUCH FOR YOUR TIME!

If you would like to be contacted with more information about additional support for you and/or your family, please fill out the following:

Name: ________________________________

Phone number: ______________ Email: ______________________________

I’m interested in: (please check all that apply) ☐ Individual Support ☐ Support Groups

If you wish, detach this portion of the survey to maintain your privacy.

However, please return both the survey AND this detachable page to the survey box.

THANK YOU
CONSENT FORM
(Parent Form for Self)

Appendix 2

Version Date: May 2010

Title of Project: Support Group for Parents of Children Having Cancer

Purpose of Research: The diagnosis and treatment of childhood cancer can be a devastating event for the whole family. In particular, parents often experience the most psychological distress. The main objectives of this study are to: (1) Test the feasibility of a parent support group at SickKids (2) Utilize information gained to formulate recommendations for the planning and delivery of future evidence-based parent support groups.

Description of The Research: A feasibility study can be broadly defined as a preliminary study undertaken to document and determine a program’s viability. Specifically, the feasibility of a drop-in support group particularly catered towards the needs of parents of children recently diagnosed with cancer will be assessed on 4 areas:
A. Acceptability of the group, including how willing parents are to attend the group each week
B. Recruitment and retention, including how many parents are approached each week versus how many attend.
C. Were we able to carry out the group over the 8-week time period as planned?
D. Preliminary Outcomes, including whether or not the group was beneficial to parents.

The general structure of the parent support group will be as follows:
   After sign-in, completion of forms and introductions, an informal group discussion will be led by facilitators. Parents then will complete post-session forms.

Risk and Risk Minimization
   We know of no harm that taking part in this study could cause you. You may experience some discomfort when talking about your child’s illness or treatment but we do not expect these feelings to have long lasting effects. You can decline to answer any question(s) that make you feel too uncomfortable. Additionally, if you experience severe distress during the course of the study, this will be addressed by the Registered Social Worker, Wendy Shama, who has many years experience working with children with cancer and their families. Moreover, should you experience any distress or discomfort from participating in this study at a later time, Wendy Shama will assist you and your family in obtaining appropriate services. Also, if you would like, we will provide information about additional resources for you and your family.

Potential Benefits:
   • Parents will benefit from general information about resources offered to families having a child diagnosed with cancer.
   • We cannot guarantee that you will benefit in other ways from participating in this study.
• Some parents may benefit from the support group by feeling more at ease and less stressed after interacting with other parents undergoing similar life circumstances.
• Parents may feel empowered when asked to share their perceptions and feelings about their needs.
• Parents may feel a sense of altruism, participating in this pilot study, knowing that they are encouraging the advancement of future evidence based parent support groups being implemented in cancer care centers.
• If families are interested in receiving general information about the study progress and a copy of the publication(s) at the end of the study, we will provide them with the relevant materials. Families will not be receiving individual summary reports regarding their responses to the measures as the data will be reported as group data.

Confidentiality:
We will respect your privacy. No information about who you or who your child is will be given to anyone or be published without your permission, unless the law requires us to do this. For example, the law requires us to give information about you or your child if a child has been abused, if you or your child has 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 Monitors, employees of the funder or sponsor of the study, or the regulator of the study may see your (your child’s) health record to check on the study.

By signing this consent form, you agree to participate as a parent/guardian in this study. We will put a copy of this research consent form in your child’s research records. We will give you a copy for your files.

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 and then destroyed as required by Sick Kids policy. Published study results will not reveal your identity.

The results of the tests we describe in this form will be used only for this study. If another health care professional needs to see these results, you will have to give us your permission. We will ask you to sign a form saying that you agree that this person can see your results. We recommend that only a registered psychologist or doctor tell you what the results of these tests mean.

During the group meeting we will remind everyone that the information shared is private and should not be repeated outside the group but we cannot be sure that information about you will be kept private. People in groups may share information with others outside the group.

Reimbursement:
We will reimburse you for parking expenses or provide you with the equivalent traveling expenses to participate in the study.

Participation:
It is your choice to take part in this study. You may remove yourself from this study at any time. The care your child gets at SickKids will not be affected in any way by whether or not you or your child takes 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 study staff, any people who
gave money for the study, or the hospital are still responsible, legally and professionally, for what they do.

**Conflict of Interest:**
I, and the other research team members have no conflict of interest to declare.

**Consent:**

1) You have explained this study to me. You have answered all my questions.
2) You have explained the possible harms and benefits (if any) of this study.
3) I know what I could do instead of taking part in this study. I understand that I have the right to refuse participate in this study. My decision about me taking part in the study will not affect my child’s health care at SickKids.
4) I am free now, and in the future, to ask questions about the study.
5) I have been told that my research records will be kept private and you will give no one information about me or my child unless the law requires you to do so.
6) I understand that no information about me 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 Parent/Legal Guardian

Parent/Legal Guardian’s signature & date

Printed Name of person who explained consent

Signature & date

Printed Witness’ name

Witness’ signature & date

(if the subject/legal Guardian does not read English)
Appendix 3

PARENT SUPPORT GROUP
INFORMATION FORM- Demographics

Date: ______________________

The Hematology/Oncology Department at SickKids in collaboration with Ontario Parents Advocating for Children with Cancer (www.OPACC.com) are offering a parent support group to families having a child with cancer. The creation of a parent support group was based on results from the Parent Support Survey parents completed Feb-April 2009 at SickKids. Information gained from the survey helped us to design this group. To offer the best possible support, we ask you to complete this brief information form.

GENERAL INFORMATION ABOUT YOU:

1) Date of Birth MM/YYYY : __________
2) Gender: 1 Male 1 Female

3) Marital status: 1 Single 1 Married/Partnered 1 Divorced/Separated 1 Widowed

4) Education: 1 Less than high school 1 High school diploma 1 Post-secondary & above

5) Please check the box that best describes your employment status:

<table>
<thead>
<tr>
<th>Working Now</th>
<th>Retired</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Part-Time 1 OR Full Time 1</td>
<td>1</td>
</tr>
<tr>
<td>Unemployed and looking for work 1</td>
<td>On leave because of child’s illness 1</td>
</tr>
<tr>
<td>On disability 1</td>
<td>Homemaker 1</td>
</tr>
<tr>
<td>Other (Please specify):</td>
<td></td>
</tr>
</tbody>
</table>

6) Were you born in Canada? 1 YES 1 NO and if not, what is your country of birth?_____

7) Language(s) spoken at home: __________________

8) How comfortable are you with the English language?
   • *Speak* 1 Not at all 1 Very little 1 Somewhat 1 Completely Fluent
   • *Write* 1 Not at all 1 Very little 1 Somewhat 1 Completely Fluent

9) Where do you live (city/town)___________

10) Travel distance from home to Sick Kids hospital: _____ km

INFORMATION ABOUT YOUR CHILD HAVING CANCER:

12) Child’s Date of Birth: ________________  Child’s gender: 1 Male 1 Female
    Diagnosis: ________________________
Date of diagnosis (mm/dd/yy): ________________

13) Is your child: 1 On Treatment or 1 Finished Treatment, and if so, date treatment ended (mm/dd/yy): ________________

14) Has your child experienced any side-effects as a result of treatment? 1 YES 1 NO and if yes, please explain.

_______________________________________________________________________

15) Do you have other children? 1 YES 1 NO.
If yes, please state their age & gender:
Child 1: 1 Male 1 Female;  Age: ______  Child 3: 1 Male 1 Female;  Age: ___
Child 2: 1 Male 1 Female;  Age: ______  Child 4: 1 Male 1 Female;  Age: ___

Would you like to receive a copy of the study results upon its completion?
YES _____  NO ______

If you have any questions about this study, please call Kristen Maunder (Project Coordinator) at (647)268-7933

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 4

PARENT SUPPORT GROUP
INFORMATION FORM - Resource Information

Date: ___________________

1) Have you ever utilized supportive resources within your community for parents of children having cancer (i.e. parent support groups)? 1 YES 1 NO and if yes, please list.

________________________________________________________________________

2) Have you ever utilized supportive resources within the hospital for parents of children having cancer (i.e. seeing a psychologist or social worker)? 1 YES 1 NO and if yes, please list.

________________________________________________________________________

3) What types of family or other resources have you utilized to care for your family (i.e. extended family, outside help etc.)?

________________________________________________________________________

________________________________________________________________________

4) Would you be interested in joining a future parent support group that includes a yoga component? 1 YES 1 NO

5) Have you ever made use of an online parent support group?
   If yes, how useful did you find the group?
   1 Very useful  1 Useful  1 Neutral  1 Not useful  1 Very not useful
   How frequently did you use the group?
   1 Daily 1 Once a week 1 Once a month
   What were the advantages/disadvantages of the group? Please explain:

________________________________________________________________________

6) Are there other ways that Sick Kids and OPACC can help you and your family?

________________________________________________________________________

7) Do you have any additional comments or suggestions?

________________________________________________________________________

THANK YOU
Appendix 5
Please mark, on each line, with an “X”, the point that you feel represents your perception of your current state.

*Pre-Session Questions*

1) At the moment, I feel confused concerning my child’s treatment options and/or how to manage side-effects as a result of his/her treatment.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2) At the moment, I feel as though I have little knowledge concerning how other parents cope with the stress of having a child with cancer.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3) At the moment, I am unaware of supportive services and programs (i.e. parent support groups, family activities groups, etc.) offered within my community.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4) At the moment, I feel unsure concerning how to manage family and/or relationship issues.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5) At the moment, I feel alone and as if no one understands what I’m going through.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>
6) At the moment, I feel tense and/or ‘wound up’.

| Strongly Agree | Strongly Disagree |

7) At the moment, I feel tired and without energy for no apparent reason.

| Strongly Agree | Strongly Disagree |

8) At the moment, I feel frustrated and/or fearful about what will happen next.

| Strongly Agree | Strongly Disagree |
### Post-Session Questions

1) At the moment, I feel confused concerning my child’s treatment options and/or how to manage side-effects as a result of his/her treatment.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

2) At the moment, I feel as though I have little knowledge concerning how other parents cope with the stress of having a child with cancer.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

3) At the moment, I am unaware of supportive services and programs (i.e. parent support groups, family activities groups, etc.) offered within my community.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

4) At the moment, I feel unsure concerning how to manage family and/or relationship issues.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

5) At the moment, I feel alone and as if no one understands what I’m going through.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>

6) At the moment, I feel tense and/or ‘wound up’.

<table>
<thead>
<tr>
<th>Strongly Agree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
</table>
7) At the moment, I feel tired and without energy for no apparent reason.

| Strongly Agree | Strongly Disagree |

8) At the moment, I feel frustrated and/or fearful about what will happen next.

| Strongly Agree | Strongly Disagree |

THANK YOU!
Appendix 6

ACCEPTABILITY QUESTIONNAIRE

We would appreciate your feedback regarding the parent support group.

1) What did you like about the parent support group?
   Please check all that apply: How Important was this for you?

   1 (not important at all)  2 (of little importance)  3 (moderately important)
   4 (important)  5 (very important)

   Meeting other parents
   Finding out more about treatment & side-effect management
   Having a place to express my frustration & fears
   Getting advice on how to manage family & relationship issues
   Finding out more about community resources

   1  2  3  4  5

2) Would you recommend the parent support group to other families?
   Yes 1 No 1 __________________________ (please explain why)

3) What would you change about the parent support group?

   _______________________________________________________________________
   _______________________________________________________________________
   _______________________________________________________________________
   _______________________________________________________________________

4) Do you have any additional comments/suggestions?

   _______________________________________________________________________
   _______________________________________________________________________
   _______________________________________________________________________
   _______________________________________________________________________

   THANK YOU!