

**CHILDREN'S PERCEPTIONS OF A PSYCHO-EDUCATIONAL PROGRAM
ABOUT PARENTAL MENTAL ILLNESS**

by

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ABSTRACT

Children of parents with mental illness (COPMI) are often referred to in the literature as *invisible* given the lack of services dedicated to this large population at increased risk for a multitude of psychosocial difficulties. Of the services available, few have been empirically validated. This study undertook a qualitative evaluation of *Kids in Control*, a psycho-education and support program intended to enhance the resilience of children of mentally ill parents. The goals of this study were to: determine whether the program was beneficial to the participants, identify the critical program elements deemed helpful/unhelpful by the participants, determine whether program objectives were being met, and to provide insight on how to improve the program to better meet the needs of this population. It is ultimately hoped that this research will give children of parents with mental illness a voice, thereby boosting their *visibility* and contributing to their psychosocial well being.

Flanagan's (1954) critical incident technique (CIT) was employed to determine the participants' perceptions of helpful and unhelpful aspects of the program. Twelve participants (10 boys, 2 girls) ranging in age from 8-12 were recruited from 4 groups held in the Lower Mainland of British Columbia. Semi-structured interviews were conducted, followed by telephone interviews to discuss and verify the information shared. Participants reported a total of 121 critical incidents, which were classified into 8 helpful categories (105 incidents) and 2 unhelpful categories (16 incidents). The eight helpful categories were: identifying, communicating and managing feelings; learning about mental illness; helpful messages about responsibility, control, and empowerment; effective facilitator group management skills; having fun; connecting with other children

experiencing parental mental illness; learning about stigma; and identifying supports. The unhelpful categories were: ineffective facilitation skills, and disruptive behaviour exhibited by other group members. Participants recommended improvements related to the areas of group instruction, time management, and group management. In addition, a 10-point rating scale was administered to determine the participants' overall perception of program helpfulness. A mean rating of 7.63 was obtained which corresponds to *very helpful* on the scale. A comparison of incident categories with program objectives indicated a high degree of consistency, with a few exceptions. Implications for program improvements, wider program dissemination, and counselling practice are discussed. In addition, methodological issues related to using the critical incident technique with children are outlined.

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DEDICATION

In memory of my brother,

Allan Samuel Hamill,

1964 – 2008.

CHAPTER I: INTRODUCTION

Introduction to the Problem

Invisible is a term often used in the literature to describe the status of children of parents with mental illness (COPMI). This vulnerable population is at an increased risk of developing psychosocial problems, yet the experiences and needs of these children have historically been overlooked within the mental healthcare system and by the research community (Devlin & O'Brien, 1999; Fudge & Mason 2004; Maybery, Ling, Szakacs, & Reupert, 2005; Mordach & Hall, 2002). For example, mental health professionals often fail to inquire about the parental status of their adult clients, resulting in missed opportunities to identify and support children of mentally ill parents (Fudge & Mason, 2004; Nicholson, Biebel, Hinden, Henry, & Stier, 2001). In addition, research on the needs of these children has been negligible, and has only begun to emerge in recent years. (Fudge & Mason, 2004; Gladstone, Boydell, & McKeever, 2006; Maybery et al., 2005; Mordoch & Hall, 2002; Nicholson et al., 2001). Consequently, few programs and services exist for this population, and those that do have been described as fragmented, poorly coordinated, and under-funded (Nicholson et al., 2001).

The *invisibility* of these children is a significant concern considering the adversity and risk associated with parental mental illness. These children are often raised in demanding and unpredictable environments with little information about mental illness or its impact (Garely, Gallop, Johnston, & Pipitone, 1997; Mordoch & Hall, 2002; Stallard, Norman, Huline-Dickens, Salter, & Cribb, 2004). In some cases, the children must assume additional roles and responsibilities in the family such as caregiver and family manager, bearing this burden with few community supports (Aldridge, 2006; Mordoch &

Hall, 2002; Polkii, Ervast, & Huupponen, 2004; Thomas et al., 2003). This burden is further compounded by factors such as stigma, poverty, marital and family discord, substance abuse, inconsistent parenting, and periods of parental separation (Mordoch & Hall, 2002). Retrospective reports by adult COPMI describe feelings of anger, isolation, shame, fear, sadness, chaos, neglect, helplessness, loss and confusion (Lancaster, 1993; Marlowe, 1996; Marsh, Appleby, Dickens, Owens & Young, 1993; Marsh & Dickens, 1997; Roberts, 1996).

In addition to the day-to-day challenges of living with a mentally ill parent, the children are also at risk of developing a multitude of psychosocial problems. Numerous outcome studies have consistently found that COPMI have higher rates of mental illness, developmental delays, behavioural problems, lower academic achievement, and poorer social relationships compared to the general population (Barocas, Seifer, & Sameroff, 1985; Beardslee, Versage, & Gladstone, 1998; Canton, Cournos, Felix, & Wyatt, 1998; Cowling, Luk, Mileskin & Birleson, 2004; Hammen, Burge, Burney, & Adrain, 1990; Maybery, Reupert, & Goodyear, 2006; Mowbray et al., 2004; Oyserman, Mowbray, Meares, & Firminger, 2000; Weissman et al., 1997, 2006). Risk studies indicate that a complex interaction between genetic and environmental factors contributes to the development of psychosocial impairments in COPMI (Beardslee et al., 1998).

While many children of mentally ill parents are at a higher risk of developing psychosocial disorders, many others do not experience serious psychological, behavioural, or social difficulties. Those children that seem to avoid negative outcomes are said to be “resilient” (Beardslee & Poderofsky, 1988). Hence, having a parent with a mental illness does not assure poor outcomes in children. Some protective factors that

have been identified to promote resilience in COPMI include having knowledge of mental illness, possessing a positive self-concept, strong social skills, and the use of effective coping strategies (Devlin & O'Brien, 1999; Place, Reynolds, Cousins, & O'Neill, 2002). The focus of research has now largely shifted away from the area of risk to that of resilience, as knowledge about the protective factors underpinning resilience has the potential to be translated into prevention programs that aim to mitigate risks and promote normal development.

Statement of the Problem

Research on resilience combined with an emerging understanding of the needs of children living with parental mental illness is gradually being transformed into preventive interventions (Hinden, Biebel, Nicholson, Henry, & Stier, 2002; Nicholson et al., 2001). While Durlak and Well's (1997) meta-analytical review of 177 mental health prevention programs for children and adolescents shows general evidence for the effectiveness of prevention strategies, many prevention programs for specific vulnerable populations such as children with mentally ill parents have not been empirically studied. Pitman and Matthey (2004) note that the majority of programs for COPMI report positive outcomes but have not been empirically validated. Further, evaluation outcomes are often reported in intra-agency documents rather than in peer-reviewed journals, making it difficult to access the information. The small number of interventions that have been empirically studied report positive outcomes for children such as increased knowledge of mental illness and improved communication and social skills (Beardslee, Gladstone, Wright, & Cooper, 2003; Finkelstein, Rechberger, Russell, & Vandemark, 2005; Orel, Groves, & Shannon, 2003; Maybery et al., 2006; Pitman & Matthey, 2004). Although these results

are promising, Nicholson and colleagues (2001) describe a pressing need to evaluate existing programs dedicated to parental mental health issues, and to replicate those that are beneficial. In addition, Weisz, Sandler, Durlak, and Anton (2005) identify the general need for prevention research to establish the efficacy of programs for various disorders, to identify change mechanisms, to identify the necessary and sufficient elements of a program, to link prevention to treatment, and to make tested interventions more accessible and effective in community and practice settings.

This research project undertook an empirical evaluation of *Kids in Control*, an eight-week psycho-education and support group for children of mentally ill parents, aged 8 to 13 years of age (British Columbia Schizophrenia Society, 2005). This program was developed in 1994 by Dr. Robert Lees and Marge de Lange for the British Columbia Schizophrenia Society (BCSS). The overall aim of the program is to foster resilience in children through the promotion of a number of protective factors. Interactive games and activities are used to educate children about mental illness, to assist them with the development of effective coping and interpersonal skills, and to enhance their self-esteem and sense of self-efficacy. The group experience is designed to give children the opportunity to connect with other children in similar circumstances, and to potentially build new support networks. Connecting with others is intended to normalize the experience of parental mental illness, thereby reducing shame and isolation.

Kids in Control underwent its first formal evaluation in 2006, ten years after its inception. Richter (2006) studied three program outcomes associated with resilience including level of self-esteem, use of coping strategies, and knowledge of mental illness using the Coopersmith Self-Esteem Inventory, the Kids Coping Scale (KCS), and the

Kids Knowledge Scale (KKS). These tests were administered at the beginning of the program, at the end of the program, and at the eight-week follow-up group reunion. A recurrent institutional cycle design was utilized in which one cohort of participants was assessed before and after their participation in the program and then compared to the next cohort of participants entering the program.

Although Richter's original intention was to analyze the results using inferential statistics, his sample size was too small, thus a descriptive approach was utilized (Richter, 2006). He reported some evidence to suggest that *Kids in Control* helped to increase participants' knowledge of mental illness and their level of self-esteem. He reported a decline in the use of coping skills over the course of the study, a result that he argues could be positive or negative depending on how adaptive the coping strategy is.

The results of Richter's study were inconclusive due to the small sample size. Among Richter's recommendations, he proposed a repetition of this study with a larger sample size to determine the effectiveness of the *Kids in Control* program. However, given the small pool of children available for recruitment, he suggested that a qualitative or mixed methods study might be more fruitful to establish the effectiveness of the program.

This research project is intended to complement and elaborate on the work done by Richter (2006). I have followed his recommendation and pursued a qualitative study as another means of gathering information about the effectiveness of the *Kids in Control* program. Flanagan's (1954) Critical Incident Technique (CIT) was used to conduct this qualitative evaluation.

The main questions that formed the basis of the inquiry were: (a) Which parts of the program were helpful? (b) Which parts of the program were unhelpful? (c) Why was this helpful/unhelpful? and (d) What was missing from the program that might have made it better? For the purpose of this study, “parts” of the program were defined as behaviours, attitudes, activities, events, processes, or experiences. The meaning of the terms “helpful” and “unhelpful” were determined by the study participants’ own perceptions of these terms. However, the intent was to determine aspects of the program that were somehow *important* or *useful* to participants in managing their parent’s mental illness.

Twelve children were recruited from four *Kids in Control* groups held between April 2007 and February 2008 in the Greater Vancouver area. The participants were interviewed using a semi-structured interview format. Subsequent telephone interviews were conducted to share and verify the information exchanged in the interviews. Themes were extracted from the interviews and classified into helpful and unhelpful categories. In addition, the children’s perception of overall program helpfulness was measured using a 10 point rating scale. The results of the study were then examined in light of the Kids in Control program objectives and the extant literature on children of mentally ill parents.

Rationale for the Study

This research study was undertaken to address several gaps in the existing literature on children impacted by parental mental illness. First, a qualitative approach was selected to explore the children’s perceptions of program helpfulness in order to address the gap in our understanding of COPMI’s subjective experiences and needs. This is in keeping with the recommendation made by Gladstone and colleagues (2006) to

consult children in the development and evaluation of programs to ensure interventions are responsive to their needs. It is hoped that this research will give children living with parental mental illness a voice, thereby boosting their *visibility* and empowering them in matters that affect their lives.

This study is also intended to respond to the calls within the research community to empirically validate prevention programs for COPMI. An important goal of this study was to determine whether *Kids in Control* was beneficial to its participants, and whether wider dissemination of the program is appropriate. This study helps to establish *Kids in Control* as an evidence-based program.

This study was also undertaken to provide new knowledge about the essential ingredients in prevention programs from the perspective of children. As Weisz and colleagues (2005) point out, many prevention programs are omnibus in style, utilizing multiple procedures and teaching multiple skills. They suggest that there is a need to determine the necessary and sufficient intervention elements. Thus, finding out what does and does not work for the participants that attend the *Kids in Control* program will provide insight into what elements are most important and useful for children.

Overall, this research study is intended to improve the delivery of services to this vulnerable and under-recognized population. Participants' perceptions of *Kids in Control* will assist program developers and facilitators to assess whether program objectives are being met, and provide insight on how to improve the fit between the program and the needs of this population. Finally, this study ultimately seeks to contribute to the psychosocial well being of COPMI so that they may lead productive lives despite the significant challenges they face.

CHAPTER II: REVIEW OF THE LITERATURE

A review of the literature on children affected by parental mental illness was undertaken. The literature was located online through a search of the PsycINFO, ERIC, and MEDLINE databases for studies from 1990 to the present. Combinations of the following key terms were used: parental mental illness, maternal depression, mental illness and children, mental illness and families, child outcomes, risk, resilience, prevention programs, psychological interventions/psycho-education programs and children. This was followed by a cited reference search of the literature located online. In addition, an Internet search using the above terms was conducted on Google Scholar.

First, the literature on the prevalence, experiences, and needs of children of parents with mental illness (COPMI) will be examined to provide a contextual background for this study. The focus will then turn to the literature on risk and resilience to provide a theoretical understanding of the science underpinning *Kids in Control*, a resilience-based intervention program. Finally, an examination of the literature on interventions for children of mentally ill parents will follow.

Defining COPMI

In order to define who *children of parents with mental illness* (COPMI) are, it is necessary to define what *parents with mental illness* means. When discussing parents with mental illness, the term *parental mental illness* is also commonly used in the literature (British Columbia Schizophrenia Society, 2005; Devlin & O'Brien, 1999; Mordoch & Hall, 2002; Nicholson et al., 2001).

According to Mordoch and Hall (2002), the majority of research completed on COPMI involves parents diagnosed with depression and schizophrenia as defined by the

Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2000). They note that parents with alcoholism and other substance use problems are usually excluded when referring to children of parents with mental illness, although they recognize that substance misuse frequently occurs with mental illness.

Nicholson et al. (2001) define parents with mental illness as “adults who have ever lived with a psychiatric disorder, and who have ever given birth to or fathered a child” (Introduction, ¶5). Within this broad conceptualization, they include any adult who defines themselves as parents, regardless of whether their children are dependent on them.

The *Kids in Control* program manual refers to COPMI as those children that have a parent with a diagnosable psychiatric illness that impairs the parent’s ability to think, feel, behave, and function well in day-to-day life (British Columbia Schizophrenia Society, 2005). Such mental illnesses are typically serious and persistent such as schizophrenia, major depression, and bipolar disorder. Children with a parent with a substance misuse disorder but not a diagnosed mental disorder do not meet the criteria for inclusion in the program. According to the British Columbia Schizophrenia Society (2005), the children that typically attend *Kids in Control* have a parent who has been hospitalized for mental illness, is seeing a psychiatrist and/or is taking medication for the illness.

Prevalence of COPMI

There are currently no specific statistics available on the number of children impacted by parental mental illness in Canada. However, the prevalence of COPMI can be estimated using data from prevalence studies of mental illness in a population,

combined with estimates of how many of those adults are parents. The Public Health Agency of Canada (2002) reports the lifetime prevalence of mental illness among Canadian adults to be 20%. Gopfret, Webster, and Seeman (1996) have estimated that 50% of adults with mental illness are parents. Thus, it can be inferred that a large number of children in Canada are impacted by parental mental illness.

Lees and Chovil (2006) estimated the prevalence of COPMI in British Columbia based on the number of parents in a population of mental health consumers. Mental health professionals in three health regions in British Columbia were surveyed to assess how many of their clients had minor children. Out of a total of 3,423 cases reviewed, 1821 or 36% of their clients had minor children. Of these children, about one-third were preschoolers, and one-half to two thirds of these children lived with their ill parent. Another one-third were school aged, and two-thirds to three quarters of these children lived with their ill parent. The final one-third were high school aged children, and approximately two-thirds of these children lived with their ill parent.

The prevalence data on COPMI from other countries is also scant. In the United States, the US National Co-morbidity Survey (Kessler et al., 1997) estimated that nearly half of the population report some form of psychiatric disorder or addiction to substances. A significant number of men (50%) and women (67%) with a lifetime prevalence of mental disorder are or will become parents (Nicholson et al, 2001). In Sweden, one study found that 28% of adult patients admitted to a psychiatric hospital were parents to minor children under the age of 18 (Ostman & Hansson, 2002). Another study completed in Western Australia found that 55% of adults visiting community mental health clinics reported having children. Of these, two-thirds were mothers and one-third were fathers

(Ahern, 2003). Maybery and colleagues (2005, 2006) estimated that approximately 21-23% of children living in Australian household have at least one parent with a mental illness, equating to one million Australian children affected by parental mental illness.

Nicholson et al. (2001) recommend that more data need to be collected on both the prevalence of parents with mental illness and their children. Further, data are required to describe COPMI in terms of age, gender, living and caring arrangements in order to better understand the children's circumstances and needs.

The Invisible Children

Although prevalence estimates suggest that there are a substantial number of children with mentally ill parents, this population has often been referred to as *invisible* in the literature given the lack of mental health services and research dedicated to this high risk group (Devlin & O'Brien, 1999; Finkelstein et al., 2005; Fudge & Mason, 2004; Maybery et al., 2005; Mordoch & Hall, 2002). Barriers within the mental health system will be outlined first, followed by a discussion of how the research community has contributed to the invisibility of children of parents with mental illness.

Neglect within the Mental Health System

Within the mental healthcare system, children coping with mental illness have gone unrecognized for several reasons. Mental healthcare providers often focus treatment at the individual level, failing to consider their clients in family contexts. Thus, many providers fail to inquire about the parenting status of their clients, thereby missing opportunities to identify children that may be in need (Nicholson et al., 2001). Further, many mental healthcare professionals lack the necessary knowledge and training to deal with families affected by parental mental illness (Reupert & Maybery, 2007).

Nicholson et al. (2001) suggest that the stigma associated with mental illness is another barrier to services for parents and their children. They propose that many healthcare providers make assumptions that individuals with mental illness are not parents or cannot parent successfully. On the other hand, many parents fail to advocate for services for their children out of fear of custody loss due to societal views of the mentally ill as incompetent, violent, or dangerous (Hearle, Plant, Jenner, Barkla, & McGrath, 1999; Nicholson, 1996).

Aldridge and Becker (2003) also suggest the division of adult mental health, child mental health, and child welfare and protection into separate systems contributes to the invisibility of children. Arbitrary barriers between systems and within systems means that services are offered to parents and children on a fragmented basis, rather than focusing care on the family as a whole (Nicholson et al., 2001). Further, services are deficit-based meaning that children only become visible once diagnosable problems emerge or if they show signs of abuse and neglect (Nicholson et al., 2001; Nicholson, Geller, Fisher, & Dixon, 1993). Smith (2004) notes that better coordination between adult mental health and child services is necessary to ensure that COPMI are properly identified and treated.

Neglect within Academia

Historically, a limited scope of research in this field has contributed to the *invisibility* of children with mentally ill parents. The vast majority of research has focussed on the prediction of risk for children, rather than exploring their subjective experiences or accounts of what might be useful to them in coping with parental mental illness (Garely et al., 1997; Gladstone et al., 2006; Mordoch & Hall, 2002; Nicholson et al., 2001).

This failure to consider subjective experiences and needs in research has stalled the development of policies and interventions to support these children to deal with their difficult situations (Fudge & Mason, 2004; Nicholson et al., 2001; Maybery et al., 2005; Mordoch & Hall, 2002). Fortunately, interest in the experiences and needs of COPMI has increased in recent years, and a better understanding of their unique perspectives is beginning to emerge. A review of the literature of children's experiences of parental mental illness will be followed by an examination of the literature on their needs.

COPMI's Experiences

Research on children's subjective experiences of parental mental illness has grown over the last fifteen years. Much of the earlier research about children's experiences was based on retrospective accounts of adult COPMI (Lancaster, 1993; Marlowe, 1996; Marsh & Dickens, 1997; Marsh et al., 1993; Roberts, 1996). Accounts from children in the midst of living with parental mental illness have emerged in recent years (Aldridge, 2006; Aldridge & Becker, 2003; 2005; Riebschleger, 2004; Stallard et al., 2004).

In the lay and empirical literature, common themes reported by COPMI include anger, isolation, shame, fear, sadness, chaos, grief, neglect, feelings of helplessness, frustration, confusion, identity problems, poor self-esteem, and trust and intimacy problems (Marsh & Dickens, 1997; Marsh et al., 1993). Mordoch and Hall (2002) describe the life of some children with mentally ill parents as laden with stress, anxiety, and uncertainty. Garley and colleagues (1997) and Stallard and colleagues (2004) describe how children of mentally ill parents are often uninformed about their parent's

disorder, and struggle to understand their parents symptoms. In the absence of information, these children often blame themselves for their parent's behaviour.

Aldridge and Becker (2003) interviewed 40 children of parents diagnosed with depression or manic depression. Some of the themes that emerged included fear about developing the disease themselves, concern about parents becoming permanently hospitalized, and worry that they may have caused the illness. In addition, they spoke of the grief associated with the loss of a *normal* family and their experience of the stigma associated with mental illness.

The literature has also noted other losses, such as the loss of childhood due to the assumption of care-giving responsibilities for ill parents and/or siblings (Devlin & O'Brien, 1999; Garely et al., 1997, Marlowe, 1996, Marsh & Dickens, 1997). The care-giving tasks that are assumed by some children include emotional care responsibilities for their parents, critical crisis support, as well as the management of household duties and childcare responsibilities (Aldridge, 2006). Mordoch and Hall (2002) note that the shift in the treatment of mental illness from institutional to community settings has increased the burden on children to care for ill parents.

Children's experience of parental mental illness is often compounded by such factors as poverty, marital discord, and substance abuse that tend to accompany parental mental illness (British Columbia Schizophrenia Society, 2005). Children have also described the difficulty of inconsistent parenting and parental absences as the result of hospitalizations or separation due to custody loss (Marsh et al., 1993).

Finally, the stigma associated with mental illness has further contributed to the burden of children with mentally ill parents. Hinshaw (2005) describes how the shame

and embarrassment of mental illness often limits ill parents from seeking treatment, as well as support for their children. Torrey (2006) describes how children will often distance themselves from their parent's illness, avoiding discussion or seeking help from others. In addition, Torrey discusses how there are often fewer supports for those coping with mental illness compared with other biological diseases, which are generally perceived as being less stigmatizing and easier to understand. This adds to the children's sense of alienation.

Despite the numerous descriptions of children's negative experiences with parental mental illness, positive experiences have also been documented. Gladstone et al. (2006) point out that much of the literature on COPMI has focussed on children's experiences as victims and has failed to acknowledge the resilience of children and the positive aspects that may emerge out of difficult family circumstances. Adult children of mentally ill parents report developing strength, independence, empathy, compassion, assertiveness, tolerance and understanding because of the difficulties they faced (Kinsella & Anderson, 1996; Marsh et al., 1993). In addition, Aldridge (2006) found in interviews with children, parents, and support workers that COPMI's care-giving responsibilities do not necessarily have a negative impact on the parent-child relationship, nor does it inevitably contribute to a child's risk of harm, neglect or developmental delay.

COPMI's Issues and Needs

In recent years, the research community has begun to focus more attention on the needs of children coping with parental mental illness. A small number of studies have emerged that examine the perceived needs of COPMI (Cowling, 1999; Fudge & Mason, 2004; Kinsella & Anderson, 1996; Maybery et al., 2005).

Kinsella and Anderson (1996) retrospectively interviewed twenty adults about what their issues and needs were as children growing up with a sibling or parent diagnosed with mental illness. The common themes included the need for information or an explanation about the mental illness, the need for support groups and connection to others affected by mental illness, the need for individual attention, and inclusion in the treatment process to enhance coping. In addition, participants reported the use of both healthy (e.g. engaging in activities, seeking support) and unhealthy (e.g. internalizing emotions, isolating from others) coping strategies to manage their challenging family situations.

Cowling (1999) conducted a focus group with parents to determine the issues and needs of COPMI. The parents identified the need for the continuity of care when parents are hospitalized, the need to educate children about mental illness, the need for outside supports for children to talk to, and the need for programs for children to meet others in the same situation.

Fudge and Mason (2004) conducted several focus groups and peer interviews involving children and adolescents to determine children's issues and needs in an effort to develop service guidelines for COPMI in Australia. Key issues for the participants included the burden of extra care-giving responsibilities, communication problems with service providers and between families, the lack of practical and emotional support, and the need for universal education and stigma reduction regarding mental illness. Factors that helped children to cope included supportive adults or peers, participation in activities, having information about mental illness, respite, and having someone to talk to.

Maybery and colleagues (2005) sought to extend the previous studies by examining different viewpoints regarding the issues and needs facing COPMI. They conducted separate focus groups of parents and children. The greatest concern for both children and parents was related to episodes of parental hospitalization as this has been identified as a distressing and disruptive experience for all family members. The other two themes common to both the parent and child groups were the importance of siblings for support in crises, and the development of various coping mechanisms such as withdrawal, avoidance, and distancing. Maybery and colleagues note that these coping strategies used by children have been identified in the literature as unhealthy if maintained on an on-going basis. Parents differed from the children's group by identifying the need for professional external support, education about mental illness, and respite as important. Children on the other hand, identified their friends as a source of support and considered the assumption of additional roles when their parents are sick as important issues. Thus, this study revealed that perceptions of issues and needs differed somewhat between parents and their children. Maybery and colleagues suggested that the issues and needs identified by children themselves are important to be taken into consideration when developing programs aimed at COPMI to ensure their relevance.

Summary of Research on Prevalence, Experiences, and Needs

A shift has taken place within the research community in recent years that has shed some light on the experiences and needs of children affected by parental mental illness. However, it is clear that more research on the prevalence of COPMI, barriers to services, and COPMI's needs is required to facilitate the development of effective programs and services for this population at risk (Devlin & O'Brien, 1999; Nicholson et

al., 2001). The focus of the literature review will now shift to reviewing the research on risk and resilience as it relates to child outcomes. This will provide a theoretical background on the science underpinning the *Kids in Control* program.

COPMI Outcome Studies

The one area where significant research has been conducted on children of mentally ill parents is in the area of child outcome studies. The majority of the research has focussed on the effects of parental depression on children, especially the effects of maternal depression, although some studies have also examined parental psychosis (Smith, 2004).

Research conducted over the last several decades using cross-sectional, retrospective, and longitudinal designs has clearly established that children of parents with mental illness are at a heightened risk of developing a multitude of psychosocial disorders. These disorders include higher rates of mental illness, developmental delays, lower academic achievement, behavioural problems, interpersonal difficulties, and more physical health problems (Barocas et al., 1985; Beardslee et al., 1998; Canton et al., 1998; Cowling et al., 2004; Hammen et al., 1990; Maybery et al., 2006; Mowbray et al., 2004; Oyserman et al., 2000; Weissman et al., 1997, 2006).

Estimates of psychopathology in children with mentally ill parents vary greatly from study to study. A meta-analysis conducted by Lavoie and Hodgins (1994) found that approximately 61% of the children of parents with major depressive disorder will develop a psychiatric disorder during childhood or adolescence, and are four times more likely to develop an affective disorder than children of non-ill parents (as cited in Beardslee et al., 1998). For children of parents with psychotic illnesses, there is a high rate of lifetime

prevalence of psychosis at between 5-14% (Cowling et al., 1995 as cited in Devlin & O'Brien, 1999).

Cowling and colleagues (2004) asked parents diagnosed with mental illness to complete the Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) to assess psychosocial impairments in their children. Twenty-five percent of the children were in the clinical range for being at risk, and their probability of developing mental illness was 2.5 times greater than the general population. Likewise, Maybery and colleagues (2006) asked parents of children participating in the *VicChamps* intervention to complete the SDQ and found that 60% of participants in their intervention group scored in the “at risk” category for mental health, while 39 % of the children fell into the clinical risk range.

Despite the increased risk for emotional and behavioural problems, not all children will develop difficulties. Many COPMI will avoid the development of significant problems and grow into well-adapted adults (Beardslee et al., 1998). Mowbray and colleagues (2004) found that 31% of children in their study sample were high functioning with no major mental health issues. These children are described as resilient for their ability to overcome significant adversity. This has prompted researchers to look for protective factors to explain why some children are more resistant to risk than others. A review of the literature on risk factors that increase the probability of poor outcomes for COPMI will be presented next, followed by the research on protective factors that are associated with resilience.

Risk factors associated with negative outcomes

There are several risk factors associated with increased rates of psychosocial impairment in children of mentally ill parents. These include (1) genetic influences, (2)

marital and family discord, (3) parenting problems, and the (4) chronicity and severity of parental illness (Beardslee et al., 1998; Nicholson et al., 2001).

A genetic connection between psychopathology in children and parental affective disorder is well established through a number of family, twin, and adoption studies (Beardslee et al., 1998). These studies reveal that there is a higher incidence of affective disorder in relatives of depressed individuals compared to the general population, and the more closely related relatives are, the greater the risk for developing disorders. Hence, COPMI are more genetically vulnerable to developing mental illness than the general population. In addition to the role of genetics, scientists also recognize the role of environmental-familial factors in the development of affective illness and suggest that a complex interplay of factors accounts for the development of psychosocial impairments in children (Beardslee et al., 1998).

Marital and family discord is an environmental risk factor for the development of negative outcomes in children. Families with parental depression experience higher rates of marital discord, family discord, and divorce. Marital discord has been associated with lower academic achievement, poor social skills, and conduct problems (Nicholson et al., 2001). In addition, children often grow up in family environments characterized by chaos, lower family cohesion, increased parent-child conflict, and poorer communication (Nicholson et al., 2001). Decreased family functioning has been associated with increased risk for emotional and behavioural problems in children.

Another risk factor for children is the impact of mental illness on parenting behaviour. A number of studies have observed that mothers with mental illness show decreased verbal and emotional responsiveness, and in the case of depressed mothers

express more sadness, irritability, hostility, and fewer positive emotions (Goodman & Gotlib, 1999, as cited in Nicholson et al., 2001). In some cases, these parenting characteristics impair normal child development leading to poorer attachment and developmental delay in language, attention, and social competence (Goodman & Brumley, 1990, as cited in Nicholson et al., 2001). In addition, the parenting style of depressed mothers may make their children more vulnerable to developing maladaptive coping styles, interpersonal skills, and negative cognitive styles that increase their children's chances of developing depression and anxiety (Goodman & Gotlib, 1999, as cited in Nicholson et al., 2001).

The severity and chronicity of the parental illness are other risk factors for children. The research suggests that the more severe and chronic the parent's illness is, the greater the risk of psychopathology in children (Beardslee et al., 1998). However, Rutter (1981; 1990) challenges this by suggesting that children may be less impacted by more severe and chronic parental disorders because they may be more accepting of the parent as "ill" and develop coping skills in response to continued exposure that leads to more adaptive functioning (cited in Beardslee et al., 1998). In addition, early onset of parental depression (before the age of 30) is associated with poorer outcomes for their children (Beardslee et al., 1998; Nicholson et al., 2001).

Protective factors associated with resilience

A protective factor is a variable that moderates the risk in a positive direction (Little, Axford, & Morpeth, 2004). Protective factors may work to reduce some COPMI's risk of developing psychosocial problems, thereby making them more resilient in the face of adversity.

In two reviews of the literature, Place and colleagues (2002) and Devlin and O'Brien (1999) identified protective factors at the child, family, and community levels. Protective child factors include the following: a child's ability to sustain psychological separation from the parent's mental illness, ability to resist over-identification with the ill parent, strong social skills, intellectual competence, effective coping and problem-solving abilities, knowledge of mental illness, a low risk temperament, possessing a positive self-concept and a positive attributional style, being able to think independently, an ability to self-reflect, and high levels of activity. Protective family factors were identified as effective parenting practices; the existence of a strong bond between the child and at least one parent; presence of a supportive, non-ill parent; warm and emotionally supportive family dynamics; and an intact family. Protective community factors include having an external adult role model, quality peer relationships; and an extended support system.

Researchers have been interested in studying protective factors for their potential to be incorporated into interventions that seek to moderate risks and enhance resilience. However, it has been noted in the literature that research on COPMI has been slow to inform the development of policies and practices to meet the needs of this vulnerable population (Devlin & O'Brien, 1999; Nicholson et al., 2001).

Interventions

Research on COPMI is slowly being translated into policies and interventions as awareness of their experiences, needs, and risks grow (Cowling, 2004; Hinden et al., 2002; Nicholson et al., 2001). Nicholson and colleagues (2001) have characterized the existing programs for COPMI as sparse, poorly funded, and difficult to sustain. As discussed earlier, most interventions that have been developed target children and their

parents once psychosocial impairments are detected or following evidence of child abuse or neglect (Nicholson et al., 2001). However, some prevention programs have also been developed for children to reduce risk factors and enhance protective factors as a means of averting the adverse impacts of parental mental illness. A general review of the prevention research will be outlined, followed by an examination of specific prevention programs for children of mentally ill parents.

Prevention research

Over the last decade, more attention has shifted to the development of methods to promote healthy development, reduce risk, and enhance competencies in children and youth (Weisz et al., 2005). Prevention programs have been developed targeting a range of youth issues such as drug use, pregnancy, child maltreatment, and health promotion. The general aim of prevention is to enhance strengths as a means of reducing the risk of poor outcomes and increasing the likelihood of positive development (Weisz et al., 2005). Universal prevention focuses on reducing risk in entire populations, while selective prevention narrows in on specific populations at-risk such as COPMI.

Along with the development of new preventive interventions, there have been calls from governments, family advocacy groups, and patient groups to ensure that these interventions are beneficial (Weisz et al., 2005). Efforts to establish prevention programs as evidence-based practices have been gaining attention. Durlak and Wells (1997) conducted a meta-analysis of 177 universal programs and found significant mean effects ranging from 0.24 to 0.93 depending on program type and target population. In another review of 130 prevention programs targeting populations showing early signs of disorder, mean effects were found in the 0.5 range (Durlak & Wells, 1998). Other meta-analytic

reviews of prevention programs targeting specific populations at risk also show beneficial effects, for instance, child abuse prevention programs (Davis & Gidycz, 2000) and programs to reduce the negative impact of parental divorce on children and parents (Lee, Picard, & Blain, 1994).

It appears that there is some evidence to suggest that prevention programs in general can be important in reducing future rates of social, behavioural, and emotional problems in children and youth. However, Weisz and colleagues (2005) suggest that more work needs to be done in the field of prevention. Among their recommendations, they point to the need to establish the efficacy of programs for an array of problems and disorders, to identify change mechanisms that produce the effects, to identify the necessary and sufficient elements of a program, to link prevention to treatment, and to make tested interventions more accessible and effective in community and practice settings.

Prevention programs for COPMI

Several prevention programs for COPMI have reported positive outcomes for children including increased knowledge of mental illness and improved communication and social skills (Beardslee et al., 2003; Finkelstein et al., 2005; Maybery et al., 2006; Orel et al., 2003, Pitman & Matthey, 2004). However, Pitman and Matthey (2004) note that outcome details are often reported in internal documents rather than in peer-reviewed journals, making it difficult to access the information and to ascertain the merits of the program. Further, most evaluations use informal methods such as anecdotal reports rather than formal empirical methods to validate the effectiveness of interventions (Hinden et

al., 2002; Nicholson et al., 2001; Pitman & Matthey, 2004). A review of the interventions that have been empirically validated follows.

Quantitative evaluations

Program evaluations for COPMI often utilize quantitative measures to assess specific outcomes. For instance, Beardslee and colleagues (2003) evaluated two prevention programs for COPMI using measures to assess children's understanding of mental illness and their use of internalizing behaviour pre and post intervention. Orel and colleagues (2003) used self-esteem, family functioning and knowledge measures, among others, to determine the effectiveness of their *Positive Connections* program. Pitman and Matthey (2004) used a "knowledge of mental illness" measure and a "life skills" measure to assess improvements in children participating in the *SMILES* program. Maybery and colleagues (2006) administered a range of measures to evaluate changes in the well-being of participants attending the *VicChamp* program. Likewise, Richter (2006) used a self-esteem, coping skills, and knowledge scale to measure outcomes for the *Kids in Control* program. Richter's (2006) study will be described in detail in a subsequent section.

While quantitative research strategies are important to determine whether change occurs in the mental health and functioning of children, this study has a different focus. This study used a qualitative approach to measure children's perceptions of program helpfulness. Thus, studies that have utilized qualitative methods to assess program helpfulness are reviewed below.

Qualitative evaluations

Only two studies were located in the literature that used a qualitative approach to measure children's positive and negative perceptions of prevention programs. These

studies asked children about what they liked and disliked, or what was helpful and unhelpful about the programs they attended.

Orel and colleagues (2003) evaluated the effectiveness of *Positive Connections*, a program for children 8 to 13 years of age that seeks to enhance their ability to understand and cope with their parent's mental illness. The program consists of a 5-week psycho-educational group, a 5-week peer support group, and a 6-month mentoring program in which participants are paired up with trained volunteers. A number of measures were used to evaluate the program, including an open-ended questionnaire. Eleven participants were asked to identify what was helpful and unhelpful about the program, and what they liked and disliked. Helpful program aspects included: learning general coping skills (two respondents), taking one step at a time (one respondent), knowledge that things that happen in a family is not the fault of the child (one respondent), dealing with feelings (one respondent), talking to others in the group (3 respondents), developing a better understanding of parent's illness (one respondent), and improved social communication (one respondent).

Aspects of the program that participants liked included: other people in the group (7 respondents), learning about mental illness (2 respondents), and learning to deal with problems (one respondent). In terms of aspects of the program that were disliked, ten respondents indicated that there was nothing that they disliked, or that they liked everything. One respondent indicated that the length of the program was a problem.

Pitman and Matthey (2004) also evaluated *SMILES*, a three day program for children aged 8 to 16 with a mentally ill parent or sibling. The aim of the program is to increase children's knowledge of mental illness and equip them with the life skills

necessary for coping by way of games, activities, and discussions. Several evaluation methods were used including a daily feedback form that asked children about what they liked or did not like about the program, what they felt that they had learned, and what else would have been helpful to have had in the program. All of the participants reported in the feedback forms that the program was helpful, and most indicated that there wasn't anything that they disliked about the program. Aspects of the program that the children found helpful included: learning about mental illness, feeling less isolated and responsible, meeting new people, developing new problem-solving and communication skills, learning about the importance of friendships, and finding out how to get help. Some of the aspects of the program that they did not like included food, singing, writing, meditating, sitting too long, and filling in sheets, among other things. Some of the comments children made about improving the program included wanting a longer program, to learn about how to deal with death, and how to become more attached to their parent.

The quantitative and qualitative data that have been collected on COPMI indicate that efforts are underway to establish an evidence-based approach to the development of interventions for this population. However, more interventions need to be empirically validated and published to ascertain whether they are of benefit to the participants, and whether wider dissemination is warranted (Pitman & Matthey, 2004; Nicholson et al., 2001; Weisz et al., 2005). Thus, it is the intention of this researcher to add to the literature by evaluating the helpfulness of the *Kids in Control* program from the perspective of COPMI.

Kids in Control

Kids in Control (BCSS, 2005) is a psycho-educational and support group for COPMI between the ages of 8 and 13 years of age. It was developed by Dr. Robert Lees and Marg de Lange in 1994 on behalf of the British Columbia Schizophrenia Society. The program is modeled after the *Circle of Encouragement* program for children of chemically addicted parents. The name *Kids in Control* was proposed by the first group of children to participate in the program in 1995.

The program is offered over eight consecutive weeks with each session lasting one and one-half hours. The sessions are facilitated by a mental health professional and delivered according to the content and procedures set out in a program manual. It is recommended that the sessions be co-facilitated by an adult who has experienced parental mental illness as a child, given that this individual will be able to relate to the children's personal experiences and provide additional support.

The program aims to educate children about parental mental illness, develop healthy coping skills, and provide support in order to foster resilience in the participants. It offers children the opportunity to meet in order to normalize their experience of parental mental illness and to develop a sense of connection and belonging with others. Children are provided choices around activities to reinforce the message that they do have control over some aspects of their lives. Interactive games and activities are used to promote healthy communication, self-care, and self-esteem. Children are taught to deal with the stigma attached to mental illness and to combat feelings of fear and self-blame. The program targets younger children in an effort to prevent the development of

psychosocial problems and improve the chances that the participants will develop into healthy, well-adjusted adults.

An outline of the program objectives for each of the eight sessions can be found in Table 1.

Table 1. Program Objectives

Session	Title	Objectives
1	Group Building & Storytelling	<ul style="list-style-type: none"> • Become familiar with others and setting • Create identity as a group based on common and shared experiences • Become acquainted through game playing • Develop a feeling of belonging by sharing stories
2	Group Building & Learning to Identify Feelings	<ul style="list-style-type: none"> • Learn how to identify and validate feelings • Learn about 4 basic feelings -mad,sad,glad,scared • Learn all feelings are acceptable and okay • Learn that we can be the boss of our own feelings
3	Learning about Healthy Boundaries & How to Communicate Feelings	<ul style="list-style-type: none"> • Learn about “detachment” and “boundaries” • Learn appropriate ways to communicate feelings • Learn that mental illness is not their fault or anyone else’s
4	Learning About Mental Illness	<ul style="list-style-type: none"> • Learn about what mental illness (M.I.) is and how it is treated • Learn that M.I. is psychologically-based • Learn terminology associated with M.I. • Learn facts & dispel myths about M.I.
5	Learning About the Treatment of Mental Illness	<ul style="list-style-type: none"> • Learn about the different treatment options • Learn factual information about hospital treatments
6	Developing Resiliency	<ul style="list-style-type: none"> • Understand what it means to be resilient • Provide opportunity for children to see and experience themselves as resilient • Create resiliency expectation within each child • Provide tools to increase resiliency
7	Societal Attitudes and Stigma	<ul style="list-style-type: none"> • Explore personal feelings regarding attitudes towards parents with mental illness • Help decrease stigma • Help deal with personal feelings of shame/guilt
8	Self-Care and Self-Esteem	<ul style="list-style-type: none"> • Learn the importance of taking care of oneself • Learn that it is okay to feel good about self • Learn ways to affirm and value self

British Columbia Schizophrenia Society (2005)

Kids in Control utilizes two existing methods to evaluate its effectiveness in an on-going manner. In the last session, participants debrief their experiences of the program as a group. In addition, they complete a feedback questionnaire consisting of eight multiple choice questions related to the educational component of the program. Participants are also asked to answer six open-ended questions: “What I learned in the group was...”; “When I think about the group I...”; “What I learned about feelings is that...”; “One thing that I liked best about the group was...”; “If I was a kids’ group leader I would...”; and “One thing I would change about the group is....” While these informal methods of evaluation are useful, formal evaluation is also needed to establish the validity of the program as an evidence-based practice.

Richter (2006) conducted the first formal effectiveness evaluation of *Kids in Control*, ten years after its inception. Thirty-three participants from seven program sites were recruited from six communities in British Columbia. The study focused on resilience related program outcomes. The participants’ self esteem was measured using the Coopersmith Self-Esteem Inventory (1981; 1989), the use of coping skills was measured using the Kids Coping Scale (KCS) (Maybery, 2005), and knowledge of mental illness was measured using the Kids Knowledge Scale (KKS) (Richter, 2006). These test were administered at the beginning of the program (pre-test), then end of the program (post-test), and at the eight-week follow-up group reunion (post-post test). A recurrent institutional cycle design was utilized in which one cohort of participants are assessed before and after their participation in the program and then compared to the next cohort of participants entering the program.

Of the 33 participants in the study, 16 were in the experimental condition and 17 were in the comparison condition. Due to attrition, the number of participants in the experimental condition dropped from 16 at the pre-test, to 14 at the post-test, down to 7 at the post-post test. Due to the small sample size, Richter shifted from an inferential to a descriptive analysis of the data

Richter (2006) reported some evidence to suggest that *Kids in Control* helped to increase participants' knowledge of mental illness and their level of self-esteem. He reported a decline in the use of coping skills over the course of the study, which he argues could be positive or negative depending on how adaptive the coping strategy is.

There are several limitations with this study. First, the small sample size limited the researcher's ability to utilize inferential analysis in evaluating program outcomes, which was the objective of the study. The lack of participants also contributed to the ambiguity of findings in the descriptive analysis. Two of the measures employed, the KCS and the KKS, are new instruments that are not standardized, evaluated, or validated. Richter noted that the use of an equivalent comparison group and a longitudinal framework to study change over time would strengthen future studies. Richter recommended repeating this study with a larger sample size to determine the effectiveness of the *Kids in Control* program. However, given the small pool of children available for recruitment, he suggested that a qualitative or mixed methods study might be more fruitful to establish the effectiveness of the program.

Purpose of the Study

This study extends the evaluation work begun by Richter (2006). A qualitative evaluation of *Kids in Control* was conducted to explore children's perceptions of helpful and unhelpful aspects of the program, as well as potential areas for improvement.

This research was undertaken to accomplish several goals. First, an empirical evaluation of *Kids in Control* was conducted to determine whether the program was beneficial to the participants, and whether wider dissemination of the program is warranted. Second, the findings may facilitate program improvements by providing *Kids in Control* administrators and facilitators with information on the strengths and weaknesses of the program. In addition, the findings should provide program developers with knowledge about which components of prevention programs are perceived as useful to children. This may result in the development of new programs that are responsive to the unique needs of children of mentally ill parents. Further, it is hoped that this study provides children with an outlet to voice their needs and opinions, thereby making them more visible and involved in the delivery of services. It is ultimately hoped that this study will contribute to the resilience and psychosocial wellbeing of children impacted by parental mental illness.

Research Questions

The broad question under study is "What are the children's perceptions of the *Kids in Control* program?" The specific questions that the participants were asked are: (a) Which parts of the program were helpful?, (b) Which parts of the program were not helpful?, (c) Why was this helpful/not helpful to you?, and (d) What was missing from the program that might have made it better? For the purpose of this study, "parts" of the

program are defined as behaviours, attitudes, activities, events, processes, or experiences.

Additional questions under investigation include: (e) How do the children's perspectives relate to the literature on COMPI regarding their issues, experiences, needs, and risks?,

(f) How do the children's perspectives relate to the objectives of the *Kids in Control*

program?, and (g) What are the critical ingredients of the *Kids in Control* program from

the perspective of the participants?

CHAPTER III: METHODOLOGY

This chapter provides a summary of the procedures utilized in the study, including a description of qualitative methodology in program evaluation, an overview of the critical incident technique, and ethical considerations when working with children. Data collection and analysis procedures follow, and strategies for establishing rigour will be presented.

Qualitative Methodology and Program Evaluation

A qualitative evaluation of *Kids in Control*, a resilience-based psycho-educational and support program for children aged 8 to 13 years of age was conducted. The purpose of the study was to explore children's perceptions of *Kids in Control* by inquiring about which aspects of the program were helpful, which aspects were unhelpful, and whether there were aspects of the program that were missing that would have made it better. A qualitative approach was adopted for several reasons. First, a quantitative study of the program was recently completed (Richter, 2006). In the study recommendations, Richter pointed out the need for further qualitative analysis of the program. In addition, the British Columbia Schizophrenia Society (BCSS) expressed a desire to conduct formal qualitative research as another means of collecting data about the value of their program.

There are several characteristics of qualitative research that make it suited to program evaluation. The first characteristic is its focus on participant perspectives. A primary objective of qualitative research is to understand the personal experience and meaning that participants attach to an event (McMillan, 2004). Using open-ended questions and in-depth interviews, qualitative research can provide a rich description of participants' experiences in a manner that cannot be achieved with quantitative scales. In

the case of program evaluation, it is only appropriate to seek direct input from the participants to determine whether the program is meeting their perceived needs as they are in the best position to judge which aspects are effective (helpful) and which aspects are ineffective (unhelpful). Seeking subjective accounts of psycho-educational program experiences is particularly important in the case of COPMI whose subjective needs and experiences have historically been neglected by mental healthcare providers and researchers (Devlin & O'Brien, 1999; Gladstone et al., 2006; Maybery et al., 2005; Mordoch & Hall, 2002). According to Gladstone and colleagues (2006), "Children should be consulted in matters that affect them, including the design and implementation of policies directed toward them and the services provided on their behalf"(p.2547-2548). Thus, this study assumed that the child participants were competent to express their views and recount their experiences in a manner that would provide meaningful feedback about the effectiveness of the intervention in meeting their perceived needs.

Another feature of qualitative research that is useful in program evaluation is its exploratory and inductive nature (McMillan, 2004). Rather than limiting data collection to pre-determined hypotheses (program outcomes), qualitative research is open ended which facilitates the gathering of intended and unintended outcomes of a program, providing a more holistic understanding of the impact and efficacy of a program.

Finally, qualitative research's focus on process is useful in program evaluation because it allows the researcher to determine not only whether program outcomes were achieved, but also gain information about how and why the outcomes were achieved (McMillan, 2004). For instance, if a program outcome is to educate children about mental

health, qualitative research may also explain how the children gained this new knowledge and why this knowledge is helpful or not helpful to children.

Although there are many different methods of qualitative research to choose from that possess the characteristics described above, this study utilized the critical incident technique (CIT) developed by John Flanagan (1954).

Overview of the Critical Incident Technique

The critical incident technique has been identified as an effective exploratory and investigative tool to generate detailed descriptions of content domains over the last 50 years (Butterfield, Borgen, Amundson, & Maglio, 2005). The technique was developed by Flanagan (1954) in his studies of US airforce pilots during World War II. Since then its use has expanded from its roots in industrial and organizational psychology to other disciplines such as nursing, education, and counselling (Butterfield et al., 2005). In particular, Woolsey (1986) recognized CIT's potential to serve as a unique methodology for the field of counselling psychology as its approach is "consistent with the skills, experience and values of counselling psychology practitioners" (p.252).

The critical incident technique offers a systematic yet flexible set of interview procedures for collecting information from individuals about their direct observations of their own or others' behaviour (Woolsey, 1986). According to Butterfield and colleagues (2004), the focus of CIT is on "critical events, incidents, or factors that help promote or detract from the effective performance of some activity or the experience of a specific situation or event" (p.483). Although Flanagan (1954) developed the method to describe overt critical behaviours, such as the behaviours important in piloting an aircraft, CIT has been modified over the years to also collect data on feelings, beliefs, attitudes, and

perceptions (Butterfield et al., 2004; Woolsey, 1986). Thus, CIT is well suited to the purpose of this study, which was to examine the effective (helpful) and ineffective (unhelpful) aspects of Kids in Control from the perspective of the child participants. This study adopted a broad understanding of critical incidents to be any behaviours, attitudes, activities, processes, or experiences that were helpful and not helpful to the participants.

This study utilized an *expanded form* of CIT that has been implemented by other researchers in recent years to explore meanings associated with critical incidents (Bedi, 2004; Milis, 2006). In addition to exploring the content of the critical incidents, the meanings that participants associate with the helpful and unhelpful aspects of the program were also examined. Specifically, the participants were asked to explain how or why the critical incidents they identified were helpful or unhelpful in managing parental mental illness.

Flanagan (1954) outlined five steps in a critical incident study: (1) establishing the general aim of the activity being studied; (2) making plans and setting specifications; (3) data collection; (4) data analysis; and (5) interpreting the data and reporting the results. These steps were incorporated into the design of this study.

Using the Critical Incident Technique with Children

CIT was deemed an appropriate methodology to use with children for several reasons. First, its flexibility allows for modifications with children. Flanagan stated that CIT “does not consist of a single rigid set of rules governing such data collection. Rather it should be thought of as a flexible set of principles that must be modified and adapted to meet the specific situation at hand” (1954, p.335). Modifications to ensure effective

communication with children were implemented into the research design. These modifications will be described in the “Data collection” section.

In addition to CIT’s inherent flexibility, its method of eliciting specific examples of critical incidents is suitably concrete and developmentally appropriate for children between the ages of 8 and 13 years of age. Several studies have established that the critical incident technique is an effective method of measuring children’s perceptions in participants ranging from 5 years of age to late adolescence (Bonnstetter, 2007; LeMare & Sohbat, 2002; Ross & Egan, 2004; Tulley & Chui, 1998).

Ethical Considerations with Children

Many of the same ethical issues important in research with adults are also important with children. However, several ethical issues are particularly important to address when working with children. A report developed by the State of New South Wales and Social Justice and Social Change Research Centre (2005) provides helpful guidance to researchers working with children on ethical issues related to power imbalance, informed consent, limits to confidentiality, and the researcher’s duty of care. These issues were addressed in the following manner and will be discussed in greater detail in subsequent sections.

To address potential power imbalances, assent was sought from the children to ensure that their participation was voluntary. In addition, interviews were conducted in a collaborative manner in which the participants were viewed as the *expert*, as opposed to taking a *researcher as expert* stance.

Written informed consent was sought from the parent(s)/guardians given that the participants are minors (Tri-council Policy Statement, 1998 with 2000, 2002, & 2005 updates).

With respect to limits on confidentiality, participants and their parent(s)/guardian were notified that confidentiality would be broken and that the Child Protection Services of British Columbia would be contacted if child abuse or neglect was disclosed or suspected (Canadian Counselling Association's Code of Ethics, 1999). Additionally, the following steps were taken to ensure the confidentiality of participants and their families: (a) all names and identifying information was removed from transcripts, (b) names were replaced with participant numbers, (c) electronic files were stored on a computer with password protection, to be deleted after 5 years and (d) paper documents were stored in a locked cabinet in the principal investigator's office at the University of British Columbia. They will be kept for the next 5 years, after which the files will be shredded.

To address the researcher's ethical duty of care, the participants were invited to withdraw from the study/interview at any time in the event of distress. A contact list of child support services was also provided at the end of each interview.

This study conforms to the standards and principles set out by the Canadian Counselling Association's Code of Ethics (1999) and the Tri-council Policy Statement (1998, with 2000, 2002, & 2005 updates). Approval of this study was obtained from the University of British Columbia's Behavioural Research Ethics Board on April 12, 2007.

Data Collection

Permission to conduct this study and recruit group facilitators and research participants from *Kids in Control* groups was granted by Gary Glacken, the executive

director of the British Columbia Schizophrenia Society (BCSS). A letter of endorsement can be found in Appendix A.

Recruitment of participants

Four *Kids in Control* group facilitators from the Greater Vancouver area voluntarily consented to assist in the recruitment of research participants. Facilitators were provided with a facilitator consent form (Appendix B) that outlined the purpose of the research, recruitment procedures and responsibilities, confidentiality measures, and the risks and benefits of participating in the research. One facilitator later withdrew as he was unable to recruit enough participants to run a group. The three remaining facilitators recruited from groups that were conducted between April 2007 and February 2008. For each group, the facilitators completed a facilitator questionnaire (Appendix C) that provides descriptive information about the group site, the facilitator's training, experience, and administration of the *Kids in Control* program.

The facilitators acted as the first point of contact with potential research participants and their parent(s)/guardian to ensure that the anonymity and confidentiality of group members was maintained. The facilitators informed the parent(s)/guardian about the opportunity for their child to participate in this research study during the first session of their groups. The facilitators distributed the participant information letter (Appendix D) to the parent(s)/guardian and asked them to read it to their child to determine whether their child was interested in participating in the study. The facilitators also sought verbal consent from the parents to permit me, the researcher, to run a brief information meeting at the end of a group session to explain the research study and to seek their consent for their child's participation in the study.

Informed consent and participant assent

Since this research involved minors, written informed consent was required from a parent/guardian (Tri-council Policy Statement, 1998 with 2000, 2002, & 2005 updates). Parent/guardian consent forms (Appendix E) were distributed at information meetings conducted by the researcher. The researcher, rather than the group facilitators, distributed the consent forms so that group members and their parent(s)/guardian did not feel any undue pressure to participate in the study. It was made clear when meeting parents/guardians that they were free to decline to participate at no detriment to them or their child. In some cases, group facilitators distributed the consent forms directly to the parent(s)/guardian.

In addition to obtaining parent/guardian consent, the assent of the child participant was sought to ensure voluntary participation and to foster the principle of the child as an equal collaborator in the research process. Their rights as participants were explained at the beginning of each interview, including their right to choose to participate and to withdraw from the study at any time. Written assent (Appendix F) to participate was obtained. Every effort was made to communicate this information in a clear, simple, and impartial manner.

Demographic questionnaire

In addition to the parent/guardian consent form, a demographic questionnaire (Appendix G) was distributed to gather information about the child's age, gender, ethnicity, living situation, and parental diagnosis. This information was collected as a means of describing the participants and to provide contextual information about the child's experience of parental mental illness. Completion of the questionnaire was

optional to respect the privacy of the family. Parents of all the participants in this study completed the questionnaire.

The consent forms and demographic questionnaires were returned to the researcher in person or mailed at a later date in stamped envelopes that were provided. Facilitators were asked to distribute reminder notices (Appendix H) to prompt those interested in participating to send in their forms.

Description of participants

Individuals were eligible to participate in the study if they had completed the *Kids in Control* program only once, attended 75 % of the sessions (6 of 8 sessions), and had parental permission to participate. Participants who met these criteria were selected for interviews in the same order that the consent forms were received.

Twelve participants, 10 boys and 2 girls, were interviewed for this study. Participants ranged in age from 8 to 12 years, with a mean age of 10.25. The ethnic background of the participants, as identified by the parent/guardian included: 4 Caucasian/White, 4 Canadian, 2 Indo-Canadian, and 2 mixed ancestry. On average, each participant had 2.1 siblings. Seven of the participants (58%) had one parent with mental illness, while five participants (42%) had two parents diagnosed with mental illness. Parental diagnoses, as identified by the parent/guardian included the following illnesses: depression, bipolar disorder, schizoaffective disorder, anxiety, attention deficit disorder, post-traumatic stress disorder, and drug and alcohol addiction. Five of the parents (42%) had concurrent disorders. Eight of the participants (67%) were currently living with a mentally ill parent, while five (33%) were living with other family members or in foster care.

Participants were also asked to rate their level of family stress on a 10 point scale (0= no stress, 5= medium stress, 10= very, very stressful). The ratings ranged from 4 to 10, with a mean of 6.5. The two participants in the study that rated their family stress at the maximum level of ten were living with two parents diagnosed with mental illness.

Nine participants (67%) reported having one or more psychosocial difficulties, including seven participants (58%) that reported having one or more clinical diagnoses. Diagnoses included: ADHD (3 participants), ADD (1 participant), depression (2 participants), high functioning autism (1 participant), schizophrenia (1 participant), and a learning disability (1 participant). More general reports of psychosocial impairments included poor academic achievement (3 participants), behavioural problems (4 participants) and poor peer/family relations (5 participants).

In CIT methodology, the sample size is not determined by the number of participants, but by “the number of critical incidents being observed or reported and by whether the incidents represent adequate coverage of the activity being studied” (Butterfield et al., 2005, p.479). Hence, critical incidents are gathered until redundancy is achieved (Flanagan, 1954; Woolsey, 1986). Butterfield and Borgen (2005) estimate that the redundancy of critical incidents is typically established within 10 to 15 participant interviews. The redundancy criterion was established after 12 interviews in this study.

Description of Kids in Control groups

The twelve participants in the study were recruited from four groups held in four different communities in the Greater Vancouver area between April 2007 and February 2008. These groups were led by three female facilitators, with one facilitator leading two of the four groups. Two of the facilitators had a Masters degree in Social Work while

the third one had a Masters degree in Counselling Psychology. All of the facilitators had previous experience leading *Kids in Control* groups and reported having led 4, 7, and 14 groups prior to the ones from which the participants were recruited. Three of the groups had female co-facilitators with backgrounds in social work, counselling, and childcare. One co-facilitator had personal experience with parental mental illness.

Participants were recruited from groups with an average of 6 group members. Out of a total of 24 group members, all but one member completed the groups. Three of the groups were held over eight consecutive weeks, meeting 1.5 hours each session. One group was offered as a 6 day summer program, meeting two hours each day.

Facilitators were asked to estimate their degree of adherence to the *Kids in Control* manual, with 0% being no adherence and 100% being strict adherence. The degree of adherence ranged from 70% to 85%, with an average of 76 % adherence to the manual. One facilitator noted the need to adapt the manual to the unique needs of each group.

Interviews

Interviews were scheduled at locations chosen by the family that were deemed private, child appropriate, and convenient. Seven interviews were conducted at the participants' home, two at a church, two at a McDonalds restaurant, and one at a park. Interviews were scheduled within a month of the end of the program to ensure greater precision in the recall of critical incidents.

Interviews followed a semi-structured format and ranged from 19 minutes to one hour and 12 minutes in length. At the outset of the interview, participants were read the participant information letter (Appendix D) aloud, which outlined the purpose and

significance of the research, research procedures, and the rights of the participant. The participants were invited to ask questions. Written assent (Appendix F) was then obtained.

A brief overview of the interview protocol will be provided here, but a detailed account can be found in Appendix I. Interviews began with general questions about the participants' group experience as a means of building rapport and providing a contextual backdrop to facilitate the recollection of critical incidents. Participants were then asked to recall critical incidents (important behaviours, attitudes, activities, events, processes, or experiences) from the *Kids in Control* program that were helpful or not helpful to the participants. At first, a general focus was adopted that simply asked the participants to recall helpful and unhelpful incidents. Participants were then asked to review the eight session titles (Appendix J) and leaf through the *Kids in Control* manual to see if anything *stood out* as being helpful or unhelpful. This material was presented to provoke discussion and to assist the children in the recall of incidents. This step was very helpful to those participants that required additional structure.

Flanagan (1954) suggested that the accuracy of self-reports could be inferred from the level of full, precise details given by the participants (as cited in Butterfield et al., 2005). To facilitate the identification and full exploration of critical incidents, active listening skills such as basic empathy, open-ended questions, paraphrasing, clarifying, and probing were employed. These techniques were especially important with children in order to elicit as much information as possible. In addition, extra time was allotted to give children time to consider their responses, and multiple opportunities to respond to questions were provided (State of New South Wales and Social Justice and Social

Change Research Centre, 2005). When the participants had difficulty responding, efforts were made to rephrase questions and practical examples were provided in a limited way, so not to unduly bias the participants.

Given that this study utilized an expanded form of CIT, participants were encouraged to explain the significance of each critical incident they identified. Probing questions such as “Why was this helpful to you?” or “How does this help you with your parent’s mental illness?” were asked to elicit information on the meaning of critical incidents.

Finally, participants were asked to think about things that were missing from the program. Participants generated a *wish list* of things that would have made the program better.

To ensure that no harm was caused during the interviews, participants were monitored for signs of distress and frequent check-ins were conducted to ensure that participants were at ease with the process. None of the participants reported feeling any distress. All participants were offered a list of support services for children in the Lower Mainland (Appendix K).

Rating scales

In addition to collecting qualitative data on the participants’ experiences with the *Kids in Control* program, descriptive data were also collected. At the end of the interview participants were asked to complete two 10-point scales that measured their degree of family stress, and their overall rating of program helpfulness (see Appendix I for details). The family stress data were collected to provide descriptive information about the participants’ living situation, and has already been reported under “Description of

participants” earlier in this section. The participants’ rating of program helpfulness will be reported in the “Results” chapter.

Data Analysis

All interviews were audio-taped and transcribed verbatim by a professional transcriptionist who was required to sign a confidentiality agreement prior to beginning work (Appendix L). To protect the identity of participants and facilitators in the transcripts, names were removed and participants were assigned identity numbers.

Critical incidents were extracted from the transcripts and copied onto cue cards. Informal spoken language was translated into standard written language using as many of the participants’ own words as possible. An incident was judged critical if the participant was able to provide details of the experience and recall why the incident was a helpful or unhelpful experience.

Once the critical incidents were extracted for each interview, a summary letter was sent to each participant and a follow-up telephone interview (Appendix M) was conducted to verify whether the participants’ perceptions were accurately captured. Ten of the twelve participants confirmed that the information was correct and offered no additional information. Two of the participants were unreachable for telephone follow-up.

The critical incidents were then organized into a classification system. According to Flanagan (1954), the purpose of data analysis is to create a classification system that summarizes and describes the data in an efficient manner “...while sacrificing as little as possible of their comprehensiveness, specificity, and validity” (p.344). Flanagan (1954) outlined several steps involved in the development of a classification system.

The first step involved establishing a frame of reference for the classification of critical incidents based on the intended use of the data. In this study, the frame of reference was the aspects of the *Kids in Control* program which were helpful and unhelpful to the participants. The frame of reference was broad and general in order to capture both intended and unintended outcomes of the program, thus attaining a more comprehensive account of the impact and effectiveness of the program.

The second step was category formation. This was an inductive process that Flanagan (1954) describes as more subjective than objective, relying on the researcher's insight, experience, and judgement. The critical incidents were sorted and resorted into analogous piles until mutually exclusive categories were formed. Both the content of the critical incidents and the underlying meanings were taken into account when sorting the incidents into common themes.

The third step in data analysis was to determine the most appropriate level of specificity to use in reporting the data (Flanagan, 1954). This was an intuitive process in which the advantages of maintaining specificity were weighed against the simplicity of a small number of headings.

A number of credibility checks were undertaken to enhance the objectivity of the categorization process. Details are provided in the next section.

Rigour

Credibility checks

This study has incorporated all nine of the credibility checks identified in the Butterfield et al. (2004) synopsis of the critical incident technique. These credibility checks were conducted to enhance the validity or trustworthiness of the results.

First, interviews were audiotaped and transcribed verbatim to ensure the accurate recording of participant accounts.

Second, the initial interview was reviewed by Dr. Norman Amundson, an expert in CIT methodology. He determined that the interview was conducted appropriately and in accordance with CIT methodology. The subsequent interviews were conducted in a similar fashion.

Third, a members check was carried out to verify that the data were interpreted accurately. A letter was sent to each participant summarizing the critical incidents that were shared. This was followed by a telephone interview (Appendix M) in which children were given the opportunity to give their feedback and revise their comments. Ten of the twelve participants were contacted and reported no revisions or additions. Attempts to contact the other two participants were unsuccessful. One participant failed to return the researcher's calls, and the telephone number of the other participant was out of service.

Fourth, full coverage of the domain under study was ensured by tracking the point where critical incidents and new categories stopped emerging. This is typically when only two to three novel critical incidents emerge from the last 100 incidents gathered. The 10 helpful and unhelpful categories emerged within the first 30 incidents gathered. An additional 91 incidents were collected to flesh out the scope of the categories.

Fifth, a counselling psychology graduate with experience in using the critical incident technique acted as an independent coder. Approximately 25 % of the total critical incidents were independently extracted to determine the level of agreement in the identification of critical incidents. The level of agreement was 94%, indicating precision

in the extraction of critical incidents. The discrepancies that existed were discussed, and consensus was reached on the extraction of the incidents.

Sixth, an independent judge was used to place approximately 35% of the critical incidents into the categories that had been tentatively formed. A counselling psychology graduate with CIT experience performed this task. The level of agreement was high at 96% , verifying a reliable system of classification. The few discrepancies that existed were discussed, and consensus was reached on the appropriate classification of those critical incidents.

Seventh, the participation rate for each category was determined by calculating the number of participants who cited the incident, then dividing that by the total number of participants. According to Flanagan (1954), “The greater the number of independent observers who report the same incident, the more likely it is that the incident is important to the aim of the study” (as cited by Butterfield et al., 2004, p.487). All categories reported in this study follow the typical guideline of a 25% participation rate or greater.

Eighth, tentative categories were submitted to Dr. Darryl Maybery, an Australian expert on parental mental illness to determine their usefulness and comprehensiveness. He confirmed that the categories had face validity and stated that they were consistent with what he would “expect” to find.

Ninth, theoretical validity was ascertained by consulting the literature to establish that the categories corresponded to the existing research. The categories that emerged were consistent with the literature with a few exceptions. A detailed account of this can be found in the section titled “Fit with Literature” in chapter 5.

Finally, given that qualitative research is fundamentally interpretive, it was necessary to acknowledge and explore how my own biases, values, and interests have shaped the study (Creswell, 2003). According to Gladstone and colleagues (2006), “Researchers need to be reflexive, recognizing that their own reports of childhood are affected by their conceptual stance toward children” (p.2547). Thus, my personal experience and underlying assumptions about children and parental mental illness are explored below.

Situating the researcher

My interest in *Kids in Control* emanates from my commitment to supporting families with mental illness. Personal contact with a number of families struggling with mental illness over the years has made me amply aware of the fact that it is not only the individuals with mental illness that suffer, but those around them as well. This interest in supporting families affected by mental illness was further reinforced while attending a lecture at UBC with a guest speaker from the British Columbia Schizophrenia Society (BCSS). The lecture discussed the need for evidence-based research in the area of families and mental health. On further investigation, I discovered that BCSS offered a number of support programs for families that seemed beneficial, but had limited empirical data to support them. Given my background as a teacher and my commitment to the welfare of children, I decided to conduct an evaluation of the *Kids in Control* program.

I am aware of certain biases that I bring to this study. My view of children has been influenced by my experience as a teacher. I tend to see children as resilient individuals capable of adapting to difficult situations and even having potentially positive

experiences because of them. Resilience in my mind is similar to Luthar and Cicchetti's (2000) concept that it is not solely based on extraordinary attributes of an individual, but is an ordinary process of adaption shaped by life experiences. Thus, a working assumption about the COPMI in this study was that they are adaptive and capable individuals in need of tools to help themselves. This is in keeping with Gladstone et al.'s (2006) proposal of recasting COMPI from "at risk" to "competent though at risk"(p. 2546).

Further, I feel that there is a strong need to include children's perspectives in research, as it is my belief that children should be consulted in matters affecting them. This view is consistent with much of the recent literature that has criticized research practices for neglecting the voices of children and contributing to the *invisibility* of COPMI (Gladstone et al., 2006). Thus, I worked under the assumption that children are competent to express their views and recount their experiences.

While conducting this study, I was aware that my views had the potential to bias the interpretation of the findings, given my desire for effective interventions for children. Thus, I sought to minimize bias as much as possible through on-going self reflection, and by closely following the methods and protocol set out in my research proposal.

Finally, I have no previous involvement with *Kids in Control* or the facilitators of the program. Likewise, I have no affiliation with the British Columbia Schizophrenia Society.

CHAPTER IV: RESULTS

Twelve children were recruited from four *Kids in Control* groups that were held between April 2007 and February 2008 in the Greater Vancouver area. Interviews were conducted to determine the participants' perceptions of helpful and unhelpful aspects of the program. The critical incident technique was used to extract themes from the data and organize them into helpful and unhelpful categories.

This chapter reports the results of the study. First, the helpful and unhelpful categories will be presented in table format, followed by a detailed description of each of the categories. Next, the participants' rating of overall program helpfulness will be provided. The participants' "Wish list" consisting of recommendations for program improvements will be outlined. Finally, the correspondence between *Kids in Control* program objectives and the incident categories generated in this study will be presented.

Overview

A total of 121 critical incidents were extracted from interviews with the twelve participants. Of these, 105 incidents were perceived as helpful program experiences. Sixteen critical incidents were perceived as unhelpful. The critical incidents were classified into a total of 10 categories, 8 categories of helpful incidents and 2 categories of unhelpful incidents. Tables 2 and 3 display the distribution of the critical incidents for each of the helpful and unhelpful categories. All of the helpful and unhelpful critical incident categories had participation rates that in most cases far exceeded the minimum criterion of 25% for inclusion.

Table 2. Helpful Critical Incident Categories

HELPFUL CATEGORIES	Number of Incidents	% of Incidents	Number of Participants	% of total participants
1. Identifying, communicating, and managing feelings	27	26%	12	100%
2. Learning about mental illness	21	20%	10	83%
3. Helpful messages about responsibility, control, and empowerment	13	12%	10	83%
4. Effective facilitator group management skills	12	11%	8	67%
5. Having fun	10	10%	8	67%
6. Connecting with other children experiencing parental mental illness	9	9%	7	58%
7. Learning about stigma	7	7%	7	58%
8. Identifying supports	6	5%	5	42%
TOTAL NUMBER OF HELPFUL INCIDENTS	105			

Table 3. Unhelpful Critical Incident Categories

UNHELPFUL CATEGORIES	Number of incidents	% of Incidents	Number of Participants	% of total participants
1. Ineffective facilitation skills	12	75%	7	58%
2. Disruptive behaviour exhibited by other group members	4	25%	3	25%
TOTAL NUMBER OF UNHELPFUL INCIDENTS	16			

Helpful Incident Categories

Category 1: Identifying, communicating, and managing feelings

Learning about feelings was an important aspect of many participants' experience in the program. This category was the largest of all helpful incident categories, with 100% of participants reporting 26% of all helpful incidents. The specific games and activities that participants identified as being helpful are described below.

Ten participants specified that the *Feelings BINGO* game helped to increase their feelings vocabulary, enhancing their ability to accurately identify their own feelings and those of their parents. The participants noted that being able to identify feelings facilitates communication with their parents and others. The quotes below illustrate how *Feelings BINGO* was helpful for the participants:

We know what we are feeling so we aren't confused. When we are asked what's wrong we can say the proper word.

It helps me to explain my feelings to Mom and other people

If your parent has mental illness you might feel sad or scared. If your parent is going through a hard time you can think of their feelings and compare it to your feelings...we can talk about why she's [Mom] unhappy or sad...

Five participants cited the *Warm Fuzzies & Cold Pricklies* activity as being helpful to learn the difference between positive and negative feelings. According to one participant, this activity was helpful for the following reason:

P: If she [my mom] is having a bad day, I could identify all the bad feelings...and if she's having a good day, then I could identify the good feelings.

I: Why is it important for you to be able to identify the feelings?

P: 'Cause if she's mad then I know that I shouldn't try to make her happy 'cause it might make her madder. I should just leave her alone.

Two participants spoke of learning about the use of "defenses" to hide their true feelings. One of the participants was surprised to learn that others in the group managed their feelings in similar ways:

P: Almost everybody else was doing the ones [defences] I was doing...

I: How is it helpful to know that other kids use the same defences?

P: 'Cause then we know we're all the same and we weren't the only one doing it...and [I] wouldn't be embarrassed to tell people.

Two participants spoke of learning to "feel my feelings" by way of the *SMILE* acronym, which teaches children to reflect on their feelings and then take a course of action. According to one participant, "It helps me to control myself more...to calm down so I don't explode."

Four participants identified specific strategies that they found helpful for expressing and managing sad and angry feelings. These included taking deep breaths,

writing it down, talking to someone, bouncing a ball, and scribbling on a piece of paper and then ripping it up.

Overall, participants found it helpful to gain awareness of their own feelings, as well as those of their ill parent. They also valued strategies that helped them to communicate and manage their feelings. Several participants noted that having more awareness of their parent's adverse moods cues them to modify their behaviour to be more supportive, helpful, and respectful of their parent's space.

Participants reported that learning about feelings was not only helpful with ill parents, but with other aspects of their lives as well. One participant anticipated that learning about feelings would improve communication with his psychiatrist, thereby making him feel less "scared" at appointments. Another participant noted that anger management strategies were useful in dealing with a troublesome brother. Yet another participant spoke of how peer relations at school were improving with new awareness of how her behaviour was affecting others.

Category 2: Learning about mental illness

Many participants found it helpful to learn about mental illness. Twenty-one incidents were reported by 10 participants, accounting for 20% of helpful incidents. Incidents in this category encompass reports of specific learning activities and references to information that enhanced the participants' understanding of the biology, symptoms, and treatment of mental illness. The specific learning activities that the participants identified as helpful included: a word search of terminology, a question and answer game about mental illness, a crossword puzzle, a ball toss game that required participants to think of different types of mental illnesses, a worksheet that displayed how illnesses

affect different parts of the body, a worksheet that compared a healthy brain to a brain with a chemical imbalance, a story about mental illness, and a discussion on the treatment of mental illness.

When participants were asked to explain how learning about mental illness was meaningful to them, some participants described how it enhanced their understanding of their parents' behaviour. One participant spoke of being "less confused" about his parent's emotional lability. In particular, it was important to several participants to know that their parent's angry and sad behaviours were symptoms of mental illness that were attributable to a biological disease, rather than the fault of the parent or themselves. For example:

Some diseases that we learned about...like bipolar, you can't help if you're mad or sad at one point. It just happens...They just got a chemical imbalance...It makes me feel a little better 'cause I know it's not her fault. It's the disease's fault 'cause if she didn't have bipolar she'd probably be happy....

... I didn't really know they [my parents] had a mental illness—so it helped me understand them better...if they get pissed or something then I know why most of the time...It's not their fault or my fault...they get angry a lot. I used to blame myself for everything they did wrong.

My mother has depression so now that I know what it is and I know she is very moody with sadness, I know how to help that.

In addition, learning about mental illness enhanced some of the participants' ability to empathize with their parents and find ways to support them. For instance:

I liked when we talked about... all the kinds of depression and all the mental illnesses... We learned about...what depression can do and then how come your parents...need some alone time and stuff...Then I know what my mom's going through and how I can help her if she needs help... It helps me to feel better 'cause I know what she's going through, but I'm still not happy that she has it.

Notably, learning about mental illness helped some participants understand their own mental illness. One participant spoke of learning the importance of taking his medication everyday to treat his own illness. Another participant spoke about his own depression and how he learned that "...I can't cause any of it and it's natural for me to be depressed more...."

Category 3: Helpful messages about responsibility, control, and empowerment

Ten participants contributed 13 incidents to this category. The incidents reported make reference to *The 3 Cs*, an abbreviation for the aphorism "I can't cause it. I can't change it. I can care for myself."

The 3 Cs was significant to the participants' in several ways. First, the explicit message "I can't cause it" was helpful for the children to understand that they were not responsible for their parents' mental illness. For instance, a participant said:

You can know that you shouldn't be hard on yourself because you didn't cause it and your parents are the only ones responsible for their mental illness. But you're just responsible for yourself and to watch out for yourself.

The children's understanding that they did not cause their parents' illness was also reflected in the last category, "Learning about mental illness", in which the participants' feelings of culpability decreased as their knowledge of mental illness increased.

Some of the participants noted that the second statement in *The 3 Cs*, "I can't change it" was helpful in defining limits on their responsibility to control or alter the situation. For instance, one participant commented, "...my mom has depression, I know that I can't just go zap and change it [and] she'll be all better." Another participant

reflected, “You can’t change your parents’ mental illness. You can’t make it better but they can... Only your parents can fix their mental illnesses.”

Finally, participants found the third statement in *The 3Cs*, “I can care for myself” empowering, letting them know that they do have control over their own wellbeing. When one participant was asked why it was helpful to know this, he talked about being resilient: “Instead of being mad you could turn the situation around and become happy.”

Another participant reflected on his ability to be independent:

So you can take care of yourself and not depend on them to take care of us...instead of saying ‘I need a bath or shower’ you can learn how to do it. I can learn how to do things and I don’t depend on her [my Mom] to do it... I can give her a rest...so that she doesn’t have to get up and do everything for me.

Category 4: Effective facilitator group management skills

Eight participants described 12 incidents that identified effective facilitator group management skills as helpful. These incidents can be further subdivided into two types: behavioural management strategies and personal facilitator qualities that contributed to a positive group environment.

Nine of the incidents made reference to specific behavioural management strategies. These strategies included the following: the game *Silent ball* which encouraged attentiveness, the *Check mark* game in which participants earned a prize when they achieved 5 check marks for good behaviour, praise for good behaviour, assigning participants the role of helpers, having group rules, and talking about behavioural issues.

With reference to the use of praise, one participant described how his facilitator made a special effort to acknowledge his good behaviour in the group. The participant

proudly noted, “I felt like an example...it made me feel important”. In another critical incident, a participant described the usefulness of talking behavioural problems through:

[The group leader] always finds out a way to handle the kids...she would calm everyone down. She just didn’t go “Sit down! Calm down!”. She would [say]“Why are you feeling mad?”...She would usually try to get us to talk.

Three participants also spoke of facilitator qualities that they found helpful. These qualities included being organized, knowledgeable, and caring, as well as speaking “nicely and calmly” to the participants.

When participants were asked to reflect on the importance of effective group management skills, one participant said: “It helped me to learn to be quiet, not to distract others kids so that we could hear everything.” Another typical response was: “It helped me to play nicely and talk nicely with the others in the group...I learned to use my manners.” Both of the participants quoted above were diagnosed with ADHD and reported that the behavioural techniques used by their facilitators helped them to manage their disorders.

Category 5: Having fun

Eight participants identified 10 incidents related to the theme of having fun. The incidents made general reference to having fun by playing games, earning prizes, making crafts, and having an end-of-group party in the last session. In general, the participants felt that having fun was important for their engagement in the group. A typical response was, “Having fun was important so the group wasn’t boring... You can’t live without fun.”

Category 6: Connecting with other children experiencing parental mental illness

This category contains incidents that describe how participants found it helpful to meet other children experiencing parental mental illness. Seven participants identified nine incidents in this category.

The participants found it helpful to connect with other COPMI for several reasons. According to one participant, it was helpful to realize that "...I wasn't the only one with a parent that had depression." Another participant spoke of how meeting other COPMI reduced his sense of isolation:

I don't have a lot of people in my life so it was helpful to get to know other kids...I felt kind of lonely--didn't really have anybody to talk to sometimes so when I went there I experienced other kids.

Thus, for some of the participants, meeting other COPMI made them realize that they were not alone and normalized their family situation.

Other participants noted that being able to share personal stories with others who had a common experience was meaningful because everyone in the group could relate: "In the first session we shared stories about our experiences, the good times and the bad times with the rest of the group...Other people understand what I've been through." Another participant spoke about the support network that formed: "...[we] all had parents with mental illness so if we knew someone was going through a hard time, then we could easily help them." It was also noted that group members acted as helpful resources: "I met two other boys that already knew a lot about mental illness. I could ask them questions and they helped me."

Finally, two participants reflected that making new friends made them feel “good” and “special.” This suggests that making new social connections was a boost to their self-esteem.

Category 7: Learning about stigma

Fifty-eight percent of participants contributed seven critical incidents related to learning about stigma. Participant responses made reference to gaining awareness of their own attitudes about mental illness, learning about negative societal attitudes about mental illness, and the injustice of discriminating against those with mental illness. Participants also reported their thoughts on how people with mental illness should be treated and on how they would respond if someone was disrespectful toward them or their parent. The following quotations from two different participants typify the incidents in this category:

If people are being mean, saying things that aren't true, then you can ignore them...Just because they think it's strange...they say bad things about people with mental illness...It's not fair, they're pretty much the same...they just have something that's affecting their brain ...It's not fair to be mean to people just 'cause they have differences. So you should cheer them up.

Well, it was helpful to me because what I...found out is...there are some people out there that may not like you if you have ADD or a mental illness and you can't do anything about it. But those things will happen, but it's not your fault...so you don't have to feel bad about anything. Don't let that take you down.

In the second quotation above, the participant is reflecting on how learning about stigma was helpful with managing his own diagnoses of ADD and depression. Again, participants spoke of not blaming themselves or their parents for having mental illness and disregarding what others think.

Category 8: Identifying supports

This category consists of incidents in which participants found it helpful to identify individuals and organizations that can support them in times of crisis. Forty-two percent of participants contributed 6 incidents to this category.

Four participants directly referred to a worksheet called *Things I can do to help myself*, which required participants to fill in contact numbers for emergency services and for individuals that could provide emotional support during difficult times. One participant reported that it was helpful to make an emergency plan: “I know what to do if my Mom has a mental breakdown.” For another participant, having a list of supports made him feel more secure: “It makes me feel safer.”

Unhelpful Incident Categories

Category 1: Ineffective group facilitation

This category consists of incidents that describe ineffective facilitation in the areas of instruction, curriculum planning, time management, and group management. This is the largest unhelpful category with 58% of participants contributing 12 incidents, accounting for 75% of all unhelpful incidents.

Four of the incidents related to issues with instruction including insufficient explanations, irrelevant program activities, and too much repetition. For example, one participant commented that the facilitator did not provide a thorough explanation of concepts: “Our group leader should have explained the meaning of different kinds of feelings better. For instance, give us examples of situations in which we might experience those feelings.” Another participant reported that some of the programming was irrelevant to the topic of parental mental illness: “...some of the games...like *What time*

is it Mr. Wolf?...I was...wondering what does that have to do with the group?...We played that a lot.”

Four other incidents in this category described issues of poor time management. According to one participant: “[My group leader] was always late picking me up...” This participant also noted that group meetings started late “...half of the time.”

Finally, four incidents made reference to weak group management skills. For example, one participant described how his group could get out of control: “...we just got louder and louder and louder...She [the facilitator] lost heart and there wasn’t a proper way of getting everybody to be quiet.”

Category 2: Disruptive behaviour exhibited by other group members

This category consists of four incidents reported by three participants. The incidents recount how the disruptive behaviour of a few group members interfered with the participants’ ability to engage in group activities and/or feel comfortable in the group. The following exemplifies the incidents in this category: “One [kid] was jumping around... hurting his brother...They were...running around hitting each other...And then they were hitting...this other kid.” The participant found this behaviour “distracting” and said he felt “a little scared.”

Program Helpfulness Ratings

The rating of overall program helpfulness was measured using a 10-point scale in which 0 represented *no help*, 5 represented *medium help*, and 10 corresponded to *very, very helpful*. The twelve ratings ranged from scores of 5 to 10, with a mean rating of 7.63. A mean rating of 7.63 is half way between *medium help* and *very, very helpful* and approximately corresponds to *very helpful* on the scale.

Participant Recommendations for Program Improvements

The wish list is a collection of participant responses to the question, “What was missing from the program that would have made it better?” Eight participants contributed 10 recommendations for improvements. In Table 4 the participants’ recommendations have been paraphrased and organized into three categories: instructional improvements, time management improvements, and group management improvements.

Table 4. Wish list: Recommendations for Program Improvements

Instructional improvements
<ul style="list-style-type: none"> • More detailed information about the different types of mental illnesses. A list of internet resources that we can refer to on our own time would be helpful. • Explaining concepts better, such as how mental illnesses affect the body. A body model/skeleton might be helpful. • More activities to keep us active (not sitting around) so we don’t get bored. These activities should be relevant to parental mental illness because some of the games I played were not.
Time management improvements
<ul style="list-style-type: none"> • Group sessions that start on time. (recommended by two participants) • A break to play with toys so that I can rest my body before going back to work.
Group management improvements
<ul style="list-style-type: none"> • Enforcement of rules to keep the group under control. • A good method of getting everyone’s attention. For example, ringing a bell. • Strategies for dealing with disruptive kids, such as talking to the people causing problems or giving them a <i>time out</i> to calm down. • A larger, open space to hold group sessions because it was difficult to do some of the activities. The space was too cramped with furniture.

Correspondence Between Program Objectives and Critical Incident Categories

This section reports the correspondence between the children's perceptions of helpful and unhelpful aspects of the program with the intended program objectives laid out in the *Kids in Control* manual (British Columbia Schizophrenia Society, 2005).

Table 5 provides an overview of program objectives, as well as the critical incident categories that correspond with these objectives.

Table 5. Correspondence Between Program Objectives and Critical Incident Categories.

Session	Title	Objectives	Incident Categories
1	Group Building & Storytelling	<ul style="list-style-type: none"> • Become familiar with others and setting • Create identity as a group based on common and shared experiences • Become acquainted through game playing • Develop a feeling of belonging by sharing stories 	<p>Helpful Category 4: Effective facilitator group management skills</p> <p>Helpful Category 6: Connecting with other children experiencing parental mental illness</p> <p>Unhelpful Category 1: Ineffective facilitation skills</p> <p>Unhelpful Category 2: Disruptive behaviour exhibited by other group members</p>
2	Group Building & Learning to Identify Feelings	<ul style="list-style-type: none"> • Learn how to identify and validate feelings • Learn about 4 basic feelings - mad, sad, glad, scared • Learn all feelings are acceptable and okay • Learn that we can be the boss of our own feelings 	<p>Helpful Category 1: Identifying, communicating, and managing feelings</p>

3	Learning about Healthy Boundaries & How to Communicate Feelings	<ul style="list-style-type: none"> • Learn about “detachment” and “boundaries” • Learn appropriate ways to communicate feelings • Learn that mental illness is not their fault or anyone else’s 	<p>Helpful Category 1: Identifying, communicating, and managing feelings</p> <p>Helpful Category 3: Helpful messages of responsibility, control, and empowerment</p>
4	Learning About Mental Illness	<ul style="list-style-type: none"> • Learn about what mental illness (M.I.) is and how it is treated • Learn that M.I. is psychologically-based • Learn terminology associated with M.I. • Learn facts & dispel myths about M.I. 	Helpful Category 2: Learning about mental illness
5	Learning About the Treatment of Mental Illness	<ul style="list-style-type: none"> • Learn about the different treatment options • Learn factual information about hospital treatments 	Helpful Category 2: Learning about mental illness
6	Developing Resiliency	<ul style="list-style-type: none"> • Understand what it means to be resilient • Provide opportunity for children to see and experience themselves as resilient • Create resiliency expectation within each child • Provide tools to increase resiliency 	Helpful Category 8: Identifying supports
7	Societal Attitudes and Stigma	<ul style="list-style-type: none"> • Explore personal feelings regarding attitudes towards parents with mental illness • Help decrease stigma • Help deal with personal feelings of shame/guilt 	Helpful Category 7: Learning about stigma
8	Self-Care and Self-Esteem	<ul style="list-style-type: none"> • Learn the importance of taking care of oneself • Learn that it is okay to feel good about self • Learn ways to affirm and value self 	Helpful Category 3: Helpful messages about responsibility, control, and empowerment

A cursory review of Table 5 indicates that many of the category themes generated in this study are related to the program objectives. All of the session objectives can be linked to the category themes in this study, with a few specific exceptions that will be highlighted in the discussion below. While the helpful incident categories provide evidence to support that the program objectives are being met, the two unhelpful incident categories appear to hinder the intended program outcomes. An in depth analysis of how the critical incident categories relate to the program objectives for each session is outlined next.

Session 1 objectives

The objectives of the first session titled “Group Building and Story Telling” are to become acquainted with others, develop a group identity of common and shared experiences, and instil a feeling of belonging by sharing stories. These objectives closely relate to the 9 incidents reported by 7 participants contained in “Category 6: Connecting with other children experiencing parental mental illness.” Participants reported that it was helpful to meet other COPMI as it normalized their situation, reduced their sense of isolation, provided opportunities to share stories with others that could relate, and acted as a support network.

In addition, 8 participants described 12 helpful incidents in “Category 4: Effective facilitator group management skills” which reinforce the program objective of building cohesive groups. Participants spoke of behavioural management strategies and personal facilitator qualities that contributed to an orderly, positive group environment. Thus, the incidents reported by participants in helpful categories 4 and 6 provide evidence that the program objectives of group building were being achieved.

In contrast, two unhelpful incident categories generated in this study seem to hinder the goals of group building. First, in “Category 1: Ineffective facilitation”, 3 participants identified 4 unhelpful incidents related to poor group management. Participants made reference to the inability of the facilitator to maintain order and found this disruptive and unpleasant. Second, in “Category 2: Disruptive behaviour of other group members”, three participants described 4 unhelpful incidents related to disorderly behaviour by other participants that disrupted activities, distracted others, and made one of the participants feel “a little scared.” These incidents seem to suggest that group functioning was impaired at times.

While it is clear that the participants view effective group management skills as helpful, and ineffective group management skills and disruptive participants as problematic, very little guidance is provided in the *Kids in Control* manual about these issues. Only one sentence is dedicated to desirable facilitator skills. With respect to behavioural problems, the manual does advise screening out children with significant behavioural problems. However, the manual does not provide specific screening criteria to determine the eligibility of participants with behavioural problems.

In summary, 10 participants identified 21 helpful incidents that were consistent with the program objectives of group building, while 4 participants described 8 incidents that are inconsistent with objectives. Although the participants’ positive perceptions exceed the negative ones, the unhelpful incidents related to poor group management and disruptive participants were nevertheless viewed as unhelpful by the participants. This issue will be addressed in the section titled “Fit with Program Objectives” in Chapter 5.

Session 2 and 3 objectives

The objectives of Sessions 2 and 3 were combined here as they both relate to the topic of learning about feelings. In particular, the objectives of learning to identify and validate feelings, learning to be the “boss” of your feelings, and learning appropriate ways to communicate feelings are closely related to the helpful incidents reported by participants in “Category 1: Identifying, communicating, and managing feelings.”

Learning about feelings was reported to be the most helpful aspect of the program, with 100 % of participants identifying 27% of all helpful incidents. Participants described helpful incidents in which they learned to identify both their feelings and their parents’, as well as learning about strategies to manage and express their feelings in constructive ways.

In addition, the program objectives of learning about “detachment” and “boundaries,” as well as learning that mental illness is not the fault of the child or anyone else’s, is closely related to the incidents reported in “Category 3: Helpful messages about responsibility, control, and empowerment.” In this third largest category of helpful incidents, participants described incidents related to the aphorism, “I can’t cause it. I can’t change it. I can care for myself.” The participants describe detaching themselves from their parent’s illness by no longer taking responsibility, recognizing boundaries in terms of what is within their control, and realizing that they do have the ability to care for themselves. Hence, the program objectives set out for session 2 and 3 are consistent with the incidents participants described in helpful categories 1 and 3.

Session 4 and 5 objectives

The program objectives for session 4, “Learning about mental illness” and session 5, “Learning about the treatment of mental illness” were combined here because they both correspond to helpful “Category 2: Learning about mental illness.” This category had the second highest participation rate of 83%, reflecting the importance that the participants attached to psycho-education. Incidents in this category included references to helpful activities that taught about the biology, symptoms, and treatment of mental illness. The one objective that participants did not make reference to was “learning factual information about hospital treatments.” Otherwise, the critical incidents touched on all of the objectives in these sessions.

Session 6 objectives

The program objectives for the sixth session titled “Developing resiliency” included: learning what it means to be resilient, providing an opportunity for children to see and experience themselves as resilient, creating the resiliency expectation within each child, and providing tools to increase resiliency. None of the participants reported any incidents related to the objective of learning what it means to be resilient. In fact, when the lesson title was reviewed with participants in an effort to twig their memory, none of the participants knew what resiliency meant. When they were given a basic definition, it still didn’t seem to ‘ring any bells’ for them. A few participants suggested that they may have forgotten the lesson or that their group may have skipped this lesson since they didn’t know what resiliency was. One thing from the lesson that 5 participants did identify as helpful was the activity “Things I can do for myself” which involved identifying supports to contact in case of an emergency. This activity corresponds to

helpful category 8. It is assumed that identifying supports fits with the last objective of providing tools to increase resiliency. Since fostering resiliency is one of the major goals of this program, this issue will be further addressed in the “Fit with Program Objectives” section of Chapter 5.

Session 7 objectives

The program objectives for the seventh session titled “Societal Attitudes and Stigma” included: exploring personal feelings regarding attitudes towards parents with mental illness, decreasing stigma, and dealing with personal feelings of shame and guilt. These objectives are consistent with helpful “Category 7: Learning about stigma.” In this category, 7 participants reported 7 critical incidents that related to stigma. Participants spoke of learning about negative societal attitudes and the injustice of discriminating against those with mental illness. They also spoke of not blaming themselves or their parents for having mental illness and disregarding what others think. Thus, the critical incidents reported are consistent with the program objectives related to stigma.

Session 8 objectives

The program objectives for the last session titled “Self-care and Self Esteem” included: learning the importance of taking care of oneself, learning that it is okay to feel good about self, and learning ways to affirm and value self. The first objective of self-care is consistent with critical incidents reported in “Category 3: Helpful messages about responsibility, control, and empowerment.” These incidents made reference to the 3 Cs statement, “I can care for myself,” and described self-care activities such as learning to take a bath, healthy eating habits and exercise. However, the 3 Cs were taught in an earlier lesson. When the participants leafed through the material for session 8, none of the

12 participants reported doing any of the activities, nor did they report any helpful or unhelpful incidents related to the lesson. Once again, participants suggested that either they had forgotten the material or they had not covered the lesson in their group.

Further, the participants did not report any critical incidents specific to the objectives related to self-esteem. This is not to say that the program did not boost their self esteem. For example, two participants noted that making new friends made them feel “special” and “good,” and another participant spoke of feeling “important” when his group leader praised him. However, no specific helpful or unhelpful incidents related to learning about self-esteem were reported. Thus, the self-care objective was consistent with critical incidents reported from an earlier lesson, but no critical incidents specific to self-esteem were reported.

It should be noted that helpful “Category 5: Having fun” does not fit with any of the program objectives outlined in Table 3. In addition, there were 8 incidents within unhelpful “Category 1: Ineffective facilitation skills” related to the facilitators’ poor management of time and ineffective instructional skills that do not correspond with any of the program objectives. These unhelpful incidents have the potential to undermine program objectives. These issues will be addressed in “Fit with Program Objectives” in the next section.

CHAPTER V: DISCUSSION

This study evaluated the helpfulness of the *Kids in Control* program from the participants' perspective. Twelve children were recruited from four groups that were held between April 2007 and February 2008 in the Greater Vancouver area. The children were interviewed and themes were extracted using the critical incident technique.

The discussion will focus on putting the results into context and reflecting on the practical implications of the study. First, the results will be interpreted in a brief summary. Next, a discussion on how the findings correspond to the objectives of the *Kids in Control* program will be provided. This will be followed by an examination of how the findings fit with the extant literature on children of mentally ill parents and the interventions designed to help them. The practical implications of the study will be presented, including implications for program improvement, program dissemination, and counselling practice. A discussion of this study's contributions will follow. Finally, limitations of the study will be reviewed, and directions for future research will be outlined.

Summary of Results

The results from the twelve research participants indicate that the *Kids in Control* program was on the whole, very helpful to the participants. Out of a total of 121 critical incidents reported, 105 incidents were perceived as helpful by the participants for dealing with parental mental illness. On the other hand, only 16 unhelpful incidents were reported, suggesting that there are far more beneficial aspects of the program than detrimental ones. In addition, the participants' overall rating of program helpfulness was 7.63 on a scale ranging from 0 (*no help*) to 10 (*very, very, helpful*), which roughly falls

into the *very helpful* range. This too provides evidence that the program is beneficial from the participants' perspective.

The eight helpful and two unhelpful incident categories reported by the participants have face validity, reflecting the types of themes one would expect to find. All of the critical incident categories have substantial participation rates, lending credibility to the results given that a large percentage of participants independently reported the same or similar critical incidents.

Fit with Program Objectives

The 105 helpful critical incidents reported by the participants closely correspond with the program objectives, with a few exceptions. Specific program objectives that were not identified as helpful or unhelpful by the participants included information about hospital treatments, learning what it means to be resilient, and objectives related to enhancing self-esteem. Given that building resiliency and self-esteem are major goals of the *Kids in Control* program, it will be important for program administrators to determine why these objectives were not identified in this study. One simple explanation is that learning about resiliency and self-esteem are not perceived as helpful or useful to COPMI. Another plausible explanation is that these topics were not covered sufficiently due to time constraints or other factors that required facilitators to limit the material covered. This is possible given that these lessons were taught near the end of the program, and that not all the material in the manual was covered since the facilitators reported a mean adherence rate of 76%.

In addition, the 8 unhelpful critical incidents related to poor group management and disruptive behaviour have the potential to undermine the goal of developing safe,

cohesive groups. Further, another 8 unhelpful incidents related to the facilitators' poor management of time and ineffective instructional skills were reported. All of these unhelpful incidents have the potential to undermine the objectives of the program. However, it is important to keep in mind that these unhelpful incidents are in the minority compared to the number of helpful incidents reported. These unhelpful aspects of the program will be addressed further in "Implications for Program Improvement".

The one helpful category that does not correspond to any program objective is "Category 5: Having fun". For the participants in this study, playing games, earning prizes, making crafts, and having an end-of-group party was a very important part of their group experience. The participants reported that a fun atmosphere enhanced their level of comfort and engagement in activities. The program manual does make the occasional reference to having fun and has created a program full of interactive games and activities. However, it may be helpful to explicitly communicate to program facilitators the importance that participants place on their enjoyment of the program. This will be addressed further in "Implications for Program Improvement".

Fit with the Literature

The existing literature outlined in Chapter 2 will now be discussed in relation to the study findings to determine how consistent the results are with what has already been published on children of parents with mental illness.

Barriers to services

In the literature review in Chapter 2, the barriers to services that exist for children of mentally ill parents are outlined. Although this study was not designed to address this issue, it was observed that the referral rate to *Kids in Control* programs was low.

For example, when attempting to recruit participants from the *Kids in Control* groups for this study, it was often the case that groups were delayed due to insufficient numbers. In fact, one facilitator who had agreed to participate in this study withdrew because he was unable to recruit enough members to run a group. The reason for the low referral rate is unknown. It may be symptomatic of what the literature refers to as the *invisibility* of children of parents with mental illness in the mental health care system. For instance, the failure to identify and refer COPMI to appropriate services because mental healthcare providers either fail to inquire about the parenting status of their adult clients, or are not informed about the issues and needs of these children (Fudge & Mason, 2004; Nicholson et al., 2001). On the other hand, parents may not be interested in having their children participate in programs like *Kids in Control* as a result of stigma, or fear of custody loss (Hearle et al., 1999; Nicholson, 1996). It could also be that the facilitators have failed to effectively market their program to mental health agencies, children services, and schools as recommended in the *Kids in Control* manual (British Columbia Schizophrenia Society, 2005). Whatever the reason, it is important to ascertain whether there is in fact an issue with low referral rates, and then determine the causes to minimize barriers preventing children from accessing the program. This issue will be discussed further in the section “Implications for Program Improvement.”

COPMI issues and needs

Some of the helpful categories that emerged in the study are consistent with the existing literature on the issues and needs of children with mentally ill parents. For instance, the literature (Cowling, 1999; Fudge & Mason, 2004; Kinsella & Anderson, 1996; Maybery et al., 2005) points to the need for education about parental mental

illness which is consistent with the participants' perception that learning about parental mental illness was helpful. In addition, Fudge and Mason (2004) refer to the need for stigma reduction which corresponds to the participants' view that it was helpful to learn about stigma and societal attitudes toward the mentally ill.

The literature also talks about children's needs for support including supportive adults and peers to talk to, as well as the need to meet other COPMI in support programs (Cowling, 1999; Fudge & Mason, 2004; Kinsella & Anderson, 1996; Maybery et al., 2005). This is consistent with the participants' perceptions that it was helpful to connect and talk with other COPMI, as well as identify community supports that can be called upon in times of crisis.

Another issue identified in the literature is the use of coping strategies to manage stressful family situations, some of which may be harmful to children over the long term (Maybery et al., 2005; Kinsella & Anderson, 1996). Consistent with this, two participants spoke of how it was helpful to learn about their use of defences such as withdrawal to hide their true feelings. In fact, all of the participants in this study reported that learning about feelings and strategies to manage them was the most helpful aspect of the program. This finding suggests that learning to manage feelings is a significant need of children impacted by parental mental illness.

The burden of additional care-giving responsibilities is another key issue for children in the literature (Fudge & Mason, 2004; Maybery et al., 2005). A few participants in this study touched on this issue. For instance, several participants stated that their parent's mental illness was not their responsibility. In addition, one participant

noted that “only your parents can fix their mental illnesses” and suggested that his mother should “take care of herself.”

One issue in the literature that was not identified by participants in this study was the problem of parental hospitalizations, which is addressed in session 5 of the *Kids in Control* manual (British Columbia Schizophrenia Society, 2005). Although participants did not address the issue of hospitalizations directly, they did find it helpful to identify potential supports in times of crisis, such as when a parent has a mental breakdown.

In summary, the existing literature on children’s issues and needs fits closely with the participants’ reports of what was helpful in the program. This provides some evidence to support the claim that the *Kids in Control* program was successful in meeting some of the key issues and needs of children experiencing parental mental illness.

COPMI outcome studies

The participants in this study reported having a number of psychosocial difficulties. Nine participants (75%) reported psychosocial impairments, including seven participants (58%) that reported having clinical diagnoses. The specific impairments can be found in Chapter 3 in the section titled “Describing the participants.” These findings are consistent with outcome studies in the literature that indicate that COPMI experience higher rates of mental illness, developmental delays, lower academic achievement, behavioural problems, and interpersonal difficulties (Barocas et al., 1998; Beardslee et al., 1998; Canton et al., 1998; Cowling et al., 2004; Hammen et al., 1990; Maybery et al., 2006; Mowbray et al., 2004; Oyserman et al., 2000; Weissman et al., 2006).). This is also consistent with Maybery and colleague’s (2006) study which found that 60% of

participants in an intervention group scored in the “at risk” category for mental health based on the results of the Strengths and Difficulties Questionnaire (Goodman, 1997).

Of note, five participants reported that the program was helpful to not only understand and deal with their parent’s mental illness, but also their own psychosocial problems. For instance, two participants with ADHD noted that group management strategies targeting behaviour were helpful in learning to control their behaviour and interact with other group members. In addition, two other participants diagnosed with depression reported that learning about mental illness helped them to understand and manage their own illnesses. Thus, it appears that this prevention program may have treatment effects as well.

The fact that so many participants are already experiencing problems brings to mind a few questions. First, are these children being referred to the *Kids in Control* program because their psychosocial problems are already visible? Are children with no symptoms being overlooked? It may be important to determine whether the program is what Nicholson and colleagues (1993) refer to as a deficit-based service, meaning that services only become available once diagnosable problems emerge or if children show signs of abuse and neglect.

Secondly, is *Kids in Control* a prevention program or a treatment program? The program manual states:

...the program is not designed as a group therapy directed at changing behaviours. If a child is experiencing problems, then appropriate referrals should be made. The “Kids in Control” program is a psychoeducational group with a prevention focus, it is not a therapeutic group (p.18).

It also states: “By intervening at a young age, we can increase the chances that these children will overcome adversity and grow up to be adjusted healthy adults” (p.12).

Given that so many participants are already experiencing psychosocial problems at a young age, it may be that the intervention has come too late for some participants.

Perhaps children under the age of eight also need to be targeted by the program. These issues will be addressed further in the section “Implications for Program Improvement”.

Qualitative program evaluations

A comparison of the existing literature on interventions using qualitative evaluation methods with the findings of this study was undertaken. Some consistency in helpful themes exists. Five of the helpful categories that emerged in this study were also identified as helpful by children in other evaluations: learning about feelings, learning about mental illness, feeling less responsible, feeling less isolated by meeting and talking with other COPMI, and identifying supports that can help (Orel et al., 2003; Pitman & Matthey, 2004). The three helpful categories that emerged in this study that were not identified in other qualitative evaluations include: effective facilitator group management skills, having fun, and learning about stigma.

With respect to unhelpful aspects of interventions, there was no overlap between the findings of this study and other qualitative evaluations. In this study, participants identified ineffective facilitation skills and disruptive group members as unhelpful, while other studies identified such issues as the length of the program or disliking singing, writing or meditating (Orel et al., 2003; Pitman & Matthey, 2004).

Finally, there was no overlap in themes with respect to program improvements recommended by children. In this study participants recommended improvements related to instruction, time management, and group management. In Pitman and Matthey’s

(2004) study, recommended improvements included a longer program, learning how to deal with death, and learning to become more attached to their parent.

One thing that the other qualitative studies did have in common with this study were participants that reported very few, if any, negative program aspects and offered few suggestions for program improvements (Orel et al., 2003; Pitman & Matthey, 2004). In this study, out of a total of 121 critical incidents, only 16 were identified as unhelpful. When participants were asked about unhelpful aspects of the program or about possible program improvements, typical responses included, “It was all good” or “It’s perfect just the way it is.”

While there are some areas of overlap with respect to helpful program aspects, there is little overlap with the existing literature on unhelpful program aspects or recommendations for improvements. One reason for this discrepancy is that little qualitative data has been published in this area. Another relates to the quality of the qualitative data published in other studies. In contrast, this study was able to collect detailed qualitative data in a systematic manner that is organized into coherent themes. The merits of the critical incident technique will be discussed in greater detail in the subsequent section titled “Study Contributions.”

Implications for Program Improvement

One of the goals of this study was to determine whether the *Kids in Control* program was beneficial from the perspective of children, as well as to ascertain whether the children’s perceptions of the program were consistent with program objectives. While the findings suggest that the children in this sample found the program very helpful in dealing with parental mental illness and that there was a high level of consistency

between helpful aspects of the program and program objectives, there are still areas for improvement. Recommendations for improvement flow from the findings of this study and address issues of accessibility, screening, program objectives, and facilitation.

Accessibility

- Determine whether there is, in fact, a low referral rate to the *Kids in Control* program.
- If a low referral rate exists, investigate potential barriers.
- Follow the *Kids in Control* manual guidelines to market the program to mental healthcare providers, children services, and schools.

Screening

- Inquire about psychosocial impairments when screening new group members. Facilitators should be aware that some group members may find the group helpful to understand and manage their own mental health issues.
- Inquire about potential behavioural problems that may be disruptive to the group.
- Develop clear referral and selection criteria for entry into the group. Children with serious behavioural issues should be referred to other services if the child cannot be accommodated within the group.

Program objectives

- Revisit the program's focus on prevention since many of the participants in this study already have psychosocial difficulties. Be aware that this program may have therapeutic treatment effects for those participants with mental illness, or other emotional, social and behavioural issues. Consider adapting the program to meet the needs of younger COPMI aged 5 to 7 in an effort to prevent psychosocial difficulties from emerging.
- Emphasis should be placed on aspects of the program that children found helpful: identifying, communicating, and managing feelings; learning about mental illness; helpful messages about responsibility, control, and empowerment (The 3 Cs); having fun; connecting with other COPMI; learning about stigma; and identifying supports.
- Determine why the objectives of learning about hospital treatments (lesson 5), understanding what it is to be resilient (lesson 6), and learning about self-esteem (lesson 8) were not reported as helpful/unhelpful by the participants. It may be

that participants simply did not view these as important aspects of the program. It may also be the case that these lessons were not sufficiently covered in the program due to time constraints or other factors.

Facilitation

- Continue to practice the effective group management skills that participants reported as helpful in Category 4 of the “Results” section.
- Consider facilitator training to enhance instructional skills, time management skills, and group management skills.
- Develop behavioural management guidelines for facilitators and include this in the program manual.
- Consider implementing the “Wish List” improvements recommended by the participants in Table 4 of the “Results” section.
- Ensure that groups are fun and interactive to engage group members. Having fun was an important aspect of the program for study participants.

Implications for Program Dissemination and Development

One of the goals of this study was to determine whether wider dissemination of the *Kids in Control* program is warranted. At the moment, the program is only offered in suburban communities in the Greater Vancouver area and Victoria. However, the program has the potential to serve a much larger population of COPMI within the province of British Columbia, other parts of Canada, and beyond.

This study has contributed to the evidence base to support the wider dissemination of the *Kids in Control* program. From the perspective of the participants, the program was reported to be very helpful for dealing with parental mental illness. Further, there is a high degree of consistency between program objectives and the participants’ perceptions of helpful program aspects. This offers evidence that the participants have internalized the curriculum and provides some degree of validation that

the program objectives are being achieved. Several recommendations have been made to improve the program, but in general, it was beneficial to the participants in this study.

While more evidence to support the efficacy of this program by way of outcome studies is desirable, this empirical study begins to establish the program as an evidence-based practice. This is very important to policy makers and funding bodies who require evidence to support interventions like the *Kids in Control* program.

In addition, this study provides important information to program developers who may be interested in creating their own interventions for COPMI. One of the objectives of this study was to determine what the essential components of the intervention were for children. In other words, what ingredients are necessary to make a program successful from the perspective of the consumers. The helpful and unhelpful incident categories that emerged in this study and the specific activities that participants identified as helpful will provide program developers insight into what program elements are useful to COPMI, to ensure that future interventions are responsive to the children's needs.

Implications for Counselling Practice

An important goal of this study was to increase awareness among mental health professionals about parental mental illness, thereby boosting the visibility of COPMI and their unique needs. A list of counselling practice guidelines has been developed for mental health professionals to use when counselling COPMI and their parents. These guidelines flow out of the finding of this study and the literature review on children of parents with mental illness:

- Increase professional awareness and knowledge of parental mental illness and its impact on children through reading, attending lectures and other professional development opportunities.

- Learn about what services are available for children in your community (e.g. *Kids in Control*). If there aren't any, start something.
- Make it part of your practice to routinely inquire about children when counselling adult clients with mental illness. Consider the children when developing a treatment plan.
- When appropriate, invite children in for individual or family counselling sessions to discuss how their parent's mental illness is impacting them.
- Assess whether children are experiencing their own psychosocial difficulties.
- Refer children to appropriate services and programs in your community.
- Incorporate psycho-education into your counselling sessions with parents and children. Teach clients about the causes, symptoms, and treatment of mental illness.
- Provide children with tools to identify, communicate, and manage feelings effectively.
- Introduce the 3 Cs: I can't cause it. I can't change it. I can care for myself.
- Help children to identify supports to help them through times of crisis.
- Assist children to strengthen their support network and explore opportunities to meet other COPMI with similar family situations (e.g. *Kids in Control*).
- Discuss the impact of stigma on children.
- Explore themes of self-blame, guilt, isolation, shame, confusion, sadness, anger, and a lack of control when counselling children.
- Make counselling sessions fun and interactive so that children feel more engaged in the counselling process.

Study Contributions

There has been very little qualitative data published on COPMI's perceptions of intervention programs. This study helps to fill this gap through the use of qualitative methods to collect data on children's perceptions of program helpfulness. In addition, one of the goals of this study was to give children a voice by directly consulting them on

matters that affect their lives. Through semi-structured interviews, children were able to share their thoughts and opinions on whether the program was effective in meeting their perceived needs.

Another positive contribution of this study is the quality of the data collected. The existing qualitative data in the form of feedback surveys lacks the detail and clarity of the data collected in this study. Flanagan's (1954) critical incident technique allows for the systematic collection and organization of participant perceptions into quantifiable themes with measurable participation rates. This provides the researcher with a more coherent description of the data, and indicates the relative importance of the reported incidents.

This is also one of the few studies to have used the critical incident technique with children. This study concurs with other researchers that the critical incident technique is an effective tool for measuring children's perceptions (Bonnstetter, 2007; LeMare & Sohbat, 2002; Ross & Egan, 2004; Tulley & Chui, 1998). The CIT method of eliciting specific examples of critical incidents was suitably concrete and developmentally appropriate for the participants in this study, aged 8 to 12 years. All of the participants readily understood what was meant by *helpful* and *unhelpful* parts of the program and were able to produce critical incidents. Since CIT is inherently flexible, it was possible to make modifications to the method to ensure that it was child-friendly. Active listening skills such as empathy, open-ended questions, paraphrasing, clarifying, and probing were employed to assist the children with the full exploration of critical incidents. It was also helpful to use visual material from the *Kids in Control* manual to provoke discussion and assist with the recall of incidents.

The use of the *expanded form* of the critical incident technique was found to be effective with children in the older age group (11 and 12 years). In particular, these older participants were often quite eloquent in their descriptions of how the program was helpful. In contrast, the younger participants (aged 8 and 9) found it difficult to articulate how the program helped. The caveats of using the *expanded form* of the critical incident technique with this younger age group will be discussed in greater detail in the next section.

Limitations

According to Flanagan (1954), “The aim of the study is usually not a functional description of the activity as carried on by this sample but rather a statement relating to all groups of this type. In order to avoid faulty inferences and generalizations, the limitations imposed by the group must be brought into clear focus” (p.345). Several limitations have been identified that are consistent with Flanagan’s statement.

This study is susceptible to selection bias given its reliance on a volunteer sample. It is possible that those that chose to participate in this study may differ from the larger population of COPMI. For instance, the participants that volunteered for this study may have come from higher functioning families with healthier parents that are more open to sharing family problems. On the other hand, concerns related to divulging family problems or fears of custody loss may have prevented those children from lower functioning families from participating. Thus, the findings of this study may not generalize to the larger population of COPMI.

Another potential limitation is that a social desirability bias may have influenced how participants responded. It may be that children are especially inclined to give

feedback that they think will be viewed favourably by the researcher. For instance, participants may have thought that the researcher desired positive affirmations of the program, thus explaining why very few unhelpful critical incidents were reported. On the other hand, the children may not have reported very many unhelpful critical incidents because they were highly satisfied with their program experience.

Further, the use of the *expanded form* of the critical incident technique was developmentally inappropriate for the younger participants (aged 8 and 9) in this study. These participants are in the concrete operational stage of cognitive development and have not yet developed the ability to think abstractly about issues. When younger participants were asked to explain how a critical incident was helpful, a typical response was: “I know it’s helpful but I can’t explain how.” Although it was anticipated that this would be a potential limitation going into the study, a decision was made to investigate the use of the *expanded form* of CIT with younger age groups. Based on the findings of this study, it is recommended that the *expanded form* of CIT be used with participants aged eleven and older. Since 60% of the participants in this study were aged 11 and 12, many personal reflections of meaning were still collected which greatly enriched the quality of the data.

Directions for Future Research

This study has deepened our awareness of the subjective experience of COPMI and increased our knowledge about which intervention components are most helpful to them. Program developers need to create more interventions in the future that incorporate these elements to ensure that their programs are responsive to the needs of COPMI.

In addition, this study raises new questions about how a clinical diagnosis affects the participant's experience of the program. Fifty-eight percent of the participants in this study had a clinical diagnosis and some reported therapeutic program effects. Future programs may need to be adapted to further address the current treatment needs of these participants.

More research is required to quantify and address barriers that may be limiting children of mentally ill parents from accessing services like the *Kids in Control* program. Conducting research on how to improve community linkages between schools, child protection services, and the mental healthcare system may help ensure that COPMI are being identified and referred to the appropriate services.

The prevention and treatment of psychosocial impairments in children of mentally ill parents is a research field that is largely unexplored. While this study adds to the evidence base for prevention programs for COPMI, further evaluations of interventions are required to fill the gap in the literature and add to the evidence base for practice. More qualitative studies that explore children's perceptions of program helpfulness and intervention needs are recommended. In addition, randomized control trials of programs like *Kids in Control* are needed to examine how effective programs are in preventing and treating psychosocial difficulties in children. Also, longitudinal quantitative and qualitative studies that measure the impact of programs over time are necessary to establish whether programs foster resilience and mitigate risks over the long term. Validating programs is a pressing need as policy makers and funding bodies justifiably require evidence to support policy initiatives and the allocation of scarce resources.

It is hoped that this study has played a role in building awareness and knowledge of the experiences, risks, and intervention needs of children of mentally ill parents.

Researchers, mental health clinicians, and policy makers must make a concerted effort to recognize and offer services to this large and vulnerable population to ensure the psychosocial wellbeing of these children now and in the future.

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APPENDICES

Appendix A

Letter of Endorsement



A REASON TO HOPE. THE MEANS TO COPE.
BRITISH COLUMBIA SCHIZOPHRENIA SOCIETY

Honourary Patron
 Wayne A Nygren

Honourary Directors
 Dr. F.A. Adrien
 I. Hilton
 M. J. Kirk
 P.E. Vaughan

Medical Advisory Board
 Dr. Bill MacEwan, FRCP
 Dr. William G. Honer, MD, RCPC
 Dr. Anthony Phillips, PhD., FRSC

May 7, 2007

Behavioural Research Ethics Committee
 Office of Research Services
 The University of British Columbia
 TEF III Building
 #102-6190 Agronomy Road
 Vancouver, BC V6T 1Z3

Dear Ethics Review Committee,

This letter is in support of the proposed research project on the Kids in Control program, being undertaken by Dr. Lynn Miller and Karen Hamill from the University of British Columbia. I am aware that the researchers intend to recruit volunteers from Kids in Control programs for interviews between April and November of 2007 to determine how helpful the program is to the group participants. I also support the participation of Kids in Control group facilitators in this project, providing their involvement is on a voluntary basis. I have been informed that this research is being conducted to fulfill the requirements of a Master's thesis.

The British Columbia Schizophrenia Society is dedicated to the delivery of high quality programs for mental health consumers and their families. We support the evaluation of our programs as a means of improving and refining our services. Our agency is willing to provide whatever assistance is necessary to facilitate this project. It is hoped that this research will enhance our ability to help those children that are managing parental mental illness.

Sincerely,

Gary Glacken
 Executive Director

Appendix B

Group Facilitator Consent Form

Title: Children's Perceptions of a Psycho-Educational Program about Parental Mental Illness

Principal Investigator: Dr. Lynn Miller, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia Tel. (604) 822-8539

Co-Investigator: Karen Hamill, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia Tel. (604) 689-1006

Dear *Kids in Control* Group Facilitator:

You are invited to participate in an evaluation of the *Kids in Control* Program that will be taking place from May to November of 2007. The evaluation is being conducted to determine in which ways the program is helpful or not helpful to the participants, and whether the program fulfills its intended objectives such as increasing knowledge about mental illness and enhancing coping skills as a means of fostering resilience in children.

Procedure for Recruitment:

Your assistance is needed with the recruitment process. Approximately 10-15 volunteers are required for interviews. To be eligible for inclusion in the study, group members must attend at least 6 of the 8 sessions and be first time participants in the program.

You will be responsible for:

- Informing parents/guardians and group participants about the research study, and answering any questions that they might have
- Directing inquiries that you cannot answer to the researchers
- Distributing information packages (participant information letter, 2 copies of a parent/guardian consent form, demographic questionnaire, return envelope)
- Distributing reminder notices
- Keeping any consent forms that are returned to you in a locked filing cabinet or other secure location until they can be returned to the co-researcher

The co-researcher will attend the first group session to provide interested parents with more in-depth information about the study. Parents may give consent at this time, or take the information packages home for further consideration.

Facilitator Questionnaire:

In addition to recruiting research participants, you are also asked to complete a facilitator questionnaire. The purpose of this questionnaire is to collect general information about the facilitators and program sites as a means of describing the groups from which the research participants are drawn from.

Time Commitment:

It is expected that the recruitment of volunteers will require a relatively modest time commitment. Approximately five to ten minutes of time may be required to discuss the research study with the parent/guardian during the intake interview. Additional time will

be required to distribute the information packages and reminder notices. You may have to field the occasional telephone call if parents/guardians or group members have inquiries about the research study. Completion of the Facilitator Questionnaire may require five to ten minutes of time. Facilitators will receive a small gift to compensate them for their time.

Confidentiality:

All the information that you provide about yourself and your program activities in the Facilitator Questionnaire will be kept strictly confidential. Data collected will not be linked to specific facilitators or program sites. You will be assigned an identity code in place of your name and group site. Should your name or other identifying information emerge during participant interviews, it will be altered in the transcript to protect your identity. Likewise, your name and any other identifying information will not be used in the publication or presentation of this study. The information that you share will not be disclosed to supervisors, employers, or other facilitators. Members of the thesis committee may have access to the raw data. All data entered into a computer will be password protected. All paper documents will be kept in a locked filing cabinet and shredded five years after the completion of this study.

Risks and Benefits:

This research may have both positive and negative consequences for your professional practice. Any indication that the program is not helpful to participants or effective in achieving its goals may create concerns about the administration of this program and its value to the participants. This could put your job as a group facilitator in jeopardy. On the other hand, this research may be an opportunity to affirm the benefits of the program that could ultimately lead to further program funding, wider program dissemination, and greater job security. It may also facilitate program improvements that may better serve the needs of the children. Keep in mind that this study is intended to evaluate the program and not the facilitator. However, it is possible that the research may uncover both helpful and unhelpful aspects related to the facilitator's role. You can withdraw from the study at any time.

Results:

This research study is for a graduate thesis, which is being conducted to fulfill a requirement for a Master's degree in the Faculty of Education at the University of British Columbia. You will be informed about the findings, which are expected to be ready by the spring of 2008. These results may be published in a peer-reviewed journal at some point in the future.

Inquiries:

If you have any further questions or concerns, please feel free to contact Karen Hamill at [REDACTED] or Dr. Lynn Miller at (604) 822-8539.

If you have any concerns about your treatment or rights as a research participant, please contact the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia, at (604) 822-8598.

Consent:

Your participation in this study is voluntary and you may refuse to participate or withdraw from the study without consequences at any time. By signing this consent form, you agree to assist with the recruitment of participants from the *Kids in Control* groups that you facilitate. In addition, completion of the Facilitator Questionnaire will imply that consent has been granted. By signing below, you acknowledge that you have read this consent form, and that you have been given a copy of this document for your records.

Printed name of facilitator

Date

Signature of facilitator

Date

Thank you for your interest in this study. Your contribution is greatly appreciated.

Sincerely,
Karen Hamill

Appendix C

Group Facilitator Questionnaire

Title: Children's Perceptions of a Psycho-Educational Program about Parental Mental Illness

Principal Investigator: Dr. Lynn Miller, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia Tel. (604) 822-8539

Co-Investigator: Karen Hamill, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia [REDACTED]

1. Where was your group offered? _____
2. When was the first session held? (dd/mm/yy) _____
3. How many sessions did you offer? _____
4. How long was each session? _____
5. How many children were in your group when you started? _____
6. How many children completed the entire program? _____
7. What is your gender? (please circle) Male Female
8. Describe your education and training (include most relevant) _____
9. How many times have you facilitated the Kids in Control program (not including the group involved in this study)? _____
10. Did you run the group with a co-facilitator? Yes No
11. Answer the following questions if you had a co-facilitator:
 - (a) gender (please circle) Male Female
 - (b) education and training (most relevant) _____
 - (c) How many times has he/she co-facilitated *Kids in Control*? (not including this group) _____
12. Did you or your co-facilitator experience parental mental illness as a child? (please circle) Yes No
13. Given the complexities of running a group, it may not always be possible to follow the curriculum as set out in the *Kids in Control* manual. For the group under study, please estimate your degree of adherence to the manual, with 0% being no adherence and 100% being strict adherence. _____%

Adapted from Richter (2006).

Appendix D

Participant Information Letter

Title: Children's Perceptions of a Psycho-Educational Program about Parental Mental Illness

Principal Investigator: Dr. Lynn Miller, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia Tel. (604) 822-8539

Co-Investigator: Karen Hamill, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia

Hello,

I am a researcher from the University of British Columbia. I would like to hear about your thoughts on the *Kids in Control* program. After *Kids in Control* is finished, I want to talk to you about what parts of the program were helpful to you, what parts of the program were not helpful to you, and what you think was missing from the program. The reason why I need this information is to find out if the program is helping kids like you, and to learn about how to make the program better.

I would like to meet with you for about one hour to ask you questions about the program. There are no right and wrong answers. Whatever you tell me is okay. If you don't know the answer, that's okay too. You and your parent/guardian can choose a place where you feel safe and comfortable. I will tape record our conversation so that I don't forget anything you said. Later I will send you a letter that summarizes what you said in the interview. I will call you on the telephone to make sure I got everything right in the letter.

The information you share will be kept private and stored in a safe place. I won't use your name when I'm writing the research report. I won't tell the *Kids in Control* group leader about what you said. If you had a bad group experience, it might upset you to talk about it. If you feel upset or uncomfortable talking to me, you can end the interview at any time.

Participating in this research is your choice. If you decide to take part, I will explain this information to you again at the beginning of the interview. I will ask you to sign a form that says you want to participate. It's okay if you change your mind and decide not to participate.

To thank you for taking the time to talk to me, you will be given \$10.00.

If you have any questions, you can talk to your parent/guardian, the *Kids in Control* group leader, or you can call Lynn at 604-822-8539.

Sincerely,
Karen Hamill

Appendix E

Parent/Guardian Consent Form

Title: Children's Perceptions of a Psycho-Educational Program about Parental Mental Illness

Principal Investigator: Dr. Lynn Miller, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia Tel. (604) 822-8539

Co-Investigator: Karen Hamill, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia

Dear Parent/Guardian:

Your child is invited to participate in a research study that will evaluate the *Kids in Control* program. The purpose of the evaluation is to determine which aspects of the program are helpful or not helpful to the children that attend it. The information that your child shares about their group experience may be used to make program improvements that may better serve the needs of children attending future programs.

Study Procedure:

To be eligible, this must be the first time that your child is participating in the program, your child must attend at least six of the eight sessions, and have parental/guardian consent to participate in the study.

The co-investigator will interview your child about their group experience at some point after the end of the *Kids in Control* program. A time and location that is convenient for you and your child will be chosen. Potential interview sites include libraries, community centres, *Kids in Control* group sites, or a quiet place in your home. The interviews will be approximately one hour, but may vary depending on the interest of your child. At the beginning of the interview, the researcher will seek assent from your child.

Interviews will be audiotaped and transcribed for analysis. The researcher will analyze the interviews for common themes related to the value and usefulness of the program. The researcher will mail your child a letter summarizing the information several months after the interview. The researcher will contact your child by telephone a week after this letter is mailed to ask your child if the information that was collected at the interview is correct.

Demographic Questionnaire:

You, the parent/guardian, are invited to complete the attached questionnaire. The purpose of this questionnaire is to collect background information about your child so that we may be able to describe the participants in the study. However, this questionnaire is optional. If you do not wish to complete some or all of the items in the questionnaire, your child may still participate in this study. Completing the questionnaire will imply that consent has been granted.

Time Commitment:

The total time required by your child is approximately one hour and fifteen minutes (one hour for the interview, 15 minutes for the follow-up telephone call). Completion of the demographic questionnaire will require less than 5 minutes of your time.

Confidentiality:

All names and identifying information will be changed in the transcript to protect the identity of your child, and others mentioned in the interview. Your child will be assigned an identity code in place of his/her name. Your child's name and any other identifying information will not be used in the publication or presentation of this study. Members of the research committee, graduate students assisting with data analysis, and a transcription clerk may have access to the raw data. *Kids in Control* group leaders will not have access to raw data. All data entered into a computer will be password protected. Audiotapes will be kept in a locked filing cabinet and erased after five years. All paper documents will be kept in a locked filing cabinet and shredded five years after the completion of this study.

It is standard practice in research involving children to notify parents that confidentiality will be broken if the child reports abuse or neglect during the interview. The researcher is obligated to contact Child Protection Services in such an event.

Risks and Benefits:

There are no direct benefits to your child for participating in this study. However, your child may feel a sense of pride from knowing that their experience may help other children in the future. Through this research, we may learn more about the needs of children dealing with parental mental illness. We may also learn more about how to design and improve programs to best meet those needs. Your child may experience positive and/or negative feelings while talking about the *Kids in Control* program. If your child becomes distressed for any reason in the interview, we will consult him/her about whether he/she wishes to continue. Your child is free to withdraw from the study at any time. The researcher will have a list of services for children if there is a need for further support or counselling.

Results:

This research study is for a graduate thesis, which is being conducted to fulfill a requirement for a Master's degree at the University of British Columbia. You and your child will be informed about the findings, which are expected to be ready by the spring of 2008. These results may be published in a peer-reviewed journal at some point in the future.

Compensation:

Your child will be given \$10 to compensate them for their time.

Inquiries:

If you have any further questions or concerns, please feel free to contact Karen Hamill at (██████████) or Dr. Lynn Miller at (604) 822-8539.

If you have any concerns about your treatment or rights as a research participant, please contact the Research Subject Information Line in the UBC Office of Research Services at the University of British Columbia, at (604) 822-8598.

Consent:

I understand that my child's participation in this study is voluntary and that he/she may refuse to participate or withdraw from the study without consequences at any time. I have read and understood the description of the study, and I have received a copy of this consent form for my own records. By signing below, I consent to my child's participation in this study and give the researcher permission to contact me to set up an interview with my child. I also give the researcher permission to contact my child at a later date to verify the accuracy of the information collected during the interview.

Parent/Guardian printed name Date

Parent/Guardian signature Date

Child's name _____

Location of Kids in Control group (city) _____

Telephone Number _____ E-mail _____

Mailing Address _____

Thank you for your interest in participating in this study. Your contribution is greatly appreciated.

Sincerely,
Karen Hamill

PLEASE KEEP ONE COPY OF THE CONSENT FORM FOR YOUR RECORDS.

PLEASE SIGN ONE COPY OF THE CONSENT FORM AND RETURN IT TO THE RESEARCHER BY MAIL IN THE ENVELOPE PROVIDED.

Appendix F

Child Assent Form

Title: Children's Perceptions of a Psycho-Educational Program about Parental Mental Illness

Principal Investigator: Dr. Lynn Miller, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia Tel. (604) 822-8539

Co-Investigator: Karen Hamill, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia

I have read the attached participant information letter and have had it read to me. I have had a chance to ask the researcher questions. I understand what this research study is about and I understand what the researcher wants me to do. I agree to participate in an interview about how helpful the Kids in Control program was for me. I also agree to have the researcher call me at a later time to talk about the research results. I understand that it is my choice to participate and that I don't have to answer questions if I don't want to. I know that I can stop the interview at any time. I know that the information that I share will be kept private and that no one will be able to connect me to my answers.

Print Name _____

Signature _____

Date _____

Age _____

Appendix G

Demographic Questionnaire

Title: Children's Perceptions of a Psycho-Educational Program about Parental Mental Illness

Principal Investigator: Dr. Lynn Miller, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia Tel. (604) 822-8539

Co-Investigator: Karen Hamill, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia

As discussed in the consent form, we are gathering some background information about your child and his/her living situation. This information is being collected in order to describe the participants who take part in the study. We will protect you and your child's identity. None of the answers that you provide will be linked to you or your child's name. Only answer the questions that you feel comfortable answering. If you do not complete some or all of the items in the questionnaire, your child may still participate in this study. Completing the questionnaire will imply that consent has been granted. The questionnaire will only take a few minutes to complete.

1. How old is your child? _____
2. What is your child's ethnic/cultural background? _____
3. How many siblings does your child have? _____
4. Does your child have a biological parent who has been diagnosed with a mental illness? (please circle)
 Yes No
5. Does your child have a non-biological parent/caregiver who has been diagnosed with a mental illness? (please circle)
 Yes No
6. Does your child have more than one parent/caregiver who has been diagnosed with mental illness? (please circle)
 Yes No
7. Does your child currently live with the parent/caregiver who has been diagnosed with a mental illness?
 Yes No
8. What mental illness has the parent(s)/caregiver(s) been diagnosed with?

PLEASE RETURN THIS TO THE RESEARCHER IN THE ENVELOPE PROVIDED.
 Adapted from Richter (2006).

Appendix H

Reminder Notice

Title: Children's Perceptions of a Psycho-Educational Program about Parental Mental Illness

Principal Investigator: Dr. Lynn Miller, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia Tel. (604) 822-8539

Co-Investigator: Karen Hamill, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia

Dear Parent/Guardian,

You received an information package several weeks ago that invited your child to participate in an evaluation of the *Kids in Control* program. The purpose of the evaluation is to determine which aspects of the program are helpful or not helpful to the children that attend it. The information that your child shares about their group experience may be used to make program improvements that may better serve the needs of children attending programs in the future.

If you and/or your child have decided not to participate, please disregard this notice. Your decision not to participate in the research study is respected, and it will have no negative consequences for your child.

If you have already completed and returned the consent form and demographic questionnaire, I'd like to take this opportunity to thank you and your child for supporting this research.

If you haven't returned the consent form and demographic questionnaire yet, but your child would like to participate, this is a gentle reminder to do so at your earliest convenience.

If you did not receive an information package or if it has been lost, please contact the Kids in Control group leader () at _____ to arrange to have one sent to you.

If you have any other questions or concerns about this study, please call the group leader at the number above, or contact Lynn at 604-822-8539.

Thank you,

Karen Hamill

Appendix I

Interview Protocol

Child Assent to Participate

The participant information letter (Appendix F) will be read aloud to the participant. They will be given the opportunity to ask questions. If they seem satisfied with the answers, I will then move on to the Child Assent form (Appendix G). The assent form will be read aloud to the participant. If the participant gives his/her assent, the interview will begin. If the participant refuses or seems reluctant to participate, the interview will be ended in a respectful manner.

Icebreaker

“Before we begin talking about Kids in Control, it might be nice to get to know each other a little better. I was wondering if you could tell me one thing about yourself that’s interesting or unusual. Maybe it’s a special talent, a hobby, something you like to play...”
(to build rapport I will share something about myself first)

Setting the scene:

“I want you to think back to the first time you went to the Kids in Control program.”

1. Where was the program held?
2. When did you attend the program?
3. What was the room like? Where did you sit? etc...(participants will be invited to draw the room on a piece of paper & explain the layout)
4. How many kids were in your group?
5. How did you feel about going to the group the first time?
6. Did your feelings change with time?
7. How many sessions did you attend?

“Now I want to talk about the *Kids in Control* program. I want you to try to remember what happened at the sessions you attended. I want you to think of examples of things that were helpful and not so helpful for you.”

Helpful Incidents – General Focus

“Let’s begin with parts of the program that were helpful to you. Think back to specific examples of things that helped you. Examples could include: things that you did, games you played, activities you participated in, things that the group leader said, feelings you had, thoughts you had...just about anything that helped you or anything that you thought did not help you. Remember, there are no right or wrong answers. Anything you say is okay.”

“Take your time to think about a specific example. When you are ready, I’d like you to tell me all about it in as much detail as possible.”

Follow-up Questions:

“Can you say more about...?”

“Can you give me a specific example of ...?”

“Why was this helpful/useful/important to you?”

“How does it help you in your life now?”

“How does this help you with your mom/dad’s mental illness?”

(Identify and clarify other helpful incidents using the above format.)

Unhelpful Incidents – General Focus

“Now, I’d like to switch to parts of the program that were not very helpful to you. Think back to specific examples of things that didn’t help you or weren’t useful. Take your time to think about a specific example. When you are ready, I’d like you to tell me all about it in as much detail as possible.”

Follow-up Questions:

“Can you say more about...?”

“Can you give me a specific example of ...?”

“Why was this not helpful/useful/important to you?”

“Why doesn’t that help you with your mom/dad’s mental illness?”

(Identify and clarify other hindering incidents using the above format.)

Specific Focus: Helpful & Unhelpful Incidents in Group Sessions

“Now, I want you to look at this paper that lists the topics covered in each session. (read it with the participant) Do you remember some of this stuff? I want you to try to remember the 1st session.”

Try to think back to what happened during the 1st/2nd... session. (Show them some of the worksheets/crafts etc... from the session to trigger their memory) Can you think of a specific example of something that happened that helped you? Again, it could be something that you did, something that was said, or something you felt; whatever pops into your head. If you can’t think of anything, we will move on.”

Follow-up Questions:

“Can you say more about...?”

“Can you give me a specific example of...?”

“Why was this helpful/useful/important to you?”

“How does it help you in your life now?”

“How does it help you with your mom/dad’s mental illness?”

“Now let’s do this again, but this time, try to think about things that happened in the 1st/2nd... session that were not helpful or not useful to you?”

Follow-up Questions:

“Can you say more about...?”

“Can you give me a specific example of ...?”

“Why was this not helpful/useful/important to you?”

“Why doesn’t that help you with your mom/dad’s mental illness?”

(Explore session 1-8 to identify both helpful and unhelpful incidents using the above format.)

Wish List:

“We have talked about different parts of the *Kids in Control* program that were helpful and not so helpful for you. Was there something missing in the program that you think would have been helpful to you?”

Follow-up Questions:

“Can you say more about...?”

“Can you give me a specific example of ...?”

“Why would that have been helpful/useful/important to have in the program?”

Rating Questions:

I was just wondering if you could share with me how stressful you find your family situation. On a scale of 0 to 10, with 0 being no stress at all and 10 being very, very stressful, where would you put yourself? (a visual aid will be used)

Also, I’d like to find out how helpful you found the Kids in Control program. On a scale of 0 to 10, with 0 being no help at all, and 10 being very, very helpful, where would you put the Kids in Control program? (a visual aid will be used)

Debriefing:

“Before we finish, is there anything else you would like to say? How did this go for you? Was it easy or hard to answer the questions? Is there something I can do to improve the interview?”

“We’ve talked about some sensitive things. Are you feeling upset or sad at all? I have a list of places that helps kids when they are feeling upset or confused. I’d like to give you

a copy just in case you need to talk to someone about what happened today or about your parent's illness."

"I'm going to listen to the tape of our conversation and write down the things that you told me. Then I'm going to send you a letter with a summary of what you told me. I want you to check it to make sure that I wrote everything down right. I will call you to ask you if it's okay or if I need to make changes to what you said. I will likely call you back in ___ month(s). Is it okay if I call you?

"Thank you very much for participating today. Your feedback on the *Kids in Control* program is really important because it's going to help to improve the program for other kids."

Appendix J

Kids in Control Program Overview

Lesson	Title
1	Group Building & Storytelling
2	Group Building & Learning to Identify Feelings
3	Learning about Healthy Boundaries & How to Communicate Feelings
4	Learning About Mental Illness
5	Learning About the Treatment of Mental Illness
6	Developing Resiliency
7	Societal Attitudes and Stigma
8	Self-Care and Self-Esteem

Appendix K

Support Services for Children

If you are feeling upset and would like someone to talk to, you can call the Child & Youth Mental Health Centre closest to you.

Burnaby	(604) 660-5900
Coquitlam	(604) 527-1270
Maple Ridge	(604) 466-7300
New Westminster	(604) 660-9495
Surrey	(604) 501-3237 / (604) 951-5844
Langley	(604) 514-2711
Abbotsford	(604) 870-5880
Chilliwack	(604) 795-8481
Maple Ridge	(604) 466-7300
Mission	(604) 820-4300
Tri-Cities	(604) 469-7600

Appendix L

Title: Children's Perceptions of a Psycho-Educational Program about Parental Mental Illness

Principal Investigator: Dr. Lynn Miller, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia Tel. (604) 822-8539

Co-Investigator: Karen Hamill, Department of Educational and Counselling Psychology, and Special Education, University of British Columbia

Confidentiality Agreement

I understand that I must treat as confidential all information learned through the transcription/analysis of research data, including the names and personal information of all research participants. I swear that I will not reveal such information to anyone, and will only discuss this information with the investigators of this study. I further understand and agree that this Oath of Confidentiality will continue in force even after the study has concluded.

(Print Name)

(Signature)

(Date)

(Witness)

Appendix M

Follow-up Telephone Interview Protocol

“Hi _____. This is Karen, the researcher from UBC. We talked about the *Kids in Control* program ____ month(s) ago. Do you remember me? Is this a good time to talk? Is it okay if we talk about the results of the interview we had? You don’t have to talk to me if you don’t want to. It’s okay to say no.”

“You told me about parts of the program that were helpful and not helpful to you. I sent you a letter last week summarizing everything you said. Did you get that letter? Did you have a chance to read it? Did someone read it to you? Do you have the letter handy? I’m going to read it over to you.”

“Did I write down everything you said correctly? Was there anything wrong with it? Is there anything you would like to change? Is there anything you would like to add?”

“Thank you very much for talking to me today. Your feedback on the *Kids in Control* program is really important because it’s going to help to improve the program for other kids.”

Appendix N



The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - FULL BOARD

PRINCIPAL INVESTIGATOR: Lynn Miller	INSTITUTION / DEPARTMENT: UBC/Education/Educational & Counselling Psychology, and Special Education	UBC BREB NUMBER: H07-00413
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
<small>Institution</small> N/A	<small>Site</small> N/A	
Other locations where the research will be conducted: A convenient location chosen by the participant and their parent/guardian such as a local community centre, public library, or the site where the Kids in Control group was held.		
CO-INVESTIGATOR(S): Karen Hamill		
SPONSORING AGENCIES: N/A		
PROJECT TITLE: Children's Perceptions of a Psycho-Education Program about Parental Mental Illness: An Evaluation of "Kids in Control" Using the Critical Incident Technique		
REB MEETING DATE: April 12, 2007	CERTIFICATE EXPIRY DATE: April 12, 2008	
DOCUMENTS INCLUDED IN THIS APPROVAL:		DATE APPROVED: May 17, 2007
<small>Document Name</small>	<small>Version</small>	<small>Date</small>
Protocol: Proposal: Children's Perceptions of a Psycho-Education Program about Parental Mental Illness: An Evaluation of "Kids in Control" using the Critical Incident Technique		
	Version 1	March 29, 2007
Consent Forms:		
Facilitator Consent Form	version 2	May 10, 2007
Parent/Guardian Consent Form	version 2	May 10, 2007
Assent Forms:		
Child Participant Information Letter	version 2	May 10, 2007
Child Participant Assent Form	version 2	May 10, 2007
Advertisements:		
Child Participant Information Letter	version 2	May 10, 2007
Questionnaire, Questionnaire Cover Letter, Tests:		
Facilitator Questionnaire	version 2	May 10, 2007
Interview Protocol	version 2	May 10, 2007
Demographic Questionnaire	version 2	May 10, 2007
Follow-up Telephone Interview Protocol	version 2	May 10, 2007
Letter of Initial Contact:		
Child Participant Information Letter	version 2	May 10, 2007
Other Documents:		
Confidentiality Agreement	version 1	May 10, 2007
Support Services for Children	version 2	May 10, 2007
Reminder Notice	version 2	May 10, 2007
The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.		
<p>Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:</p> <p>Dr. Peter Suedfeld, Chair Dr. Jim Rupert, Associate Chair Dr. Arminee Kazanjian, Associate Chair Dr. M. Judith Lynam, Associate Chair Dr. Laurie Ford, Associate Chair</p>		