

FINDING THE RHYTHM, MAINTAINING THE FRAME: HOW CHILDREN
MANAGE LIVING WITH A PARENT WITH A MENTAL ILLNESS

by

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ABSTRACT

This grounded theory study examined the perceptions of children living with a parent with a mental illness. The interpretive qualitative design was guided by symbolic interactionism. The aim of the study was to construct a substantive theory that would explain how children perceived and managed the experience of living with a parent with a mental illness. Data were collected through interview, participant observation and field notes. Twenty-two children between the ages of six and sixteen, who were living part or full time with a parent with a mental illness, were interviewed. Theoretical sampling was used to identify incidents and participants; ten of the children were interviewed twice. Data collection and analysis were undertaken concurrently. Constant comparative analysis was used to develop the substantive theory via open, selective, and theoretical coding.

The basic social psychological processes suggest that children focus their energy and time on finding the rhythm with their parents while maintaining the frame, by establishing connections within a safe and comfortable distance between themselves and their parents. To find the rhythm, these children monitored their parents and their daily rhythms and then adjusted to their parents' behaviours to try to maintain family security, stability, and their connections to their parents. In maintaining the frame of their relationships with their parents, children preserved themselves by finding a way to have a life and identity of their own without being engulfed by the mental illnesses of their parents. The children also gauged how able they were to preserve themselves and how much they were prepared to remain invested in their parent/child relationships. "Fitting

in” was the social structural condition which provided a context for children to consider how they were measuring up in the outside world.

The findings suggest that most of these children were comfortable in their homes and wished to be there, that children and parents co-existed in reciprocal relationships and that the children were often managing their circumstances with little information about the mental illnesses or external help. All of the children navigated through the ongoing emotional currents that affected their efforts to find the rhythm and to maintain the frame. These children valued their parents and were able to see their parents beyond the mental illnesses, nevertheless, they experienced painful emotions while managing their circumstances. The findings from this study have important implications for nursing practice, education and research, as well as for policy development, to address the larger issues that affect these children and their families.

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CHAPTER ONE

INTRODUCTION

Personal Perceptions about the Problem

During my clinical practice as a mental health nurse in both acute and emergency psychiatry, I have been intrigued by the etiology of mental illness, the influence of childhood experiences on its development, and its impact on the family, particularly the children. As the Program Manager of COPE, Care of Psychiatric Emergencies, I had the opportunity to witness clinical situations involving the hospitalization of parents who had been diagnosed with mental illnesses. During hospitalizations, generally health care providers offered minimal formal explanation and assistance to the children beyond survival needs, such as placing the children in care and ensuring that their basic needs of food and shelter were met. One particular incident made a critical impression on me. A single mother, with three children, the eldest 13 years of age, was accompanied by the police and involuntarily admitted to the hospital via the emergency department. Responding to an inquiry regarding the children, the police stated that the children had been taken to Child and Family Services and that "they were not in much better shape than their mother". I was left with the impression that these children were already deemed to have behavioural problems. There appeared to be limited intervention from mental health services to mitigate the effects of living with a parent with mental illness, and some people appeared to view the children's mental health as compromised. This clinical situation affected me profoundly.

My empathy and curiosity about children's experiences is perhaps increased by the fact that, at the age of eight, I experienced the death of a parent. I have wondered whether having a parent with a mental illness represents a form of death and loss for the children. From my life experience and my practice in mental health nursing, I have become increasingly interested in how children experience their parents' mental illnesses, and in particular, what they do to manage in the context of limited professional support. My understanding of the mental health

system and my exploration of the literature have reinforced my belief that children's perceptions of their experiences of living with parents with mental illnesses are not well understood. Lack of consideration of children's perceptions prevents effective intervention that could assist them to successfully manage their experiences. My experiences and reflections have led me to the proposed topic for my doctoral dissertation: The experience of children living with a parent with mental illness.

Background to the Problem

The World Health Organization (WHO) indicated that four of the ten leading causes of disability in developed nations are mental disorders which account for 23% of the disease burden in high-income countries (WHO, 1999). The Disability-Adjusted Life Year (DALY) measures the impact of premature death and disability on populations. Because this instrument measures time lived with disability, the burden of mental illness has become more visible and significant (Allender & Spradley, 2001; WHO 2003, 2001). The impact of the burden of mental illness is demonstrated in biological, psychological and social problems for people living with mental illnesses. Physiologically, many people struggle with medication side effects which influence their functioning and quality of life, compliance with medications, poor nutrition, vulnerability to communicable diseases and varying degrees of ability to care for themselves. Psychologically, people living with mental illnesses often struggle with concurrent chemical addictions and poor self esteem. Socially, people living with mental illnesses often cannot develop or sustain supportive relationships within their lives (WHO, 2003; 2001). By 2020 it is predicted that the global burden of mental and neurological disorders will account for 15% of global disease burden (WHO, 2001).

Statistics indicate that one out of five Canadians will suffer from a mental illness during their lifetime. Furthermore, 80% of the Canadian population will experience the effects of a mental illness through a colleague, friend, or family member (Health Canada, 2002). Research

by the Manitoba Center for Health Policy (2004) revealed that 33% of people, over the age of ten years, had been treated for mental illnesses within the past five years. In addition, people with low incomes and those in northern communities require the most service but receive the least service. Social stigma and fear of mental illness contribute to the problems people experience while living with mental illnesses (Allender & Spradley, 2001). The severity and nature of the disease also influences the burden people experience when living with mental illnesses. The incidence of particular diagnoses provides some insight about the impact of mental illnesses on society.

Statistics on the global prevalence of depression and its resultant burden on quality of life are significant. The Global Burden of Disease indicates that, in developed countries, major depression is the leading cause of disability (WHO, 1999). Depression is the most common psychiatric disorder and accounts for almost 12% of all disability among all diseases (WHO, 2003). Within the age group of 15 – 44 years of age, depression is the second cause of disability (WHO, 2003). Gotlib and Avison (1993) stated that 8 to 18% of the population will develop a clinical depression at least once in their lifetime, while Health Canada (2002) reports that 8% of adult Canadians will experience depression and 1% will experience bipolar disorder. Moreover, 8 to 15% of women develop a postpartum depression (Grace, Evindar & Stewart, 2003; Person, 1992). Canadian statistics indicate that hospitalizations for mood disorders are one and one-half times higher for women than men. Hospitalizations for bipolar disorders are increasing for both women and men between the ages of 15 and 24 years (Health Canada).

Schizophrenia, while affecting only 1% of the population, is extremely costly in terms of human suffering and loss of potential. As such, it greatly impacts family members' experiences (Torrey, 1983). In Canada, over half of women who develop schizophrenia retain some custody of their children (M.V. Seeman, personal communication, October 24, 2002). Statistics for Canadian children who live with a parental mental illness are difficult to obtain; however,

Gopfert, Webster and Seeman (1996) suggested that 50 of every 100 mentally ill patients are living with children. Oates (1997) noted that 60% of women with serious chronic mental illnesses have children under the age of 16 years and that 26% of women with schizophrenia live with children under the age of 16 years. In addition, 12% of all new female psychiatric referrals have a child under the age of one, and 25% have a child under the age of five (Oates). Thus women with mental illnesses are parenting children and while these women may come into contact with the mental health system, their role as parents may be overlooked (Nicholson & Biebel, 2002). Given the prevalence of mental illnesses, and the invisibility of patients as parents within the mental health system, health care professionals, inclusive of nurses, are challenged to understand how family relationships are affected by mental illnesses (Blanch, Nicholson, & Purcell, 1994; Nicholson, Biebel, Hinden, Henry, & Stier, 2001; Mowbray, Oyserman, & Ross, 1995; Oates). Developing an understanding of the effects of mental illness on family members will facilitate the development of strategies that promote the health of children and families. Clearly, statistics suggest a need for nursing to be proactive in assisting children, families and communities to manage the burden of living with mental illnesses.

Little is known about fathers with mental illnesses who are involved in the care of their children. The majority of the research on parents concentrates on the role of the mother; reference to fathers is made only with respect to the increased pathological effects on children when both parents have a mental illness (Gammon, 1983). Ekdahl, Rice and Schmidt (1962) noted that the mental illness of the father potentially affected family finances but had little effect on daily functioning within the home. Such a claim appears to separate loss of income from the effects of such losses on families' day-to-day lives and the effects of job loss on male self-esteem. Feldman, Stiffman and Jung (1987), found a positive association between a father's mental illness and stressful life change events, precipitated by financial losses. In today's society, fathers are becoming more involved with rearing their children than in previous

generations and the effects of paternal mental illnesses may be more complex. It is unknown how many fathers with mental illnesses are parenting their children, either alone or in partnership.

Significance of the Problem

Due to community mental health initiatives, shorter hospital stays, and the increased incidence of mental illness (Manitoba Center for Health Policy, 2004), more parents with mental illnesses will be raising their children in the community. The new system of psychiatric care places patients in the community much earlier and often leaves the burden of their care to the family. Parents with mental illnesses may be expected to resume their family roles as soon as they return to the community. Consequently, they may have responsibility for parenting when they are still having difficulty meeting their own needs. Services to assist parents with children concentrate on basic survival needs, such as food and shelter, with little family intervention focused toward parenting skills or the emotional and psychological needs of the children. Further, when well parents are burdened with caring for a partner with mental illness, they may not be fully available to children. This situation has the potential to augment the effects of parental mental illness. Children in single parent homes may require diverse care arrangements and may be at risk of witnessing more acute stages of the illness.

Research suggests that parental mental illness places children at triple the risk to develop mental health problems (Gammon, 1983; Gershon et al., 1982; Warner, Weissman, Fendrich, Wickramaratne, & Moreau 1992; Weismann et al., 1984). In one study, 65% of children whose parents had been diagnosed with depression met the criteria for psychiatric diagnoses (Keller et al. 1986). Meta-analyses of studies from a ten year period indicated that 61% of children who had a depressed parent developed a psychiatric disorder by adolescence and that 40 to 70% of those children had a co-morbid diagnosis of substance abuse, anxiety and dysthymia (Beardslee, Versage, & Gladstone, 1998). Other research has indicated co-morbid diagnoses of conduct

disorder, attention deficit disorder, depression, and oppositional defiant disorder are increased in children whose parents suffer from depression (Weissman et al., 1984; Weissman, Paykel, & Klerman, 1972; Welner & Rice, 1988). Wickamaratne and Weissman (1998) indicated that depression, anxiety, and conduct disorder are increased in children whose parents have depressive disorder but that there is no increase in any of these diagnoses in adolescence. Parental depression may have other effects on a child's life such as shyness, isolation and reading difficulties (Rolf & Garnezy, 1974). On the other hand, parent-child interactions have been shown to be satisfactory in some families despite a diagnosis of parental depression (Anthony, 1974; Burbach & Borduin, 1986; Keller et al., 1986; Rutter, 1978; Werner & Smith, 1982). In concert with parental mental illness there are other complicating features, such as marital discord, illness chronicity, and lack of parental availability that may predict children's mental pathology (Beardslee, 1984; Rutter & Quinton, 1984; Sameroff, Seifer, & Zax, 1982; Werner & Smith).

While a substantial body of literature exists on the children of parents with mental illnesses, the research has largely been quantitative. Some studies have suggested that some children living with parental mental illness were "super kids", however, those projects have largely ignored the subjective and emotional experiences of children (Fisher, Kokes, Cole, Perkins, & Wynne, 1987; Garnezy, 1987; Kauffman, Grunebaum, Cohler, & Gamer, 1979; Werner & Smith, 1982). There has been relatively little research on intervention strategies to mitigate the identified risks for children because the majority of efforts are directed at identifying and treating pathology that develops later in life (Bleuler, 1974; Canadian Mental Health Association, 1987; Devlin & O'Brien, 1999; Dunn, 1993; Ekdal et al., 1962; Escalona, 1974; Grunbaum & Gammeltoft, 1993; Lancaster, 1993; Philips, 1983).

Absent from this body of literature is the subjective experience of children living with a parent with mental illness. Findings from the professional literature are in opposition to the lay

literature, which provides retrospective accounts of adults who have lived in homes with a parent with a mental illness. Those adults claimed their outward childhood competence hid their inward chaos and discomfort (Marsh & Dickens, 1997). The effects of parental mental illness on children may be better understood by using qualitative methods, which emphasize children's perceptions. Those approaches would also address parents' concerns about their children's perspectives being neglected (Wang & Goldschmidt, 1994; 1996). Qualitative research strategies would enable understanding of the effects of parental mental illness on children, inclusive of their perceptions and aid in the development of meaningful primary interventions.

As such, nursing is challenged to develop understanding of children's perceptions about living with parental mental illnesses in order to understand and intervene meaningfully in children's lives. Nurses are in a pivotal position to intervene with children and families who are living with parental mental illnesses. Both public health nurses and psychiatric mental health nurses interface with this population and can be instrumental in providing primary, secondary, and tertiary services and developing health care policies to assist children and their families. In order to do so, nursing research soliciting the perceptions of children is needed to help nurses develop services and policies which address children's needs.

Statement of the Problem

There is a considerable body of literature about children whose parents have been diagnosed with mental illness; however, the work has examined the factors associated with children's outcomes reflective of researchers' assumptions about children's pathology, diagnostic categories and resilience. Because research that examines children's perceptions about managing family life with a parent who has mental illness has not been undertaken, professionals have limited understanding of the dynamics that characterize children's experience of family life circumstances and how children manage those dynamics in a complex social context.

Purpose and Goals of the Study

The purpose of the study is to understand children's perceptions of living with a parent with mental illness. The specific objectives of the study are to understand how children manage their lives in the context of living with a parent with mental illness and to understand children's perceptions of factors that have helped or hindered their efforts to manage their lives. The study goals are to construct a substantive theory that will assist nurses to plan care for children and families living with a mental illness and to develop further research questions and hypotheses based on children's experiences of living with a parent with mental illness.

Research Questions

The general question for the study was: How do children experience living with a parent who has a mental illness? Specific sub questions further directed the study including: How do children manage the experience of living with a parent with mental illness? What is helpful to manage this experience? What is unhelpful to manage this experience? What are the outcomes for children who are trying to manage their experience of living with a parent who has a mental illness?

Theoretical Basis of the Study

The theoretical framework for the proposed study is symbolic interactionism, which emphasizes the connection between symbols (shared meanings), and interactions (non-verbal and verbal actions and communications). That interplay is pivotal to our understanding of how children experience the mental illness of a parent. La Rossa and Reitzes (1993) underscored the importance of symbolic interactionism for understanding dynamics and roles in family life. Thus, the experience of children living with a mentally ill parent is well addressed with a symbolic interactionism approach, which has been utilized in family studies (La Rossa & Reitzes). I will describe Symbolic Interactionism in detail in Chapter Three of the dissertation.

Background of the Investigator

I have been a Registered Nurse specializing in Psychiatric Mental Health nursing since 1987. I have obtained Baccalaureate and Master Degrees in nursing from the University of Manitoba and a counseling certificate with honours from Red River College. Since 1999, I have been enrolled in the doctoral program at the School of Nursing at the University of British Columbia. During my studies, I have concentrated on the area of psychiatric mental health nursing.

My clinical practice as a registered nurse has been in the area of psychiatric mental health in acute care, emergency care, and in the community working with abused women and the well elderly who experience depression. As part of my practice as a psychiatric mental health nurse in emergency, I had the opportunity to develop and implement programs and to practice within the Care of Psychiatric Emergencies (COPE) program (Mordoch, 1995). This program attempted to improve access to services for mental health clients and their families, to decrease stigma regarding mental illnesses within the emergency room, to provide seamless care for clients and their families, and to advocate for appropriate services. Clients and family members were invited to participate on the advisory board of the program and were an integral part of COPE program development and evaluation. From this experience, my practice of psychiatric mental health nursing became more inclusive of clients as partners in planning care. Experiences within this program also heightened my awareness of issues for children who were living with parents with mental illnesses and caused me to reflect on existing nursing interventions for this population.

I have been involved in action-based research projects largely resulting in new services for the clients. Examples of these projects are: the St. Boniface and St. Vital Community Health Needs Assessment resulting in the formation of a community nurse clinic (Gregory, Mordoch, Wotton, McKay & Hawranik, 1995; Russell, Gregory, Wotton, Mordoch, & Counts, 1996); the

Norman Primary Health Care Project, resulting in the adoption of a community primary health care model (Gregory, Patterson, Mordoch, Davidson Dick, & Katz, 1998); an evaluation of an inner city harm reduction program for marginalized people resulting in continued levels of funding for this population (Village Clinic, 1998) and COPE, a Short Term Emergency Project, which contributed to the development and permanent funding of the role of mental health nurses in the emergency room (Mordoch, 1995). I have also served as a board member of the Anxiety Disorders Association, a member of the Advisory Board for the Formation of a Support Group for Children Living with a Parent with Mental Illness, and a volunteer with Nurses at Risk, an intervention program for nurses with addictions.

All of my experiences have assisted me to know clients and families at different levels of functioning within the trajectory of mental illness and mental health. These experiences have provided me with both a deeper clinical understanding and a deeper curiosity about how children manage the experience of living with a parent with a mental illness.

Summary

In this introductory chapter, I have explained the background and significance of the problem. I have articulated the importance of the problem from my personal perspective, the purpose, goals and the research questions of my study and indicated that symbolic interactionism is the theoretical framework underpinning the study. In Chapter Two, I will provide an overview of theories about the cognitive and emotional development of children. As well, I will provide a critical analysis of this literature including the classic and contemporary research on children living with a parent with a mental illness. I will also discuss the context of the mental health care system as it relates to psychiatric/mental health nursing practice. Finally, I will discuss the literature about parents who are parenting with a mental illness. In Chapter Three, I explain the theoretical framework for the study, symbolic interactionism. In Chapter Four, I describe the research design and the grounded theory method, the ethical considerations of doing research

with children, study procedures, data collection, constant comparative analysis, and how rigour is achieved in grounded theory. Chapter Five provides the study sample characteristics and a description of the substantive theory that I developed from the data. Finally, Chapter Six includes a discussion of the study findings in the context of the literature, the limitations of the study, and the implications of the study for nursing practice, education, and research. References and appendices follow the last chapter.

CHAPTER TWO

THE LITERATURE REVIEW

Traditionally, the purpose of the literature review is to ascertain what is already known in relation to the problem of interest, to explore aspects of the problem about which little is known, and to bring the problem into sharper focus in order to formulate research questions. The literature review also provides a broad conceptual context into which the problem will fit and thus contribute to the larger body of knowledge (Polit & Hungler, 1991). The literature review is also intended to demonstrate the significance of the research problem. Qualitative researchers, review the literature in order to help focus the study purpose, however, there is also intent to avoid preconceiving the research findings (Streubert-Speziale & Rinaldi-Carpenter, 2003). Undertaking an extensive literature review at the end of a qualitative study places the findings in the context of what is already known about the phenomena.

The purpose of the literature review in grounded theory is controversial. In order to clarify decisions concerning the literature review, I will begin with a discussion of the purpose of a literature review in grounded theory as proposed by Glaser (1978; 1992; 1998). In the remainder of the chapter, I will discuss the rationale for inclusion of specific literature reviewed and critically analyze that literature within the context of the current health care system.

Glaser (1992; 1998) has advocated reading in substantive areas that are not directly related to the study topic in order to avoid contaminating the emerging theory. He also argued that such reading will maintain a researcher's theoretical sensitivity, awareness of conceptual codes, and use of social theory. He suggested that the literature necessary to place the findings in a broader context will become known with the development of the theory. This reading may also be useful to the researcher for generating categories and properties, stimulating thinking, and providing direction for theoretical sampling. Glaser (1992; 1998) suggested that the researcher read in a wide variety of areas and use sources of information to remain sensitive to

theoretical ideas and to weave the appropriate literature into the developing theory during the write-up stage of the research process. Appropriate literature can consist of a variety of sources, for example, diaries, manuscripts, records, reports, and biographies (Glaser, 1992). Glaser (1998) suggested that it is not advisable to turn to the substantive literature too early, as the researcher may preempt the findings of the study.

Glaser (1992; 1998) created a list of reasons for not doing a literature review prior to beginning a study including: being “grabbed” by existing concepts; developing a preconceived “professional” problem of no relevance; becoming overly influenced by pundits in the field, which would detract from the researcher’s own confidence in developing a theory, eroding theoretical sensitivity with rhetorical jargon, and lacking a sense of which literature is relevant prior to the study. Stern (1980) concurred that attempting a literature review before the study is unnecessary. She argued that it might be detrimental to the study and suggested selective sampling of the literature as the theoretical analysis developed. In summary, some grounded theorists have argued that a literature review of the topic under study has the potential to stifle and constrain the researcher’s attempts to find relevant concepts that work and fit and places the researcher at increased risk to develop concepts that verify existing constructs in the literature.

Funding sources and academic standards require a traditional literature review. Morse (1998), in her discussion on designing funded qualitative research, posited that the qualitative researcher read in the general area of the study topic, become familiar with the literature but not bogged down in minute detail, and return to the library later in the study.

Considering the conflicting views of the utility of a literature review, I have attempted to occupy a middle ground. In spite of my awareness of the potential pitfalls of conducting a literature review prior to beginning a grounded theory study, I conducted my literature review to establish the credibility of the research question for funding and academic purposes and to situate my research questions in existing knowledge. While Glaser (1998) suggests that avoiding the

literature review assists the researcher to approach the research subject “*tabla rasa*”, (without preconceptions of what should happen in the data) as opposed to being burdened with constraints and preconceptions, I would argue that this is unlikely to occur when a researcher is studying in her substantive area. A researcher would be already immersed in the literature in that area and would be aware of seminal work and important concepts. Nonetheless, Glaser’s position that preconceived ideas can influence the data analysis is well taken. For example, in my substantive area, the emphasis on the critical importance of the first three years of development has overshadowed other areas of child development, such as, adolescent brain development, which is now being noted as equally important

(<http://www.pbs.org/wgbh/pages/frontline/shows/teenbrain/interview>, Giedd, 2004).

My approach to the literature review allowed me to develop an understanding of the existing research which satisfied academic and funding purposes, while I attempted to minimize the influence of the literature review on any preconceptions about the study findings. In attempting to contain the influence of the literature review, I consistently questioned the influence of my assumptions on interpreting the data, thereby, ensuring that my interpretations were not unduly influenced by ideas external to the data. In other words, while realizing that I could not approach the literature or my study “*tabla rasa*” (without any biases), I attempted to be aware of my biases and to ensure the developing theory reflected the data as much as possible.

In placing my literature review in the context of the health care system, it is important to elucidate the changes that have occurred in the system. Generally, mental health care reform has resulted in shorter hospitalization for mental illness and earlier discharge to the community leaving the family to become the major providers of the long term care necessary for individuals with chronic and persistent mental illness (Doornbos, 2002). Hatfield (1994), estimates that 60% of families of the mentally ill are primary caregivers with little respite or guidance from the mental health care system. Such changes have created situations wherein children are

experiencing more acute periods of mental illnesses within their family homes and more involvement in family care giving for their parents.

Children, in families with parental mental illness, have long been recognized as relatively powerless within society and the family system (Canadian Mental Health Association, 1987; Shachanow, 1987). Currently, there appears to be few resources for children living in these circumstances (Nicholson et al., 2001). As such, it is conceivable that they are more vulnerable to the effects of stigma, which represents a “formidable obstacle to future progress” (United States Department of Health and Human Services, 1999, p. 5) in the care and treatment of mental illness. Although understanding and treatment of mental illness has dramatically improved, several factors contribute to the stigmatization of the mentally ill and their families. These factors include the double burden that families and clients have to bear, namely the mental illness and the societal shame of having a mental illness, the silence and secrecy surrounding mental illness and the limited life opportunities that result from the illness experience.

Given the nature of the population I am studying and the phenomenon of interest, I will discuss the literature under the following topics: the cognitive and emotional development of children, the context provided by society and the health care system, research on children of parents with mental illnesses, and parenting in the context of mental illness. Due to the lack of empirical information about children’s perspectives about living with a parent with mental illness, I have reviewed the literature on parents’ perspectives of parenting with a mental illness.

I have chosen to review the cognitive and emotional development of children in order to understand the theories about childhood norms and the critiques of children’s development. I also wanted to gain an understanding of how children process information at different ages and how they express their emotions. This knowledge provided me with direction for approaching children of different ages (from 6 to 16 years of age) and accessing their perceptions.

A review of the context provided by society and the health care system was helpful to understand the macro issues that influence children and their families. This also provided me with an understanding of the context in which nursing practice is situated. I believed it was important to consider the context that society, in general, and the mental health care system, in particular, provided for children who were living with parents with mental illnesses, especially due to the recognized stigma associated with mental illness.

Reviewing the literature on children's outcomes associated with their parents' diagnoses and the multi-causal factors affecting children's outcomes and experiences provided me with an overview of the dominant theoretical perspectives concerning my study population and the opportunity to further situate my research questions. The classic and contemporary research on children living with a parental mental illness (depression, bipolar illness, and schizophrenia) helped me to understand the influence of the biomedical model on the development of this literature. I have also incorporated the literature that has examined parents' perceptions of parenting while struggling with mental illnesses. I will begin by discussing and critiquing the literature on the cognitive and emotional development of the child.

The Cognitive Development of the Child

Within the field of childhood cognitive development, Piaget's work, which spanned six decades, has been influential (Bee, Boyd, & Johnson, 2003); it has provided the basis for most of the developmental literature. At the same time, Piaget's (1952; 1970) stages that describe change over the growth and development of children are controversial. Piaget's theory has been critiqued for being primarily descriptive, with insufficient development of underlying process; placing little emphasis on individual differences and diverse pathways of learning; and negating the influences of the context wherein children's learning takes place (Harter, 1999). In this section, I will provide an overview of Piaget's stages of cognitive development which is relevant

to the ages of the study population, 6 to 16 years of age. I will also discuss the neo-Piagetian critiques of cognitive development.

The Preoperational Child

The preoperational child is between the ages of 2 – 7 years. The preoperational stage is characterized by some limitations in thought processes that may cause a child to focus on one aspect of the situation and to have difficulty considering other aspects (Piaget, 1952; 1970). Children at this stage have limited abilities to differentiate appearance from reality. Preoperational logic is further limited by the concept of irreversibility, wherein a child cannot understand that an action can go more than one way, i. e., children will worry that a cut will not heal (Piaget, 1952; 1970). On the other hand, these children are developing symbolic representations and classification of objects and beginning to understand cause and effect. While Piaget (1970) suggested that egocentric children did not have the cognitive capabilities to develop empathy, recent research has suggested that younger children are more cognitively competent than previously suggested and that older children and adults are less cognitively accomplished than their representations have suggested (Graue & Walsh, 1998). Research has also demonstrated that children are much more capable of displaying empathy than previously believed, which challenges the idea that young children have delayed empathic reactions related to their egocentric patterns of perception (Zahn-Waxler, Radke-Yarrow, Wagner, & Chapman, 1992). At this stage of development, children still tend to confuse reality and fantasy and have limitations in logic.

The Concrete Operational Child

A child in the concrete operational stage of development (between the ages of 7-11 years) becomes less egocentric, more proficient at logical reasoning, and better able to separate fantasy from reality. These children are able to reflect on what they know and how they can use the information. They begin to use more complex cognitive strategies (Piaget, 1970). Piaget

determined that children's moral reasoning develops as the preoperational and concrete stages of thinking develop; egocentricity decreases as children are more cognitively able to consider alternate perspectives and to interpret rules rather than blindly following them (Piaget, 1965). The moral development of the child occurs, which is characterized by constraint and rigidity in its first stage and flexibility in its second stage (Piaget, 1965). Piaget's work on this age group has received less critique than his other stages. Findings from more recent research, particularly studies on conservation (matter can change in appearance without changing in quantity) which Piaget held did not occur before the age of 5 years, have generally supported Piaget's original ideas on when knowledge of conservation is achieved (Piaget, 1970; Sophian, 1995).

Formal Operations Stage

A child at the formal operations stage, which is generally held as occurring between the ages of 12 and 19, is considered an adolescent. This stage covers almost a decade, which encompasses a wide range of development. Formal operations comprise the ability to think abstractly, deal with possibilities, and participate in hypothetical deductive reasoning (Piaget, 1970). Elkind (1984) identified immature thought patterns that are also prominent, which may lead to argumentativeness, indecisiveness, a perception of invulnerability, hypocrisy, and self-consciousness. Some of these behaviours may be explained by current research into brain development, which provides insight to the changes in underlying neural processes that affect cognitive development (Giedd, 2004

<http://www.pbx.org/wgbh/pages/frontline/shows/teengrain/interview>).

Dr. J. Giedd (2004), of the Institute of Mental Health, Maryland, suggests that the brain continues to mature into the adolescent years through the process of extensive and significant structural changes (2004). Piaget's work (1952; 1965), while acknowledging neurological development and constraints, could not include the evolving knowledge on brain development made available by neuro-imaging techniques. Neuro-imaging research has shown that, during

adolescence, nerve fibers connecting the left and right hemispheres of the brain thicken and process information more efficiently. Neurological pruning occurs, wherein neural pathways that are not used die. This neural pruning is affected by genetics and also by the activities in which children are engaged (Giedd). For example, practicing the piano strengthens the brain neurons controlling the fingers.

In adolescence, the prefrontal cortex, where sound judgment is developed, shrinks as neural connections are pruned, but continues to develop over the teen years. The cerebellum also changes dramatically with increased complex neuronal pathway development, which may play an important function in developing thought processes (Giedd, 2004; Wallis, 2004). Neuro-imaging research, such as research conducted with magnetic resonance imaging (MRI), suggests that the anatomical development of the adolescent brain is linked to adolescents' risk taking behaviours, decision-making, and sleep changes including difficulty in getting up and going to bed at reasonable hours. The development of childhood neuropsychiatric disorders, such as Tourette's syndrome, attention deficit hyperactivity disorder (ADHD) and schizophrenia, are likely related to anomalies in brain development. MRI research highlights the development of cognitions across the life span, increases our understanding of the changeable behaviours of adolescents and offers an explanation for the development of mental illness in adolescents (Giedd).

While Piaget (1952; 1965) maintained that cognitive development was universal in all children and dependent on neurological maturation, he did not take into account individual differences and societal contexts. Research on individual differences, cognitive processes, and societal contexts has been undertaken by neo-Piagetian theorists. Case (1992) and Costanzo (1991) argued that there is significant unevenness in cognitive development, that Piaget did not recognize, and that individual differences occur at every age. Newer theories, such as, information-processing theory (Siegler, 1991) and social cultural theory (Rogoff, 1990;

Vygotsky, 1978), suggest that the process of developing cognition is more complex than Piaget's theory of universal development suggested. For example, information processing theory (Siegler) breaks down the processes of cognitive development to micro processes such as strategy construction and encoding. Strategy construction occurs as concepts are combined to achieve higher order generalizations. Encoding occurs as the most salient features of objects and events are remembered and stored as internal representations (Siegler).

Theories, such as Vygotsky's (1978) social-cultural theory, link the development of complex thinking to social and cultural milieus that influence cognitive development. A child's development may be scaffolded, wherein a child is able to accomplish a task beyond what is thought to be a usual capability, when learning is assisted by an older child or adult. Availability of such learning opportunities creates a zone of proximal development, which allows children to accomplish tasks that they could not achieve alone (Vygotsky). Recent work acknowledges that, while it is helpful to understand children's cognitive developmental norms, it is important to recognize the influence of cultural and environmental contexts on children's cognitive development (Graue & Walsh, 1998). Building on Piaget's (1952; 1969; 1970) significant contribution to the theory on cognitive development in children, recent research has provided increasingly complex insights into the processes comprising cognitive development.

My consideration and critique of the basic theories of children's cognitive development provided me with a context for considering children's experience of living with a parent with mental illness and an understanding of children's expected cognitive development and influencing factors. Understanding the norms of cognitive development and the critiques raised around those norms also assisted me to relate to the children throughout the research process. This information guided my formulation of age appropriate questions, communication strategies, and efforts to put the child at ease in the interview session.

Summary of Cognitive Development

In reviewing the theories of children's cognitive development, it is clear that Piaget's work remains influential despite its critiques (Harter, 1999). Piaget's (1952; 1970) views on children's cognitive abilities provided a structure and context for my research interviews with children, rather than a way of viewing how children generally operate. For the purposes of this study, Piaget's notion of constructivism, wherein a child as an active participant is constructing his or her understanding of the world, fits well with the theoretical framework of symbolic interactionism. Thus, while I found Piaget's model useful, I used it only as a guide. I remained open and flexible about the uniqueness of each child's cognitive development and socio-cultural life context. Equally important to and intricately connected with cognitive development is the emotional development of the child. The following section will provide a discussion on the emotional development of the child.

The Emotional Development of the Child

Emotions define the quality of human experience, facilitate prosocial behaviour and creative problem solving, and form the basis of conscience and moral behaviour (Izard, 2002). Emotions have a profound influence on perceptions, cognition, and motivational states, which influence actions (Izard). Subjective reactions begin in infancy; emotional response patterns become part of a child's personality. Initially emotions are developed in response to physiological demands. For example, an infant when hungry becomes distressed and cries. Expressed emotions thus facilitate communication of one's inner conditions. Emotions further guide and regulate behaviour as the child develops. In mid-toddlerhood, children begin to express pride, shame, and guilt, which are correlated with their developing objective self-awareness (Lewis, 1991; 1994).

A child's emotional development is influenced by the growth and developmental tasks of each age. Developmental tasks, such as the attainment of Erickson's initiative, competence, and

identity (Erickson, 1950; 1963), interact with other socially and culturally determined factors related to developmental stages (Denham & Kochanoff, 2002). Emotional development is affected by children's social contexts, inclusive of their cultural traditions, family structures, and societal values about the nature of childhood. For example, children may be required to participate in specific cultural tasks, such as a bar or bat mitzvah. Also the increasing numbers of Canadian children, who are now living in single parent families, suggest that children are adapting to changing family configurations (Statistics Canada, 1996). The social construction of adolescence in Western society has extended the period of adolescence (Otto, 1988). This is, in part, due to growth trend of increased height and weight, earlier physical maturation, and social, economic, and occupational influences (Beckman Murray & Proctor Zentner, 1997). As children attain physical maturation earlier, the expectations of developmental tasks may also shift, because children may be required to attain developmental tasks and goals at an earlier age.

Much of the emotional developmental literature suggests a reciprocal relationship between emotion and cognition (Harter, 1999; Izard, 2002). Research supports the correlation between neurological maturation within the brain and the emotional development of children (Giedd, 2004; Statistics Canada, 1996). As children's analytical abilities increase, they are able to understand more complex emotions such as shame, guilt, and pride, and to appraise the meaning of a situation (Lewis, 1987; 1992; Meerum-Terwogt & Stegge, 2001). Diffuse emotional states occur in infancy, but they progress to primary emotions, such as contentment, joy, interest, surprise, distress, sadness, anger, disgust and fear. Primary emotions are experienced and expressed within the first six months of life (Lewis, Sullivan, Stanger, & Weiss, 1989). As children develop self-awareness, they begin to experience self-conscious emotions and some aspects of self evaluation by the middle of the second year (Lewis, 1991; 1994). Self-conscious emotions are defined as pride, shame, and guilt and reflect a child's ability to be conscious of self and to evaluate self (Lewis, 1994). By the age of three years,

children have begun to consistently evaluate their own behaviour, incorporate social rules and experiences of pride, shame, guilt, and embarrassment into their evaluation of their behaviour. As emotional knowledge and emotional regulation are developing, they assist a child to attain social and personal goals (Harter).

Emotional development universally proceeds in an orderly manner, with complex emotions building on simpler emotions (Izard & Harris; 1995; Izard & Malatesta, 1987; Lewis, 1987; 1992). Within the first three years of life, four major shifts occur in brain organization, with accompanying changes in emotional processing (Sroufe, 1997; Schore, 1994). The first shift begins at 3 months of age, wherein the infant's cerebral cortex becomes functional allowing for beginning emotional differentiation. The second shift occurs between 9 and 10 months of age when the frontal lobes and limbic system mature allowing the infant to interpret emotions. During the third shift, the myelination of the frontal lobes occurs during the second year. This shift allows a child to develop self-conscious emotions and to begin to regulate emotion. As the parasympathetic system matures, a child is able to experience evaluative emotions such as shame (Sroufe; Schore). Building on these neurological shifts, children continue to recognize and process more complex emotions, proceeding to the recognition and processing of opposing emotions. A description of the development of the child's capacity to engage in this process follows.

Five Levels of Emotional Development Ages 4 – 12 Years

The work of Harter (1996; 1999) and Harter and Buddin (1987) suggests that children move through five levels of emotional development between the ages of four and twelve. Within these stages, children eventually understand simultaneous emotions, i.e., how they can have two emotions at the same time and two opposing emotions directed at the same target.

At the level zero, young children have difficulty understanding conflicting emotions and how two emotions can coexist. When children experience emotions simultaneously, they are

unable to understand or acknowledge these two emotions (Harter, 1996). These children develop separate categories for “good” and “bad” emotions. They are aware of simultaneous emotions but only if they are both from the same category, i.e. two good emotions. A child cannot understand feeling contradictory emotions towards the same person.

At level two, children, aged 5 to 6 years, develop representational mappings or logical connections between aspects of the self (“I can run and I can jump”) with a general tendency to see these characteristics in all or nothing terms. Children describe themselves as they would like to be, rather than as how they actually are. Generally, children tend to focus on the positive aspects of themselves and do not account for their shortcomings.

At level three, representational systems develop in middle childhood. Here, as all or nothing thinking declines, a child integrates features of the self into general multidimensional concepts (Harter, 1996; 1999; Harter & Buddin, 1987). Children view themselves more realistically and integrate their positive and negative emotions. They are able to do so, however, only if the emotions are directed at different targets, i.e., I am mad at dad and I am happy with my brother.

At level four, older children (12 years of age) are able to describe conflicting feelings toward the same target; i.e. loving their parent and feeling anger towards their parent. Children are able to recognize and acknowledge the opposing emotions that they experience (Harter, 1996). These children can better regulate their own emotions, are more aware of other people’s feelings, and adapt their behaviour accordingly. They begin to understand the social and cultural rules that influence the expression of emotion. These children can learn to suppress emotions in order to protect themselves from ridicule or rejection (Harter).

In summary, during beginning neurological shifts, from three months of age to three years of age, a child begins to differentiate experience and interpret emotions. Children continue to develop self-conscious emotion, emotional regulation, and evaluative emotions. A child, from

the ages of four to twelve, develops the capacity to hold and process opposing emotions (Harter, 1996; 1999; Harter & Buddin, 1987). Between the ages of 6 and 12 years, most children undergo considerable emotional development. Positive emotions originating in infancy, such as joy and contentment, promote mental and physical well being. Joy generates confidence and courage and interest generates engagement with the environment (Izard, 2002). These positive emotions play a role in maintaining close relationships with parents and in developing friendships, and are often generated by play situations. This information is helpful to understand how children relate to and view their parents. Positive emotions can act as a buffer for negative life events (Izard). Emotions, which have typically been described as negative, i.e. guilt and shame, may have positive consequences (Harter, 1999). Guilt and shame, if not excessive, motivate children to adjust their behaviours favourably. Managing negative emotions and increasing self-awareness may contribute to emotional competence and moral development (Harter, 1999). In the next section, I consider critiques of grand theories of emotional development, which have suggested that gender be taken into account.

Gender Differences in the Expression of Emotions

In grounded theory, the researcher should not assume the analytical relevance of any variable, inclusive of age, gender, race, until it emerges from the data as relevant (Glaser, 1978). Despite this caveat, I have included a brief overview of the influence of gender on children's emotional development. The overview served the purpose of sensitizing me about gender influences and provided a possible framework for understanding children's behaviour during the initial home visit and interview.

Research about children's socialization to express emotions has often been focused on the differences between the genders. Traditionally, girls have been considered more expressive of their emotions and to be socialized to be good and nice; boys, who have had to learn to repress their emotions, have been characterized as less relational as they develop (Brown & Gilligan,

1992; Levant, 1995; Thorne, 1993).

Recent research suggests that girls can use covert social aggression and social bullying in their relationships to gain power, control, and popularity (Simmons, 2002). Relational aggression, which is aimed at damaging the other's self esteem by cruel gossip, shunning and expressions of disdain, is more commonly used by girls (Crick & Grotpeter, 1995; Rys & Bear, 1997). Accepted social customs may not allow girls to learn how to deal with conflict other than by repressing their feelings (Simmons). Such customs can impede girls' emotional development and make them vulnerable in relationships, because they have not learned to handle conflict. Social aggression amongst girls begins in elementary school, continues through high school, and is particularly prevalent in adolescence (Simmons). Cairns, Cairns, Neckerman, Ferguson, and Gariepy (1989) found that adolescent girls used less physical violence, but engaged in covert forms of violence, such as gossip and rumour spreading. Because girls who are different are often singled out for social aggression, girls who have parents with mental illnesses may become targets of social aggression. Simmons suggested that girls interact in a covert network comprised of social aggression masked by the appearance of niceness. This social aggression increases in the adolescent years where competition for popularity increases. The covert social aggression of girls has not been well understood.

Much research had focused on physical aggression of boys, which has been partially attributed to androgens making boys more excitable, angry, and stronger or more aggressive (Collaer & Hines, 1995; Marcus, Maccoby, Jacklin, & Doering, 1985). These male hormones contribute to male aggressive behaviour in both the animal and the human species. The research consistently illustrates that boys use physical aggression more frequently than girls and voice approval of its use (Offord, Boyle, & Racine, 1991; Rodkin, Farmer, Pearl, & Van Acker, 2000). Socialization influences, such as gender-specific parental interaction, societal expectations, and media messages, have been held to reinforce these biological tendencies (Kail, 1998).

Chodorow (1989) explained gender differences in self worth as arising from the development of emotional experiences. Boys, with mothers as the primary caregiver, go through a stage, wherein they are required to shift their identification from their mothers to male role models. This causes them to go through a differentiation process that is held to be more difficult than the experience of girls who do not have to relinquish their identification with their mothers. This differential pattern leaves females feeling more connected and males feeling more individuated. The growing body of literature on gender differences in socialization suggests that boys are socialized to be assertive, creative, confident, and independent while girls are socialized to be cooperative, friendly, empathic, and obedient (Harter, 1999). Giedd (2004) has observed gender differences in the development of the adolescent brain; female brains mature earlier and the basal ganglion, responsible for executive functions, is larger in the females. Advances in science may provide further rationale for understanding gender differences and similarities in brain development and cognitive and emotional behaviour in children.

The preceding gender research has focused on differences; however, Kail (1998) posited that similarities among boys and girls are more prevalent than differences and that gender differences demonstrated in studies generally reflect only small differences, with significant overlap of abilities present in both genders. Harter (1999) also argued that autonomy and connectedness have been too dichotomized and too readily generalized to gender differences. For example, in studies conducted after Gilligan's (1982) work, Harter, Waters and Whitesell (1997) determined that gender difference in levels of voice, as reported by Gilligan, were more directly correlated with levels of support and encouragement, than with gender. Moreover, they claimed that Gilligan's conclusions applied only to a select group of girls. Harter et al. suggested adolescents of both genders who were characterized by a lack of voice had minimal support, validation, and encouragement. Their work suggests that it is important for both genders to remain connected to the parent while differentiating and developing autonomy in adolescence.

In this section, I have discussed gender differences and similarities as they relate to the expression of emotions. The literature has dichotomized specific attributes such as autonomy and connectedness, which may be more interrelated and less gender specific than was previously thought. New insights on adolescent brain development, hormonal differences, and social and environmental influences, provide beginning explanations for some differences in gender-specific emotional expression and similarities. I turn now to a discussion of adolescents' emotional development.

The Emotional Development of the Adolescent

Because the stage of adolescence covers almost a decade, it encompasses a wide range of emotional development. Developmental theories have delineated the periods of development as: early adolescence, beginning with puberty and lasting for several years; middle adolescence, beginning when physical growth is completed; and late adolescence, when most adolescents have generally formed a more stable sense of self (Turner & Helms, 1995). Harter's (1999) work differentiates stages of adolescence, with early adolescence beginning at grade seven, middle adolescence beginning at grade nine, and late adolescence beginning at grade eleven.

In early adolescence, abstract thought is compartmentalized and the young adolescent is unable to integrate a self-portrait. This lack of integration is further reinforced by the fact that others may hold varying opinions of the adolescent to which the adolescent is particularly sensitive (Harter, 1999). In middle adolescence, normative cognitive-developmental changes account for shifting self-evaluations, unpredictable behaviours, and mood swings that many adolescents experience at this age (Harter). Middle adolescents often have difficulty integrating opposing impressions of the self and different impressions of the self in varied roles; resulting in confusion, vacillation, conflict, and distress. In late adolescence and early adulthood, these contradictions are largely overcome. With the development of higher order thinking, facilitated by scaffolding, adolescents can resolve some of their emotional upheaval and integrate differing

components of themselves (Harter).

Children's emotional development in adolescence is correlated with their cognitive and social development, in addition to ongoing brain maturation (Giedd, 2004). Current research on brain maturation posits that the brain continues to grow until late adolescence, perhaps longer (Giedd). While adults rely more on their developed prefrontal cortex for making decisions, research on adolescent brain maturation indicates that adolescents rely on the amygdala, the emotional center of the brain, wherein primal feelings arise (Giedd). Research suggests that the prefrontal cortex is underdeveloped in adolescents, which may account for the impulsivity of adolescent behaviours (Giedd). In addition, the brain continues to grow throughout the adolescent years. This recent information, largely gained from neuro-imaging, holds promise for further understanding of adolescents' emotional and cognitive behaviour.

According to Erickson (1980), the major developmental task of adolescence is identity formation. Marcia (1966; 1980) extended Erickson's work on adolescent identity formation by proposing that adolescents undergo a crisis, wherein old values are reexamined and evaluated, and that, from this evaluation, a commitment to other goals, values, and ideologies occurs. Four identity statuses are possible; identity achievement wherein a person has gone through a crisis and committed to ideological, occupation and other goals; moratorium wherein the crisis is ongoing with no commitment to goals; foreclosure wherein the person has accepted a parental or culturally determined commitment without any crisis, and identity diffusion wherein the person is neither in crisis nor made a commitment. Identity diffusion can represent either a pre-crisis state or failure to reach a commitment (Marcia).

Research on Marcia's (1966) theory of identity achievement suggests that identity formation occurs later than adolescence; it may change as one ages, vary cross culturally, and be ongoing through the life span (Sato, Shimonska, Nakazato, & Kawaai, 1997; Waterman, 1985). Gender differences have been suggested in the attainment of identity. Some research suggests

girls appear to attain resolution of identity crisis at an earlier age than boys (Lytle, Bakken, & Romig, 1997; Moretti & Weibe, 1999). Girls have a tendency to internalize information about themselves gleaned through social interactions, while boys appear to focus on internal sources of information. The context of some adolescents' lives may preclude identity achievement, as it may not be a pragmatic adaptation to their environment (Madan-Swain et al., 2000).

Summary of Emotional Development

The preceding discussion has emphasized the emotional development of adolescents inclusive of identity formation and gender influences. Identity formation, moral development, and biological maturation of the brain all combine to affect the emotional development of the adolescent. Theories on emotional development are complex, influencing cognitive development and development of self. Emotional development appears to be interrelated with other aspects of development, such as moral development, and less easy to isolate than cognition in developmental theories. In the next section, I will describe and critique Kohlberg's theory of moral development and its contributions to the knowledge on moral reasoning, which serves as a starting point for a synthesis of moral development theory as it pertains to child development.

Kohlberg's Stages of Moral Development

Kohlberg (1969) proposed that children progress through a series of stages, (preconventional, conventional, and postconventional), as they develop higher level moral reasoning. In the preconventional stage, children, aged 4 to 10 years, initially make decisions based on what are punishable offences and learn to follow rules when it is in their immediate interest. In the conventional stage, children, aged 10 to 13 years, attempt to live up to the rules and expectations of their families and their social group, by following rules and maintaining good behaviour, i.e., what helps another and is approved. Within the postconventional stage, most children, aged 13 years and older, follow self-chosen values and ethical principles, which uphold individual and social rights (Kohlberg). Adolescents develop abstract thinking skills,

within the formal operations stage of cognitive development, which can allow them to engage in hypothetical moral reasoning and internalize values and ethical principles within the context of their lives (Piaget, 1970).

There is considerable support, as well as critique for Kohlberg's (1969) theory. His hypothesis, that moral reasoning proceeds along sequential stages, has been verified, with the qualification that most people do not reach the postconventional level (Stewart & Pascual-Leone, 1992; Colby, Kohlberg, Gibbs, & Lieberman, 1983). Kohlberg's stages have been criticized for exclusion of the development of moral emotions within the development of moral reasoning (Eisenberg, 2000). Eisenberg has identified empathy as integral to the process of moral development and advocated for inclusion of age-related abilities in developmental theories to account for emotional regulation. Kohlberg's moral development theory has also been critiqued for ignoring gender differences. Gilligan's (1982) work, although coming under some criticism, suggested that girls operated more from a perspective of care and justice and perceived moral dilemmas differently than boys. Girls also maintained social relationships as part of their moral reasoning. Other research suggested that moral judgments are strongly influenced by education (Carroll & Rest, 1982), but that levels of moral reasoning do not necessarily dictate behaviour (Kupfersmid & Wonderly, 1990). More recent research suggested that moral reasoning is situational rather than developmental and that it is more contextually influenced than affected by age and stage (Elbedour, Baker, & Charleworth, 1997). Miller and Bersoff (1992) found that Hindu children and adults based their moral reasoning on the value of caring over the value of individual rights and justice, causing them to conclude that moral reasoning is influenced by the cultural values of the participants and that there are differences within cultures as to the highest level achieved.

Kohlberg's (1969, 1976) theory has prompted further research and theory development. Although children have developed moral reasoning along sequential stages, their development is

influenced by education and culture and the majority of people do not reach the post conventional level (Carroll & Rest, 1982; Miller & Bersoff, 1992; Stewart & Pascual-Leone, 1992).

Summary of the Cognitive, Emotional, and Moral Theories

Theories of cognitive, emotional, and moral development and recent research on brain maturation emphasize the complexity of childhood development. Classic theories of Piaget (1970) and Kohlberg (1969) have not considered the significant influence of environment and culture or had the advantage of incorporating neuroscience research on brain development. However, it is clear that Piaget's theory of children's cognitive development remains influential (Harter, 1999). Newer theories (Case, 1992; Costanzo, 1991) suggest that there is a significant unevenness in cognitive development. Gender differences related to physiology and socialization are implicated in child development. Awareness that children may develop at uneven rates, within the norms of their developmental stage, provided me with a perspective which allowed me to better understand children's behaviours, to be respectful of individual differences, and to be cautious of any assumptions that I might make regarding individual differences in development. Information processing theory and social cultural theory are more inclusive of influencing factors and individual differences that affect children's development (Rogoff, 1990; Siegler, 1991; Vygotsky, 1978). The literature highlights the complexities of the children's cognitive and emotional development and the significance of contextual factors in children's lives. Given the importance of contextual factors, the contexts provided by society and the health care system, are an important consideration. Thus, I turn to an examination of the context provided by society and the health care system, inclusive of nursing practice.

The Context Provided by Society and the Health Care System

In the preceding overview of cognitive and emotional development, two consistent themes in research and theoretical development are: the significance of contextual factors in

children's lives, and the complexity of children's cognitive and emotional development. Living with a parent with a mental illness predisposes children to experience societal attitudes towards mental illness. Historically, these attitudes have been discriminatory. In this section, I will discuss the general social issues affecting children whose parents suffer from mental illnesses, followed by an overview of the health care system. Building on this, I will describe the current state of psychiatric mental health nursing practice and its relationship to the study population.

The History of the Treatment of Mental Illness and the Health Care System

In order to situate current mental health services, I provide an overview of the historical developments in the treatment of mental illness. Historical understanding is important for appreciating some of the current issues affecting children and their families, i.e., stigma, family burden, the dominance of the biomedical view, the current policies of care, and the evolution of care.

Historically, society has not been accepting of people suffering with mental illnesses. In pre-literate times, those suffering from mental illness were believed to be possessed by evil spirits. This resulted in exorcism and magical cures being used as treatment (Skodol-Wilson, 2004). From early civilization, inclusive of the Renaissance period, people suffering with mental illnesses were isolated and confined; often shackled, brutalized and sent to sea "in search of reason". The late 18th and early 19th centuries witnessed the beginning of humane treatment and, importantly, to the development of psychiatric practice and a classification system of mental illnesses (Boling, 2003; Skodol-Wilson). In the late 19th and 20th centuries, public mental hospitals provided custodial care and kept those suffering with mental illness separate from general society. Within this era, two significant events of particular interest occurred. The first was the publication of a book by Clifford Beers (1943), which documented his experience of mental illness and his treatment. The second was that his book fostered the formation of child guidance clinics developed to assess and intervene in situations where children had mental

illness. These two events were significant, because the consumer's voice was acknowledged and preventative psychiatric active services were developed for children (Alexander & Selesnick, 1966).

The early twentieth century was signified by a dramatic shift to psychoanalysis and the beginning of a classification system for mental disorders (Boling, 2003; Skodol-Wilson, 2004; Sodock & Sodock, 2002). By the mid 20th century, a rift between biomedical and psychoanalytic orientations towards mental illnesses had arisen. Diverse treatments such as family therapy, group therapy, and pharmaceutical therapies, namely new psychotropic drugs were employed. New psychotropic drugs dramatically changed the treatment of mental illnesses, because physicians were better able to control or reduce the symptoms of mental illness for many patients. These drugs allowed patients to return to the community. This was further fueled by the government policy of deinstitutionalization, the process whereby services for the mentally ill were shifted from residential institutions to the community. Patients, who had lived much of their adult lives within institutions, were now shifted to the community (Boling; Skodol-Wilson).

The first wave of deinstitutionalization moved elderly people residing in the asylums to nursing homes in the community. Deinstitutionalization continued to depopulate the hospitals and eventually there was a move to avoid institutionalizing the chronically mentally ill population (Bachrach, Talbott, & Meyerson, 1987). The shift to care in community from care in large institutions resulted in significant gaps in service, and eventually a reliance on family caregiving (Morrell-Bellai, Goering, & Boydell, 2000; Picard, 2000). Patients discharged into the community during the first years of deinstitutionalization often had minimal, if any, contact with families due to the fact that they had been removed from the family for many years.

Government policies did not account for patients' needs for care required for functioning and only provided care for their basic needs. Former patients were clustered into low income and poor housing and became "ghettoized" (Bachrach, 1984; Krauss & Slavinsky, 1982).

Deinstitutionalization and the consequent lack of services for the seriously mentally ill contributed to the problem of homelessness leaving many seriously mentally ill people unable to function in society (Allender & Spradley, 2001). While Canada did not develop community mental health centers for the chronically mentally ill, the Canadian government issued transfer payments to the provinces in the 1960's and the 1970's to build general hospital psychiatric units that were run according to the biomedical model (Freeman, 1994). Unfortunately, these units did not provide care for the chronically mentally ill discharged to the community; instead they treated less ill patients (Wasylenki, Goering, & MacNaughton, 1994).

As the older de-institutionalized populations began to die, a second population of chronically mentally ill clients, who had never been institutionalized and indeed may have found it difficult to get psychiatric services, became more evident (Boling, 2003). This population posed challenges, frequently having dual diagnoses (mental illness and substance abuse). The lack of services for these clients contributed to a revolving door syndrome; homelessness followed by jail incarceration (Stein, 1989). Two-thirds of homeless people using urban shelters suffer from some form of mental illness (Canadian Psychiatric Association, 2001). This statistic reflects psychiatric bed closures and the increase in community-based treatment programs. Attention to housing, employment, and financial support is still inadequate in government policy for the mentally ill (Reynolds, 2003). The psychiatric rehabilitation movement has attempted to address some of the deficiencies within the mental health system; however, services for women who have a chronic mental illness have been noticeably unfocussed in terms of their specific needs. For women who are parents of children, there are few resources to assist them in their roles (Mowbray, Oyserman, Lutz, & Purnell, 1997; Nicholson & Henry, 2003).

While the philosophical underpinnings of deinstitutionalization appeared to be more inclusive for people with mental illness, the mentally ill were often marginalized in society due, in part, to an infrastructure that did not support their holistic needs (Lamb, 1984; 1993). The

biomedical focus on the management of symptoms, while a key component of treatment, has proven inadequate for inclusion of clients into mainstream society and failed to address the social and emotional needs of those suffering with chronic mental illness (Anthony, Cohen, & Kennard, 1990; Howe & Howe, 1987; Liaschenko, 1989; McCabe, 2002). In the 1990's, known as the Decade of the Brain, treatment became more focused on the biomedical model, with emphasis on neuroscience and brain imaging research.

Technological advances in brain imaging supported a further shift to a biomedical focus on neuroanatomical explanations of mental illness and its treatment. In response to perceived limitations of that focus, which involved a singular approach to treatment of mental illness and discrimination within the psychiatric mental health system, there was increased interest in recovery from mental illness and consumer empowerment (Anthony, 1993; Deegan, 1995). Formerly, driven by the biomedical model and brain image research, medication was the primary focus of treatment. Some consumers of mental health services became more openly critical of the mental health system and challenged the perceived constraints placed upon them by psychiatry (Deegan). Psychosocial rehabilitation became a focus of care, largely due to consumer and family advocacy groups that insisted on more holistic services (Hatfield, 1984; 1987; 1994). Consumer and family groups, such as the National Alliance for the Mentally Ill (NAMI), Siblings and Adult Children network (SAC) of the NAMI, and the Canadian Mental Health Association (CMHA) have developed in response to deficiencies of services and consumers' perceptions of judgmental attitudes within the mental health care system. In addition, Sroufe (1997) has stated that the guiding assumptions of the biomedical model, namely, that the core etiology of mental illness lies within the organic structure and function of the brain, has strongly influenced the priority of the research questions being studied and has focused attention on medical treatments, namely the use of psychiatric drugs.

Since the late 1970s, organized family groups that serve as advocates have become a

recognized force within the mental health system. The majority of organized family groups consist of family members with adult children suffering with mental illnesses (Mannion, Meisel, Solomon, & Driane, 1996). These parents have advocated for increased resources, research, and recognition as caregivers for their children (Hatfield, 1994). Groups and services for children living with a parent with a mental illness are not prominent, although the formation of groups such as SAC, suggests that children could have benefited from early intervention services. Families and consumers are becoming more actively involved in planning of services, as evidenced by a local joint initiative of consumers, family and government in developing a vision statement for mental health services (Manitoba Health, 2002). Family members generally consist of parents concerned about their adult children, without inclusion of children being parented by parents with mental illness.

The current focus on shorter hospital admissions and community treatment has consigned many people in acute stages of their illness to the community. As such, it is conceivable that their behavior and their situations leave them more vulnerable to the effects of stigma. Although understanding and treatment of mental illness has dramatically improved, several factors contribute to the stigmatization of the mentally ill and their families. In the next section, I enlarge on the effects of stigma.

Stigma

The stigma associated with mental illness is a strong force, which people and families living with mental illnesses must manage. Stigma is powerfully reinforced by societal values attached to work, independence, money, and prestige, and the social labels that are put upon those who do not attain these goals (Kenny, 2001). Stigma is a multifaceted concept that involves attitudes, feelings, and behaviours; it implies a negative label, discrimination, prejudice, and stereotyping (Kenny). People and families suffering from mental illnesses are subject to stigma from society (Mordoch, 1995; Nicholson, Sweeney, & Geller, 1998a). The stigma

associated with mental illness has been linked to decreased employment and housing opportunities, strained family relations, and increased family stress about acceptance in the community (Kenny). Two-thirds of people with a diagnosable mental illness do not seek help due to their perceptions of associated stigma (United States Department of Health and Human Services, 1999). In addition, the World Health Report (2001) stated that globally the stigma of mental illness contributes to human rights violations arising from the inhumane treatment and ignorance surrounding mental illness.

Generally, stigma arises from ignorance and lack of factual knowledge, which are compounded by fear of mental illnesses (Angermeyer & Matschinger, 1996). Stigma is experienced internally, in the form of shame and avoiding help-seeking behaviour, and externally by experiencing unfair treatment from others (Sayce, 1998). Consequently, there are likely a significant number of children who are living with parents who have undiagnosed and untreated mental illnesses, and who are at risk to experience stigma, as well as the effects of untreated mental illness in their parents.

Families suffer the double burden of mental illness of a family member, because they also experience shame, implications of blame, and limited opportunities to progress (Canadian Mental Health Association, 1991; Reinhard, 1994; Torrey, 1983). There is a strong correlation between low income and high prevalence of mental illness. Although this would suggest that poor people would use psychiatric services more frequently, it is in fact the more affluent, with the lowest prevalence for mental illness that use the services (Manitoba Centre for Health Policy, 2004). Family members are subject to 'courtesy stigma', the stigma experienced from associating with the stigmatized individual (Kenny, 2001).

Stigma is an ongoing problem for families of discharged psychiatric patients (Phelan, Bromet & Link, 1998). When families experience the negative consequences of stigma they often feel compelled to conceal their relatives' illnesses. Little empirical research has addressed

the problem of the negative consequences associated with stigmatization of family members (Phelan et al.). It is possible that the stigma surrounding mental illness prevents family members from participating in research studies. It is reasonable to suggest that the effects of stigma burden children who are living with parents with mental illness and, as such, research is needed to examine those effects on children.

Stigma reinforces the code of silence surrounding mental illnesses (Ekdahl et al., 1962; Gross & Semprevivo, 1989; Marsh & Dickens, 1997; Miller, 1996; Shachanow, 1987), which hinders the resolution of emotional reactions to the mental illness of a family member. Brief glimpses of the former self of the afflicted family member complicate the ongoing unrecognized grief associated with mental illness (McElroy, 1987). The cyclical nature of mental illness exacerbates psychological loss and grief experienced by adult family members (McElroy). Anthony (1973) and Gross (1989) posited that children may experience a chronic sense of loss and alienation from a mentally ill parent who is physically available, but emotionally and psychologically unavailable. The ambiguous nature of psychic loss, where the person continues to live on but changes profoundly, severely alters the relationship of the family and the mentally ill member (Miller). While chronic sorrow has been recognized in parents with children who are mentally challenged (Mallow & Bechtel, 1999), it is not known if children who are living with a parent with a mental illness experience chronic sorrow. As there is no natural termination to grief associated with having a parent with mental illness, it is plausible that children will experience ongoing loss and chronic sorrow. In addition, children often are compelled to take on adult roles in childhood, such as becoming caregivers to their mentally ill parents (Beardslee & Podorefsky, 1988; Marsh & Dickens, 1997). In retrospective accounts from the lay literature some adults report reflecting on and grieving for their lost childhood (Marsh & Dickens).

The preceding sections have provided an overview of the history of the treatment of mental illness and the influence of the biomedical model on the treatment of mental illness.

While there has been a trend to more holistic care driven by the consumer movement, the biomedical model continues to dominate the mental health care policy, including which services and programs are supported by public funds. The stigma associated with mental illness is a concern for those suffering from mental illnesses, their families, and their care providers. Often stigma increases the difficulty for mentally ill patients and their families to fit into the community and strains their social support networks. Understanding the historical and current treatment of mental illness from a biomedical perspective and the associated stigma provides a context in which to consider nursing practice with mentally ill patients and their families.

Psychiatric/Mental Health Nursing Practice

Current psychiatric mental/ health nursing practice takes place within the context of the health care system predominantly under the domain of the medical specialty of psychiatry. Psychiatry strongly reflects the biomedical model and as such creates a tension between the typical standards of care in institutions and the more holistic practices of psychiatric mental health nursing (Horsfall, 1997). Historically, psychiatric nursing has fallen under the control of psychiatry, with the medical profession holding the power over patients' treatment (Church, 1985; Horsfall). This dominance has minimized the effects of factors that influence treatment, such as gender, ethnicity, poverty and class; in other words the context of people's lives. Horsfall posited that nurses have become disenfranchised under the dominance of the medical model, have had limited opportunities to improve client outcomes, and have been forced to adopt philosophies of treatment that are not congruent with nursing's holistic focus.

To understand the nature of medical dominance over psychiatric nursing, a brief overview of the history of psychiatric nursing is provided. Changes in psychiatric nursing have been dictated by the prevalent biomedical treatment of the era (Peplau 1994). In the early 19th century, untrained nurses and attendants provided custodial care to patients in large mental institutions under the supervision of physicians. Training of mental health nurses began in the

late 19th century. At that time, nurses were taught by physicians. Until the middle of the 20th century, physicians continued to control the education of psychiatric mental health nurses with nursing educators gradually assuming an educational role. The publication of the first mental health nursing text was in 1920 (Peplau; Church, 1985). Dr. Peplau, credited to be “the mother of psychiatric nursing” attempted to publish her text *Interpersonal Relations in Nursing* (1952), which outlined a departure from custodial care and emphasized nursing communication skills. Publication of this text was postponed for three years due to the fact that there was no medical co-author. Her work emphasized that nursing has a much wider base of practice than was prescribed by the medical model that dominated the mental health system. In 1952, regulatory nursing bodies gave the mandate that all students have an experience in psychiatric mental health nursing within their basic nursing programs. At that time, there were increasing numbers of well-prepared nursing educators who began to control the education of mental health nurses. Graduate level courses became available, which led to nursing research and publications on mental health nursing (Peplau).

Currently psychiatric/mental health nursing is compelled to examine its practice assumptions and its position within the health care system. Liaschenko (1989) argues that the renewed influence of the biomedical model and advanced technology threatens the relational aspect of care that is a hallmark of psychiatric/mental health. Sills (1977) cautioned against a reductionistic view taken from a model of illness that negates the quality of life associated with mental health. Nursing leaders have called for nursing to be critical of an exclusive commitment to neuroscience research that ignores the social and moral context of health, inclusive of sexism, poverty, violence, prejudice, and access to quality health care (Sills).

The preceding description has demonstrated that the development of psychiatric/mental health nursing has been strongly influenced by the biomedical model. This has created tension between nurses’ identified goals of practice and the mental health care system. The Canadian

Standards of Psychiatric and Mental Health Nursing Practice identify nursing values of mental health promotion and access to services (Buchanan, Harris, Greene, Newton, & Austin, 1998). The nursing role includes advocating for family and clients despite system barriers to enacting advocacy (Goering; 1993; Goering, Wasylenki, Farkas, Lancee & Ballantyne, 1988). Values held by nurses incorporate family, and mental health promotion and have been challenged by the organization of psychiatric/mental health services and the designated role of the nurse within those services (Krauss, 1993). These circumstances may explain, to some degree, the limited effects of the holistic model espoused by nurses to improve the lives of the study population. The organization of the health care delivery system has not emphasized nurses' autonomy; it has not facilitated nurses' efforts to take a leading role in order to intervene with children of individuals who come in contact with the mental health system or to provide primary intervention.

While psychiatric mental health nursing practice has achieved more recognition, it has been constrained by the significant influence of psychiatry and the biomedical model over the organization and delivery of health care services. The biomedical model focuses on the identification and treatment of pathology of the individual and continues to exert control over the delivery of mental health services (Horsfall, 1997). Policy for mental health services, such as Mental Health Renewal (Manitoba Health, 2002) is based on a model of individual recovery, rather than a more holistic perspective of the effects of mental illness on patients' lives, which would include children as family members (B. Pageau, personal communication, December 10, 2004). Attention to the effects of mental illness on patients and their families will continue to be limited and narrow, if nurses do not take a leadership role in identifying the broader effects of mental illness, including children's unique experiences of living with parental mental illnesses. Empirical work documenting the effects of parental mental illness on children can assist nurses in taking a leadership role in policy development regarding mental health services.

While nursing practice provides opportunities for contact with children living with parents with mental illnesses, there are few nursing interventions or studies directly related to this population. Using a qualitative focus group approach, Garley, Gallop, Johnston, and Pipetone (1997) conducted a pilot study ($n=6$) exploring the subjective needs of pre-adolescent and adolescent children living with parents with mood disorders. Although their sample size was small, their findings demonstrated that children were looking for more information on mental illness, worried about their parents separating, valued friends as a source of support, and felt burdened related to the parent's illness (Garley et. al.). The researchers recommended that nurses broaden their scope of practice to include children, in order to advocate for and plan mental health services for them. Buckwalter, Kerfoot, and Stolley (1988) conducted a qualitative study ($n=9$) of children aged 12 – 20 years, whose parents had mood disorders and were out-patients in a community mental health center. The findings from this qualitative study demonstrated that the children did not openly discuss the family problems or their feelings related to these problems, and that they managed by ignoring the problem, avoiding their parent, and running away from their homes. The researchers urged nurses to broaden their scope of practice to include a family perspective which attended to children's needs for correct information and supportive resources (Buckwalter et al.). Australia is proactive in assessing the needs of children and families living with a mental illness and in developing services to meet these needs. The Tasmanian Children's Project, a collaborative venture between the University of Tasmania's School of Nursing and the Mental Health Services of South Tasmania, attempted to identify existing supports for children and parents. In addition to a survey for service providers and parents with mental illness ($n=399$), the researchers conducted interviews with 8 parents and 4 children, three of whom were siblings. The children indicated that they needed more information about mental illness, felt emotional distress related to the parent's hospitalization, and needed help with ways to manage the illness of a parent (Handley, Farrell,

Josephs, Hanke, & Hazelton, 2001). Parents expressed concern about their parenting roles and the effects of the illness on their children.

To date, the majority of the nursing literature describes children's experiences from the perspective of other disciplines and is not research-focused (Atkins, 1992; Blackford, 1988; Devlin & O'Brian 1999; Gross 1989). While nurses have identified the need to include children living with parental mental illness in their practice, the nursing literature in this areas is scant and programming for children is sporadic at best. Nursing has, however, contributed to publications for family members living with mental illnesses; for example; *All Together Now: How Families are Affected by Depression and Manic Depression* (Health Canada, 1999); *Kids Speak up, Shining Light on Mental Illness*; (CMHA, 2000); and *Families Speak Up – Shining Light on Mental Illness* (CMHA, 2000). While significant contributions, these efforts offer few chances for nursing to implement comprehensive programs to assist children. Analysis of the broader literature suggests that there are missed opportunities for nursing intervention with families and children living with parental mental illness, and that nursing has an opportunity to be instrumental in providing services. I have considered the historical treatment of mental illness, the evolution of psychiatric nursing practice, and synthesized the nursing literature about children living with a parent with a mental illness to provide an overview of the context within which nursing practice in Canada is situated.

In the preceding section, I discussed the dominance of the biomedical model and the failure of nursing practice to address the holistic needs of patients diagnosed with mental illness and their families. The biomedical and psychological literature has informed the development of theoretical concepts, applied to children living with parents with mental illness, and continues to direct philosophies of practice which limits opportunities for holistic nursing. I have considered more current contemporary discussions which are attempting to move the agenda forward to include understanding of children's experiences of living with a parent with a mental illness. In

the following section, I will present a critical analysis of the literature about children living with a parent with a mental illness.

Research on Children of Parents with Mental Illness

Most research about children living with parents with mental illness emerges from psychology and psychiatry and relies heavily on the Diagnostic and Statistical Manual of Mental Disorders (DSM). The DSM, originating in 1952 has been revised to the Diagnostic and Statistical Manual of Mental Disorders 1V- Text Revised (DSM 1V-TR). The majority of the research directed by this perspective has focused on children whose parents are diagnosed with depression, schizophrenia, and alcoholism. To date, the treatment of alcoholism has generally taken place outside of mainstream psychiatric services. Therefore, I chose to limit my literature review to studies on children living with parents suffering from depression, bipolar illness, and schizophrenia, who were likely to be treated within the mental health care system. Because these illnesses have unique presentations, I was interested in the similarities and differences associated with each illness experience, as perceived by the children.

While useful for categorizing behaviours and creating a common language between professionals, the DSM has been critiqued for cultural insensitivity and lack of recognition of contextual influences (Sampsel, Bernhard & Kerr 1992). Behaviours that have been labeled as pathological have often been reinterpreted as creative responses to extreme situations, such as incest and domestic violence (Glod, 1993). Critiques of the psychological and psychiatric literature emphasize the importance of seeking the perspective of individuals who are managing life in the context of mental illness, rather than applying external concepts that may not be valid indicators of life experiences. To offset this critique, lay and professional literature is beginning to include personal retrospective accounts of the experiences of growing up with a parent with a mental illness (Hinshaw, 2004; Lyden, 1997). While a considerable volume of literature exists on children whose parents have a mental illness, children's perceptions have generally not been

incorporated into this research. For example, no attention has been paid to children's subjective experiences of living with parental mental illness (Garley et al., 1997; Mordoch & Hall, 2002¹; Nicholson et al., 2001).

The literature about children of parents with mental illness has focused on risks associated with genetic transmission, exposure to parents' pathology, resiliency in the face of parents' pathology, and the effects of multiple elements (Feldman et al., 1987; Musick, Stott, Spencer, Goldman, & Cohler, 1987). Early research efforts identified genetics and risk from exposure to pathology for the purposes of identifying and reducing the prevalence of mental illness in children (Garmezy, 1974). Concurrently, the approach to children shifted from a biomedical disease model to a health promotion model, which resulted in a volume of literature on the strengths of children of parents with mental illness (Fisher et al., 1987). Unfortunately, literature that addressed children's strengths relied heavily on imposed views of resiliency in children and factors that influenced those imposed views of resiliency (Liddle, 1994). Over time, the focus of investigations of children has shifted to multi-causal agents, their interactional effects, and broader determinants of health (Feldman et al.). The health promotion model was intended to develop positive outcomes for children. Unfortunately, shifts to health promotion have not incorporated the perspectives of children who are living with parents who have mental illnesses. Future research endeavors should include children's perspectives to increase understanding of children's outcomes arising from living with a parent with a mental illness and the factors which influence those outcomes. I will now provide a critical analysis of

¹ Footnote: Some of the critical analysis presented in this chapter overlaps with this article. Mordoch & Hall, (2002).

the existing research on children's outcomes associated with living with a parent with a mental illness.

Factors Influencing Children's Outcomes

Factors influencing children's outcomes have been derived from research measures that are based on the assumptions of the biomedical model. The biomedical model as a paradigm to direct research has filtered children's experiences through diagnostic and behavioural measurement tools. That approach has applied a particular perspective to children's experiences. The complexity of children's efforts to manage the experience of mental illness by family members might be better captured by using qualitative research, which incorporates consideration of the effects of the family system.

The factors influencing children's outcomes when living with a parental psychiatric diagnosis will be discussed under the following headings: Emotional Deprivation, Genetics and Environment, Factors affecting Development, and Familial Influences. Although research in this area spans two decades, its applicability is limited by the focus on affective disorders and Caucasian middle class families (Nicholson et al., 2001); findings from these studies do not reflect an understanding of cultural and ethnic differences.

Emotional Deprivation

The effects of emotional deprivation are related to the argument that early parental interaction with children is a major determinant of their emotional and mental development during childhood (Chidekel, 2002; Gottman, 2001). Emotions arise from both cognitive milestones, such as the development of self-appraisal, and non-cognitive processes, such as genetic predetermination of emotionality and cultural heritage (Izard, 2002). Emotional deprivation through the absence of parental contact in early infancy has a detrimental effect on children (Bowlby, 1980).

Children can suffer maltreatment through neglect, indifference, and lack of empathy from

their primary caregivers (Harter, 1999). Children whose parents have emotional or psychotic disturbances are more likely to experience emotional deprivation arising from their social circumstances (Kendziora & O'Leary, 1993). Newberger (1973) viewed maltreatment as the inability of a parent to nurture his/her offspring, while Cicchetti (1989) described child maltreatment as pathology within the parent/child relationship. Several child development researchers have found child maltreatment and family dysfunction difficult to separate (Cicchetti; Erikson, Egeland, & Pianta, 1989). Even intermittent emotional deprivation has the potential to cause severe behavioral problems, profound chemical and neural changes of the brain, and changes to the emotion-related physiological functioning of the stress response; these characteristics impede maltreated children's acquisition of emotional knowledge systems (Izard, 2002).

Because of the symptoms associated with depression (decreased energy, avolition, depressed affect, and difficulty with concentration) maternal depression affects the emotional responses of the mother to the child, which creates the potential for emotional deprivation. Research on mothers who are depressed points to the inability of some mothers to interact warmly with their children which is influential for children's developmental problems (Beardslee et al., 1998). The body of research on postpartum depression deals with emotional deficits and attachment irregularities within the mother-child dyad, including emotional deprivation. In a critical review of this literature, Grace et al., (2003) found that these effects were more pronounced in children whose mothers were suffering from chronic and recurrent depression. Recent research suggests that maternal postnatal depression, inclusive of relational difficulties with offspring, is associated with cortisol irregularities, which are believed to predict major depression in adolescent offspring (Halligan, Herbert, Goodyer, & Murray, 2004).

Genetics and Environment

Considerable research has attempted to determine whether genetic or environmental factors cause mental illness. My review will highlight key points over time. Garnezy (1974), in his review of research methods for children at risk, noted the early studies of Hoffman (1921), Kallmann (1938), and Doppler (1932) focused on the identification of symptoms and deviant characteristics in the children of patients with schizophrenia. Research on neonates, whose parents had schizophrenia, indicated strong environmental links to pathology (Sobel 1961). Fish and Alpert (1962) studied 13 infants of mothers with schizophrenia. Their study indicated a strong genetic influence on the children's development of pathology. Higgins (1966) found no greater non-adaptive behaviour in children raised by their psychotic mothers when they were compared with children who were reared apart from their parents.

Research on children placed in foster homes, as a result of their parents' mental illness, suggested that feelings of rejection associated with being placed in foster homes might have increased their emotional difficulties (Murphy, 1972). Children who are in foster care are generally at increased risk for psychopathology and a range of behavioural and emotional problems, particularly if there are placement changes (James, Landsverk, Slymen, & Leslie, 2004; Pilowsky, 1995). Often children who are placed in foster homes linger in care for long periods of time while decisions are made on their custody status. Generally, children with parents with mental illness are not readily adopted (Jacobsen & Miller, 1998).

Although some studies indicated that most children did not develop schizophrenia, children were more likely to develop other pathological conditions (Schulsinger, 1976); research suggests that children of psychotic parents are at increased risk for pathology (Anthony, 1973; Hans et al., 1999; Orvaschel, Mednick, Schulsinger, & Rock, 1979). Rates of child psychiatric diagnosis among children who have parents with mental illnesses range from 30% to 50% compared with a 20% rate among the general population (Nicholson et al., 2001). The specific

diagnosis of maternal schizophrenia is associated with increases in mental disturbance in their adolescent and young adult children (Salmon, Abel, Cordingley, Friedman, & Appleby; 2003; Schubert & McNeil, 2003).

Controversy exists about comparing outcomes associated with children of parents with schizophrenia with children of parents without mental illness. Several studies have indicated that there is no significant difference in the incidence of pathological behaviour between groups (Beisser, Glasser, & Grant, 1967; Sussex, Gassman, & Raffel, 1963; Weintraub, Prinz, & Neale, 1978). In a 25 year follow-up study, results indicated that children who were reared with their mothers who had schizophrenia were not at increased risk to develop pathology (Higgins et al., 1997). Other research suggests that parental mental illness places children at triple the risk to develop mental health problems (Gammon, 1983; Gershon et al., 1982; Warner et al., 1992; Weismann et al., 1984). The latter findings have implications for the importance of intervening with children early to mitigate any effects of parental mental illness in order to promote mental health among these children. Weissman and Jensen (2002), in a review of community-based epidemiologic studies and longitudinal studies of families with depression, concluded that the offspring of depressed women are at high risk for depression, that depression begins in childhood or adolescence, and that depression is associated with morbidity. Of key importance, their review noted that the majority of depressed adults and children remain untreated.

Bleuler (1974) conducted a longitudinal study of 184 children of his patients with schizophrenia. Bleuler's results indicated that 10% of children of a parent with schizophrenia would develop schizophrenia but that those children were not at increased risk for other psychological pathology. His work is important as he recognized children's suffering, strengths, and sacrifices in the context of their adverse circumstances. He was sensitive to factors other than parental pathology and genetics; he acknowledged that unfortunate circumstances, such as malnourishment, could negatively affect a child's development. He attributed the differences in

his results from other studies to the fact that he had followed his subjects over a period of years. His depiction of their experience was more complex than that generated from a single research interview which focused on abnormalities (Bleuler). Bleuler's work acknowledged that growing up with parental mental illness placed children at risk for unresolved issues that could affect them in adulthood. Lay literature from the perspective of adults who grew up with parental mental illness (Marsh & Dickens, 1997) has described loss of childhood, unresolved grief, and interpersonal difficulties and supports Bleuler's insights.

In contrast to Bleuler's conclusions, the human genome project, which has advanced our understanding of the genetic makeup of humans, has placed significant emphasis on molecular genetic studies and their relationship to pathology (Cowan, Kopnisky, & Hyman, 2002). Molecular genetic research has focused on linkage and association studies, which have attempted to identify specific genes associated with susceptibility to major psychiatric mental illnesses such as schizophrenia, bipolar disorder, autism, and alcoholism (Berry, Jobanputra, & Pal, 2003; Cowan et al.; Dick et al., 2004). Generally, these studies provide evidence for gene involvement but have not provided conclusive evidence of specific susceptible genes or about their patterns of inheritance (Duffy, Grof, Robertson, & Alda, 2000; Evans, Muir, Blackwood, & Porteous, 2001; Smalley, 1991). Instead, it is becoming increasingly apparent that the genetic contribution to mental illness is complex.

Viewing a single gene as responsible for pathology is overly simplistic. Multiple alleles are usually implicated and account for small variations which all contribute to the illness (Evans et al., 2001; Rutter, 2000, 2003; Smalley, 1991). The molecular genetic research has also suggested that boundaries of some disease conditions have extended the current diagnostic criteria, which include overlap between conditions and more presenting disorders (Rutter, 2001; 2003). Recognition of the complexity of mental illnesses has generally evoked the perspective that both genetic and environmental influences likely contribute to the development of mental

illness and that the interactional effects of genetics and environment require further understanding (Berry et al., 2003; Brown, 2003; Riley, 2004; Rutter, 2001; 2003). Twin studies and adoption studies have suggested a genetic vulnerability to major mental illnesses, that is, schizophrenia and mood disorders (Kaplan & Sadock, 1998; Kaplan, Sadock, & Grebb, 1994; Kelsoe, 1991). Research suggests that monozygotic (MZ) twins develop schizophrenia at 4 times the incidence of dizygotic (DZ) twins and at 50 times the rate for the general population. Because only 50% of the MZ twins develop the illness, environmental causes are also likely to be implicated (Kaplan & Sadock). With the mood disorders of depression and bipolar illness, 65% of MZ twins were concordant for developing depression (Kaplan et al.); for bipolar illness, MZ twins were at 4 -5 times an increased risk to develop bipolar illness compared to DZ twins (Kelsoe).

Rutter (2001) posits that some of the genetic research has erroneously claimed genetic influences are causal effects of illness when environmental causes may have contributed. For example, while twin studies have demonstrated genetic linkages to the development of psychopathology in children, the research has had limitations in isolating environmental risk factors (Rutter). This has been due to several factors reflective of the complexity of the genetic and environmental risk. The main difficulty in the twin research is dealing with shared environmental effects, the assumption that monozygotic and dizygotic twins' environments will be equal, and the weak statistical power for assessing gene/environment interactions (Rutter). In addition, twin studies have not always used sound epidemiological sampling and have experienced high attrition rates. When genetic research and twin studies assume that environments of the participants are equal, results that are partially influenced by environment may be erroneously attributed to genetic influence (Rutter).

While there has been evidence for more than three decades that major mental illnesses (schizophrenia, bipolar, autism, and alcoholism) have a strong genetic basis, molecular genetic

research is only in the preliminary stages of identifying the genes that are implicated in these illnesses (Cowan et al., 2002; Gutknecht, 2001). The complexity of the trajectory of the mental illnesses and of the genetic component of the illnesses suggest that interactional effects of genetics and environment are likely both factors implicated in the development of the illnesses.

Factors Affecting Development

The timing of parental mental illness, in terms of children's developmental stages, has been identified as influential on childhood pathology. Studies indicated that, the earlier the onset of maternal depression, the greater the pathology of the child (Beardslee et al., 1998; Paffenberger, 1982; Pound, 1996; Welner & Rice, 1988). Wide ranges of critical ages, however, are suggested. Maternal depression before the child is three years of age is a risk factor for reading difficulties by the age of seven (Pound). Unresolved reading difficulties have been linked to later pathology in children, namely conduct disorder and substance abuse (Werner & Smith, 1992). Conversely, Rutter (1966) found that of children who had parents with diverse psychiatric disorders ($n=137$) compared with controls ($n=592$), young and older adolescent children were least vulnerable to parental mental illness. Children who were two years or less than two or who were well into adolescence, prior to the onset of the parental mental illness, were less vulnerable and more able to remain well (Rutter).

Rutter also noted disorders in children appeared to be associated with disorders of the same sex parent. In their review of the literature from the past ten years associated with children of affectively ill parents, Beardslee, Keller, Lavori, Stalley, and Sacks (1993) found that children whose parents had experienced depression prior to the age of twenty were themselves at a greater risk for experiencing depression than children whose parents became ill later in life. In addition, the majority of children who suffered depression did not get treatment (Beardslee et al.). Therefore, while children are identified as at risk, they are not receiving helpful intervention. This illustrates the need for continued research to determine helpful intervention strategies.

Although, most of the literature now suggests that early onset of parental depression increases a child's risk for psychopathology, Burbach and Bordin (1986) concluded that this is only one of many factors contributing to child outcomes; they suggested that the child/parent relationship could be satisfactory even in the context of the parental illness. Rutter (1978) noted that even in severe pathology, the mother's interaction with the child could be warm and supportive.

Anthony (1974) and Kauffman et al. (1979) similarly found that children who were more competent had supportive relationships with their parents despite the parental diagnosis. Their research suggested that outcomes for children of parents with mental illness are complex and to some degree unpredictable.

Familial Influences

Rutter et al. (1975) found that prolonged marital discord was more damaging to children than parental diagnosis. Rutter (1979) concluded that a combination of identified risk factors (severe marital discord, low social status, overcrowding or large family, paternal criminality, maternal psychiatric disorder, and foster care) influenced the development of psychopathology. Prolonged marital discord exacerbated by poverty, overcrowding, and psychiatric disorder may contribute to parental disengagement from children compounding the effects of parental diagnosis and the development of childhood pathology (Rutter, 1979; 1980). Accumulated life stresses related to the lack of availability of the parent were more influential on childhood pathology than the diagnostic criteria of depression (Beardslee, 1984). Keller et al. (1986) questioned if there was a reciprocal component of depression, wherein the child's depression may exacerbate parental depression. While this study included child interviews, the interviews were directed by the biomedical perspective and based on the identification of DSM-III R diagnoses. Although the data reflected reciprocity within family dynamics, the authors recommended future research on genetic etiology. A more fruitful approach might be to study dynamics of parent/child interaction that could account for such serious outcomes.

Socioeconomic status (SES) has been associated with the increased pathology of children (Escanola, 1972; Nicholson et al., 2001; Pound, 1996). A consequence of living with a mental illness is often the inability to be gainfully employed. In the Rochester prospective longitudinal study, which examined social status, severity, and chronicity of mental illness, a combination of decreased socioeconomic status and chronic parental mental illness placed a child at an increased risk for pathology (Sameroff et al., 1982). When mothers were diagnosed with depression, 87% of the poor children as compared to 40% of the middle class children exhibited signs of depression (Feldman et al., 1987). Conversely, the Ontario Child Health Study (OCHS) (n=2700 children, age 4 – 16), which is considered the most comprehensive investigation of social disadvantage and children's mental health, suggested that while poor children were more likely to suffer from conduct disorder, hyperactivity, emotional disorder, and somatisation as a group, no consistent SES effects were found on each specific disorder (Offord et al., 1987). Longitudinal studies incorporating qualitative strategies could assist researchers to understand the complex interplay of factors that influence children's health and social outcomes. Factors that a child views as important may also influence the child's level of functioning. For example, Humphrey and Humphrey (1985) contend that children may not have the same choices to manage stress as adults and may be punished for using some of the strategies that adults would use, e.g., leaving the scene.

Findings have implicated such diverse factors as family discord; hostile, critical, and blaming patterns of parental interactions with children; lack of maternal warmth; and both parents diagnosed with mental illnesses as increasing the likelihood of the development of children's mental illness. In particular, these factors were associated with the chronicity and severity of parental mental illness, a key variable in childhood pathology (Fisher et al., 1987).

Strategies used in the major studies have relied on adults' reporting of child behaviours, structured clinical interviews that yielded psychiatric diagnoses (Kiddie Schedule for Affective

Disorders and Schizophrenia, Diagnostic Interview for Children and Adolescents), and instruments, which identified subjective distress based on predetermined indicators.

Assumptions underlying testing and measuring procedures, testing in artificial laboratory settings, and incorporating and ignoring bias in sample selection illustrate some of the limitations of the literature. The lay literature now provides many retrospective accounts of children growing up with parental mental illness. Those accounts have expanded our understanding of diverse familial roles that children may acquire to manage the illness of a parent and have underscored the complexity of events that could influence pathology (Marsh & Dickens, 1997). This literature is congruent with recent emphasis on subjective experiences of consumers, families, and children being included in mental health research strategies (Nicholson et al., 2001). Qualitative research that explores the unique experiences of children could allow key issues to emerge rather than imposing preconceived ideas on children's lives. Explanatory frameworks derived from qualitative work can provide new models to explain children's experiences.

Resiliency Associated with Parents' Diagnoses

In addition to the negative outcomes associated with having a parent with a mental illness, a considerable body of literature focused on the more positive outcomes. The major focus of this research is on the concept of resilience, wherein some children were able to overcome significant adverse circumstances and flourish (Rutter, 1985). Resilience continues to be an important concept, illustrated by the continuing program of research in optimal child development (Luthar, Cicchetti, & Becker, 2000). In this section of the literature review, I will trace the development of resilience research as it relates to children of parents with mental illness and the important contributions of Anthony, Rutter, and Garmezy. This literature provides the opportunity to understand the development of resilience research in the context of my study

population. I will provide a critical analysis of the literature under the following headings: children's resiliency, individual characteristics, and interactional factors.

Children's Resiliency

Lack of consistency in the effects of parental mental illness on child development shifted the research focus to children who appeared to thrive despite their life circumstances. Currently, resilience, formerly conceptualized as an individual psychological trait, is defined as a class of events wherein success persists in the face of barriers (Bartelt, 1994). Prominent researchers in this area (Anthony & Cohler, 1987; Garnezy, 1981; 1987; Kauffman et al., 1979; Rutter, 1985; Werner & Smith, 1982; 1992) coined a variety of terms to describe children who thrived in difficult circumstances. The children were labeled as invulnerable, superphrenic, super kids, resilient, and survivors within the trauma literature related to children. The array of labels reduced the clarity of the term survivor and implied a level of health for children that may have been overstated.

Individual characteristics. The individual's ability to resist being engulfed by the illness and to view oneself as separate from the illness was inherent to the concept of invulnerability according to Anthony (1985). Other attributes included being realistically compassionate and knowledgeable about the illness (Anthony, 1970). Children who did not develop problems were of at least average intelligence, possessed an easy disposition that encouraged positive interactions, had affectional ties with a parent substitute, and had an external support system (Werner & Smith, 1982). Garnezy, Masten and Tellegen (1984) emphasized largely individual determinants of invulnerability, such as effectiveness in work and play and a belief that 'good' will follow effort and can control fate. Resiliency was based on sexist assumptions and bias in the interpretation of female behaviours. The language was inherently paternalistic. Being male was associated with invincibility (Anthony, 1970; 1974). The assumptions were also based on individual perspectives of psychological determinism that negated systemic issues such as

poverty and stigma. Studies often used measures of competence that were not grounded in the children's subjective experience (Bartelt, 1994; Kinsella, Anderson, & Anderson, 1996).

Determining resilience from this perspective failed to validate children who were not labeled as extraordinary, although to be ordinary in the extraordinary circumstances was in itself remarkable. Although the characteristics previously linked to positive mental health outcomes for children included supportive relationships, Garnezy et al. (1984) suggested that children be trained in mastery skills to sustain them in adversity. This type of intervention was based on assumptions that negated the societal influences that affected the lives of children. Further, current lay literature developed by adults whose parents were diagnosed with mental illness retrospectively describes their childhood experience. Descriptions portray an outward competence and an inward fragility that never came to the attention of the adult world (Marsh & Dickens, 1997).

Resilience and the measures by which it was determined (cognitive and behavioural tests with the underlying values of conformity and achievement) have been challenged within the educational system. Roles that children assume when a parent is ill, i.e., caregiver and housekeeper, may in fact be a form of resilient behaviour, based on the value of family cohesion at the cost of personal achievement. Therefore, a child who drops out of school and is viewed as a failure and non-resilient, may define resiliency from a different perspective, i.e., the child may have sacrificed education to assist the family (Bartelt, 1994). The child living with parental mental illness may not have energy to excel outside of the family roles. An individualistic emphasis on resiliency has the potential to absolve society of its responsibilities and may imply that children who cannot attain resilience are inferior. Labeling children as resilient has the potential to exclude them from intervention efforts (Liddle, 1994). A danger of romanticizing resilience still exists. For clinicians working with children from adverse circumstances, the idea of resilience may inspire clinical hope and positive emotion in otherwise overwhelming

situations. The idea of resilient children may enable clinicians to feel useful in situations where change is difficult to effect (Liddle). Work in other areas has suggested that abused children, who were viewed as resilient in their first five years, were not resilient by grade three (Farber & Egeland, 1987). If emotional health, as well as competence is investigated, children may not be as quickly labeled resilient. Studies have not generally addressed the subjective emotional experiences of children. In the critique of the concept of resilience, Kolbo (1996) noted that resilience is a term that has been externally applied by observers, but central to the concept are subjectively defined goals, aspirations and meanings.

Bartelt (1994) asks at what point does resilience approach irrationality on the part of the individual caught in such circumstances? Indeed, the defense mechanisms used (denial, distancing, suppression, intellectualization, isolation of affect, externalization, rationalization) by children to manage their situations, have been linked in the lay literature to interpersonal problems in adult relationships (Atkins, 1992; Marsh & Dickens, 1997). Questions arise regarding the face validity of measures of resilience. Do the measures used to capture the concept of resilience actually do so? What is being measured may not be indicative of a child's values and ways of demonstrating resilience. Many of the studies on resilience have used academic measures of competency to capture resilience. Is academic success equated with resilience? Subjective experience is a core component of resilience and to date the research has largely been derived from external objective sources (Bartelt).

The deficiencies that have been identified in the measurement of the concept of resilience call for an extended and clearer understanding of the meaning of resilience within the context of children's lives, as opposed to uniform and imposed responses that relate only to specific areas of their lives (Liddle, 1994). There are a variety of contexts within which resilience occurs and likely a variety of characteristics indicative of resilience that are perhaps culturally and class specific. Spring and Zubin (1977) contend that the same skills and dispositions that promote

competence do not necessarily promote invulnerability to mental illness. Therefore, research must be interpreted carefully, rather than making superficial claims about children's abilities. Because research has suggested that a balance between an individual's environment and personal coping skills influences resilience, more complex approaches to studying children's experiences are important. Liddle suggests that resilience is found in the narratives of the subjects interviewed. Consequently, it is important to include the narratives of children living with parents diagnosed with mental illnesses.

Multi-causal factors. Kauffman et al. (1979) compared the children of 30 mentally ill mothers with a control group of children of well mothers. Findings supported the concept of the super kids who were found to have positive interactions with their mothers, involvement in social relations, and extensive contact with an adult outside of the family. Maternal level of functioning was more important than maternal diagnosis, although maternal depression had the most negative effect on parenting. The Kauai longitudinal study on resilient children and youth is a classic study that has made a significant contribution to the resilience literature by emphasizing the holistic and contextual experiences of children. This study noted that resilience is fostered when a balance between cumulative life stressors, personal attributes, and protective factors (nurturing grandparents, an external support system and individual characteristics as discussed) exists (Werner & Smith, 1982). Although an older study, this study was influential in providing a more holistic approach to factors influencing children's outcomes. Of note, one-third of the children studied developed serious learning and behaviour problems before the age of ten. Identified risk factors were poverty, parental mental illness or alcoholism, serious central nervous system damage, and persistently poor rearing conditions. The majority of children who became criminal offenders had required remedial education by the age of ten. Children with all four factors developed the most problems.

Other significant findings were that boys had increased anti-social behaviour, children of depressed parents had increased resilience when compared to children of psychotic parents, and stress lowered resilience while lower socio-economic status increased vulnerability. The study strongly supported multi-causal influences on the development of pathology in children. The study included a sample of diverse cultural groups, and a longitudinal design that followed the participants over a 25-year period from birth to adulthood (Werner & Smith, 1982). While some interview strategies were used, generally the perceptions of children were not considered in the study.

Bronfenbrenner (1979) also challenged the focus on individualism by identifying environmental and macro-societal issues that influence human development. He argued that resilience measurements were subject to the researcher's definition of resilience and its determinants. Early studies (Garmezy & Nuechterlein, 1972) on resilient children have been critiqued for underestimating the role of reciprocity and environment and over-emphasizing the child's unique characteristics. Qualitative research is well suited to exploring the subjective experience of children, who have successfully managed their parent's illness, and the complexities of meaning and societal influences, but it has not been undertaken to address those criticisms that persist about explaining health outcomes for children (Mordoch & Hall, 2002).

The literature to date generally does not include the children's perspective from their voices. Instead, children's outcomes in the area of resilience have been largely measured by their behavioural and academic competencies from the perspective of others. I have included a review of the literature on people who are parenting in the context of mental illness for two reasons: the first is the paucity of literature on children's perspectives about growing up with a parent with mental illness; and the second is that, in general, children are in relationship with their parents and, therefore, it is important to understand parents' perceptions of parenting within the context of mental illness.

Parenting in the Context of Mental Illnesses

There has been increased interest in parents with mental illness within the last decade in the social science literature (Hartley & Phelan, 2003; Joseph, Joshi, Lewin, & Abrams, 1999; Nicholson & Biebel, 2002; Ostman & Hansson, 2002). Most literature refers to parents who have serious mental illness and who are mothers; there has been minimal research on fathers who are parents with mental illnesses (Nicholson, Nason, Calabresi, & Yando, 1991). Serious mental illness is generally denoted by diagnosis, illness duration, and number of hospitalizations. The majority of the women in the existing studies are diagnosed with psychoses, schizophrenia, schizoaffective disorder, major depression, and bipolar illnesses, or described as having chronic or severe mental illness (Ackerson, 2003; Nicholson et al., 2001). Within this literature, several themes are repeated. They are as follows: parents with mental illness are beginning to be recognized as a specific population requiring services; parents find society and the mental health system biased against them as parents; parents often feel strain between balancing the role of parent and the role of patient with a mental illness; women often experience significant losses (child apprehension) associated with becoming a parent and having a mental illness; and there are insufficient services for parents with mental illness to provide the support they require to fulfill their parenting role.

Parents with Mental Illnesses as a Specific Population

There are a considerable number of people suffering from mental illness who are also parents (Mowbray et al., 1995; Nicholson et al., 1998a; Ostman & Hansson, 2002). Estimates of the number of people with mental illness who are parents varies; however, the birth rate for people with major psychiatric disorders, such as schizophrenia or affective disorders, is rising and beginning to reach that of the general population (Ostman & Hansson). Gopfert et al. (1996) estimated that 50% of mentally ill patients are parents and that services do not reflect this adequately. Hearle, Plant, Jenner, Barkla, and McGrath (1999) found that 33% of the patients in

their study were actively parenting, while Nicholson et al. (1991) found that 82% of the women in their study population were parenting or helping to raise at least one of their children. In addition, the women in these studies with serious mental illnesses did not view their mental illness as their main identifying feature. They valued other roles in their lives, such as motherhood. The women's perspective was often different from how the mental health system viewed them (Nicholson et al.). In a later study, Nicholson et al. (1998 a) confirmed that 80% of mothers with serious mental illness were raising their children. These figures suggest that a considerable number of people with mental illnesses are parenting children.

Based on their findings, Jacobsen and Miller (1998) contended that 60% of mothers with chronic mental illnesses do not raise their children, because their children are placed in foster care primarily due to neglect or abuse. Nicholson and Biebel (2002) posited that the majority of people with mental illnesses go undiagnosed, which suggests that there are many children who are being parented by parents with mental illness who do not come into contact with mental health services. Parents who have a mental illness may not be forthcoming about their children for fear the children will be removed from their homes. In addition, health care providers may not ask about children or the parenting role, which results in this population not being identified and managing with few services to assist them in parenting.

While the statistics vary on the number of parents with mental illnesses, the literature has consistently indicated that most of those people with mental illness who are parents value their roles as parents (Mowbray et al., 1995; Nicholson et al., 1998 a; 1998 b; Sands, 1995; Savvidov et al., 2003). For some women with mental illnesses, motherhood creates meaning and can be a motivating organizing force which sustains their participation in treatment (Nicholson & Henry, 2003). Women parenting with serious mental illness have identified generic parenting concerns, such as how to get children to do homework, in addition to more specific issues related to their mental illnesses. The women in Nicholson's and Henry's study reported having difficulty with

discipline, role strain, and stress. They wanted to know how to communicate with their children, especially about their mental illnesses and to ensure that their children were aware that they were not responsible for the illnesses (Nicholson & Henry). Those mothers have identified their children's needs for encouragement, nurturance, discipline, and good role models and were interested in learning how to become good role models for their children. Ritsher, Coursey, and Farrell (1997) found that women suffering with schizophrenia had experiences which were more relationally based than men's experiences and, thus, experienced mental illnesses within a different context.

The few studies focusing on fathers who are parenting with mental illnesses reported more similarities to women's experiences than differences. Thomas and Kalucy (2003) included 7 fathers in their study but did not denote any differences related to the fathers' needs as compared to the mothers who were parenting. Ritsher et al. (1997) conducted a study to understand the impact of mental illness of the lives of men ($n=59$) and women ($n=107$). Of the fathers represented in the study, 66% reported being actively involved in the parenting of at least one of their children. Both men and women reported that having a mental illness made it more difficult to parent their children. Nicholson et al. (1991) conducted a study with fathers and found that mothers and fathers were similar in their diagnosis and their needs. Nicholson et al. (2001) noted that the National Co-morbidity Survey Data of the United States, with a national probability sample of 8000 respondents, reported that 17% of men who were parents had a lifetime prevalence of affective disorders, 20% had anxiety disorders, 6% suffered from post traumatic stress disorder, and fewer than 1% had a lifetime prevalence of non affective psychosis. This survey did not collect data on how involved the fathers were with their children; however, it highlights the significant number of fathers affected by mental illnesses.

The studies on parents with mental illnesses demonstrate that people with mental illnesses are parenting children and require specific services to help them do so. These parents

have a clinical profile that is different from other mental health consumers and, as a result of their illness and the demands of parenting, require specialized services (Nicholson et al., 1998a; 1998 b; Ackerson, 2003). There are also likely a number of undiagnosed parents struggling with mental illnesses who are also parenting children. In these situations, it is feasible that neither the parents nor the children are receiving assistance (Weissman & Jensen, 2002).

Bias towards Parents with Mental Illnesses

A consistent theme in the literature on parents with mental illnesses is their perception of bias against them as parents within the mental health care system and society. General stereotypes indicate that people with mental illnesses do not value parenting and have multiple partners (Mowbray et al., 1995; Nicholson & Biebel, 2002). Qualitative research has suggested otherwise, finding that many parents with mental illnesses value their roles as parents and are concerned about their children (Ackerson 2003; Mowbray et al.; Nicholson & Biebel). A pervasive theme identified for mothers with severe mental illnesses is their perception that pregnancy and motherhood are viewed negatively by both health care providers and family (Nicholson et al., 1998 a). This perceived bias and the awareness that they would be highly monitored and that their children could be apprehended added to the parents' stress and burden and interfered with finding services, even in the prenatal period (Nicholson et al.). Often children are removed from their parents during their parents' hospitalization. This has caused some parents to avoid hospitalization (Bender, 2004). The negative attitudes of service providers towards parents with mental illness may prevent parents from discussing parenting issues with service providers or even disclosing that they have children (Nicholson & Biebel).

Strain between Parental Roles and Patient Roles Related to Mental Illness

Parents reported that, while they experienced joy related to motherhood, they often felt distressed about trying to parent with a mental illness (Hearle & Mc Grath, 2002; Nicholson et al., 1998 a). Mothers reported having difficulty understanding the normal trials of parenting

versus the problems associated with mental illnesses. They reported feeling badly about having a mental illness in general, using drugs, and having difficulties managing their emotions (Nicholson et al.; Wang & Goldschmidt, 1994). The mothers also reported that the demands of having a mental illness, with frequent appointments, in addition to having children with special needs and consequent appointments was difficult to manage, particularly without transportation to appointments (Nicholson et al., 1998 a). Mothers had diverse levels of parenting skills and some were not able to manage the day-to-day demands of parenting. Notwithstanding, they attempted to remain involved in their children's lives and contribute to some of the decisions in their children's lives.

The stereotypical association of mental illness and violence creates the view that people with mental illnesses are more violent to children than the general population (Nicholson et al., 2001). Research on child abuse and parental mental illness is limited for several reasons. Samples were often selected from the child welfare and the court systems and the studies designed attempted to provide a profile of the abusive parent (Nicholson et al.). Because the actual numbers of parents with mental illness who are raising their children is not known, it has not been empirically validated in that population that the risk for child abuse is higher. The prevalence for parents with mental illness being abusive to their children is currently unknown (Nicholson et al.). The Ontario Mental Health supplement (OHSUP) study, however, reported an increased prevalence for child physical and sexual abuse. This was correlated with the paternal diagnoses of depression, bipolar, schizophrenia, antisocial behaviour, and any parental psychiatric disorder, with the prevalence at two to three times that in the general population (Walsh, MacMillan, & Jamieson, 2002).

It is important that adequate indicators of parent capabilities are in place to ensure both that children are not in danger and that parents are not unjustly penalized by having their children removed (Jacobsen & Miller, 1998). Children may be lost to their parents due to inadequate

assessment tools for competent parenting (Ackerson, 2003). Empirical literature on the potential for and actual violence attributed to parental mental illness is scarce. It is generally assumed that parents, who are suffering from thought disorders, hallucinations, and delusions have trouble interpreting reality. They are unable to interpret nonverbal cues correctly, or engage in social exchange, and thus are viewed as more at risk to physically abuse their children (Seeman, 1996).

Parents with mental illnesses are likely to have traumatic histories and experiences in their lives which have the potential to affect their parenting capabilities. Currently, such experiences are not routinely assessed in mental health settings. Services to assist parents to manage such experiences are therefore lacking, although the experiences can have detrimental effects on both parents and children including child physical and sexual abuse and trauma (Nicholson et al., 2001; Walsh et al., 2002).

Loss of Custody of Children

While multiple losses, such as losses related to health, relationships with spouses and others, parental rights, and personal freedom due to hospitalization, may occur in mothers who are suffering from serious mental illnesses, the most significant loss associated with parenting was the apprehension of children to temporary or permanent foster care (Dipple, Smith, Andrews & Evans, 2002). Several qualitative studies with women with serious mental illness have identified the unresolved losses associated with apprehension of children (Chernomas, Clarke, & Chisholm, 2000; Nicholson et al., 1998a). Most permanent custody losses are associated with psychotic thought disorders, with a greater likelihood of parents with mood disorders retaining their children (Bender, 2004; Mowbray, Lewandowski, Bybee, & Oyserman, 2004; Nicholson et al., 1998b). Dipple et al. (2002) found that 68% of women suffering from severe and enduring mental illness had been separated from at least one child and that there was little indication of this within the medical notes, suggesting that this issue was not addressed within the mental health care system. Joseph et al. (1999) found that half of mothers who had

lost their children felt that they needed help to deal with the sadness this situation had evoked and that they did not receive this help. Women reported fearing the loss of their children and experienced anguish when that happened (Nicholson & Henry, 2003).

Women's fear of losing their children may interfere with accessing services and complying with treatment. Treatment regimes, such as medication compliance, can interfere with women's abilities to parent and their energy to respond to their children's needs. Refusal to take medication can in turn be viewed by professionals as non-compliance. Attention to significant losses, such as child apprehension and loss of custody, and the emotional impact of such events has not been routinely incorporated into health services (Hearle & McGrath, 2000). Qualitative research suggests that child apprehension is a significant issue for mothers with serious mental illness and, as such, needs to be addressed within the services provided.

Insufficient Services for Parents with Mental Illness

The literature supports the view that, while there is growing recognition of the need for services to assist parents with mental illness to raise their children, there are insufficient services for these parents and their children (Hearle et al., 1999; Mowbray, et al., 1995; Nicholson et al., 1998a; 1998b; Savvidov et al., 2003; Wang & Goldschmidt, 1994; 1996). While incompetent parenting is the most common explanation for child apprehension, parenting issues are not routinely addressed except when the child is at imminent risk (Ackerson, 2003; Blanch et al., 1994). Instead, services have focused on parental pathology, with minimal efforts devoted to what constitutes competent parenting and how this is assessed. When parenting issues and the impact of loss of children are often overlooked or inadequately assessed, insufficient services will be provided for parents and children (Joseph et al., 1999; Nicholson & Biebel, 2002; Nicholson, Geller, Fisher & Dion, 1993).

Parents with mental illness feel that they are required to demonstrate parental fitness without being provided with adequate support services (Ackerson, 2003). At the same time, up

to 80% of patients are discharged home feeling unwell with difficulty functioning in the home (Thomas & Kalucy, 2003). Parents report being disorganized and not knowing what to do. Often those parents report that side effects of medications interfere with their functioning. Little practical help has been offered to assist such parents to resume their parenting roles (Thomas & Kalucy). Children sometimes are isolated due to the parents' lack of ability to socialize with other families and often have little understanding of the illness as it is not discussed (Thomas & Kalucy). Parents have requested help to discuss their illness with their children (Wang & Goldschmidt, 1996). Nicholson and Biebel (2002) call for service providers to acknowledge parents' strengths, the diversity that exists among individuals labeled with the same diagnosis, and to provide services based on these strengths.

Health care providers must ask the right questions in order to assess adaptive parenting and to assist parents to achieve this (Nicholson & Biebel, 2002). Rather than an individual focus on services, a family focus is needed and mothers themselves must be asked what they need (Nicholson et al., 1998a; Nicholson et al., 1998b). There is a general paucity of information in the medical notes on parental roles and children or the role of parent within the psychiatric population; few health care professionals routinely collected data on children and parenting (Nicholson et al., 1993). This situation is perpetuated by the biomedical focus on individual pathology. Newer initiatives within the mental health system, such as Programs for Assertive Community Treatment (PACT) are beginning to recognize the impact of losing custody of their children on women (Bender, 2004). Often parents fear seeking services in the event that their children are removed from them and hence rely only on available friends and family for help (Hearle et al., 1999). In addition, while some services exist for new mothers and infants, there are few services available to assist parents with older children (Hartley & Phelan, 2003). This results in children's and parents' needs being overlooked and may place children at risk for developmental problems (Hartley & Phelan).

Often the child welfare system and mental health services for the parents are dichotomized and parenting interventions become the territory of neither service. Parents have recognized a need for collaboration between agencies (Wang & Goldschmidt, 1994). Although statistics suggest that people with mental illness, particularly the younger generation, are parenting and have at least equal fertility rates as the general population (Mowbray, Oyserman, Bybee, MacFarlane, & Rueda-Riddle, 2001; Ostman & Hansson, 2002) services have not been routinely provided to assist these parents. Part of wellness intervention for the general public has included parenting education, but these programs have not been included in a comprehensive manner for parents with mental illnesses. There is a need to develop precise measurement tools of parenting skills, programs that address parental issues in treatment and rehabilitation, and programs that meet the needs of the children (Ostman & Hansson). Ostman and Hanson found that only 50% of children living with parents with mental illness had their needs met by the mental health care system. While the well parents (without mental illness) believed that their children required additional help, only 54% of these parents felt that their children's needs were met (Ostman & Hansson).

Summary of Parenting in the Context of Mental Illness

From my review of the literature, it appears that there is considerable interest in parents who have mental illnesses and that there is general agreement that these parents remain invisible as an identified group requiring services. The literature on parents with a mental illness focuses on mothers with serious mental illness. There is scant literature about fathers with mental illness and little is known about this experience. Serious mental illness refers to patients who have frequent relapses of their illness and require frequent hospitalizations. Serious mental illness is not consistently defined within the literature. Within the last decade, qualitative research has begun to address issues related to parenting and the meaning parents assign to this role. The literature strongly suggests that mothers with mental illness generally value the role of

motherhood and are interested in their children. There is a general consensus that the needs of this specific psychiatric population are currently not adequately met.

The literature on the lack of recognition of people with mental illnesses as parents illustrates a bias in the mental health system, as evidenced by limited documentation of the relationships between children and parents and a lack of appropriate services (Mowbray et al., 2000; Mowbray et al., 1997; Nicholson et al., 1993; Nicholson et al., 2001; Phillips, 1983). This places parents at increased risk to lose their children and increases potential risks to the children's development. Recent statistics suggest there are a growing number of parents who suffer from mental illnesses and that services need to be inclusive of parents' and children's needs (Nicholson & Blanch, 1994). Byrne et al. (2000) suggested that parents with mental illness use a wide range of government services, which often have conflicting practice frameworks. These services do not routinely record information on children and parents and, as such, they are not identified as a client group within either system. Miller (1996) suggested that development of criteria for parenting adequacy is needed; that mental health and the child welfare coordinate more closely; that parental assessments need to be methodologically sound; and that parent rehabilitation services are needed. Despite a decade of research on parents with mental illnesses, Mowbray et al. (2001) found that the majority of psychiatric records do not address where the children are living, even with the increased number of parents in the community. Larger representative samples are needed to establish the parameters of this parenting population which appears to be heterogeneous. In sum, parents who have mental illnesses and their children are a specific group within the psychiatric population. As such both parents and children require services to address their specific needs.

Summary

My literature review has considered the theories of cognitive and emotional development of children, the context of society and the health care system, and situated nursing practice

within the health care system. In reviewing the cognitive and emotional theories of childhood development, it is apparent that there is increased awareness of individual differences across stages of development, of the complexity of anatomical development of the brain, and of the influences of social, cultural, and ethnic diversity on children.

My consideration of the societal context, including the context of the health care system, described the influence of macro societal factors, such as stigma, on children's lives. Mental health services are delivered within the context of the biomedically-based health care system, which largely remains focused on the individual at both clinical and policy levels. Nursing practice, within the mental health system, is dominated by the biomedical model, which diminishes nurses' abilities to intervene proactively with children.

The review of the literature on children living with a parent with a mental illness has consistently demonstrated the need for qualitative research to address gaps in the existing knowledge base. The literature addressing the effects on children of living with a parent with a mental illness is mainly derived from the disciplines of psychiatry and psychology, which use a pathological lens to determine this impact. As such, children's subjective views are missing from the literature. Therefore, while there is a voluminous literature on this topic, it does not incorporate children's perspectives of the phenomena (Mordoch & Hall, 2002).

Despite the common experience of children living with parents who have mental illness, children have not been active participants in the research process. The standards used to measure outcomes, particularly the positive outcome of resilience have not incorporated children's perspectives. Adult children, who have been exposed to parental mental illness, are giving voice to their childhood experiences in the lay literature. It is apparent from their comments that the previous research strategies of measuring behavioural and academic competency and relying on observational reports from adults in children's lives failed to address the holistic experience of children. Furthermore, the traditional research strategies have presented a rather biased view of

resilience when it has been addressed. Qualitative research strategies would generate a more holistic portrayal of children's efforts to manage within the contexts of parental mental illness and of cultural interpretations of mental illness (Mordoch & Hall, 2002). Such studies will significantly contribute to the body of knowledge on children living with a parent with a mental illness. Claims about family-centered nursing and other therapeutic perspectives in general nursing policy documents make nursing a profession well suited to consider parental roles and to work with families.

Qualitative research would be helpful to explore the subjective experience of children who are living with a parent with mental illness, in a context that includes social stigma and minimal social supports (Mordoch & Hall, 2002). Although the complexity of the phenomena of children managing their lives when parents are diagnosed with mental illness has become increasingly clear, qualitative strategies that can assist children to describe their experiences, without the researcher's applied preconceptions have been absent from the research (Mordoch & Hall). Qualitative research has the potential to illuminate children's responses to parental mental illness and the meaning of their behaviour. Understanding the meaning children develop in interactions with their parents is crucial to understanding their behaviour and, ultimately, to developing effective interventions. In Chapter Three, the Theoretical Framework, I will discuss Symbolic Interactionism which provides the theoretical framework for my study.

CHAPTER THREE

THEORETICAL FRAMEWORK

This chapter describes the theoretical framework for the study, symbolic interactionism, which emphasizes the connection between symbols (shared meanings) and interactions (non verbal and verbal actions and communication). The theoretical perspective provides an interactional framework, which is pivotal to understanding how children experience the mental illness of a parent. For example, La Rossa and Reitzes (1993) underscored the importance of symbolic interactionism for understanding dynamics and roles in family life. They provide support for my position that my study of the experience of children living with a mentally ill parent is more effectively addressed from a symbolic interactionism approach. Because I subscribe to the ontological and epistemological perspectives associated with the postpositivist paradigm, which recognizes the connection between shared meanings and socially situated knowledge (Lather, 1991), the theoretical perspective of symbolic interactionism also fits well with my philosophical perspective.

Symbolic Interactionism

Symbolic interactionism represents reality as a complex network of interactions among people and describes how the self develops in the context of social interaction (Denzin, 1977). Social reality can be understood only from the perspective of actors who interpret their world (Charon, 1989). In childhood, the self evolves in response to experiences and discourses, in the context of social interaction that takes place over the developmental stages. When using symbolic interactionism as an approach to understanding children's experiences, I paid close attention to children's exposure to social interactions and to how those interactions shaped their behaviours and abilities. Although I recognized that children are active, symbol-manipulating beings that engage in mindful, self-conscious activity (Denzin), I also maintained that interactions between children and their parents who have a mental illness affect the development

of self. Using symbolic interactionism to guide my exploration of children's perspectives enables me to focus on the development of self and behaviour, in interaction with important people in the children's lives. Symbolic interactionism facilitated my inquiry about how children developed their understandings of parental mental illness in the context of action and communication in their worlds. Symbolic interactionism provided a way for me to focus on how children actively constructed and interpreted their experiences, as well as to value children as complex beings. In addition, symbolic interactionism supported my perspectives about children because it advocates that all actors, including children, be taken seriously in research endeavours (Denzin).

Symbolic interactionism proposes that human beings interpret social interactions and act based on the meaning they assign to social interactions (Meltzer, Petras, & Reynolds, 1975). Within society, human beings construct many selves and each self is related to the particular interaction within which the human is involved (Charon, 1989). The ontology of symbolic interactionism holds to an objective reality that exists independent of our social definition. However, what we see and understand about that reality is developed from our interaction with others. We interpret the world according to our social definition (Charon). The following sections describe the essential concepts associated with symbolic interactionism.

Self

The self arises in interaction with significant others and reference groups and is defined and redefined in interaction. The self is always in a sense of emergence (Mead, 1934). A human being is also continually engaged in a process of interaction with the self which guides conduct (Blumer, 1969). The actor is complex, dynamic, and essential in the definition of what is occurring. The actor defines the situation according to the present moment by perceiving, interpreting, and defining it according to the appropriate reference group; and keeps what perspectives he/she finds useful (Charon, 1989). The actor creates and recreates the world.

During growth and development, children continually create a self concept which emphasises concrete visible characteristics and later more abstract categorical definitions of self wherein the self is compared to others (Harter, 1999). While actors develop the ability to look at the self objectively, the self is always in a state of emergence. Cooley (1956) described this development of self as 'the looking glass self'. As a consequence of this development, actors become aware of how others view them, which informs their perceptions of themselves. These ideas are congruent with growth and developmental theories, which suggest that self-concept becomes increasingly abstract in elementary and high school years with children incorporating meanings from external sources and internal assessments of self into their overall self concepts (Harter; Harter & Buddin, 1987).

To illustrate these concepts using the example of living with mental illness, those children develop the ability to understand how others view them, within their normal course of growth and development. Consider the explanation offered by an adult who grew up with a parent with mental illness. At the age of seven, as part of "show and tell", the child took an object to school which she described in the terms she had always heard her mother with mental illness use to describe the object. When the class laughed and did not know what she was talking about, she recalled being surprised. She had become aware that her mother's perspective was regarded as different. From this interaction, with what symbolic interactionists term generalized others, that child became conscious of her unusual home life. She reacted as an "I" by becoming more aware of the differences in the attitudes of others, which constituted the "me". The child reacted by becoming guarded in what she openly shared with her peers. Further the child's experience with peers influenced her ongoing interpretation of her mother's behaviour (Anonymous, Personal Communication, November, 23, 2000).

Because children and their interactions with their caregivers largely determine the experience of childhood, family becomes the primary group influencing permanent conceptions

of self (Denzin, 1973). In middle childhood, the family is generally a much stronger reference group than peers, while in adolescence, peers as reference groups become increasingly important. Friendships become increasingly more intimate as adolescents learn to develop deeper friendships (Updegraff & Obeidallah, 1999). The actor (child) perceives the situation, and interprets and defines it according to the appropriate reference group (family, peers), a group whose perspective influences the actor. In the “show and tell” example cited, a symbolic interactionism interpretation of the incident would suggest that the child was very aware of her classmates’ (reference group) reactions to her story. Her interpretation of their reactions then influenced her interpretation of her mother’s behaviour.

Depending on whether the perspective is useful, the actor will either keep or change the perspective (Charon, 1989). How child actors determine usefulness will depend on a combination of their cognitive and social development and how well the perspective and behaviour work for the child in the short and longer term (Harter, 1999). Of note, social referencing, where the child can distinguish between positive and negative expressions on the faces of others is apparent in infants by 10 – 12 months of age. Children in early childhood are able to make preliminary links between other people’s emotions and situations (Dunn, 1993). Young children may reach this conclusion on a surface interpretation of interaction, not taking into account the opinion of others or expectations about normative reactions. Older children, who have acquired cognitive abilities that allow them to facilitate more holistic perspectives, may react initially on feelings but also consider the opinions of others and begin to understand social rules (Harter). As children develop, their thinking becomes less egocentric, meaning that they not only act on their own preferences, but also develop the ability to incorporate the perspectives of significant others, which will be reflected in their interpretations of interactions (Harter).

Actors actively create and recreate the world (Charon, 1989). The actor is able to take

the role of others and understand the meaning of their acts (Charon). With school age children, this level of understanding will vary but they are able to articulate what their understanding of meaning entails. According to developmental theorists, the ability to develop empathy for another's feelings occurs from early childhood (Hoffman, 1982; 1988). The development of empathy would be congruent with the ability to take the role of other. While the actor may respond to the present moment, the actor is also in the process of development and consequently brings his/her development to the present situation. Likewise, children engage in the process of developing self differently as their developmental stage progresses.

Object

Human beings live in a world of objects; things that have meaning for them. These meanings determine how actors act towards the objects within their reference groups. Actions are formed around objects, as actors decide whether they wish to act toward an object and organize their actions (Blumer, 1969). Mead (1934) indicated that symbolization constitutes objects that have not previously existed. Objects exist only in the context of social relationships, where symbolization occurs (Mead). Symbols are a class of social objects used to represent whatever people agree that they shall represent. Human action is symbolic, representing something other than what is initially perceived (Charon, 1989). Shibutani (1978) stated that whatever the symbol stands for constitutes its meaning. Meaning arises from how the person is initially prepared to act toward the symbol (Blumer). Language is a key symbol that represents a part of reality; words categorize and transfer our past experiences to new situations (Blumer).

Symbolic interactionism directs attention towards helping children describe how they act toward their symbols and the meaning that they attach to these symbols. Actors (children) may use symbols to talk to the self as well as others. These symbols may be used intentionally to communicate meaning. Research indicates that language development continues throughout middle childhood and that school age children may not comprehend language, as fully as adults

assume they do (Flavell, Speer, Green, & August, 1981). This has implications for how children construct meaning from interactions in their lives. Children are in a social group and are required to make meaning of objects in terms of their social relationships, inclusive of their primary relationship with their parents with mental illnesses. Stigma associated with mental illness creates language or silence around mental illness that influences the social meaning of mental illness. Children, who are developing language and becoming socialized within the larger society (school and community), will develop meaning from their interpretation of these symbols. With children who have a parent with mental illness, the meaning the object of mental illness takes on in their social group will affect their consequent interactions with their parents.

Social Interaction

People develop perspectives through symbolic communication with reference groups, which may arise from a variety of social worlds and vary according to specific situations (Shibutani, 1955). Symbolic interactionism suggests that humans actively interpret each other's gestures in social interactions and act on their interpretations (Shibutani). Social interaction and the meanings that arise permit people to make order out of social structures (Blumer, 1969). Many perspectives and social worlds can exist simultaneously. The perspectives developed from the reference group are shaped by interaction and become the origins of action (Shibutani). Self-concept, which provides a motive for behaviour, also mediates lines of action. A healthy self-concept developed through social interaction, encourages the person to both resist behaviour that violates personal values and to pursue self-confirming lines of action (La Rossa & Reitzes, 1993).

To illustrate these concepts with an example, a child who lives with a parent with mental illness may take on adult responsibilities and become the caretaker of the parent within the family home. In the child's peer group interactions, the child may revert to denial of the parent's illness and act in ways that would reflect a carefree existence. When confronted with parental

behaviours that are difficult to interpret, children may develop lines of action that seem useful at the time. For example, children who become involved with the psychoses of a parent may react to the world in a paranoid manner (Oates, 1997).

Meaning

All meaning arises through interaction, interaction with self, others and society; meanings are managed and modified through an interpretive process (Blumer, 1969). Individuals interact through symbols, assign meaning, and choose responses based on meanings. How human beings define the situation influences how they act and solve problems. Human beings formulate their actions based on the meaning symbols have for them. Human action is symbolic representing something other than what is initially perceived (Charon, 1989). Meanings are constructed by social interaction (Blumer).

Social Structure

Symbolic interactionism assumes that there is a tension between individual freedom and societal constraints. A person may have choices but these choices are circumscribed by larger cultural and societal structures, which limit the realistic choices available to the actor (Meltzer, 1964). Social situations are, however, also dynamic and partially determined by the attitudes and subjective definitions of the actors (La Rossa & Reitzes, 1993). Through everyday situations and actors' social interactions within these situations, details of social structure are defined. Perinbanayagam (1985) has extended symbolic interactionism theory to moral and political power issues by recognising the social contexts of the literary, philosophical, and textual traditions of a society. To illustrate with an example, children who live with a mentally ill parent and who experience the societal stigma and shame often associated with mental illness may have their choices restricted and shaped in terms of open discussion of mental illness in their family. The stigma and shame associated with mental illness may be incorporated into the symbol and construction of the meaning of mental illness.

Methodological Implications

Symbolic interactionism's strong emphasis on the actor as active and insistence on understanding the actor's interpretations of reality has implications for the research process. The meaning and value that actors attach to their experiences and objects influence how they make sense of the world (Fine, 1992). Shared meaning, behavioural expectations, and reflected appraisals contribute to the development of meanings and interpretations (Matsueda, 1992). Symbolic interactionism guides me, as the researcher, to explore implicit and explicit meaning, to probe the actor's thoughts, and to recognize that I can only determine what is taking place to the extent that I understand actors' beliefs about their world and how they develop their understandings through interaction (Charon, 1989). Implicit meaning, meaning that is understood though not directly expressed, is part of social interaction in human society. These meanings are derived from the actor's interpretation of social interactions, within social structures. Interpretations lead the actor to action based on choices, which are seen as reasonable to the actor (Meltzer, 1964).

Symbolic interactionism directs me to explore how children act, based on the interpretations that they have developed. Interpretations and consequent actions are partially based on the interaction between the parent and the child through the process of relating symbols and meaning within their social interactions. In research pertaining to children, starting from children's beliefs, understandings, and actions makes it possible for children's voices about their experiences to be heard. I must view children as unique actors who construct meanings of their experience and act, based on these meanings. Because symbolic interactionism describes an active process where the actor develops self-concept through interaction, which provides a motive for behaviour (La Rossa & Reitzes, 1993), it is particularly well suited to naturalistic qualitative research methods that are directed to understanding how human beings manage problems in their lives, for example, grounded theory.

Strengths of Symbolic Interactionism

Symbolic interactionism is a well-respected framework, which has made a significant impact in sociology as well as other disciplines, such as family studies. It is particularly well suited to family studies as it recognizes families as social groups wherein individuals develop self-concepts and their identities (LaRossa & Reitzes, 1993). The strong traditions in symbolic interactionism, associated with child development, are important. It has made a significant contribution to child development theories and has provided a theoretical framework for numerous studies of child development within a wide range of topics.

Symbolic interactionism views self as a social construction developed through social interaction and linguistic exchanges with others and has contributed strongly to ideas of how the self is developed in childhood (Harter, 1999). In terms of child development, symbolic interactionism is experiencing a resurgence of its classic ideas, particularly those of Baldwin (1897), Cooley (1902), and Mead (1925) who emphasized how the interactive processes with caregivers shapes the development of the self (Harter). These early theorists have contributed to the theoretical underpinnings informing the study of children in their formative years. In particular, Baldwin acknowledged the increasing influences outside the family as the child ages and the multiplicity of self-structure, how attributes of the self differ across and within different relational contexts; Cooley noted the internalization of appraisal of others leading to enduring attitudes about the self as well as the role of feelings in the development of self-concept, and Mead postulated that self-worth developed from the judgments of numerous significant others (Harter). Symbolic interactionism contributes a rich tradition to the understanding of child development, with an emphasis on the development of self-concept through social interactions. It recognizes the importance of meanings for human behaviour, that groups shape and motivate individual behaviour, and that larger social and cultural processes both influence and constrain individuals and small groups (La Rossa & Reitzes, 1993). Within this orientation, symbolic

interactionism has bridged the gap between the micro and macro systems of human experiences by attempting to understand the connections between situated activity and larger societal forces (Hall, 1987).

Limitations of Symbolic Interactionism

Symbolic interactionism also has a number of limits in relation to how it can be used. La Rossa and Reitzes (1993) describe the main limitations as: failure to operationally define and empirically test the key concepts and tenets of the theory, overestimation of the power of individuals to influence their lives, minimalization of the emotional and biological dimensions of human conduct, and lack of applicability to the study of large scale structures. Symbolic interactionists have had difficulty advancing symbolic interactionism as a systematically developed theory. It requires ongoing clarification of interrelated propositions (La Rossa & Reitzes). Some of the criticisms call for the inclusion of both objective, such as the biologic factors of neuroanatomy and physiology, and subjective forms of data, which include the multiple structural influences on participants' lives.

While the above limitations require acknowledgement, ongoing work is addressing some of these criticisms. The claim that symbolic interactionism has neglected the emotional dimensions of human conduct is partially refuted by the early work of Cooley who purposed that feelings were integral to the development of self (Cooley, 1902; 1956). In addition, the framework of symbolic interactionism is currently being used to develop theories on emotional development (Harter, 1996). Within the recent advances of biological investigations and state of the art technology, such as neuro imaging, concerns about the symbolic interactionism perspective's neglect of the biological reasons for behaviour and over emphasis on the individual's power to create his or her reality, require consideration (La Rossa & Reitzes, 1993).

The final limitation, wherein symbolic interactionism is not well suited to study large scale social structures and has not duly considered the influence of macro social structures such

as poverty, ethnicity, age and power imbalances, is of critical importance. Of note, there has been ongoing work to develop the symbolic interactionism perspective to be more inclusive of the broader macro influences, such as power, class, and gender on the construction of reality (La Rossa & Reitzes, 1993; Perinbanayagam, 1985). Examples of such studies include research on ethnic identity among Chinese-American pre-adolescents and Latin-American street children (Cheng & Kuo, 2000; Lucchini, 1996).

The grounded theory method is well suited to ameliorate some of the criticisms of symbolic interactionism. Grounded theory requires the full development of concepts included in a substantive theory. The method encourages theoretical linkages of concepts and their related propositions within the theoretical coding procedure. Grounded theory provides an opportunity for concepts, such as emotion, to work their way into the data. Macro systems issues and power dynamics can become part of the theoretical development, if relevant. Some of the responsibility for this will fall on me, the researcher, to acknowledge potential influences of micro and macro systems and potential power dynamics; however, grounded theory has the potential to accommodate recognition of these issues.

Summary

In this chapter, I have discussed the importance of the theoretical framework of symbolic interactionism to guide my study. Symbolic interactionism has contributed to child development theories and is well suited to research with children. I have provided an overview of its main assumptions and concepts, with examples that demonstrate its relevance to my study population. I have summarized the strengths and limitations of symbolic interactionism and suggested how the grounded theory method has the potential to offset some of the limits of the theoretical framework. In Chapter Four, the Methods chapter, I will introduce grounded theory and provide a detailed description of how the method, guided by the theoretical framework, was operationalized in my research.

CHAPTER FOUR

METHOD

I used an interpretive qualitative design guided by symbolic interactionism. A qualitative method provided an opportunity to obtain knowledge that was lacking within the existing body of literature, namely the subjective and contextual experience of a child living with a parent with mental illness. Symbolic interactionism served as the theoretical framework and informed the research questions, data collection, and data analysis. The qualitative strategy of inquiry I selected was grounded theory, which is a general method of conducting research partially derived from symbolic interactionism and pragmatism. The grounded theory method fits well with symbolic interactionism, because it focuses on the co-creation of meaning by participants and the social construction of interpretations and behaviour. Glaser and Strauss (1967), the originators of grounded theory, resituated research and theory by suggesting that theory should be generated from data in an inductive manner, rather than developed by scientists deductively and in isolation from people's lived experience.

I have described the study design. The rest of the chapter includes the following sections: research purpose and goals of the study, definitions of terms, research questions, overview of the method, nature of the sample, ethical considerations and research procedures including sample recruitment, data collection processes, data analysis and finally criteria for rigor. A summary will conclude the chapter.

Research Purpose and Goals of the Study

The purpose of the study was to understand children's perceptions of living with a parent with mental illness. The specific objectives of the study were to understand how children manage their lives in the context of living with a parent with mental illness and to understand children's perceptions of factors that have helped or hindered their efforts to manage their lives.

The study goals were to construct a substantive theory that will assist nurses to plan care for children and families living with a mental illness and to develop further research questions and hypotheses based on children's experiences of living with a parent with mental illness.

Definition of Terms

Mental Illness:	Depression, bipolar disorder, and schizophrenia as described in the DSM-1V-TR (2000)
Parent:	The biological, step, adoptive, or surrogate (substitute) parent who suffers from a mental illness, who is receiving ongoing treatment/support from the health care system and who is the primary care provider for the child.
Well Parent:	The biological, step, adoptive or surrogate parent who provides care for the child and who does not suffer from a mental illness.
Legal Guardian:	The adult who has the legal authority to oversee the well being of the child and the child's property, and to provide legal consent for the child's participation in the study.
Child:	An individual of either gender between 6 and 16 years of age inclusively.
Living with:	A situation wherein the child is living on a daily basis with a parent who has a mental illness or the child is living part time with a parent who has a mental illness. Living part time is defined as a joint custody arrangement where the child is spending a similar amount of time with each parent.

Research Questions

The general question for the study was: How do children experience living with a parent who has a mental illness? Specific sub questions further directed the study including: How do children manage the experience of living with a parent with mental illness? What is helpful to manage this experience? What is unhelpful to manage this experience? What are the outcomes for children who are trying to manage their experience of living with a parent who has a mental illness?

Overview of the Method

I chose grounded theory as the strategy of inquiry for the study. Grounded theory seeks to understand the chief concern or problem of the participants and what accounts for most of the variation in processing the problem (Glaser, 1992). Grounded theory promotes the development of novel concepts and relationships among concepts that are grounded in data from the participants; it is particularly valuable for its potential to provide new understandings of phenomena or to confirm or refute existing concepts and frameworks (Charmez & Mitchell, 2001). In addition, grounded theory is oriented to meaning construction, with an interest in context, behaviour, and meanings expressed through symbols and social interactions (Wilson & Hutchinson, 1991). Thus, a grounded theory study has the potential to extend existing concepts in the literature or eliminate gaps in our understanding about children's experiences when living with parents who have mental illness.

Grounded theory is used to generate a substantive middle range theory about conceptual categories and hypotheses about relationships among the categories and their properties (Glaser & Strauss 1967). The method was developed by Glaser and Strauss and later modified by Strauss and Corbin (1990). The form of grounded theory described by Glaser and Strauss and Glaser (1978, 1992, and 1998), was used to direct this study.

My decision to use Glaser's approach was based on the fact that the original description of the method relies on the categories earning their way into the theory versus taking a particular framework and forcing the data into it (Glaser, 1992). Versions of grounded theory described by Strauss and Corbin (1990) have been critiqued for being programmatic and overly formulaic and, according to Glaser, (1992) the recommendations by Strauss and Corbin encourage only conceptual description. Glaser's critiques led me to select the method of grounded theory espoused by Glaser because I believe it has greater potential to develop new theory, which is a valid representation of the data gathered from children living with a parent who has a mental illness.

Glaser's approach is designed to allow creativity and flexibility. The research question is loosely formulated, which allows the data to inform the questions that are generated during the research process. The interplay of data and theory is crucial. Specific techniques associated with the grounded theory method include concurrent data collection and analysis, theoretical sampling, theoretical sensitivity, memos, participant observation and the constant comparative method of analysis (Glaser & Strauss, 1967).

Nature of the Sample

Grounded theory studies do not require large sample sizes. Small samples provide the potential for increasing rapport between the researcher and the participants and increasing in-depth exploration of research questions (Glaser, 1978). Rapport and focus is imperative in researching sensitive topics, such as living with a parent with a mental illness. While no definitive number was predicted for saturation of the data, for the purposes of ethical approval, I anticipated that a sample of 30 might suffice (Sandelowski, 1995). Personal communication with Dr. Barney Glaser (March, 23, 2003) indicated that sample size could not be realistically predicted, because theoretical completeness, not numbers of participants or length of interviews, determines data saturation.

Inclusion criteria for the study were:

1. age six to sixteen years
2. male or female
3. full or part time residence with a parent who has a mental illness, specifically, schizophrenia, depression, or bipolar disorder as described by the DSM-IV-TR (2000)
4. English speaking
5. written consent provided by the child's parent or guardian
6. written assent provided by the child

In determining the age range of the children to be included in the sample, I wanted to understand the perceptions of children across the school years and how children of diverse ages perceived their parents' illnesses. I was curious to see the nature of the differences and commonalities within and between the age groups. I was interested in what helped and what did not help children manage their experiences and wondered whether or how this changed over their growth and development. The traditions of grounded theory demand that all variables must earn their way into the data. Variables, such as age or gender, are never assumed to be relevant until they emerge as such in the data (Glaser, 1978). Nonetheless, I was curious to see if children at different developmental stages would have different perceptions of and different management strategies for living with a parent with a mental illness.

Because children aged six to sixteen required consent to participate from the parent/legal guardian, the study procedures addressed parental inclusion criteria. Within the design of the study, I considered how to proceed if the parent with the mental illness was not the legal guardian. In such situations, I was prepared to seek the consent of the parent with the mental illness as well as that of the child's guardian. That situation did not occur.

Inclusion criteria for the parent/legal guardian were:

1. One of the child's parents has been diagnosed with a major mental illness, including schizophrenia, depression, or bipolar disorder as described by the DSM-IV-TR (2000).
2. The parent who has the mental illness has the child living full or part-time with him or her.
3. The parent with the mental illness is receiving ongoing support/treatment for the illness from the health care system.
4. The parent/legal guardian is competent to sign the consent form.

The diagnoses included in the sample criteria reflect major mental illnesses that are prevalent and significant in Canadian society. All three disorders have both acute and chronic presentations. For the study, I was interested in children who had fully experienced the mental illness trajectory. In other words, I recruited children who had lived with parents who were receiving ongoing treatment, had witnessed their parents' illnesses and health, and had lived with the chronic nature of mental illnesses. All parents in the study had more than one exacerbation of their illness and were receiving ongoing support from the health care system; their illnesses were ongoing.

Ethical Considerations

The ethical considerations of the study will be discussed under the headings of research considerations with children, consent and assent, confidentiality and potential crisis situations.

Research Considerations with Children

Children are identified as a vulnerable group requiring special consideration, within the research process, to protect their dignity and to decrease their risk for exploitation and discrimination (Medical Research Council of Canada, 1998). Special strategies to protect children, however, must be considered in view of the injustice inherent in their exclusion from the benefits of research. In other words, when children have been systematically excluded from

the research process, insufficient research has included their perspectives (Medical Research Council of Canada). Research with children can be conducted on ethical grounds if the research has the potential to help other children (Brock, 1994). Minimal risk, i.e., risk that relates to the research, must be determined to be no greater than children would experience within their everyday lives (Medical Research Council of Canada). All harm should be minimized and proportional to the benefits of the research.

In this study, risk was minimal. Possible risks included: long term effects of disclosing information are unknown, the child may feel disloyal to the parent if he/she disclosed disparaging information about a parent, the child may become emotionally upset when discussing different topics, or the parent may feel threatened by the child's participation and hold it against the child. A guiding principle for research with children is that the research will not expose children to more than minimal risks without the potential for direct benefits for them. The risks associated with this study were decreed to be no more than minimal risk that the children would experience in their daily lives. I received ethical approval from the Behavioural Ethics Review Board at the University of British Columbia (Appendix A) and the Education/Nursing Research Ethics Board at the University of Manitoba (Appendix B). In addition to ethical approval from the University of British Columbia and the University of Manitoba, I received administrative approval from all sites, such as the local Regional Health Authority, which were contacted to aid in sample recruitment.

Consent and Assent

In initial discussions with the parents, I explained the study, the parental information sheet (Appendix C), and consent form (Appendix D), and answered parents' questions. Parents also reviewed children's information forms (Appendix E; Appendix F) and the interview questions (Appendix G; Appendix H) prior to consenting. With the children, I followed the same procedure as I used with the parent for the child, however, I used the child's assent form

(Appendix I; Appendix J). Assent forms are commonly used for children who are unable to independently provide agreement for participation in research studies. I developed two distinct information sheets and assent forms to facilitate age appropriate understanding of the study and to acknowledge the children's rights (Appendix E; Appendix I; School Age Children) (Appendix F; Appendix J; Adolescent Children). I designed the forms to communicate clearly about the study so that children could provide free and informed assent.

Each child received an assent form (Appendix I; Appendix J) and an information sheet specific to their developmental stage (Appendix E; Appendix F). Each child had the opportunity to either read or have both the assent form and description of the study read and explained. They were encouraged to ask questions, which I attempted to answer clearly. Children were also informed that they were under no obligation to answer all questions during the interview. They were told that they could decline to answer specific questions, if they chose, and withdraw at any time, and that their decision to do so would not prevent them from receiving the movie passes that were given to all children as a token of appreciation and respect for participating in the study. Each child signed the assent form. The parent also signed the assent form and a parental consent. When some children refused to answer specific questions that arose in the interview, I respected their decisions. None of the children withdrew from the study.

During the signing of the forms, I assessed the children's understanding of the process. At times, I used a "nurse puppet" to discuss the issues of confidentiality and research with young children. This strategy was used to decrease any anxiety the child might feel with unfamiliar words such as research and confidentiality. This strategy was also used to build rapport, to facilitate explanations, and to create an atmosphere wherein the child could feel comfortable asking questions. This was generally effective with the younger children. Although challenging to ensure that children understood the concepts of confidentiality, research, and the implications

of reporting abuse, I tried to explain the concepts fully in a manner that did not intimidate or frighten the child.

Some parents wanted to take time to think about the study before approaching their children. In those cases, I discussed the study with the parent on the first visit and obtained assent from the child at a later date. I set guidelines for children's recruitment. If the parent wanted the child to participate but the child declined, I intended to honour the child's wishes. Also, in the event where children were living with two parents and only one of the parents agreed to the study, my intent was not to accept children to the study. I hoped to prevent future disharmony in the home, which could be detrimental to the children in conditions where parents were divided. Neither of these circumstances occurred.

Because of the inherent power imbalances between children and adults, I was sensitive to any potential coercion related to children's assent to participate in the study. Cooke (1994) argued that children's perspectives should take precedence over those of the adults in their lives because it cannot always be assumed that parents/legal guardian's act in the best interests of their children. Generally, the parents with the mental illnesses first informed the children about the study and then asked them if they would like to participate. Some children chose not to participate. In some families where there was more than one child, some children participated and some did not. When a child refused, I upheld the child's decision and, with the parents, emphasized the importance of free choice in the process of informed assent. I explained to parents the importance of allowing the child to choose freely to participate or not to participate, and explained the process of free assent and its contribution to the ethical conduct of research.

I also discussed the potential of power differences between adults and children to place children at risk for undue influence during the process of assent. Because the trust that a child placed in the parent/legal guardian might outweigh the child's thinking about the pros and cons of participation (Medical Research Council of Canada, 1998), I emphasized the importance of

respecting the child's decision. Offering maximum choice to the child firstly was respectful of the child as a person; secondly it had the potential to build the child's self esteem and, possibly, assist the child to exercise control over his/her environment (Weithorn & Scherer, 1994).

I had limited control over situations where the parents may have influenced the children's decision to participate. I asked the children if they were aware that they had a choice to participate in the study, that they could refuse to answer questions, and that they could withdraw at any time. In these cases, children stated that they wanted to remain in the study. All children were unknown to me prior to the study and I had no power over the lives of the children or the parents. Thus I took every precaution to ensure the child was not unduly influenced by the parent/legal guardian, initial agency contact, or by me.

If a child or a parent did not want to continue with the study after agreeing to participate, I would respect the child's and the parent's wishes. In the cases where first interviews had been conducted, I would ask the parent and the child, if the data could be used in the study. If parent and child agreed, the data would be used. My guidelines were that, if children did not want the data used, their wishes would be respected even if the parents consented to include the data. None of these events occurred in the study.

The participant observation guide (Appendix K) was explained and given to both the child and the parent prior to consenting to be in the study. A participant observation consent form (Appendix L) was signed by the consenting parent. In the event that other family members were involved, I also had a family members' consent for participant observation (Appendix M). Participant observation notes are discussed in detail within the data collection section.

Confidentiality

Parents were informed that study findings shared with them would not be those specific to their children; rather, they would represent the aggregate findings. Children and parents were informed frankly about the limits of confidentiality for the study, specifically situations, such as

abuse, which I was legally required to report. The parent and the child were informed that I was under an obligation to report any risks; i.e. that the child was at risk for harming him/herself, for harming others, or presently living in an abusive (physical, emotional, or sexual) situation. The possibility existed that, during an interview, the child could reveal information that might require me to report to child protection agencies or to refer the child and family to outside resources.

During the research study, all data collected were stored in a locked cabinet. Only I knew the names of participants. Identifying names did not appear on any of the tapes, transcribed interviews, memos, or participant observation notes. The transcriptionist signed a waiver of confidentiality (Appendix N) and did not know the full names of the participants. The transcriptionist transcribed only the audio taped interviews and not the participant observation notes, thereby, ensuring further confidentiality of the participants.

Potential Crisis Situations

The study design included potential responses to crisis situations. If children became emotionally distressed, I provided solace and assessed to the best of my ability whether the child was able to continue, without undue risk. In the event that I believed the child was incurring risk by continuing and/or the child did not wish to continue, the interview was halted. Upon request, I was prepared to provide the parent/legal guardian with a list of resources for children and families. None of the families wanted the resource list. I was prepared to exclude children from the study, if I had any concerns regarding the competency of their parents who were providing consent for their children to participate. I was sensitive to possible situations, such as, psychiatric decompensation in the parents with the mental illnesses who were providing consent, and children's behaviours of self harm and/or harm to others. These situations did not occur. My clinical experience in the mental health field and my management experience in an emergency psychiatric service program were beneficial in assessing crisis situations and in treating parents with sensitivity and respect. These skills enabled me to identify potentially

harmful or deteriorating situations in the community and to identify community mental health services for children and adults.

Research Procedures

I describe research procedures under the following headings: recruitment of sample, data collection, and data analysis. Grounded theory strategies, which were intrinsic to particular aspects of the research procedures, will be discussed within the appropriate sections.

Recruitment of Sample

I began with some purposeful sampling in order to access participants who could speak about the experience of growing up with a parent who has a mental illness (Strauss & Corbin, 1990; Glaser, 1992). Children who were being cared for by a parent with a mental illness and residing in the community were sampled. In grounded theory, once initial codes and categories are developed, the selection of participants is driven by theoretical sampling, which produces incidents that can develop the categories and their properties. Theoretical sampling will be further discussed under the topic of data analysis.

I conducted the study in a mid-sized prairie city. Several avenues were used to access my study participants. I made initial contacts with Community Mental Health Workers, nurses who practiced in psychiatry within local hospitals, and consumer support groups such as the Canadian Mental Health Association, Schizophrenia Society and Affective Mood Disorders Association. Furthermore, I distributed posters advertising the study (Appendix O) to a wide range of community and hospital settings and I placed an advertisement in a community newspaper with a distribution of 11,000 households. Word of mouth and newsletter advertising, such as in local hospital newsletters, supplemented these efforts. I designed a formal letter to introduce the study (Appendix P) and distributed it to all directors of potential sites. I went to community and tertiary care sites to explain the study to the agency administrative personnel. I presented the study to diverse acute and community health care providers and consumer group associations.

I designed the study so that the initial point of contact would be a health care professional. This professional would give an interested parent my telephone number, or if the parent consented, would give me the parent's telephone number. Most agencies preferred to have the parent initiate the contact. I left an information sheet with the health care providers (Appendix Q), which provided a telephone number where parents could leave a confidential telephone message and a contact number. Because the ill parents were concerned about how their mental illnesses were affecting their children, they initiated the contact the majority of the time. Parents contacted me directly by telephone.

After telephone contact, I met with the parent to obtain informed consent and assent and to set up an interview with the child. I obtained informed consent by providing and explaining the information sheet on the study (Appendix C), giving parents an opportunity to ask questions and read the research questions (Appendix G; Appendix H), and then obtaining written consent (Appendix D) to allow the child to participate in the study. Alternatively, upon request of the parent, the study forms (inclusive of specific forms for the children and the research questions) were mailed to the parent, who then had ample opportunity to read them prior to meeting with the researcher. If the forms were mailed to the parents, I contacted the parent via telephone within 7 days and clarified any of their questions. If the parent was agreeable, I went to the family home to further discuss the study, to obtain parental consent, and to meet the child.

Data Collection Procedures

Data was gathered through two primary procedures: interviews and participant observation. This section will discuss the specificities of data collection strategies used in the context of the interviews, including participant observation. Data were collected concurrently with data analysis. Short demographic data forms were used, one with the parent (Appendix R) and one with the child (Appendix S). Interviews were conducted using the strategies of open-ended and direct questions, as well as responding to children's cues. Participant observation

notes and field notes were written for each child who was interviewed. In this study, 22 children were interviewed once, with ten of the children being interviewed for a second time. The ten children interviewed on the second occasion were selected on the basis of theoretical sampling.

Data Collection Tools

After the children granted assent, the two short demographic data collection forms designed to describe the sample were completed, one by the parent (Appendix R), and the other by the child, (Appendix S). Data were collected about family configuration, socioeconomic status, and age of onset of illness for both parent and child, why children wanted to participate in the study, and school grade of child.

Conducting the interviews. Following assent, I interviewed the children in a mutually agreed upon location. The majority of the interviews took place in the children's homes, with three occurring in other locations. Young children were given the choice of having their parent nearby during the interview. In scheduling, I made myself available to meet young children prior to the interview if that was their preference. Most of the children were comfortable in discussing the topic with me, without the parent being present. One young child (6 years old), whose parent had recently returned from the hospital, requested that the parent be present. Another young child (7 years old) began with the parent in the room but carried on alone once he became comfortable with me. I generally took some small treat (i.e. cookies, holiday treats) for the children at the initial meeting. Those strategies helped to break the ice between the child and me. I also used casual conversation with children for considerable periods before interviews.

The expected interview time was ½ hour to one hour, with some flexibility anticipated with each child. All interviews were audio taped. Once the interview was complete, I listened to the tape within 24 hours and made notes and initial memos for each interview. Initially, I assumed that one interview would likely be sufficient for the majority of the participants; however, within the parameters of grounded theory, I remained flexible in following up the

emerging categories. Second interviews took place after a period of several months and up to one year after the first interview. This was because of difficulty in arranging secondary visits, at times due to relocation, overwhelming circumstances in the family home, and busy schedules of some households.

I used a semi-structured interview format to allow flexibility in the research interview. Flexibility is of particular importance when interviewing young children who may have limited attention spans. Combined with a non-directive approach, flexibility optimizes the gathering of both facts and emotional information (Faux, Walsh & Deatrick, 1988; Gubrium & Holstein, 1997). Furthermore, in all research with children it is important to keep the research child-focused (France, Bendelow & Williams, 2000). Semi-structured interviews encourage description of the participant's experience and allow for clarification and elaboration of answers (Faux et al.; Oakley, 2000). Children were given time to respond to the questions and questions were reworded if the child appeared not to understand. Interview questions were designed in consultation with dissertation committee members, one of whom had clinical expertise with children. The questions elicited information about the meanings children assigned to their everyday reality. The interview guides were designed to access the complexity of their experience. All families and children had the opportunity to read the interview questions prior to the interview.

Open-ended questions. The interview questions were open-ended, because children were encouraged to discuss their ideas freely with prompts from the researcher. Using open-ended questions enabled the children to respond in a variety of ways. The combination of open-ended questions and active listening assisted me to encourage each child to speak freely. I adjusted questions to each child's level of comprehension and comfort. Two developmentally appropriate interview formats were used as guides for discussion (Appendix G; Appendix H). Standard communication techniques such as broad questions, unconditional positive regard, and respect

towards the participant were used to avoid leading questions, to elicit genuine responses, and to build rapport (Fertig-McDonald, 2000).

Direct questions. I used direct questions to elicit answers which helped children elaborate on their ideas and tell their stories. Direct questioning allowed me to clarify any points about which I was not sure. Communication strategies, such as silence, paraphrasing, gentle probes and empathy, facilitated communication throughout the research interview. Initial questions were modified during the course of the interviews to incorporate questions about categories that had emerged from concurrent data analysis (Appendix T).

Children's cues. Throughout the interview process, I paid attention to children's verbal and non-verbal cues. For example, if children did not want to answer a question, appeared uncomfortable, or overwhelmed, I was gentle and sensitive to their discomfort. In these situations, I moved to a different area of questioning, which was less distressing for the children. At times I returned to the questions if the child appeared more comfortable later in the interview. All three strategies, open ended questions, direct questions and attentiveness to children's cues were effective for eliciting information from children during the data collection.

Communication Strategies Using Art, Play and Story

To offset inherent tensions between children and adults, the researcher must be prepared to offer communication strategies that will bridge the gap between adult and child (France et al. 2000). With young children, strategies of drawing, story and play have been effective to assist them to describe their experiences (Faux et al. 1988; Graue & Walsh, 1998). I offered children the opportunity to draw a picture in answer to a question or to draw what they saw as an important part of what they had discussed. Offering children of all ages the opportunity to draw, gave the children another means of communicating their thoughts and feelings (Steele, 1998). It has also been helpful to have children explain their drawings so adults can understand the children's perceptions (Malchiodi, 1998). Some children were very interested in drawing their

ideas and appeared to enjoy this means of communication. Others declined to draw. During the course of the interviews, eleven drawings were created.

Although artwork with children has been associated with therapeutic intervention and analysis of children's problems, I used artwork only as a vehicle for discussion, not for the purpose of therapeutic analysis with the child (Schoen Johnson, 1995; Steele, 1998). The artwork made the child's perceptions clearer to me and, as such, the art was incorporated into the development of categories and properties. The "draw and write" technique of gathering data has been recognized as a powerful tool in research involving both younger and older children (France et al., 2000). In this technique children are asked to draw their responses and then write a brief explanation under the drawings (France et al.). I found that the children in my study preferred only drawing. Children were then asked to talk about what they had drawn and their responses were incorporated into the data.

Story and play were also used to enhance rapport and communication. I used puppets to engage younger children in the interview process, to maintain their attention, to pose hypothetical questions, to help them tell their stories, and, at times, to offer respite within the context of the interview. Vignettes (Appendix U) and stories were also used. Vignettes, a form of story, have been successfully used with children to explore their beliefs and perceptions and to facilitate interview participation (France et al., 2000). On occasion, a short vignette depicting the mental illness of a parent in a family situation was used to enhance communication. At the end of the interview some children were shown storybooks and workbooks that were designed to discuss mental illness with children (Brindamour, 2000; Fran, 1994; Kelbaugh, 2002). Hearing the vignettes and examining the books facilitated further discussion of the children's experiences. Generally, children enjoyed the techniques of story, art, and puppets. These techniques not only facilitated discussion with the children, but also developed rapport with them

and introduced an element of fun, which the children highly valued. These strategies assisted me to decrease any anxiety the child may have felt during the interview process.

The tools helped the children to describe their experiences. For example, when children were initially shown the book *Can I Catch it Like a Cold?* (Kelbaugh, 2002), several noted the dissimilarity between their parent and the parent portrayed in the book. In this book where there was a picture of a sad and dejected father depicting depression, some children noted that was not what their parents looked like when depressed and, instead, they described examples of irritability and anger in the parents.

Participant Observation Notes

Participant observation notes were written pre and post-interview. In this study, participant observation notes included physical appearance, behaviour, and mannerisms, affect, speech patterns, and the child's way of being with the researcher, i.e. does the child relate in a cooperative or suspicious manner, portray confidence or appear ill at ease? (Appendix K). Participant observation notes also described interactions between family members that were observed before and after the interviews. I spent approximately 60 hours doing participant observation in the participants' homes. I described details of the home environment, the family members present in the household, the location where the interview was conducted, and the community environment. Notes were hand written immediately after the interviews.

Field Notes

Field notes have been used to describe the circumstances around events and may be focused to specific issues or take account of a wide range of circumstances (Perakyla, 1998). I used field notes to depict events during the interview and during the telephone conversations with parents to add detail to my impressions about the interviews. Field notes served the purpose of raising my awareness of surrounding detail, thereby facilitating the incorporation of the children's contexts into the data base (Glaser, 1998). I spent 30 hours on the telephone with

parents and caregivers. Descriptive and reflective notes were written after all telephone conversations with the parent. Often the initial telephone conversations elicited important details about the context of the child's life and the parent's illness experience. Notes were handwritten immediately after the telephone interviews.

Data Analysis

The data were analysed using the constant comparative method. Techniques associated with constant comparative analysis include open, selective and theoretical coding, theoretical sensitivity, intense memoing, and theoretical sampling.

Constant Comparative Method of Analysis

The constant comparative method of analysis is designed to aid the researcher to produce an integrated, plausible, elegant substantive theory (Glaser & Strauss, 1967). The purpose of the constant comparative method is to generate theory systematically. It includes concurrent analysis and data collection. The basic defining rule for constant comparative analysis is "while coding an incident for a category, compare it with the previous incidents in the same and different groups coded in the same category" (Glaser & Strauss, 1967, p. 106). The coded data are constantly categorised, collapsed and examined for the purpose of data saturation. When data saturation is reached, no new data alter the conceptual properties of the developed categories or their relationships. Saturation signifies the end of data collection (Glaser & Strauss; Glaser, 1998). Glaser and Strauss described four stages in the constant comparative method; comparing incidents, integrating categories and their properties, delimiting the theory, and writing the theory. Open, selective, and theoretical coding is supported with intense memoing during data analysis. The following discussion describes how I used the four stages of developing a substantive theory, the levels of coding, and theoretical sensitivity.

The Four Stages of Grounded Theory and Related Levels of Coding

The four stages of grounded theory are: comparing incidents to categories, integrating

categories and their properties, delimiting the data, and writing the theory. These stages were incorporated into the coding and analysis. I used the final stage of writing to further develop theoretical relationships between the categories. Three questions, which guided the coding and analysis, were constantly asked of the interviews and the participant observation notes:

1. What are the data a study of?
2. What category does this incident indicate?
3. What is actually happening in the data? (Glaser, 1978).

I used these questions in a systematic manner, to help me to construct the initial categories and to identify underlying relationship patterns in the data. An example of how these questions were used follows. One child described her parent as unique and indicated that mental illness was not all bad. In this example, the three questions lead me to conceptualise that the child's perceptions included aspects of the parent as positive and not viewing the mental illness of the parent as an overwhelming negative experience. As part of a beginning category, the reciprocal nature of the parent/child relationship I noted that children might not regard mental illness as the predominant meaning they associated with their parent. These ideas further informed the category of connectedness in the basic social psychological process (BSPP) of "finding the rhythm". A BSPP is a type of core category that accounts for most of the variation in a pattern of behaviour, and has two or more distinct stages; i.e. monitoring and adjusting (Glaser, 1978). Throughout this process, I was theoretically sensitive. A discussion of theoretical sensitivity follows.

Theoretical Sensitivity

My theoretical sensitivity affected every stage of constant comparative analysis and coding. According to Glaser (1992) theoretical sensitivity refers to "the researcher's knowledge, understanding and skill, which foster his generation of categories and properties and increase his ability to relate them into hypotheses, and to integrate the hypotheses according to emergent

theoretical codes” (1992, p. 27). Although I began the research process with as few predetermined ideas as possible, which was recommended by Glaser, (1978) my experience with the population being studied and familiarity with the literature increased my theoretical sensitivity.

Specifically, my experience in emergency, acute, and community psychiatric/mental health nursing provided me with an extensive knowledge base about mental illness and the mental health system. For example, my experiences in psychiatry sensitized me to children who did not see vulnerability in parents who presented with behaviours of mania. I understood the nature of manic behaviours and accepted that children did not always view their parents as fragile or vulnerable. Professional experience, personal experience, and in-depth knowledge in the area under study increase the researcher’s sensitivity to generate categories and properties (Glaser, 1992). My training in the grounded theory method also contributed to my theoretical sensitivity in the process of data collection and analysis.

Theoretical sampling, wherein the properties of concepts or categories may determine the nature of the sample or the incidents that are sampled, arose from my theoretical sensitivity. After interviewing siblings whose parent had mental illness, their descriptions of their mutual support and my knowledge of the potentially alienating effects of mental illness, made me theoretically sensitive to the difficulties of only children living with a parent with a mental illness and I tried to include these children in my sample.

Coding: Open, Selective and Theoretical

Coding is the process whereby the data is conceptualised. In coding, the researcher constantly compares incidents from the data. As this process continues, categories are developed. Incidents are then also compared to the developing categories. This process leads to the development of more categories and their properties and, eventually, to the saturation of categories (Glaser, 1992; 1998). The levels of coding are: open, selective, and theoretical.

These levels are developed in the process of constant comparative analysis, whereby the analyst codes incidents in terms of categories, properties and theoretical connections (Glaser, 1992). Open coding and selective coding produce substantive codes; open coding serves as the initial level of coding and proceeds to the next level of coding, selective coding. Substantive codes conceptualise the empirical substance of the area of research (Glaser, 1978). Theoretical coding explains how substantive codes relate to each other and the core category. Theoretical codes account for how participants resolve their main concerns. Theoretical codes integrate the theory (Glaser, 1978; 1998).

Open Coding

In open coding, the analyst starts with no preconceived ideas but remains entirely open to what is in the data (Glaser, 1992). I began with line-by-line open coding, with notations on the margin. I selected *in vivo* codes, such as having a routine and valuing a parent, which captured the meaning of the incidents. I then used the *in vivo* codes to raise the empirical data to a conceptual level by naming similar incidents as categories and dissimilar incidents as properties of categories. Glaser (1978) has described *in vivo* codes as “behaviours or processes, which explain how the basic problem is resolved” (p. 70).

Open coding, using the three identified questions, assisted me to focus on patterns in the data and to move to a clustering of incidents defined by codes. Data were integrated using written memos and participant observation notes, and by comparing incidents within and between interviews. In open coding, a considerable number of incidents were clustered in “give and take”, an *in vivo* code. Give and take represented emerging reciprocal interactions between the parents and the children. During this time, codes about what parents did for their children, and which actions children valued, emerged strongly. One of the categories that emerged with early open coding was what I initially thought of as altruism, developed from the “*in vivo*” codes of helping others and wanting to help, wherein children appeared to make sacrifices for the

parent. This category was not sustained by additional data and comparisons. The data did not bear out its relevance or fit. The ideas behind what I called “altruism” in the early stages of coding, I clustered more effectively within the concept of “reciprocity”. Reciprocity arose from further open coding, comparison of incidents, and clustering of the *in vivo* codes represented. I achieved these changes by integration, the process of constant comparison of incidents leading to comparison of incidents to emergent properties (Glaser & Strauss, 1967).

Sometimes incidents seemed to illustrate more than one emerging category. For example, at times children’s behaviour appeared to be both altruistic in regards to what they did to help their parent and how they made allowances for them and also it appeared to meet children’s needs. Sometimes it appeared that the children had their own needs met by behaviour that may initially have looked like altruistic behaviour. In later analysis, I decided that the children’s behaviour fit more appropriately within the category of “adjusting”. Memoing was helpful to clarify my thinking about properties of categories and comparison of incidents to codes. Coding was always interrupted to memo in order to capture memo ideas before they were lost.

The notions of “reciprocity” led to ideas around boundaries between the parent and the child and questions of why and when children felt the need to reciprocate in their parent/child relationships. This also led to questions such as to what did children attribute their parents’ behaviour? The open coding and resultant questioning of the data, contributed to the development of the BSPPs, of “finding the rhythm” and “maintaining the frame”. The categories subsumed by “finding the rhythm” and “maintaining the frame” were suggested in the open coding of the data, originally coded as “trying harder”, “give and take” and later refined to “reciprocity”. As Glaser (1998) noted, correctly naming a category can be quick or time consuming. Constant comparisons of categories and their properties and recognition of patterns helped me to develop more fitting and workable names for emerging categories and to take them to a higher level of abstraction.

Throughout the process of constant comparative analysis, I followed the emerging categories in the data and asked questions about “reciprocity” and interaction between the parent and the child. When further refining the coding for “reciprocity”, I discovered that “reciprocity”, indicating equal input and output of energy within the relationship, was not supported by the data. Rather, “give and take” was affected by the mental illness, which caused shifts in the dynamics of the parent/child relationship and levels of intensity acceptable in the relationship, wherein children assumed more responsibility in the relationship with the parents. The BSPPs, “finding the rhythm” and “maintaining the frame”, were developed and fit the children’s perceptions of their experiences.

Open coding from the early interviews also raised questions about how children assigned “blame” for the cause of the mental illness, how children got “off the hook” regarding blame, and how children made meaning of their parents’ discharge experiences. Weight given to the category of blame was not supported in the ensuing analysis and the category of “blame” was collapsed into the category of “emotional currents”. Open coding revealed many “*in vivo*” codes about positive family differences. This was an important emergent concept, which supported the connection between positive experiences that children had in their families, and the importance of recapturing rhythms in their relationships with their parents and maintaining a safe frame. The development of these categories aided in the development of the category of “gauging” in which children evaluated their costs and benefits of maintaining their frames.

Properties of categories consisted of either properties that I named, or properties that were constructed from the language of the research participants. Generally, categories that the researcher constructs offer explanations for the categories that are taken from the language of the study. For example, my dissertation supervisor, Dr. Wendy Hall, and I constructed the category “emotional currents” after many comparisons and detailed memoing. The category of “trying to preserve myself” was developed from, the words of the children (dealing with it) but more aptly

captured the process children were describing as part of their efforts to “maintain the frame” with their parents safely. While clarifying the properties of the category of “trying to preserve myself”, ideas around the importance of friends were absorbed into the properties of “living my life”, “selective sharing” and “putting it aside”. Therefore, some of the open codes for categories did not develop into densely saturated categories. Instead, these codes were eliminated or became properties of a larger emerging category that more completely explained the processes children were using to manage their situations.

As the theory developed, the process of delimiting assisted me to reduce the data. Delimiting occurs in two ways; firstly, the theory solidifies as the researcher recognises underlying commonalities in terms of categories that may be collapsed or perhaps eliminated where the data is too thin. Through this process, the researcher formulates the theory with fewer high level categories (Glaser & Strauss, 1967). For example, in the early analysis assigning “blame to self”, “moving”, “importance of friends”, and “school as stressor and as solace” all seemed to be key concepts that were central to the process whereby children managed living with a parent with a mental illness. With ongoing data analysis and comparison of the data, these ideas became absorbed into more broad conceptual categories, i.e. “trying to preserve myself” and “emotional currents”, or were eliminated because the data was too thin. Concurrently, there was a reduction of theoretical language, i.e. categories were collapsed and became fewer reducing the language needed to describe the process.

During the continuing analysis, “finding the rhythm” and “maintaining the frame”, emerged as the fundamental processes by which children managed their circumstances. To determine if a category is a core variable, it must be central, reoccur frequently, have grab, be clear, relate meaningfully to other categories, and have considerable explanatory power (Glaser, 1978). BSPPs differ from a core variable in that they have two or more emergent stages that describe a process occurring in the data (Glaser, 1978). Not all core categories are BSPPs. The

discovery of a core category or a BSPP assists the integration (to be discussed later in this chapter) of the theory, so that it is dense and saturated or accounts for most of the variation in a pattern of behaviour. In accordance with Glaser's (1978) suggestion, once open coding ceases, all of the categories and their properties should be developed as fully as possible, and the BSPP constructed. Selective coding follows open coding.

Selective Coding

According to Glaser (1992) selective coding begins when open coding ceases and the core category has emerged. At that time, the data is delimited in order to selectively code for variables that relate to the core variable or BSPP (Glaser, 1992). The analysis becomes guided by the core variable/BSPP (Glaser, 1978). In accordance with Glaser, I coded the data to develop categories that supported the core variable (an emergent variable that is frequently noted and can offer rich explanation). In my study, there were two BSPPs (core variables with a minimum of two distinct stages, (Glaser, 1978)); "finding the rhythm" with the stages of "monitoring and adjusting" and "maintaining the frame" with the stages of "trying to preserve myself" and "gauging". The two core variables enhanced theoretical saturation, wherein new data no longer emerged within select categories, by focusing on data that related to the core BSPPs (Glaser). Selective coding occurred along with the ongoing process of comparing incidents. An example of selective coding and comparing incidents is illustrated below.

In my early thinking, the category of "adjusting" potentially fit in the developing categories of "honouring parents", "getting along with parents", "pulling away and coming together". These categories were not substantiated in the data throughout the ongoing analysis and were collapsed in higher conceptualizations wherein the "*in vivo*" codes became denser. I noted children made adjustments in their own behaviour to deescalate situations by attempting to become closer to the parent, i.e. offering comfort and caring, or distancing themselves, i.e. removing themselves physically or choosing not to respond. These observations suggested that

the category of “respecting fragility” with two distinct properties; “awareness of the behaviour” and action “related to the behaviour” was an acknowledgment of vulnerability. However, the category of “vulnerability” did not fit well with “finding the rhythm” and “maintaining the frame” and the notions of noticing behaviour and acting in response became stages in the process of finding the rhythm.

Incidents from these categories of awareness of behaviour and action related to the behaviour were compared to other incidents in the data. Later with integration, further comparisons, and selective coding, two new categories emerged: “monitoring and adjusting”. Those categories better captured the interaction between the parental behaviour and the children’s behaviour and fit with the BSPP of “finding the rhythm”. Once the BSPPs (“finding the rhythm” and “maintaining the frame”) were identified, the above description was an example of how I delimited the data to selectively code for the variables that related to the BSPP of “finding the rhythm”.

Delimiting reduces (by focusing attention only on data that fits with the identified BSPP) the theory and the categories, and thus helps to clarify logic, and to recognize both similarities and non-relevant properties in the data (Glaser & Strauss, 1967). I have described delimiting at the level of categories and their properties, but delimiting also occurs within logical links between the theoretical categories (Glaser & Strauss, 1967). By delimiting, I was able to link “monitoring”, “adjusting” and outcomes to “finding the rhythm”

In my efforts to conceptualise the data, I discussed categories and theoretical relationships with Dr. Wendy Hall, my dissertation supervisor who challenged my thinking and moved the conceptualization of the data to higher levels. Within this process of constant comparative analysis, conceptual diagrams were used to develop clear linkages among the categories. These diagrams were reworked as the data analysis proceeded. Diagrammatically conceptualizing the theory was helpful to refine the theory, to recognize the gaps and to develop relationships among

the categories and the BSPPs (Figures 5.1, 5.2, 5.3). This occurred after memos were beginning to be sorted and after theory had been delimited in order to allow the emergence rather than forcing of the data.

It has been suggested by the originators of grounded theory that when data are collected by theoretical sampling and concurrently analysed, data integration will emerge naturally (Glaser & Strauss, 1967). I found that data integration was developed through extensive coding and considerable reading and rereading of the interviews, the participant observation notes, and the memos. The theory did not emerge, I constructed the theory.

Theoretical Coding

Theoretical coding explains how substantive codes (codes that conceptualise the empirical substance of the area) relate to each other as hypotheses (Glaser, 1978). I developed the conceptual relationships between categories and their properties, using theoretical codes that enabled me to maintain a conceptual level and not to become bogged down in the data (Glaser 1978). Theoretical codes become conceptual connectors, meaning that these codes relate to other codes and help the researcher to form hypotheses which are integrated with the theory (Glaser, 1992). For example, the category of “emotional currents” emerged as a theoretical code as it was always present and foundational to the theory. The category of “emotional currents” explained the relationship of categories such as “trying to preserving myself” and “monitoring and adjusting” to the BSPPs of “finding the rhythm” and “maintaining the frame”.

Once the BSPPs, “finding the rhythm” and “maintaining the frame”, were developed, other components of the theory were clearly connected to the BSPPs. “Finding the rhythm” and “maintaining the frame” subsumed the categories of “monitoring and adjusting”, “trying to preserve myself” and “gauging” in addition to their goals, and demonstrated how they related to each other. Theoretical coding was helpful to further delimit the theory and clarify the categories that enhanced the development of the theory.

Using theoretical coding allows different categories to become integrated with other categories and pushes the researcher to understand the theoretical relationships (Glaser & Strauss, 1967). For example, in the category of “emotional currents”, children identified positive emotions related to their parents and their parents’ contribution to their lives. When developing the category of “gauging”, wherein children gauged their efforts to preserve themselves as leading to more costs or benefits, I noticed that children, who had dominating positive emotions regarding their relationships with their parents, gauged their efforts to preserve themselves more favourably. The children, who had higher levels of negative emotions with fewer feelings of love and connection to their parents, gauged their efforts to preserve themselves less favourably. This is an example of how different categories, such as gauging and “trying to preserve myself”, were integrated by the category “emotional currents” and related to “finding the rhythm”. From my integration of “emotional currents”, questions arose which extended the theory. For example, what makes it difficult for children to feel positive emotion toward their parents, what factors do children use to gauge their experiences to conclude if they are effectively managing to preserve themselves, why do children have differing emotional reactions? At such times, memoing, continued comparison of incidents to codes, and “one-upping” with my supervisor clarified my thinking on properties of the categories. As defined by Glaser (1978), “*one-upping*” is a “collaborative theoretical effort to raise the data as quickly as possible while carefully fracturing it” (p. 59).

To assist in theoretical coding, Glaser (1978) proposed 18 coding families, a discussion of which is beyond the scope of this study. Glaser offered these coding families to help the researcher develop sensitivity to the important data. The coding families, known as the “Six C’s” (cause, context, contingencies, consequences, covariance, and conditions) are the most general codes to keep in mind when coding and act to help the researcher conceptualise the data (Glaser). In the context of my analysis, I will describe some of the coding families that I used.

In analyzing the data, I used aspects of the coding families, such as, cutting points, strategies and processes (Glaser). In the cutting point family, i.e. to what extent significant breaks are noted that may help develop the theory, Glaser suggests codes such as boundary, critical juncture and turning point. Those codes help to generate theory as they indicated where differences occurred. Cutting points were used to determine points wherein children felt less connected with their parent and lost affection for them. For example, one child who was overtly hostile to his parent helped to determine a cutting point in the parent/child relationship. I asked the question, what was it in his situation that caused disconnection between himself and his parent that set him apart? The cutting point was around his parent's behaviours that both exacerbated the mental illness and betrayed standards the child believed his parent had set for him. This helped me to break with the idea that children always maintained an underlying positive loving connection to the parent. Furthermore, I used the cultural family i.e. the social norms, values, and beliefs (Glaser), which got at the stigma of mental illness, to identify "fitting in" as the social structural condition that influenced children's situations.

I modified my initial category to, "trying to preserve myself", which was the first stage of "maintaining the frame", through the theoretical coding process. The original category of "dealing with it" did not incorporate children whose goals were not achieved. Part of maintaining a safe frame with parents was refined to "trying to preserve myself". Thus, the negative cases pushed me to ask different questions of the data. For example, why is this child having more difficulty with "maintaining the frame" as compared to other children; why is this child dealing with the experience less successfully than other children; what factors make it more likely children will be less able to deal with the experience? When some of the children's goals were compromised in trying to "maintain the frame", the children were more likely to feel disconnected and disengaged from their parents.

Data codes that were originally related to the school experience, e.g. “school as a stressor or place of solace”, were later conceptualised as strategies that children used to manage their experiences and related to each other either by the category of “trying to preserve myself”, or incorporated into the social structural condition of “fitting in”. Some codes were moved among categories if they no longer seemed to fit in their current categories (Glaser & Strauss, 1967). Properties were shifted and collapsed to more accurately explain the process children used to manage their circumstances. “Considering”, originally depicted as a property of “adjusting”, was shifted to “monitoring” to more fully explain how children monitored.

In considering alternative hypotheses, negative cases were used to examine difference and to refine hypotheses about relationships (Glaser, 1978). Negative cases caused me to ask further questions of the data. For example, in a family of four, the one child who did not have a positive connection to the parent and whose relationship to his parent was bordering on hostility, lead me to question how relationships between “finding the rhythm” and “maintaining the frame” differed for him. One of the key factors, in a cluster of other factors, was his lack of understanding about the mental illness. I compared incidents where children had adequate knowledge of the mental illness to situations where children indicated they did not have adequate knowledge and the effects of their perceptions. Furthermore, I considered the influence of gender and age in the situations where children were less positively connected to their parent. Older boys seemed to express the most difficulty.

My ability to conceptualise was developed by ongoing discussion and intermittent on site visits with Dr. Wendy Hall, my supervisor, who has an in-depth knowledge of the grounded theory method. Within these discussions, the process of “*one-upping*” developed my conceptual thinking about the emergent theory. This process of intellectual challenge between colleagues, whereby one colleague posits a different perspective on the emerging categories and their

relevance to each other, moves the conceptualization process along if conducted in a respectful manner (Glaser, 1978).

The final stage of constant comparative analysis is the writing of the theory. Glaser (1992) claims that the writing is an important phase of the analysis where categories and their relationships are further refined. During the writing, my supervisor and I refined the language used to describe the categories and their properties by ongoing dialogue and on site visits. Also we continued to refine the relationship between the categories and their properties.

Data Saturation

Data saturation occurs when no new data emerges which would further develop the categories (Glaser & Strauss, 1967). I saw repeated similar incidents, such as, when children concluded that there was nothing to be done about mental illness. I also noted negative cases that challenged the categories, properties of categories, and relationships among categories that had been developed from the data. Those elements and the necessity to account for them in the theory contributed to saturation because negative cases were taken into account by the hypotheses (Glaser & Strauss). For example, when children who stated that there was nothing to be done when their parents were ill, the data suggested that once children began to believe this, they experienced different emotional reactions; acceptance of their circumstances, or increased disappointment with their families. If data saturation is not achieved in the ongoing coding, the researcher must return to the existing data to see if something has been missed in the analysis or collect more data (Glaser & Strauss). Data saturation was quickly achieved in properties of “trying to preserve myself” and “monitoring and adjusting”. Other categories, such as “gauging” and its properties, were developed more slowly and consequently data saturation was slower.

Theoretical Sampling

Following the grounded theory method, a theoretical sampling strategy was used. Theoretical sampling is driven by theoretical purpose and relevance and, as such, guides data

collection. Emerging categories and their properties directed me to sample specific incidents to further the development of the categories. I used the incidents to create an abstract hypotheses closely connected to the emergent data (Glaser, 1978). Theoretical sampling filled out the categories which were then compared to each other and integrated into a theoretical framework (Glaser 1978).

Theoretical sampling also helped to explore the relationships among categories. For example, children who had recent experience with the hospitalization of a parent were re-interviewed in an attempt to sample specific incidents about hospitalization. The experience of hospitalization of a parent was more distressing when children did not have all of the information about what had happened to their parents. Further questions were directed to understand these experiences. This led me to develop categories such as “knowing” and “not knowing” what was happening in the family. These later collapsed to become “having only part of the story”.

The incidents associated with hospitalization confirmed the emerging categories of “monitoring” and “emotional currents”, because it became clear that children increased monitoring behaviour when parents were hospitalized and experienced intense emotions around their hospitalizations. In another example of theoretical sampling, I undertook considerable effort to find a single parent and her children whose situation would develop the concepts of “trying to preserve myself” and “gauging” within the structural conditions of poverty and chaos with which the family was struggling. The BSPPs of “finding the rhythm” and “maintaining the frame”, with the interrelated categories of monitoring and adjusting, “emotional currents”, “trying to preserve myself” and “gauging” in addition to goals were all developed by sampling theoretically.

In developing the category of “trying to preserve myself”, I sought out participants who had found satisfactory ways of managing their situation, without compromising their safety and security, and I also sought children who were struggling in their situations. In the development

of the category of “gauging”, I sought out children who came up with different conclusions after “gauging” their situations.

Given the vulnerable and complex nature of my sample, I moved quickly to interview 14 children representing 9 families as they volunteered for the study, but prior to being able to follow leads suggested by the data analysis. Moving quickly to collect interview data limited my ability to sample theoretically because analysis was not able to keep pace with the data collection. My efforts to sample theoretically were also limited by children being unavailable due to having moved, leaving no forwarding address or telephone number, being placed in foster care with access to the child denied, or living in chaotic life circumstances that did not allow energy for a second interview. In accordance with Glaser (1992), the circumstances, which prevented theoretical sampling, were incorporated into the data, with memos made about these circumstances. Incorporating those materials helped me to develop some categories. A basic tenet of grounded theory purports that “all is data” (Glaser, 1992). Thus, I incorporated families’ circumstances and life complexities into the analysis to inform theoretical sampling, constant comparison, and concept generation.

Memos

Theoretical memos are the bedrock of theory generation within grounded theory (Glaser, 1978). Writing memos is a crucial and creative process for the theorising and conceptualisation of the data, which occurs throughout the research process. Memos need to be written as quickly as creative thoughts occur. Memos are written without regard for the inhibitions of correct prose in order to capture the ideas and insights of the moment (Glaser, 1978). By recording ideas as they occur, they form a basis to raise the description of the data to a theoretical level and, thus, to assist the process of theory generation (Glaser).

I wrote early memos to explore the meaning of developing codes and potential relationships among codes that could be clustered to form categories (Appendix V). I asked

questions in the memos about whether codes represented properties or categories. Later, my memos concentrated on analysis and theory construction emphasising the conceptual development of theoretical relationships (Appendix W).

An early memo (April 3, 2001) written on “humour” noted that humour brought families together and offered joy, comfort, and positive interactions within the family home. “Humour” was an important factor in the children’s lives and seemed to be emerging as a major category. More memoing helped me to locate the use of “humour” as a strategy for making adjustments to the parent’s behaviours. Questions were generated from the early memos such as: “was humour a form of optimism or a way of enjoying life; did children have different objectives in different circumstances for using humour?” These questions pushed my analysis of humour further. Later using “humour” was moved into adjusting as “humour” developed as a skill that children cultivated to manage difficult situations in their parent/child relationships. The shift to memoing from coding causes the researcher to reflect and integrate emergent information (Glaser & Strauss, 1967).

Memos allow the sorting, resorting, and reworking of ideas and are crucial to the conceptualization of theory (Glaser, 1978). My memos were stored in a highly sortable memo file in a binder under names of possible emerging categories. I put the memos into natural categories. Memo writing guided my thinking and reworking of categories and allowed me to remain open to possibilities in substantive and conceptual areas. For example, the initially elusive core category of “finding the rhythm” emerged in later stages of memo writing and coding which served to develop and refine the category and its properties. Previous memos that contributed to the core category were about “respecting fragility”, “respecting vulnerability”, “reciprocity”, “give and take”. None of these memos completely captured the process of “finding the rhythm”, but other memos were written to re-conceptualise the categories and to develop “finding the rhythm” and “maintaining the frame”. The memos evolved after many

hours of constant comparative analysis across interviews, theoretical sampling, rereading the interviews, delimiting, and recoding the interviews for broadened conceptual categories.

As my memos became more complex, patterns and relationships were more clearly developed. Memos also helped me recognize data saturation. The core categories emerged after framing the categories and their properties and hypothesizing about their relationships to each other in a memo. The memo indicated that a category code “keeping in step” was too rigid to capture the fluidity and the sometimes unpredictable behaviour within the parent/child relationship and that “emotional swirling” or “running the emotional gauntlet”, did not capture the intensity or nature of the emotions and the onslaught of emotions as well as the category of “emotional currents”. Each category was further refined to provide the language that captured processes more completely.

Field Notes and Art Work

Field notes were written about information that parents shared over the telephone upon initial contact. Parents were relieved that someone was researching their children’s perspectives and provided detailed unsolicited information about what was happening in their lives and their concerns for their children. This helped me understand more completely what the context of the children’s lives had been and was now, in conjunction with the data from the children’s interviews. I was able to compare the children’s perceptions of their lives with the parent’s perceptions of their lives.

During the coding of the interviews, participant observation notes and field notes were read and reread to help to develop codes and provide properties for categories that had been developed from the data. The field notes contributed to the memos. For example, participant observation notes about information from the conversations I had with parents contributed to the development of the properties of the category “monitoring”, particularly the property of “having only part of the story”, wherein the child often had partial information or no information on what

was wrong with the parent. Field notes across the sample in relation to the property of being informed were used in conjunction with the interviews of the children. The properties of “adjusting”, particularly, the “acting” property were partially developed from participant observation notes documenting interactions between child and parent before and after interviews. The children’s drawings and the verbal descriptions of the drawings they offered were also incorporated into the analysis. I wrote field notes and memos on the context within which the drawings were created and included the field notes as contextual information. The data from the use of story and puppets, as previously discussed, were also recorded in the interview process and analyzed within the constant comparative method.

Criteria for Rigour

General Qualitative Criteria for Rigour

In general, the rigour of qualitative research is demonstrated by a clear link between the data and theory derived from the data. (Denzin & Lincoln, 1998). Rigour is supported by an audit trail, which is defined as a clear decision trail from the beginning to the end of the study that documents the conceptual development of the theory (Denzin & Lincoln; Sandelowski, 1986). The audit trail explains how the researcher became interested in the study, viewed the participants, included the subjects, and collected and analyzed the data (Sandelowski). The audit trail also includes discussions about the impact the researcher and the participants had on each other, the nature of the setting, the purpose of the study, the inclusion and exclusion of categories in the analysis, how the data were weighed, and the applicability of the study findings (Sandelowski).

In the preceding chapters, I have described how I became interested in the study and my perceptions of the children of parents with a mental illness. This chapter has clearly described how I recruited and included the participants, and how I collected the data. I have also indicated how I coded the data initially as *in vivo* codes, which lead to higher level coding and the

development of categories, and how I developed theoretical links for the categories and their properties. To make the study design and conceptual development of the theory transparent to the reader, I described the data collection and data analysis procedures in depth. In accordance with Sandelowski (1986), I have provided examples of decisions made during the process of data collection and analysis, in an effort to clearly describe, explain, and justify my decisions. I have described the development and refinement of the BSPPs “finding the rhythm” and “maintaining the frame”, as well as the levels of coding that were involved in their development. These strategies have made the decision trail transparent and address rigour in this study. The impact that the children and I had on each other will be described later in my discussion of reflexivity and relationality.

Other issues that Sandelowski (1986) suggests influence the rigour of qualitative research are: the holistic fallacy (wherein patterns are reported without consideration of all the data), elite bias (the sample consists of the more articulate members of the population), and limited representativeness of the data as a whole (not all elements of the data are represented within the categories or examples). When using grounded theory, I would argue that the holistic fallacy is unlikely to occur if the method of constant comparative analysis is used correctly. Constant comparative analysis requires consideration of all incidents in the data and of negative cases. Limited representativeness of the data in the developing categories is also an unlikely outcome. The use of the constant comparative method required me to stay grounded in the data from all interviews and to compare incident to incident, which developed codes and properties to account for the most variation in the data.

I developed patterns in the data after consideration of all the study data, working and reworking the data, and incorporating new data. Hours of coding and meticulously comparing incident to incident were undertaken to ensure that most of the patterns within the data were considered. Extended engagement in analysis reduced my risk for holistic fallacy and limited

representativeness. In addition, by working closely with my dissertation supervisor, Dr. Wendy Hall, I avoided the holistic fallacy and representativeness through ongoing discussion of the data and developing concepts. “One upmanship”, with my supervisor and others, challenged me intellectually and guided me to consider representativeness of all incidents versus focusing on pet theories and appealing ideas.

Elite bias is an important consideration. It has had some influence on the study. The parents who participated in the study were parents concerned about their children who wanted to know how their children were managing. They also wanted to know the effect of their mental illnesses on their children. The parents in this study valued research. Thus, the children in this study came from homes where the parents were able to express their concerns about the welfare of their children, and to seek to participate in the study. These parents believed that the children might benefit from telling their stories. They encouraged their children to discuss their perceptions. There are likely other children, living with parents with mental illnesses, whose parents are not able to participate or interested in participating in a research study. Thus, the study may have attracted a select group of parents and children who were comfortable about telling their stories. Other children, living with a parent with mental illness, who may not be encouraged to share their perceptions and their experiences may have different experiences. Given those concerns, I made every effort to incorporate all of the children’s perceptions regardless of their ease with articulating their perceptions.

Grounded Theory Criteria for Rigour

Grounded theory has its own specific criteria for rigour which include: fit, work, relevance, modifiability, parsimony and scope (Glaser, 1978; Glaser, 1992). A discussion of rigour associated with these criteria follows.

Fit. Glaser (1978) defined fit as the relationship of the core category to the social problem being investigated. The BSPPs of “finding the rhythm” and “maintaining the frame” offer a

coherent explanation of how children manage their problems when living with a parent with a mental illness. Fit refers to the ability of the core category to account for the most variation in the data (Glaser, 1978, 1992; 1998). The BSPPs, “finding the rhythm” and “maintaining the frame” have captured the most variation in the data, wherein children tried to resolve what was happening in their lives.

The BSPPs, “finding the rhythm” and “maintaining the frame”, not only explained how children participated in their relationships with their parents on a day-to-day basis, but also over time and their assessments of their successes. “Finding the rhythm” and “maintaining the frame” explained how children found a way to connect with their parents while trying to feel safe and secure. “Finding the rhythm” and “maintaining the frame” were the processes children used to manage what was happening in their lives. Children were clear that, although they felt a need to connect with their parents in “finding the rhythm”, they needed to do so safely by “maintaining the frame”. The processes accommodated the variation in the experiences of children by capturing the experiences of those children who felt compelled to disconnect from their parents. Thus, the BSPPs fit the data; because they accommodated the continuum of perceptions and experiences of all children I interviewed who were living with a parent with a mental illness.

Work. Glaser (1978) defined work as the ability of the core category to relate the other concepts and their properties. If a core category fits, is relevant, and works, it will integrate theory and be readily modifiable to generate a dense and saturated theory (Glaser, 1978). When a basic core category is grounded in the data, the other categories that emerge will relate to the issues of the participants and be relevant (Glaser, 1998). Concepts must not be overly dense or too thin and must not dilute the core ideas of the theory (Glaser, 1978). Through detailed memoing, constant comparisons of the interviews, and the participant observation data, I developed the categories and their properties by returning to the data and ongoing memoing. The core categories of “finding the rhythm” and “maintaining the frame” brought “monitoring

and adjusting”, “preserving myself”, “gauging”, and the children’s goals and outcomes together to produce a dense theory. Because those categories fit, were relevant, and remained closely tied to the data, they worked to explain the processes by which children managed their lives. The category of “emotional currents” ran through the aspects of the BSPPs of “finding the rhythm” and “maintaining the frame”, by accounting for the way the emotions influenced children’s efforts, as well as what the children described as their outcomes.

The BSPPs worked as they linked all categories inclusive of outcomes to the other categories and their properties. I spent considerable time determining the goals, from the concepts of “monitoring and adjusting” and “trying to preserve myself” and “gauging” and their relationship to the overall outcomes associated with “finding the rhythm” and “maintaining the frame”. I spent further time and consultation with my dissertation supervisor, Dr. Wendy Hall, in determining how the BSPPs resulted in overall outcomes for the children. These efforts determined how the BSPPs related to the other categories and worked together to best explain the process of living with a parent with a mental illness.

The BSPPs of “finding the rhythm” and “maintaining the frame” and the developing categories of the theory also guided the conceptualisation of the social condition of “fitting in”. According to Glaser (1978) a sociological construct is a category that has analytical ability and imagery, and, as such, it relates easily to other codes and does not have to be explained repetitiously. It also provides a broader sociological view. “Fitting in” accounted for the interface between the BSPPs of “finding the rhythm” and “maintaining the frame” and the larger world. The children did not live their lives with their parents in isolation and encountered difficulties when their ways of managing did not fit with societal expectations. The interface with social expectations highlighted the struggle that these children encountered in trying to meet societal expectations and to “fit in”, in addition to all the other aspects of their lives that they were managing.

The substantive theory was integrated and dense because the theoretical links were well supported by the BSPPs and their properties. For example in the stage of “preserving myself”, properties of “living my life”, “getting away”, “selective sharing” and “opting out” all worked well with the BSPP of “maintaining the frame”. They explained most of the variation in the data; i.e. from strategies of “living my life” to “opting out”, which explained the range of behaviours that children used in their efforts to maintain the frame in their relationships with their parents, while preserving and developing their identities.

Relevance. Relevance is the relationship of the theory to the problems of the participants in the substantive area (Glaser, 1992). When the concepts are well named, fit with the data, and are grounded, relevance follows. While Glaser has stated that following the grounded theory method will ensure relevance, I agree with Benoliel (1996) who suggested that contextual elements must be acknowledged. Benoliel also suggested that participants do not generally understand the BSPPs that people use to deal with situations in which they find themselves at the conscious level. This is of additional importance in determining relevance in studies with children when abstract concepts are articulated. Determining relevance from child participants’ perspectives may not be reasonable, because their cognitive development may not permit them to see their stories captured by abstract concepts. In this study, I was trying to conceptualise the BSPPs of participants who had often not yet developed abstract thinking skills. In consideration of Benoliel’s comments and children’s cognitive developmental stages, I did not validate the relevance of the theory with child participants.

As I followed the grounded theory method described by Glaser, (1967, 1978, 1992) I also paid particular attention to the writing, and the reading of participant observation notes and field notes. These notes served as a continual reminder of the context of children’s lives and were incorporated into the analysis. This ensured relevance of the theory to understanding the experience of the children within the context of their lives. The final versions of the BSPPs were

refined and honed to more accurately reflect the children's experiences. Within the second set of interview questions, children validated some of the emergent categories. For example, a question such as; "What does your parent tell you about the illness?", was designed to determine the general knowledge level of the children. Their responses reinforced the relevance of the concept of "having only part of the story", which influenced the children's perceptions. Relevance was further obtained by coding all the data manually in order to stay strongly grounded in the data. I decided not to use a computer program to prevent further fracturing of the data. Therefore, I achieved relevance by the meticulously establishing work and fit of the theoretical concepts, and by incorporating contextual influences within the data analysis.

Modifiability. When the BSPPs fit and the other categories work with the BSPPs, modifiability can be achieved in grounded theory (Glaser, 1978). When a theory is modifiable, it has the potential to be used to explain other foundational phenomena. The BSPPs of "finding the rhythm" and "maintaining the frame" could be foundational to explaining relationships other than child/parent relationships, within the context of mental illness. Children who live with a parent with chronic physical illness may have similarities in their efforts to manage their relationships with their parents. Those children may also invest energy in "finding the rhythm" and "maintaining the frame". Children, who are fortunate enough to live with healthy parents, also invest energy to find the day-to-day rhythms and maintain the frame, in order to get along with their parents and to feel safe and secure within their relationships. That may be particularly true in situations where parents are separated and in the process of divorce. The fundamental process of "finding the rhythm" and "maintaining the frame" in relationships may extend to other relationships such as husband/wife relationships, employer/employee relationships, and friendship relationships. In all of these relationships, people find rhythm in their relationships, which partially relies on how they may maintain the boundaries that they find comfortable in their relationships. Employees learn the appropriate rhythm with their employers in order that

they are able to maintain their jobs and have satisfactory relationships with their employers. Disgruntled employees may opt out of the relationship after gauging the costs and benefits of preserving themselves within the relationship. These basic ideas could apply to the other suggested relationships, wherein both parties find the rhythm and maintain the frame according to their needs. The context of the relationships will vary but the fundamental process of “finding the rhythm” and “maintaining the frame” will apply.

Because grounded theory is based on constant comparisons, new incidents can be readily included in the theory. My theory suggests that “finding the rhythm” and “maintaining the frame” are not dependent on psychiatric diagnosis but reflect a more fundamental process. Thus, if incidents did not arise in the data collection, my theory can still be modified and changed to include new information at a later date. This is true in the context of specific relationships, for example, student nurse/doctor relationships, wherein a theory like “finding the rhythm” and “maintaining the frame” could be modified to incorporate new incidents within the context of the participants’ lives. If the theory is to be generalized to another area, incidents and data from that area will modify the theory (Glaser, 1998). Thus, while the basic tenets of the theory appear to be useful in the identified relationships, the theory may be modified by further study of other participants and the context of their lives and relationships.

Parsimony and scope. Parsimony and scope refer to the ability of the theory to account for variation in the data with the least number of concepts (Glaser, 1978). The presence of these criteria contributes to the rigor of a grounded theory research process. When a theory is parsimonious, or the fewest concepts capture what is happening in the data, it is dense and saturated. During the ongoing analysis, I worked to collapse the categories that were thin, in order that the fewest concepts formed the theory. The most parsimonious theory of the greatest scope has only those categories that develop as working the problems. Glaser (1978) suggests that there are never more than six to eight categories at most if all are properly saturated in

service of the core category. My theory consisted of eight specific components, “finding the rhythm”, “monitoring”, adjusting”, “maintaining the frame”, “trying to preserve myself”, “gauging”, “emotional currents” and “fitting in”. I attempted to ensure that all categories were relevant to the BSPPs, with categories and their properties linked to the respective BSPPs. By undertaking the systematic process of coding and delimiting, my theory developed increased relevance because it became more parsimonious and elegant. If all criteria for rigour are upheld, the theory will be integrated and dense (Glaser, 1978; 1992). For example, integration occurred when “trying to preserve myself”, incorporated incidents in the data which lead to the properties, of “getting away”, “living my life”, “flying solo”, “selective sharing” and “opting out”.

Integrating the incidents and properties made the theory dense.

Theoretical saturation according to Glaser (1992) occurs when no new categories emerge and the same properties emerge as one goes through the data. I achieved theoretical saturation when, after meticulously coding the interviews and reading and rereading the participant observation notes, I was unable to find new patterns of the data. Data saturation occurred quickly for the reciprocal interaction between parent and child, the positive feelings children had for their parent and the subjective emotional distress children often felt. These ideas were the foundations of the BSPPs of “finding the rhythm” and “maintaining the frame” and the category of “emotional currents”. Data was also quickly saturated for the range and intensity of emotions that assailed the children.

Relationality and Reflexivity as Criteria for Rigor in Grounded Theory

Hall & Callery (2001) posited that relationality and reflexivity have not been incorporated routinely in the criteria for rigour of grounded theory studies and are aspects of rigor that need to be included. Relationality addresses power and trust relationships between the participant and the researcher, while reflexivity refers to the influence of researcher and participant interaction on the construction of data (Hall & Callery). While grounded theory does

not include a specific discussion of the concepts of relationality or reflexivity, Glaser (1992, 1998) would suggest that all of the observations of the researcher are data and thus influence the findings. Glaser does not acknowledge the construction of data by the participant and the researcher but treats the data as transparent. I would not agree that the data are transparent. Rigorous contemplation was required to establish patterns and included the effects of reflexivity and relationality on its construction. I will discuss relationality and reflexivity, as I believe they related to this research study.

Relationality, where power and trust are reciprocal between the participants and the researcher, is critical in research with children. Children are recognized as relatively powerless within society and within adult/child relationships (Medical Research Council, 1998). As such the child will likely perceive the researcher as more powerful. Children, who face adverse life circumstances, potentially may have felt powerlessness and experienced situations wherein they lost trust with adults. Children bring these experiences to the research/participant relationship. I needed to consider these elements in my interactions with the children. Knowing that I was aware of their parents' mental illnesses may have made some children feel powerless, particularly if they had not been open to sharing this information with others. I undertook specific strategies to offset power imbalances in the child/researcher relationship, while gaining informed assent, and conducting the interview process. Strategies included the use of art, puppets and stories; things that children, particularly younger children, valued. These strategies helped to create trust and decreased their sense of 'power over' by the researcher. I tried, through these strategies, to acknowledge power dynamics and validate children, in an attempt to meet them on "their ground". I also advised children that the research findings would be made available for them in a format, likely a small booklet, and in language that they could understand. I told parents about the resources for children, such as the group "Name That Feeling" which

helped children understand mental illness of a parent. Despite all my efforts, I cannot assume that power and trust issues did not affect the interviews.

To participate in research, children who give assent do so only after parental consent. Power differences exist within the child/parent relationship. Some children assented to the study because they wanted to please their parents. This was sometimes revealed in the child's demographic form where the researcher asked the child to state the reason for being in the study. Children generally appeared interested in the interview questions, receptive to the idea of having the findings presented to them at a later date, and confident to ask questions, refuse to answer questions, and clarify uncertainties. For example, they asked, 'what do you mean', declined to draw or said they didn't want to answer specific questions (two children did this). Some children stated that they liked talking to me and enjoyed the interview process. Older children stated that they thought it was important to talk about their experiences and that they welcomed an opportunity to do so. Two children were noticeably less talkative and I concluded that they were somewhat distrustful or anxious about the interview.

As a researcher, the only ways that I could attempt to equalize power in the interview process were to be non-threatening in my demeanour, be clear about my expectations for the child, offer explanations in terms that were understandable to the child, and be non-judgemental in my responses to their answers as best I could. I also noted the children's reactions during interviews in my participant observation notes and incorporated them within my analysis.

Some children may not have participated in the study, due to their perception of power that I held. Children who had been apprehended previously may have been more sensitive to the fact that adults could change their lives. Also, children, who may have been fearful of apprehension or family disruption as a result of sharing information about their parent, may have adjusted their answers to avert these consequences. However, I believe that the majority of the children did not perceive their situations to be that precarious at the time of the interviews.

Because I had a genuine interest and cared for the children in this population, I responded to them with empathy during the interview process. This may have encouraged them to share their emotional reactions more freely. My experience as a mental health nurse at times influenced my responses, i.e., empathy, self-disclosure, and validation. This was helpful in some situations to encourage children to talk, build trust, and to demonstrate caring. In addition, when I gained the trust of children, I believe the majority were open to discussing their situation. The effect of relationality on child participants raises issues about whether it is reasonable to assume that shared power and trust can be established.

Reflexivity, the influence of the researcher/participant relationship on the construction of the data, must also be considered particularly with research involving children. When relating to children, adults often speak in a different way than when speaking to adults; i.e., using a softer voice, attempting to use the language of adolescents, and using humour. This tendency to treat children differently, perhaps by attempting to protect them, requires consideration within the research process. Unintentionally, the researcher may respond to children in this manner and, as such, guide them to respond in different ways than they might have otherwise done. The use of facilitative communication skills is paradoxically helpful and hindering. On the one hand, the facilitative skills will build trust and demonstrate caring; on the other hand, they may lead the child to respond in certain ways. At times, I noted that I made a leading comment such as, "good", to some of the children's responses. This could have influenced what children shared. As a researcher, I was aware of this potential and strove for a balance wherein the child would feel comfortable and supported, but also feel able to respond spontaneously. In doing research with children on sensitive subjects, I felt that children required some validation of their experiences to help them respond to the questions; however, I attempted not to lead the children to answer in a particular way.

I acknowledged contextual influences that affected each child's situation and development by being aware and respectful of cultural influences. Existing theory on child development has been critiqued for lack of sensitivity to cultural and contextual influences on children's lives (Harter, 1999; Vygotsky, 1978). I attempted to be aware of my own cultural ethnocentrism, which might have influenced the interpretation of children's behaviour. For example, the ideas and values that I learned in my middle class Anglo-Saxon childhood home insidiously and directly influenced my interpretations of children's impoverished circumstances. I made efforts to be aware of my assumptions regarding children's perceptions of their environments and of their parents' illness. Several children in impoverished circumstances found favourable aspects of their lives that I did not immediately see. Also, having been influenced by the formal psychiatric health care system where I had practiced and which tends to view parents with mental illnesses in a reductionist manner, I was constantly made aware of the children's ability to see beyond the mental illness of their parents and recognize their inherent value. I attempted to be sensitive to other worldviews and the circumstances of children's lives, which might have influenced their responses to me. Part of this was routinely asking myself and discussing with my dissertation chair, Dr. Wendy Hall, why I was thinking in particular ways and what assumptions I was making regarding the children's circumstances.

Summary

Within the traditions of grounded theory, a theory is conceptualised as "ever developing" and "theory as process" not a perfected finished product (Glaser & Strauss, 1967, p. 32). In the methods chapter, I have described my study design, research purpose, definitions of terms, research questions, overview of the method, nature of the sample, ethical considerations, and research procedures, including sample recruitment, data collection processes, data analysis, and finally, criteria for rigor. Throughout the chapter, I have attempted to make my decision trail transparent regarding the criteria as outlined by Sandelowski (1986). I have described the

decision making trail leading to the BSPPs, several other categories, and relationships among the categories. In addition, I have addressed the specific criteria of rigour from a grounded theory perspective: fit, work, modifiability, parsimony, scope, and relevance (Glaser & Strauss, Glaser, 1978; Glaser, 1992) and extended my discussion of rigour to include an analysis of how relationality and reflexivity affected the study and the development of the theory.

In Chapter Five, Findings, I will present a detailed account of the study findings and my theory that explains children's perceptions of living with a parent with a mental illness and how children managed their experiences.

CHAPTER 5

FINDINGS

This chapter will describe the findings from the grounded theory study of children's experiences of living with a parent with a mental illness. The basic social psychological processes (BSPPs) of "finding the rhythm" and "maintaining the frame" explained how children managed their experiences of living with their parents. These BSPPs suggest that the children spent a considerable amount of energy and time to find the rhythm with their parents and to maintain their frames with them, by using strategies to maintain or re-establish their connections with their parents while also using strategies to maintain a safe and comfortable distance between themselves and their parents.

The rhythm represented patterns, the sequencing of daily events, in the children's lives and in their relationships with their parents. To find the rhythm, these children monitored their parents' behaviours and the family's daily rhythms. They then adjusted their behaviours to help maintain or re-establish daily connections with their parents and rhythms in their families. They used specific strategies to get along day-to-day, to maintain their connections to their parents, and to maintain some sense of family stability.

In "maintaining the frame" with their parents, children used strategies to "try to preserve" themselves, by having lives and identities of their own so that they were not engulfed by the mental illnesses of their parents. "Maintaining the frame" is similar to the concept of maintaining healthy boundaries in relationships, which allows both participants in a relationship to interact in a manner that supports their individuality as well as their connectedness. As part of "maintaining the frame", the children gauged how well they were able to preserve themselves and on the basis of their assessments considered how much they were prepared to remain invested in their relationships with their parents.

I will begin this chapter with a description of the children who participated in this study, which will provide a context for the study findings. I will follow that description with an overview of the two BSPPs, a more detailed description of their stages, and other key categories in the substantive theory.

Sample Descriptors

Over a 13 month period from September 2002 until October 2003, selected participants were interviewed twice. Those participants' first and second interviews are denoted as follows, Interview identifier/1 and Interview identifier/2 with the gender and age of the child following the identifier and interview number. Some details of the participants' quotations have been altered to protect their identities. These alterations are of a minor nature and do not influence the integrity of the findings.

Sample Characteristics

Twenty-two children from a Canadian mid-western mid-sized city participated in this study. There were 14 boys and 8 girls. Eleven children were between the ages of 6 and 12 years and 11 children were between the ages of 13 and 16 years. All children lived, either full or part time, with a parent who had schizophrenia, depression, or bipolar disorder (Table 5:1). Because 13 of the children were siblings, 14 families were involved in the study. In addition to the primary diagnoses of schizophrenia, bipolar disorder, and depression, parents also identified co-morbid disorders (Table 5:2). Eleven of the parents with the mental illnesses were mothers and 3 were fathers. During the course of the study, 2 children were removed from their homes, one to a detention center, and one to a foster home. The children lived in a variety of family arrangements: two-parent, single parent, extended families, and blended families. The findings represent 32 interviews in total; 10 of the children were interviewed twice. Parents suffered from co-morbid disorders as noted in Table 5:1 and Table 5:2, in addition to depression, bipolar

disorder, and schizophrenia. In one family, both parents were diagnosed with mental illness.

Two siblings, a brother and a sister, preferred to be interviewed together.

Table 5.1: Sociodemographic Data

Family (F.)	Children Interview No.	Age/Gender	Ill Parent	Diagnosis	Child's Age at Onset of Illness
F. 01	01	7 girl	Mother	Depression Anxiety	Birth
	02	10 boy			10 months
F. 02	03	13 boy	Father	Depression	Unknown
	04	7 boy			
	05	9 boy			
F. 03	06	13 boy	Mother	Schizophrenia, Depression, Borderline Personality	11 years
F. 04	07	16 girl	Father	Depression, Anxiety Psychoses NOS	4 years
			Step-Mother	Unknown	Unknown
F. 05	08	10 girl	Mother	Depression, Anxiety	Birth
F. 06	09	16 boy	Father	Bipolar	6 years
	10	14 boy			4 years
	11	11 boy			Birth
	12	9 boy			Birth
F. 07	13	11 girl	Mother	Bipolar, Anxiety	Birth
	14	13 boy			Birth
F. 08	15	14 girl	Mother	Depression, Anxiety Personality Unspecified	Birth
F. 09	16	16 girl	Mother	Bipolar	Birth
F. 10	17	10 girl	Mother	Depression	Birth
F. 11	18	14 boy	Mother	Depression, Borderline Personality	Unknown
	19	16 boy			
F. 12	20	6 girl	Mother	Depression, Anxiety	3 years
F. 13	21	13 boy	Mother	Bipolar	Birth
F. 14	22	7 boy	Mother	Depression	3 years

Note. Psychoses NOS (Not Otherwise Specified). Unknown: Some parents could not remember the exact age that their child was when the parent first experienced mental illness. These parents described the child as very young, meaning preschool or earlier.

Table 5.2: Principal Diagnosis of Parent and Co-morbid Diagnosis

Principal Diagnosis	Number Of Parents	Co-Morbid Diagnosis	Number of Parents
Schizophrenia	1	Depression	1
Depression	9	Anxiety	6
		Personality Disorder	2
		Psychoses (not otherwise specified)	1
Bipolar	4	Anxiety	1

Family Characteristics

Data were collected on educational level, socio-economic status, family structure and work status of the ill parent (Table 5.3). Some parents reported being unable to complete post secondary education courses as a result of their illnesses. Two parents were currently studying, one was planning to resume her graduate studies, and one parent was hoping to resume upgrading.

The families included 7 two-parent families, one of which was a blended family. Five of the 6 female single parent families lived in subsidized housing and received social assistance. One single parent was a father. The single father had one of his extended female family members living in the household. In the single female parent homes and the blended family, 4 children had consistent ongoing contact with separated well parents. The children spent summers, weekends, or alternate weeks with their well parents. In one family, children changed homes, i.e. living with different parents, twice during the study. One child lived alternate weeks at different residences. Parents were employed as cooks, secretaries, daycare workers, counselors, retail clerks and in public relations. Some parents were on leave from teaching, social work, educational courses, and the health care field. Two parents reported a significant

decrease in their ability to maintain a job. Five parents were on long-term disability. One family declined to share family income information.

Table 5.3: Family Characteristics

Category	Descriptor	Number of Families
Educational Level	High School Completion	14
	Some Post Secondary	8
	College Certificate	1
	University Degree	2
Family Income	Under \$10,000	1
	\$10,000 - 20,000	5
	\$21,000 - 30,000	2
	\$31,000 - 40,000	2
	\$41,000 - 50,000	1
	\$51,000 - 60,000	1
	Over \$ 60,000	1
Family Structure	Two Parent	7
	Divorced	7
Work Status of Ill Parent	Employed	7 (2 fathers 5 mothers)
	Disability	5 (1 father 4 mothers)
	Return to work program	1 (mother)
	Upgrading	1 (mother)

Note. The Low Income Cut Off Pre-Tax figures used by Statistics Canada (2003) to determine poverty are as follows: yearly income for a two person family, \$24,745; yearly income for a three person family, \$30,774 and yearly income for a four person family, \$37,253. Based on these estimates 7 families had incomes which would be classified as indicating poverty.

As shown in Table 5.4, a number of parents required hospitalization . Three parents were hospitalized twice and 1 parent was hospitalized seven times in the past two years. Many parents required crisis stabilization admission, with 2 parents being admitted twice and 1 parent being admitted 8 times. One parent used the consumer run crisis unit for respite. Parents used the Mobile Crisis Team and the Mobile Crisis Team phone services. Some parents used more than

one service. The most frequently used services were the hospital and the crisis stabilization units.

Table 5.4: Utilization of Psychiatric Services by Parents in the Past Two Years

Service	Number of Parents Using Service
One Hospital Admission	2
Two or more Hospital Admissions	4
One Crisis Stabilization Unit Admission	2
Two or more Crisis Stabilization Unit (CSU) Admissions	3
Mobile Crisis Team Home visit or phone assistance	2
Consumer Run CSU Admission	1
Psychiatric Home Services	2

Table 5.5: Parents' Social Support When Ill

Helpers	Number of Parents Identifying Helpers
Friends, Neighbours and Relatives	6
Children	2
Well Parent	8
Boyfriend	1

Note. Some parents identified more than one source of social support.

Parents reported differing experiences when they were ill and needed help. Well parents did not always live with the children in this study. Some well parents lived in the same city but others lived in other provinces. When well parents were in the home, they were heavily used for support by the ill parents. Because of the nature of her illness, one woman would not seek assistance. She relied on her children to assist her and look after each other when she was ill. Some single parents, without any perceived support, stated they did not want to go to the hospital as it was not helpful and was too disruptive for their children. Two parents stated that no one helped them but themselves and one parent identified the daycare as helpful.

Characteristics of Children's Lives

The following section will summarize the characteristics of the children in order to provide the context for the study. I will describe the children's stated reasons for being in the study, details of their school lives, services used by children, extracurricular activities, moving, and the importance of the children's pets.

Most of the children identified helping other children in similar situations to themselves as their major reason for being in the study. Other reasons for being in the study included: to help myself, because of the "cool stuff" (the tape recorder, puppets, art supplies), to learn more about mental illness, and because my brothers were in the study. Only one child stated he agreed to the study because of the movie passes. Despite the researcher's attempts to ensure that children assented freely, 3 children entered the study to please their parents.

All children were in the public school system, except for 1 child who attended a faith-based private school. The children identified issues in the school setting that were troublesome to them such as bullying (6 children), low grades (6 children), and expulsion (2 children). Five children were doing remedial work, which indicated that children were unable to keep up with their schoolwork. Resources to help children were varied. Some parents felt that children who required remedial work were not getting sufficient help. One child went for private remedial assistance. The children would see counsellors infrequently; some felt they could go back to the school counselor as needed. Not all children valued this service. Some children had been diagnosed with mental health problems such as attention deficit disorder (3 children), attention deficit hyperactivity disorder (1 child), and a social phobia disorder (1 child).

Many parents felt that there was little help for their children; most did not know about the children's group at the Schizophrenia Society. This group was a resource for children who lived with parents with mental illnesses. The group was inclusive of any diagnosed mental illness, not only schizophrenia. Some parents tried to obtain help for their children, often initiating contacts

with helpers; however, even if they were aware of resources, they often could not get their children there due to transportation difficulties. The children expressed an interest in talking to other children who had parents with mental illnesses but did not know how to make contact.

Some families had no money for extra curricular activities for children. Other children had many opportunities. Several parents stated they sacrificed so that their children could participate in activities. The children who were involved in extracurricular activities outside of the school represented 6 families and 12 children in the study.

Table 5.6: Children's School Grades, Services Used and Extra Curricular Activities

Category	Descriptor	Number of Children	Gender
School Grade	Kindergarten	1	girl
	Two	1	girl
		2	boys
	Four	2	boys
	Five	2	girls
		1	boy
	Six	1	boy
		1	girl
	Seven	1	boy
	Eight	3	boys
	Nine	1	girl
		2	boys
	Ten	1	boy
	Eleven	2	girls
Services used by Children	Drop Out	2	boys
	Mobile Crisis Team	1	girl
	Community Organizations	2	girls
	School Counselors	2	girls
		5	boys
	Community Counselling	2	boys
	Family Therapy	1	girl
		1	boy
Extra Curricular Activities	School Based	3	girls
		3	boys
	Community Based	5	girls
		6	boys
	Part Time Jobs	2	girls
		3	boys

Table 5.6 Children's School Grades, Services Used and Extra Curricular Activities (continued)

Note. Drop Out: Two boys had quit school. Both were contemplating going back.

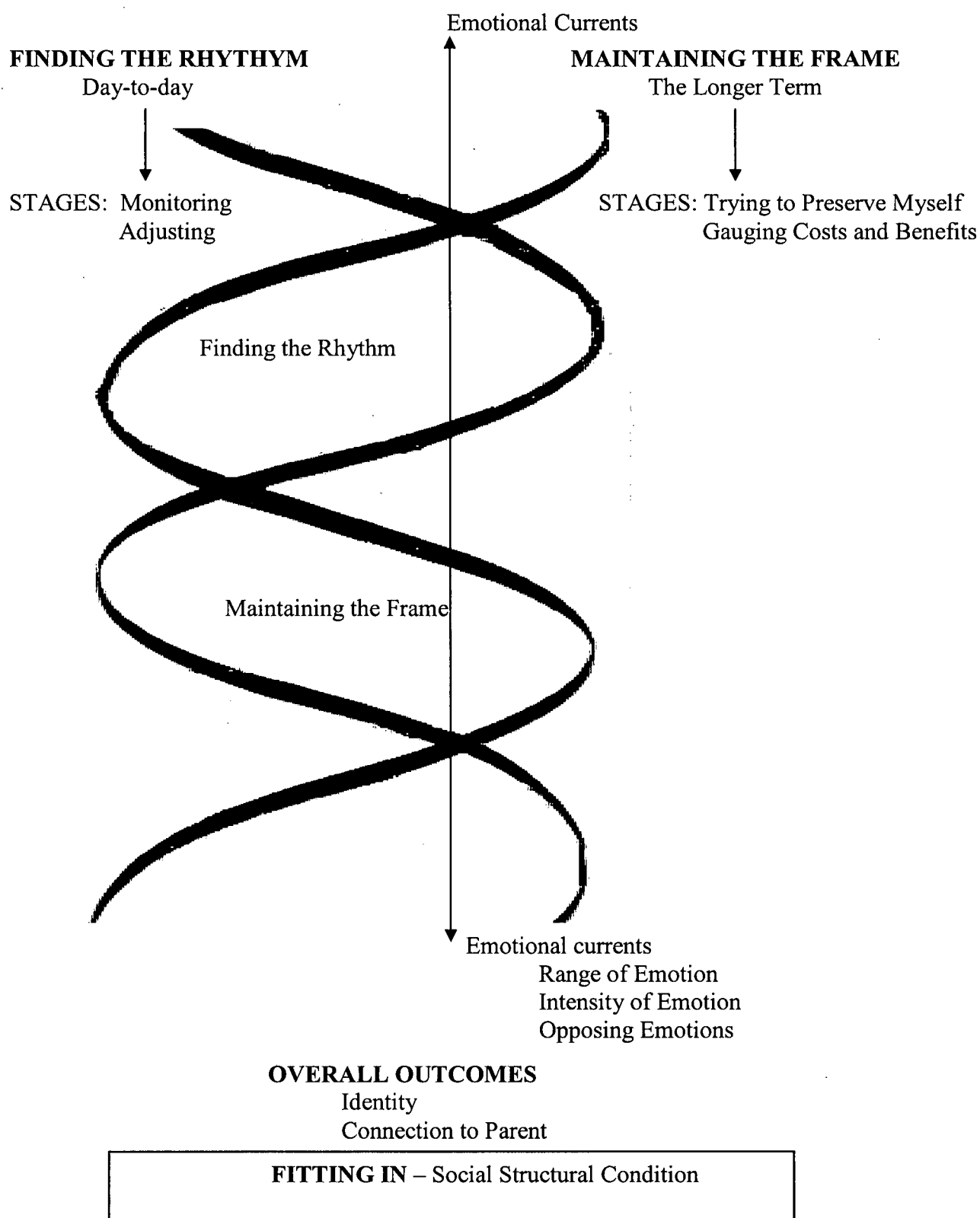
Fourteen children indicated they had changed dwellings, with 9 children indicating that moving required them to change schools. This represented 8 families. Two older children were able to attend their old school. Parents supported this in an attempt to minimize changes. Some children who were receiving remedial help in their old schools lost services or were delayed in receiving them when they moved to new schools. Moves were precipitated by children being bullied, contacting neighbourhood gangs, parents attempting to improve the children's environments, and a parent's job loss. In situations where parents were separated, some children chose to be with the parent with the mental illness, because they felt safer with that parent. The children did not always know why the family had moved.

Pets were important in children's lives because they valued them and were proud of them. Nine children had pets including cats, dogs, fish, a hamster, and a rabbit. The children shared stories about their pets and felt sad when they were lost. The children identified them as part of their families and as fun.

An Overview of the Substantive Theory

"Finding the rhythm" and "maintaining the frame" are the two BSPPs by which the children managed living with their parents with mental illnesses (Figure 5.1). They occur in the context of "emotional currents" and the social structural condition, "fitting in". "Finding the rhythm" was composed of two stages: "monitoring" and "adjusting", with their respective properties. "Maintaining the frame" was composed of two stages: "trying to preserve myself" and "gauging costs and benefits", with their respective properties. While the BSPPs were separate processes they also were intertwined and affected each other. The children attempted to find the rhythm, the daily patterns within their lives and in their relationships with their parents,

Figure 5.1 The Basic Social Psychological Processes: Finding the Rhythm
and Maintaining the Frame



in order to get along day-to-day. How effectively they were able to do so, influenced how they were able to maintain the frame of the relationship with their parents. Their abilities to maintain the frames affected how comfortable they were in persisting in their efforts to find the rhythms. Both processes were influenced by the category, “emotional currents”. “Emotional currents” pervaded the children’s lives and were affected by their development, what they understood about the mental illnesses, and the acuity of the illnesses. The children’s “emotional currents” affected and were affected by how effectively the children found the rhythms and maintained their frames. Each BSPP had specific goals with overall outcomes from the combined processes (Figures 5.1, 5.2, 5.3). A brief description of each of the BSPPs, their stages and specific goals, as well as the overall outcomes follows.

Overview of Finding the Rhythm

Finding the rhythm was the process the children used to get along day-to-day while living with parents with mental illnesses. The stages of “finding the rhythm” were “monitoring”, wherein the children monitored their parents’ behaviours, their families, and their daily rhythms; and “adjusting”, wherein children made changes to their own behaviours in response to their observations while “monitoring” (Figure 5.2). Rhythms are defined as the daily patterns within the children’s lives and relationships with their parents. The children found rhythms with their parents that could persist for long periods, but exacerbations of the mental illness introduced unpredictable disruptions in the rhythm. These could be minor fluctuations or a complete breakdown in the rhythms. “Finding the rhythm” not only involved children navigating their relationships with their parents on a daily basis but also navigating the rhythms of the household in order to ‘get along’ within day-to-day activities. The children were actively engaged in finding the rhythm in their relationships with their parents. The children got up in the morning and attempted to find the rhythm of the day.

How will their parents act today? What are their parents' moods this morning? How should they best respond to the mood? When their parents had a mental illness, there was a considerable of uncertainty and change involved with how their parents would behave. The parents' behaviour could change suddenly or insidiously, due to acute exacerbations of the mental illness. The rhythms of the parent/child relationships were disrupted, because behaviours had changed. The changes in their parents' behaviours affected the children and their families, and how their families and the children were viewed in the world outside of their families.

The children had to pay careful attention to what behaviours and daily patterns in routines were occurring so that they could detect differences. Their efforts to do that took the form of "monitoring". The properties of "monitoring" included the nature of "monitoring", ways of "monitoring", consideration of the meaning of what children observed, "monitoring fallout and influences on "monitoring". In order to find the rhythm, many of the children became astute at watching, listening and sensing signs of disruption within their relationships with their parents and in their daily routines. As children monitored for signs of change, they became more aware of the significance of the behaviour and what it might imply for their daily lives. Over time, and with the sharing and/or gathering of information from outside sources, the children monitored and then recognized the patterns of behaviour that indicated an interruption in the rhythm of their relationships with their parents. In getting along day-to-day, particularly in periods of acute illness, the children tried to detect the changes in the rhythm of their relationships by "monitoring" their parents' behaviours.

The second stage of "finding the rhythm" was "adjusting". Children adjusted their behaviours in order to determine actions which they hoped would minimize the immediate effects of the illness behaviours on them and their families. Adjusting included: taking action by helping directly and helping indirectly; and evaluating the effects of their actions. Based on the

meanings children assigned to the behaviours they monitored, they made adjustments to minimize the disruption to the rhythms of their relationships with their parents and to their daily routines. Children made adjustments to their environments, to their general behaviour, and to their ways of interacting with their parents. They then evaluated their adjustments and readjusted their action in whatever manner the children viewed as appropriate; whatever they thought worked best.

Most of the children attempted to find the rhythm, because they cared for their parents and wanted to find ways to stay connected with them. They were also attempting to keep peace in the house, to restore the daily patterns to a more harmonious beat, and to minimize the effects of their parents' behaviour on themselves and their families. Most children valued their relationships with their parents, recognized that their parents were doing their best, and acknowledged their parents' positive contributions to their lives, as well as their parents' limitations. Their regard for their parents was a strong motivator. They expended energy in finding the rhythm, so that they could stay connected to their parents, thereby developing and preserving their relationships with their parents and the integrity of their families.

Through "finding the rhythm" by "monitoring" and "adjusting", the children anticipated minimizing the effects of their parents' illnesses. The intensity of the "emotional currents" that children faced would also be dampened. More intense "monitoring" and "adjusting" was needed to sustain the rhythm of their relationships in the acute stages of the illness. If the child was knowledgeable about the illness, the child was better able to recognize the parent's patterns of behaviour as illness and to interpret the behaviours within the context of illness. Cognitively, this could help the child understand and determine what adjustment might best manage the situation. This knowledge dampened the intensity of the "emotional currents" that the children experienced and helped the children decide what adjustments to make. While having knowledge of mental illness did not alleviate all the emotional turmoil for the children, it gave them a frame

of reference to make sense of what was happening. Having only part of the story, led to children formulating unrealistic scenarios of death and dying, adding needlessly to their emotional turmoil.

At times, when the parents were well “finding the rhythm” flowed easily and became effortless, like riding a bicycle on a flat surface. One child described her feelings about the process.

It was kinda just like a big hill and then, it's kinda like it peaks. Like everything was not going good . . . and then it peaked and then it started getting better and better and then we're just back to normal again. Now we're back to normal. We're on the flat surface. Just riding our bicycle along the road. Oh, it's easy, yeah. Life goes by
(Interview 16/2, Girl, Age 16).

At other times, when the illnesses were acute, “finding the rhythm” could be exhausting. The same girl described how difficult it could be.

What's a word that is slow but really fast? Like excruciating, but it flies by you.

Well at the time, everything was horrible and I felt like nothing in my life was going right. It was like a movie. Like when I look back on it, it's like movie clips . . .

I can make that year a movie. Just the way everything started and then how it ended up.

Exhausting, and like, emotionally exhausting. Everything was just really like exhausting. So everything was just . . . like a hassle (Interview 16/2, Girl, Age 16).

The children attempted to “find the rhythm” with their parents on a daily basis in order to achieve the goals of daily family stability and positive interactions with their parents.

Overview of Maintaining the Frame

When the children maintained the frame they were trying to keep a safe and comfortable distance between themselves and their parents while trying to stay connected to their parents.

“Maintaining the frame” consisted of the stages of “trying to preserve myself” and “gauging”. In

dance, “maintaining the frame” refers to keeping the right distance between yourself and your partner. The idea of “maintaining the frame” is similar to the concept of maintaining healthy boundaries in relationships, which allows both participants in a relationship to interact in a manner that supports their individuality as well as their connectedness. The children described the frame of their parent/child relationships fluctuating with the intensity of the illness and its consequences (family disruptions, hospitalization, stressful relationships, loss of jobs, and financial burdens). The children tried to “preserve themselves”, by maintaining and supporting their existing and developing identities while staying connected to their parents. When the children were “gauging”, they were weighing how they were managing in terms of their identities and their overall comfort in their relationships with their parents.

When “trying to preserve myself”, finding the right distance in the frame was intimately intertwined with “finding the rhythm” with their parents. Most of the children wanted to stay connected with their parents and tried to dance in rhythm with them, but in order to “preserve themselves” they also had to find their separate rhythms. Both “finding the rhythm” and “maintaining the frame” were affected by the “emotional currents” that the children experienced. As the parents became ill, the children could feel that the frame had shifted. Many children indicated that their parents became more distant, unavailable, and non-receptive, being physically unavailable due to hospitalization, and/or psychologically unavailable to the child. On the other hand, some children described their parents being overly demonstrative, needy, and intrusive. Due to exacerbations of the illnesses, the parents were not readily available to the children and the distance in the frame could be stretched to the point of the children being unable to have meaningful interactions with their parents. To manage this disharmony, the children struggled to find a distance that would work while staying connected to their parents. One child who was unable to do so, distanced himself further from the already distant parent, expressed anger toward his parent, and held his parent to be responsible for the problems. This child saw

no way to maintain a safe and comfortable distance and support his own identity with a parent he viewed as unable or unwilling to participate meaningfully.

Can't even have a conversation with him. I just focus on my own stuff

(Interview 09/2, Boy, Age 16).

When the children had difficulty "maintaining the frame", they tried to reconnect with their parents, but at times had to disconnect from their parents when "trying to preserve themselves". They used strategies to preserve themselves, including getting away, living my life, flying solo, selective sharing, and opting out. All of these strategies assisted the children's efforts to affirm themselves, stay connected to others, and "maintain the frame" with their parents.

The second stage of "maintaining the frame", "gauging", consisted of weighing the costs and benefits of "maintaining the frame" with their parents. They determined if they were able to achieve respite, self-affirmation, connections with others, problem solving, and space for themselves. When "gauging", the children used strategies such as: comparing the past to the present, inclusive of the progression of their parents' illnesses; comparing self to others; and comparing their parents and families to others. As part of "gauging", the children determined how they were managing, in terms of things being better or worse, and how comfortable they were within the frame of their relationship with their parents. Most children decided that they were comfortable within their relationships with their parents. "Maintaining the frame", with the stages of "trying to preserve myself" and "gauging" described the children's efforts to keep a safe and comfortable distance between their parents and themselves; in other words to remain connected while sustaining a sense of themselves. The goals of maintaining the frame were personal safety and security which determined whether children were maintaining a comfortable distance between themselves and their parents.

“Finding the rhythm and maintaining the frame” were intimately interconnected because they described the processes of how children managed their circumstances both in terms of daily patterns and connections and in terms of overall safety and security. The children were simultaneously attending to safe and comfortable distances between themselves and their parents while managing the rhythms of their relationships with their parents. As described by this teenage girl, living with a parent with mental illness is like dancing. The child attempts to follow the rhythms and the steps, and tries to keep the frame with the parent in order to move forward smoothly.

I don't know. Uh. Dancing. Like uh. I guess I'm trying to go smooth with her, sometimes mess up, and then I've messed up. I think, I guess. . . . Uh well, I guess like when you, when you're dancing, it's like, when you're, I guess dancing good, like everything's okay like you're, everything's going fine. That would be like if everyday everything's okay with your mom. And then uh say someone missed a step and then, . . . and then she like gets depressed and then you sort of have to deal with like, I guess learning to, . . . learn that step so that, like I guess what made her depressed and then to deal with that and then you go on and on, I guess (Interview 15/2, Girl, Age 14).

The children used both these BSPPs of “finding the rhythm” and “maintaining the frame” to try to attain particular outcomes, beyond the goals of each process. These outcomes were connecting with their parents, and establishing an identity. The outcomes were achieved in varying degrees depending on the children's circumstances, efforts, and their levels of support.

Overview of Fitting In

The children were also affected by the macro societal influences, such as school and community, and the expectations that these areas placed on children and their families. “Fitting in” was the basic social condition that affected these children's efforts to “find the rhythm and maintain the frame”. In “fitting in”, the children considered how they were measuring up in the

outside world and whether they could “fit in” with external social expectations and rules, that they could perceive as challenging for them and their families. The children described how “fitting in” affected their efforts. For some children, structural conditions such as poverty, created more strain in their efforts to adjust to mental illnesses in their families while meeting additional societal expectations of “fitting in”. These children’s family circumstances, in terms of their parents’ mental illnesses, sometimes dictated that they moved, changed schools, lost connections with friends, lost resource teachers and support systems. In other family situations, children were unable to participate in organized sports and leisure activities. Other children needed to adapt to altered family configurations. Even when changes to their lives were out of their control, the children felt that institutions, outside of the family, such as school, still expected them to “fit in”. Thus children, while “finding the rhythm and maintaining the frame” with their parents, were also expected to “fit in” with larger societal expectations placed upon them and their families.

This concludes the section which briefly describes the BSPPs of “finding the rhythm” and “maintaining the frame”, their stages and properties, and the social structural condition of “fitting in”. An in-depth discussion of each part of the theory follows, beginning with the BSPP of “finding the rhythm” and its stages of “monitoring” and “adjusting”.

Finding the Rhythm

“Finding the rhythm” (Fig. 5.2) represents the children’s efforts to manage their daily rhythms and their rhythms in their relationships with their parents who were diagnosed with a mental illness. These children could not predict when the nature of their relationships with their parents would be changed by symptoms that arose from their parents’ illnesses. Equally, they could not predict when their regular routines and activities, if they had them, would be disrupted by exacerbations of their parents’ illnesses. Within the trajectory of the mental illness, parents’ behaviors could change dramatically or there could be subtle changes. The children were often

exposed to a new pattern of behaviour and did not have experience in that set of circumstances to find the rhythm with their parents. There were variations in how hard the children had to work to find the rhythm. The changes in relationship rhythms and day-to-day rhythms not only affected these children, their families, and their parents, but also affected and were affected by the ways in which they connected with the outside world, e.g. school, friends, extracurricular activities.

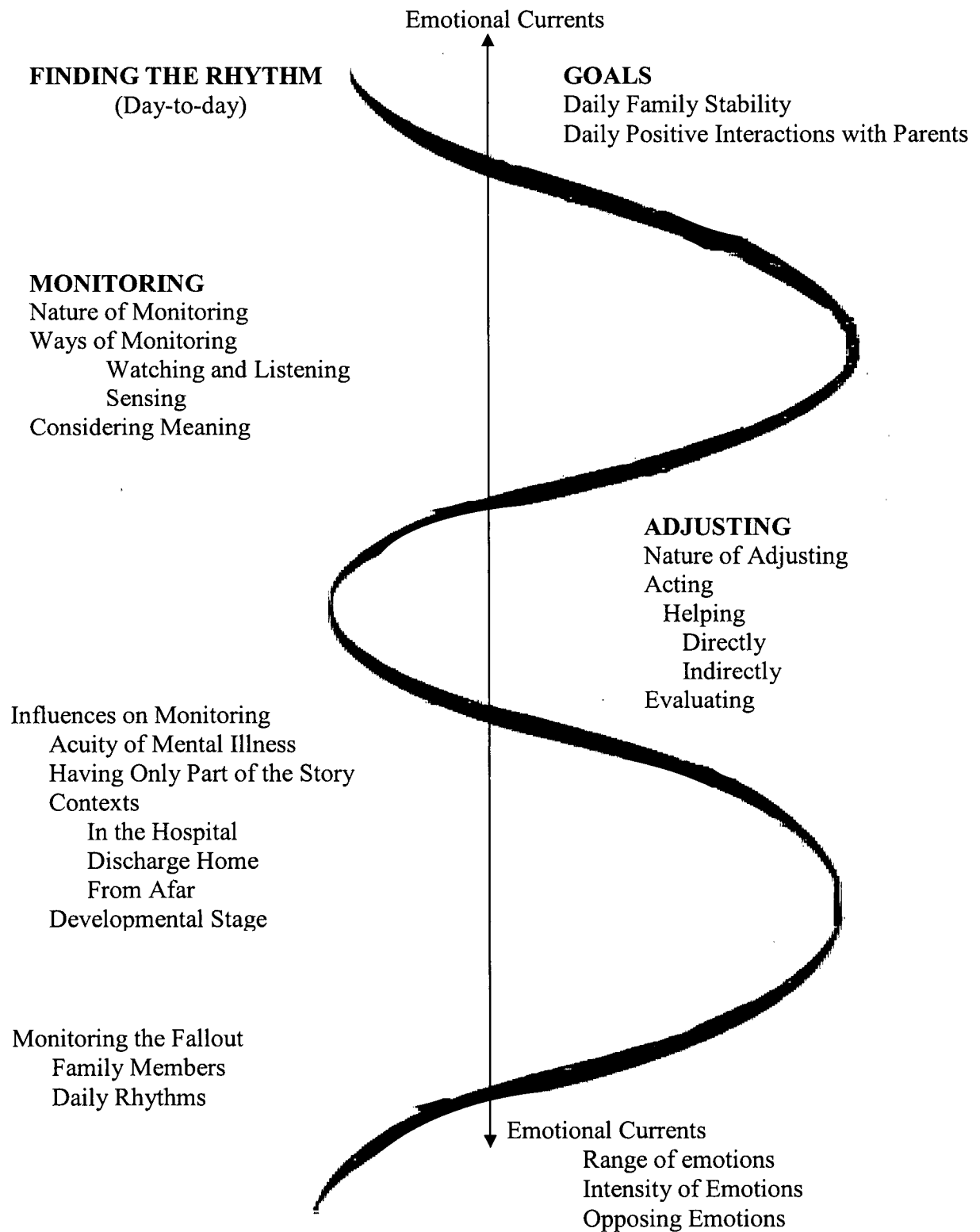
Interactions with other people from outside or inside the family either facilitated or hindered “finding the rhythm”. For example, some fathers and mothers separated and moved to different locations, which forced children to choose between their parents. In other cases, children were removed from the home by the authorities in order to protect the children, without awareness of the efforts children were making to find a rhythm with their ill parents. Some children indicated that they were afraid to seek outside help while they tried to find and maintain a rhythm, because that help might result in them being removed from their parents’ homes and terminate their efforts. Knowing about mental illness, in the form of information shared by people from inside or outside the family facilitated rather than hindered children’s efforts to find the rhythm with their parents. Knowledge about mental illness helped children put their parents’ behaviours in a context. This facilitated their recognition of symptoms while “monitoring”, helped them with strategies for “adjusting”, and helped them get some sense of what was under their control and what was not. Some children recognized there were symptoms that did not respond to their efforts to adjust their behaviours and it was not their fault that the situation was worsening. Knowledge about mental illness also helped children to find the rhythm with their parents without fear that their parents were dying when they were hospitalized. The children indicated that knowledge in the form of information from outside the family was not as effective as receiving knowledge about the illness from the parent with the mental illness or the well parent and openly communicating about it in the family setting.

Like they (parents) told me everything you know. Like what's inside their head and like they explained everything. And it actually like helped me a lot and . . . I used to get mad at her and . . . I was, like I just didn't understand and of course that makes it harder for her right. So it made it a lot easier in once they explained it (mental illness) to me and I processed everything. And I, I had the patience to like understand and I just hope that other kids, like are like that. Cause it's like twice as hard on the parents when their kids don't understand so (Interview 16/1, Girl, Age 16).

In "finding the rhythm", the children in this study monitored their parents' and family members' behaviors and the daily rhythms of their lives. They then adjusted their behaviors and their environments. These children monitored by watching for cues in their parents' expressions, interactions, activities, and mood. They noted alterations and tried to attach meaning to those in terms of whether the illnesses were worsening or something else was happening to their parents. The children also used other sources to assist them with their "monitoring", such as extended family members and well parents. In response to their decisions about what was happening, the children adjusted their behaviours through a number of strategies, e.g., providing comfort for their parents, withdrawing from the situations, protecting their younger siblings, and refraining from fighting with siblings. They also adjusted their environments by removing potential irritants to their parents such as mess and noisy video games. "Finding the rhythm" in day-to-day activities, which involved the children helping to establish some routines and get household work done, minimized the difficulties associated with the mental illness trajectory for themselves, their parents, and siblings. The children believed that by "finding the rhythm" they could decrease the effects of the illnesses on their parents and on their own lives, and alleviate their parents' suffering. "Finding the rhythm" helped children to connect with their ill parents and preserved their love and caring.

The children found the rhythms while navigating the "emotional currents" that ran

Figure 5.2 The Basic Social Psychological Process of Finding the Rhythm



throughout their lives. Those emotions moved over the “bedrock” of what most of the children would describe as love and caring for their parents. Most children indicated they valued their parents, recognized their contributions to their lives, and their efforts to help them. Their positive emotions motivated the children to keep trying to find the rhythm in relationships with their parents on a daily basis and over time. Nonetheless, on that bedrock were layered emotions such as anger, despair, pain, sadness, hostility, frustration, confusion, pride, inspiration, fear, sympathy, anxiety, hope, and, in one case, loathing. Navigating the “emotional currents” affected how these children found rhythms with their parents through “monitoring” their parents’ behaviours and their environments. The “emotional currents” also affected how they adjusted their behaviours and their environments.

And like they (people with mental illness) can’t do things. . . I don’t know, sometimes she (mother) gets upset like a lot easier than when she’s not being depressed. . . It’s not really good, but when that happens, I just I don’t know, I try to adapt. . . If it’s sad, like if we’re in a fight or something, I usually like go out or something. And when I come back I’m happier, and like, I bring happy with me so maybe I could like spread it and share it and stuff like that (Interview 15/1, Girl. Age 14).

The children’s love for their parents allowed most of them to recognize and appreciate their parents’ suffering. Nonetheless, the nature of their “emotional currents” and their intensity affected how they interpreted their parents’ behaviours and how far they were prepared or able to go to adjust to these behaviours.

Stages of Finding the Rhythm: Monitoring and Adjusting

“Monitoring” and “adjusting” were the stages of BSPP “finding the rhythm”. The children “monitored” and then “adjusted” to the behaviours of the parent when the parent became ill or when children thought that was the case. These stages also took into account the daily routines and rhythms of the children’s lives because it was more difficult to find a rhythm

with their parents when their family lives were chaotic and unpredictable. The following section will discuss the nature of “monitoring”, ways of “monitoring”, the meaning of “monitoring”, influences on “monitoring”, and “monitoring” targets. Following “monitoring”, I will discuss “adjusting” under the headings of acting, helping directly, helping indirectly, and evaluating. I will then discuss the goals of “monitoring” and “adjusting” and provide a summary of the stages of “monitoring” and “adjusting”.

Nature of Monitoring

The children initiated “monitoring” in response to their need to know what was happening. The children monitored cues in their parents’ physical appearance, interactions, activities, and mood, in addition to changes in the daily rhythms of their lives. They noted alterations and decided whether the parents’ illnesses were worsening or something else was happening to them. In order to monitor, children watched, listened, and sensed what was going on around them. They then considered the meaning of what they monitored. The children also used outside sources, such as extended family members and well parents, to assist them with “monitoring”.

At times the children inadvertently monitored, overhearing conversations in situations where they could not help but do so. Several children described these situations while playing or resting in their homes. One child described how he knew his mother was ill when she called her mother and stayed in her room:

Sometimes I’m sitting on the rocking chair watching TV and I can still hear her (mother) I’m usually playing on the ground so I usually hear through there (vent), cause it (sound) goes right through. . . . But sometimes she doesn’t come out, (of her room) and she’ll call my grandma. . . . I just get really sad that she won’t come out and. . . . When she phones my grandma, she’ll always say “Hi Mom,” cause it’s her mom and that’s how I know (Interview 22, Boy, Age 7).

Inadvertent “monitoring” often triggered self-initiated “monitoring” of the parent. As children recognized changes in their parents’ behaviours, they increased their monitoring and noticed things like “they (parents) lose interest in things that they used to like (Appendix X)... and they get sadder and sadder” (Interview 08, Girl, Age 10). Part of this child’s drawing illustrated how the parent was usually interested in ladybugs the child showed her, but when depressed displayed no interest.

A child who had been exposed to several exacerbations of the illness, recognized patterns and quickly picked up cues during “monitoring”.

I’ve seen him so many times when he’s in the hospital and what he’s like the day before he goes to the hospital and stuff... He sleeps like till three in the afternoon. And he wakes up and he just smokes and drinks coffee and walks around and lies down on the couch.... cause he’s always like sleeping (Interview 10/2, Boy, Age 14).

The children monitored the intensity of the behaviour to determine the severity of the illness and if the symptoms were worsening; “. . . Like it usually doesn’t get very, like that bad (as it did)” (Interview 15/2, Girl, Age 15). The children questioned their parents about their day; “and I asked her ‘How’s your day?’ and it wasn’t that bad...usually she says ‘Oh I was so tired’ ... she says it wasn’t that bad, so I know its (light therapy lamp) helping a little bit” (Interview 17, Girl, Age 10).

Many children were aware of their parents’ routines and recognized unusual patterns of behaviour or strange behaviour that might signal illness and an impending disruption in their daily rhythms. “He’s weird. Like he’s really weird. . . He doesn’t know what he’s saying and stuff” (Interview 11/2, Boy, Age 11). The children, who were as young as seven, independently monitored for signs that their parents might be unwell. These signs could signal further disharmony would develop in the home, such as fighting or parental distress, leading to disruption in the rhythms of daily life and also the parent/child interactions. The children noted

“Usually it’s (when mom is sad) like ...cause my mom and dad sometimes have fights”

(Interview 22, Boy, Age 7). Because the children recognized that household rhythms changed when their parents were ill, that was part of their “monitoring”. The following quotations illustrate some of the rhythms that children monitored:

“There’s something funny about the cleaning, I have to clean up lots” (Interview 22, Boy, Age 7).

“We always eat dinner together It’s really important in our family. . . She’d be sleeping at 11:00 o’clock and that’s not her, that’s not normal” (Interview 16/1, Girl, Age 16).

The children were astute at “monitoring” changes in their parents’ daily rhythms.

Sometimes the well parent requested children keep watch on the ill parent and report back to the well parent. As the following two children noted:

When he’s not being himself. She (mother) like kinda talks to him and tells him. But my dad, when he’s not his usual self, he’s like, oh I’m not sick, I’m not sick and then. . . he’s going constant, he’s just like groaning. . . . He’s not being himself. Well my mom tells (us) and then. . . We talk to her about what we see. (Interview 11/1, Boy, Age 11).

I probably wouldn’t have done that (checked up on mother) if he (well parent) didn’t, if he didn’t, say you need to go home and you need to be with your mom. . .

(Interview 16/1, Girl, Age 16).

When the well parent requested “monitoring” it could increase the children’s concerns, depending on how the well parent explained the situation. Requested “monitoring” also had the potential to assist children to find the rhythm with their ill parents under unusual circumstances, such as when their parents were discharged home but still unwell and children were required to monitor their parents’ safety.

Some ill parents triggered “monitoring” by telling children that they were unwell. The children learned to incorporate signs of changing behaviour and mood into “monitoring”; “I didn’t know why then, like the second, third and fourth (time) I started to get to know ” (Interview 10/1, Boy, Age 14). If daily rhythms were not predictable in the home, children were still aware of the parents’ usual habits. As this adolescent girl noted:

She doesn’t usually go out very often. She’s got lots of doctors. She goes to the doctors and stuff. . . .We don’t usually like eat supper at a table, supper table or anything like that. It’s just casual; whenever we’re hungry...I don’t think I’ve ever like done that on a regular basis (Interview 15/1, Girl, Age 14).

The children monitored changes in their parents’ behaviours and also in the rhythms of their daily lives because changes alerted them to exacerbations in the illnesses and difficulties in “finding the rhythm” with their ill parents.

Ways of Monitoring: Watching, Listening, Sensing

In order to monitor, the children in this study used methods such as watching, listening, and sensing in strategic ways. They watched and listened for signs of changes in parental behaviours, daily rhythms, and family dynamics. In sensing, they described tapping in to their feelings of whether something felt right or wrong, without being able to articulate clearly how they did that.

Watching and Listening

These children monitored by watching and listening for changes in their parents’ behaviour, affect, and cognition. Once exposed to symptoms of illness, they monitored for particular behaviours that they had previously seen at difficult times. The children described what might be considered as classic signs of mental illnesses. These were changes in parents’ demeanors, actions in terms of drinking or personal hygiene, and attentiveness. Several children noted such behaviours:

There's when they're always sitting alone. Like they're by their selves. . . .That's another sign I think. And one more sign is when like you talk to someone and, like; it takes them a while like to register what you ask them (Interview 03, Boy, Age 13).

That was actually, that was one thing I could tell, when she was, when she's getting upset was, because she would drink and she doesn't drink. She'd drink and she'd start saying, like, really like depressing things and then . . . I'd be like, okay (Interview 16/2, Girl, Age 16).

Um. The way he looked. Like he's just like, mad like. He's just mad. Yeah. He just looked so different. Yeah... Uh, kind of scary. Um. Well, his posture. . . .Well, he just slumped down, but then, like, as he got better, I guess . . . straighter, like he actually, he combed his hair and that (Interview 10/1, Boy, Age 14).

Some events left strong impressions on children regarding their parents' abilities to parent.

I remember when "A" and I were little kids, and I was about 3 or 4, she (mother) was um just sitting there totally blanked out and my sister was screaming and crying because uh, my older brother was ah making fun of her or something and she was trying to get to my mom and he wouldn't let her and she was just sitting there and doing nothing at all. Just.... blanked out (Interview 19, Boy, Age 16).

Seeing their parents acting strangely increased children's need to monitor. For example, "Uh she just starts twitching and stuff. Like if she starts pacing around like walking back and forth. (saying) Like everything's okay, everything's okay" (Interview 13/2, Girl, Age 11). This behaviour triggered the girl to observe more closely. Other children observed the following behaviours in their parents:

The way I see it is, she has really highs at times, she's like we're doing this and we're doing that and we're going on vacation. I'm like, really. And then, there's lows, where

she doesn't even get out of bed. (Interview 16/1, Girl, Age 16).

And when he's manic, he'll be up all night and he'll be kinda edgy and stuff...he'll be starting arguments and stuff. . . . it's like his mind is racing. . . . it's full of ideas and stuff and he just, he just doesn't care (Interview 10/2, Boy, Age 14).

For many of the children, particularly younger children, the first sign they monitored was their parents becoming irritable with them. Younger children noted this behaviour as well as sadness and "sometimes they get tired" (Interview 04, Boy, Age 6). The children experienced parents as grumpy, angry, yelling at them, and becoming easily upset; "She flips out" (Interview 08, Girl, Age 10). This was common in both mania and depression. Some children were protected from parental problems, sometimes by their well parents and at other times by their ill parents, as best they were able to protect their children. Some situations were more challenging for children to interpret what was happening with the parent. Two siblings noted:

Sometimes she snaps like. If she sees something it like makes her like really mad, she'll just like snap all of a sudden. . . . Well like, she's all happy and then all of a sudden she gets mad. She all, just like, starts getting mad at me and stuff (Interview 13/2, Girl, Age 11).

I agree, like she'll get just really mad for no reason. Well she thinks it's a big reason but when you look at it, its stuff she usually wouldn't get mad about. Cause she's like a pretty nice mom (Interview 14/2, Boy, Age 13).

Another younger child noted:

I like, it is better . . . when my Mom is smiling, not yelling at me. Because she's pretty upset and stuff. Because she's sad because I don't keep my room clean so, she gets really sad and she starts yelling but she said she promised she wouldn't spank (Interview 01/1, Girl, Age 7).

The children also monitored their parents' handling of day-to-day issues around influencing factors; "It's kinda hard to like [get] hold of good jobs and stuff like that" (Interview 09/1, Boy, Age 16). The children were aware of the difficulties their parents experienced and any changes in their daily rhythms and, at times, medication use.

She usually stays in here. She takes lots of naps during the day and I don't know, there's lots of medication around, all over...She has a little pillbox, that she fills up everyday kinda thing... She stays in here watching a movie. She colours a lot (Interview 15/1, Girl, Age 14).

The parent's colouring was a new behaviour that the child interpreted positively as the parent was previously artistic.

Sensing

At times, the children described "knowing or having a feeling" that something was different with their parents, without being able to articulate how they "knew". In families with siblings, the older children identified that they "just knew", while the younger children did not always know yet; "My brother is and I (am aware), my little brother, no, not always" (Interview 06, Boy, Age 13). Some of the children firmly believed that their abilities to sense were accurate in terms of "monitoring" parental behaviour. They trusted their senses even when their parents stated that nothing was wrong. Despite their parents denying that they were ill, children were convinced otherwise.

I would just ask her what's wrong. See if she's okay. Usually she'll just say, 'Oh, I'm fine, blah blah blah. She won't really tell me. She doesn't want me to know or whatever. *But I know something's wrong (italics added)*...I knew there was something wrong... just knew (Interview 19, Boy, Age 16).

"Monitoring" by sensing developed over time. It developed from an ability to be aware of cues that their parents were becoming ill and a limited ability to articulate this, within the

children's developmental levels. Even older children who knew something was wrong were not always able to explain why they believed this, other than stating they "just knew". Levels of sensing were partially dependent on the children's environments and interactions; for example, some children were protected from the illness by older siblings. The greater the number of exacerbations of the illness the children witnessed, the more they were able to accurately sense what was happening and sometimes to name it. "It was really dark in the hallway. So she was there panicking. Like I knew she was gonna have a panic attack." (Interview 13/2, Girl, Age 11). The children had confidence in their sensing abilities; "Yeah cause I know, I know my mom real good" (Interview 14/2, Boy, Age 13).

At times, sensing allowed children to suspend "monitoring" and entrust their parents to others, because they felt that it was safe to do that.

I have a feeling that she'll, that she will be safe. Safe from anything. It makes me feel good that she's . . . Safe from, safe from anything. . . Yeah. Cause I know the people at work will take care of her and stuff and I know she'll be okay (Interview 01/2, Girl, Age 7).

The children also indicated when they sensed everything was alright "I knew she was being gonna be okay" (Interview 01/1, Girl, Age 7). They trusted their senses to monitor their parents' behaviours and to reach conclusions about their parents' risks.

Considering Meaning

When the children considered meaning they interpreted the behaviour that they were "monitoring". Considering the meaning of the parental behaviour, in the context of the parent/child relationship, was the bridge connecting "monitoring" and "adjusting". When parents were ill, they had less capacity to align their acts with those of the children; therefore, these children had to work harder to interpret what was happening so that they could find the rhythm in their relationships with their parents.

At times, children assigned meaning to parental behaviours based on their knowledge, and at other times they were forced to guess. The children sometimes did not know how to interpret what was happening, for example, when there was fighting, irritability, and suspiciousness. After several exposures to these patterns of behaviour and explanations from other sources, they were able to consider them as signs of upcoming illness. Some children wanted more information about the illnesses to help them consider the meaning of their parents' behaviours. It was difficult for most of these children to get further information. One boy struggled with this and did not see any way that he would be able to get more information.

Cause my father has the illness...I'd like to know more about it. I gotta understand it more. I wanna know symptoms of it. I'd like to know what way to...try to prevent it. . . . If I go to a hospital to talk to a mental illness doctor there, he'd probably just tell me to get out of here, we're too busy or something like that (Interview 09/1, Boy, Age 16).

Similarly, another sibling stated:

They (adults) don't get them (children) help. They don't speak to them about it. They don't speak to the kids about it....They (children) should know that, if he has a illness...if he had that illness he wouldn't be himself, *like right away you'd see it like this. Then he'd just stop being himself. He'd like try to make trouble (italics added)* (Interview 11/1, Boy, Age 11).

Parental behaviour that was contrary to what the child believed was acceptable or what the child had been taught to do themselves by their parents was puzzling for the children in terms of assigning meaning. For example:

When my dad started, when we brought him to the hospital the second time, or the first time, I don't know, I think it was the second time, uh I think he was a little bit, smoking something and it triggered something. . . . But then he told me, I remember that time I

got really paranoid (after smoking drugs), it was like he's telling me not to do this because he knows that it'll like alter my mind (Interview 09/1, Boy, Age 16).

In circumstances where children had difficulty assigning meaning, "finding the rhythm" became more challenging. If these children were unsure how to assign meaning to their parents' behaviours that they had monitored, they were unable to move forward. The unpredictability and range of behaviors associated with mania were particularly confusing for children to interpret; "He was crying all the time, he was happy one minute, he was laughing one minute, then he was right down crying again" (Interview 09/1, Boy, Age 16). The children struggled to decide if their parents' behaviour was part of their mental illnesses or an overreaction to household situations.

Yeah.... she's like um.... I don't know what the word is, but she, there's sometimes they're different um like things the symbolize mental illness (symptoms) or whatever. Like before she might do this and like for a while and then she might do this other thing for a while. Like she might be crying for like a couple months straight, and then she might uh be nervous instead of crying or whatever (Interview 14/2, Boy, Age 13).

In the process of assigning meaning, children recognized the actual and potential loss of their parents to them and also the suffering of their parents due to the illnesses; "You won't be able to talk to him if he's not on his medication, sometimes you just can't when he is not on his medication" (Interview 10/2, Boy, Age 14).

Like I don't know if she was just like just so, so bad, like, talking about like, wanting to like, slit her wrists or something and like, and I didn't know, I didn't know what to do (Interview 15/2, Girl, Age 14).

In assigning meaning, children considered what their parents' behaviors signified so they could make sense of what was happening and use what they understood to decide how to help themselves, their parents, and their families.

We don't think she's sad cause she's, she doesn't have a sad face. But then we hear her just start crying. And then we go in there. Me and my dad (Interview 22, Boy, Age 7).

The children became adept at interpreting signs of mental illnesses. They recognized changes in affect, behaviour, concentration, spontaneity, and triggers for anxiety; however, some signs of mental illness could be difficult to discern. The children verified their suspicions with their well parents, if available, and with further "monitoring" of their ill parents. The children noted any changes in parents' behaviours, which could mean their parents, were improving or slipping. This child was perplexed with the unfounded accusations of the parent, a sign that the parent was becoming ill.

And that was when I knew, I, I said to myself, I'm like, this is not her, this is her sickness. And she, we had come home from the lake. She just had this crazy idea that I had a party, which I really; I honestly did not have a party. And she just had this idea in her head...and then she starts fighting with my dad and then she's like, 'your father just kicked me out, I'm leaving forever.' And, it was like, 'What are you talking about, Mom?'(Interview 16/1, Girl, Age 16).

When parents made false accusations, children interpreted that behaviour as an indication that their parents' word could not be trusted and that their parents' abilities to parent consistently were diminished. Regarding her mother's suicide attempts, one child described her experience as "Like the first time (suicide attempt) I was like, I was, like, really, I understand, and she's like, I won't do it again I promise. But it happened 5 other times" (Interview 16/1, Girl, Age 16).

Unfounded accusations and untruths were difficult for the children to understand and reconcile. In considering meaning, children began to label patterns of those types of remarks.

Influences on Monitoring

"Monitoring" was influenced by the acuity of the illness, having only part of the story, and the developmental stage of the child. To "find the rhythm" with their parents, the children

monitored their parents' behaviours, which was challenging in complex situations generated by the illness trajectory, and other situational factors.

Acuity of the Illness

The intensity of "monitoring" behaviour depended on the acuity of the parent's illness and the disruption it caused to the rhythm of the parent/child relationship and to rhythms in family life. Unpredictable behaviour associated with the illness kept children on edge and increased their need to monitor. At times, the children found it almost impossible to find the rhythm in their relationships with their parents. Their "monitoring" helped them to determine when the rhythm in their relationships with their parents was totally disrupted. At these times, "finding the rhythm" required much additional effort from the children due to their parents' incapacity to contribute to the relationships meaningfully. The children described their own emotional reactions to constant uncertainty and "monitoring". This boy described being under ongoing strain due to the uncertain nature of exacerbations in the mental illness.

Frustration, nervousness. You never know when it's gonna pop up so. It's pretty much every morning and it varies from hour to hour, from day-to-day, from week to week.

It's always different so. Well like I said, it varies a lot so sometimes she is, sometimes she isn't so (upset) (Interview 21, Boy, Age 13).

In acute illness the children thought about the meaning, in terms of where their parents were in relation to the range of mood/behavioural outcomes that the children had witnessed; "... he's still kinda sick but I guess he's getting there. ... he's gotten better. ... he'll be back to himself. ... like happy, confident, has, has a job and everything" (Interview 11/2, Boy, Age 11). In acute episodes, many children noted personality changes which made it more difficult for them to find the rhythm.

Some illnesses were of a cyclic nature and occurred at certain times of the year. The children monitored not only their parents' behaviours but also changes in the cycles of their

parents' behaviours. Whenever the cycles changed they became worried that their parents were getting worse. As an adolescent boy noticed:

It usually comes in the summer but it really started this winter and it stayed since then.

So it's getting worse. Before it was just in the summer, but now it's been since the winter.

Since like November that it's been like this. . . . It's getting worse (Interview 21, Boy, Age 13).

When the parents were symptom free, "monitoring" was reduced, and "finding the rhythm" with parents became easier. The daily rhythms proceeded predictably and parents were more available as resources for their children. Parents were able to respond more appropriately and meaningfully to their children's efforts to have positive interactions on a daily basis. As parents become well, children monitored their levels of functioning. "She started part-time, just like 3 days a week. And it has just progressed and now she's working Monday to Thursday, 8 hours a day" (Interview 16/2, Girl, Age 16) and considered the implications of the differences in functioning not only for the parent but for themselves; "Oh yeah. It's just, good. Everything's so much better" (Interview 16/2, Girl, Age 16). At the times when the children felt the rhythm was maintained comfortably, they gradually decreased "monitoring" and enjoyed the respite from the acute illness.

Having Only Part of the Story

There was general consensus among the children that most children were not informed about mental illness. The children felt when adults did not talk about mental illness it suggested that mental illness was not important. Secrecy around mental illness also led the children to think, that having a mental illness was "bad" and must be hidden.

Well no, *I'm not thinking that's (mental illness) not important (italics added)*. It just seems like it's not important if people don't talk about it or learn about it, or know about it (Interview 15/1 Girl Age 14).

The children living with parents with mental illnesses felt that they knew more than the children whose parents did not have a mental illness, but that they needed more information about mental illness in order to monitor more effectively.

Being informed about the mental illness made “monitoring” easier because children were not left to draw their own conclusions. Often some children thought there was something else wrong and ascribed different meaning to their parent’s behaviour. Uninformed children described worrying about their parents dying.

Well, dad’s sick, but, you know it happens again and again and again. And the kid, you know, you eventually start thinking well there’s something definitely not right here, you know, either my dad’s dying or there’s something you’re not telling me” (Interview 07, Girl, Age 16).

Often the children were not given information by their parents about the illnesses. This young girl described her experience when her mother was ill; “She didn’t really tell me. She was talking about it and I was sitting beside her giving her a glass of milk and giving her lots of huggies” (Interview 01/2, Girl, Age 7). In this situation, although the mother was acutely suicidal, she talked to the child in vague terms leaving the child to wonder what was actually happening.

Although most of the children were “monitoring” their parents’ behaviors, cognitions and affect with limited factual information about what was happening, they believed that having information about mental illness was important for “monitoring”. They felt it would help them to consider the meaning of behaviors and to reduce their fears about the unknown.

The kid will say, you know, that’s some part of the disability. I should ...call someone.

Well yeah. And I think it’s better for them (children) to know ahead of time. Cause ... a lot of times you’ll ask what’s happening with somebody ... even if it’s just an aunt or an uncle, or your grandma or grandpa and a lot of time there’s apprehension

cause your parents don't want to tell you cause they think you're too young, you're not mature enough to hear it. . . . And they don't want to cause you any stress or whatever but it causes, I don't think parents realize this, but *it causes more stress not to know, not knowing what's going on. Just because . . . you're kind of left in the back field . . . and you don't know what's going on. And so you're kind of lost as to what's happening* (*italics added*) (Interview 07, Girl, Age 16).

Having only part of the story added to the complexity of "monitoring" for children. Younger children often equated being ill with being physically sick, not necessarily seeing the mental illnesses as sickness, even though the mental illness greatly compromised the children's lives. They had difficulty in putting the pieces of the puzzle together with limited information.

Uh. . . it's (mental illness) like you can't like walk or anything, or you can't see, or you can't like talk or anything, say hello. I don't really know what it (mental illness) is. Uh. (well parent told child) that he (father) was smoking and that he was coughing all over so he had to go to the hospital. That everything's gonna be alright with Dad (Interview 12/1, Boy, Age 9).

For some children, participation in the study opened discussion about mental illness in their families. One child described how her parent had explained depression to her prior to the interview. Previously her parent had not spoken to her about the illness.

Well it's like, when you think that you don't exist, you don't want to exist, and you think your worst and you're not even supposed to be here and you think that you can't do anything and people just push you around and all that and you just don't do anything about it (Interview 17, Girl, Age 10).

This description by the ten-year-old girl captured her parent's experience. This child had limited information previous to the study and had been unclear as to what was happening to the parent.

Contexts

The contexts, wherein “monitoring” occurred, became more important when the parent was hospitalized, discharged home, or when the children were removed from their homes. These changes in context disrupted the rhythm in their relationships so that “finding the rhythm” with their parents became more fragile, tenuous and largely controlled by others.

Parent in the hospital. With the hospitalization of their parents, the children were in situations where control of “monitoring” was now in the hands of strangers. Prior to hospitalization, the acuity of the illnesses necessitated that children intensely monitor their parents and the daily rhythms in the family. Daily rhythms were often interrupted by family arguments and unreasonable requests by their ill parents. More frightening for the children, was the deterioration of their well parents under the strain of the situation; “and then my mom gets all down and all that... she has to do all this extra work” (Interview 12/2, Boy, Age 9). It is “Bad, sad and unhappy that she (well parent) is all alone at home” (Interview 12/1, Boy, Age 9). The children in this family switched their “monitoring” to the well parent during their ill parent’s hospitalization. They looked for signs of stress, which was worrying when they only had the well parent holding the family together.

Hospitalization sometimes meant these children were removed from their family homes, resulting in major changes in their daily rhythms; “I don’t get to see the cats very much when I’m not allowed in the house...Every week I got to see her (mother) and every week I got to see the cats after that day” (Interview 20, Girl, Age 6). When the parent was in the hospital the child would monitor from afar for signs that the parent was all right and improving while the child navigated through “emotional currents” of fear and sadness; “It’s kinda hard not to think about it (hospitalization of the parent)...Like I was really really upset and cried. The first time it happened I didn’t know what to think” (Interview 16/1, Girl, Age 16). The children appreciated knowing what was happening and hearing how their parents were progressing. Having a parent

in the hospital, constituted a severe disruption in the rhythm with the ill parent. When parents were in the hospital younger children were concerned that their parents might die, “that Mommy will get really sick and die” (Interview 20, Girl, Age 6). The children attempted to monitor their parents from afar as best they could, but they were constrained by their physical locations and lack of information.

And you just know that he’s sick and stuff and I don’t know. He’s just at the hospital.

And you only have your mom and she’s like, it’s hard on her too. So, it’s kinda like seeing both my parents kinda down. (Mental illness is hard on) Yeah, marriage and family (Interview 10/2, Boy, Age 14).

The children monitored the impact of hospitalization on their families and were aware that the illnesses affected their families. When they visited the hospital, children attempted to monitor what was happening to their parents through their observations and asking others for information.

Discharge home. The children, who expected to pick up the rhythms with their parents once their parents were discharged, were often faced with puzzling behaviours of parents who were unable to engage in activities and conversations with them. Parents were attempting to resume their roles as parents while experiencing difficulties related to titration of medication, side effects, and remaining effects of exacerbations of their illnesses. The children monitored these situations because they did not understand what was happening; “No one cleans the house. Dad doesn’t help out anymore really. He’s lazy. That’s all” (Interview 09/2, Boy, Age 16). When the parent was recovering often the rhythms of the home were disrupted and family functioning was strained. Many children noticed that efforts to maintain daily rhythms were disrupted after parents were discharged from hospital.

My mom was keeping things in order then. But now both of them don’t even care.

... He should at least help to clean the house. The house is always dirty and everything.

All the kids are up till four and like the parents don't even have authority over their own kids (Interview 09/2, Boy, Age 16).

The children who were knowledgeable about the side effects of the medication were more understanding regarding their parents' conditions and less troubled by their parents' behaviours; "She's pretty tired cause from the drugs. She has to sleep a lot then" (Interview 20, Girl, Age 6). Knowledge of medication was not necessarily dependent on the age of the child. In this example, the younger child, aged six, had more knowledge of the medications than the sixteen-year-old child in the previous quotation, who did not understand that some of his father's behaviour was related to medication.

At times, the children believed their parents were still unwell and unsafe once discharged. They felt unsure of their relationships and how to find a rhythm with their parents and thus increased their "monitoring". For example, one adolescent girl came home daily from school to monitor her mother's progress and safety; "There's some days where I'll come home from school. I come home every day at lunch. Cause she doesn't like to be alone.....I couldn't leave her alone for one day" (Interview 16/1, Girl, Age 16). When the children and their parents had been separated for long periods of time the rhythms between them were further disturbed. When the parents and the children were reunited both partners needed to work at finding a new rhythm to their relationships.

From afar: child out of the home. Difficulties in "monitoring" also occurred when children were removed from their homes. Three of the children in the study had this experience. While the parent was hospitalized, one child described care by informal caregivers and another described being placed in foster care. In the third situation, the child lived in the detention centre. In these situations, "finding the rhythm" was difficult as the children had little control over contact with their parents. The child in foster care, described how she continued to monitor her ill parent from afar as best she could; "They (foster parents) didn't want us to see her. I

didn't like that. I used to call my auntie a lot that we stayed with first. . . (Children need to know) what's going on so that they know, like, how they're (parents) doing and stuff" (Interview 08, Girl, Age 10). Within the constraints of their situations, children attempted to monitor and find the rhythm despite being removed from the home. Even the child embroiled in the legal system still needed to know how his parent was faring despite the discord that had preceded his confinement; "I know my mom is gonna do good. I can tell she's already going to get that job and do all the stuff" (Interview 19, Boy, Age 16). Younger children, in general, had fewer options and skills to contact their parents. "Monitoring" was difficult for children out of the home, because the family had now become involved with another layer of systems, youth justice, child welfare, and psychiatric acute care services. The child/parent relationship now had rhythms imposed by others around getting together and interaction.

Developmental Stage of the Child

"Monitoring" behaviours occurred regardless of the children's developmental stages. In most cases, even young children became adept at "monitoring" the behaviours and mood of their parents. The ways in which meaning was assigned were partially determined by the options available to the children, which were restricted by age. Older children had more options to discuss their observations with peers and counselors and to be more able to put labels on what they were seeing than younger children. The level of "monitoring" also varied. Younger children were so pleased to have their parents at home; they sometimes could see nothing wrong, while older children became more critical of their parents' progress which increased "monitoring". While some younger children monitored less, they still adjusted to changes to find the rhythm with their parents. For some, lower levels of "monitoring" occurred because they had older siblings and families to monitor and to protect them. "I don't know if D. knows that though. My younger brothers, I don't think they know anything about that, like, that drugs can trigger it (mental illness)" (Interview 09/1, Boy, Age 16). Some younger children, as young as

age 7, but who were the oldest in their families, were more adept at “monitoring”. All of the children decreased their “monitoring” when crises were over. They were, however, sensitive to any upcoming signs of trouble at which time they again increased the intensity of their “monitoring”.

Monitoring the Fallout

In “finding the rhythm”, these children primarily monitored their ill parents, but they also monitored the effects of the mental illness, the fallout, on their siblings, their well parents, and the daily rhythms of their homes. They monitored other family members and daily rhythms to get a sense of how their families were managing.

Family Members

The children were able to recognize that the illness upset the whole family; “We were all down. That’s about it...like we were sad and, we sunk farther” (Interview 09/1, Boy, Age 16). The children were more likely to monitor family members whom they recognized as potentially fragile. “We’re gonna give auntie a break cause she doesn’t have to put up with the two *little ones* (italics added). . . . ‘been sad the last couple of days’ (Interview 03, Boy, Age 13). Several children worried about their siblings who showed signs of possible mental illness and monitored them for signs of problems.

But he’s (brother) kinda, he kinda has the traits of depression a little bit.

He’s really like, . . . not very much self-esteem. . . . But, minor. It’s not. It’s not a problem. . . . But I can just kinda see it in him” (Interview 16/1, Girl, Age 16).

Older siblings felt protective of younger siblings and were aware of their vulnerabilities.

“I don’t know, they’re (mother and son) both just really depressed. He takes on, he takes after her. . . . He has anxiety problems. He never like, for like 3 or 4 months he’d never leave the house or do nothing. He’d get like really nervous around people and stuff so (Interview 19, Boy, Age 16).

“Monitoring” family members added more responsibility to the children’s lives.

When children had their well parents living in the home they also monitored them. The children were generally aware when their well parents were burdened, as opposed to when they acted as strong role models. In one family, where the well parent was vocal about the burden of the mental illness, the children monitored intently for signs of family disharmony and marital breakdown.

My mom gets all down and all that . . . my mom, she’s all depressed, too, I guess. She has to do all this extra work and that. . . Yeah . . . I didn’t want her to get like; I didn’t want her to break down or like that. . . Cause like I know . . . my mom now won’t go away or anything like that, or take off. . . she like sometimes she feels like she’s gonna do that but she doesn’t, cause she knows what will happen to us (Interview 11/1, Boy, Age 11).

The children monitored their well parents’ reactions to their ill parents for signs of family disharmony. Where the well parents presented as strong, children tried to mimic their parents’ reactions to their ill parents. They believed their well parents could handle it and this helped them to find the rhythm with their ill parents. One young girl described how her well parent, her father, helped her and her sibling when explaining the picture she had drawn (Appendix Y).

I think he’s helped us a lot, being calm, and um like that. He’s like so used to it that . . . He said ‘it’s okay’. . . and then, it (Appendix Y) says ‘she’s panicking’, and then he said ‘Oh brother!’. He’s taking it seriously, but he’s not like. He’s not as worried as we are. Yeah he says, I don’t know, he tells us not to worry too much because, I don’t know, he can handle it later, but just don’t worry about it (Interview 13/1, Girl, Age 11).

When children monitored their well parents they sometimes learned strategies to manage their situations. At other times, “monitoring” their well parents increased their concerns about the stability of their family situations and whether their families would remain intact.

Daily Rhythms

The children monitored the daily rhythms and routines in their lives. They were aware that disruptions to the daily rhythms arose from the mental illnesses. They were also aware of the strain this caused in their families, and of their need for additional help. The disruptions threatened the existing household rhythms and routines, which helped to make children’s lives manageable. At times these disruptions even placed the children in dangerous circumstances.

Yeah. Like before when there used to be like 5 of us living there. I don’t know, we’d always be fighting all the time. Me and my brother and sisters. Then my sister started bringing her friends over and they’d drink and do drugs and all that. My mom couldn’t really do anything about it because she’d be depressed, she didn’t know what to do, right. So she’d . . . sit back and pretty much watch it . . . But I couldn’t really sleep then. I think every night there’d be loud music and people running around my house and crowds banging at the door all hours of the night. My brothers bringing back guns to the place and . . . alcohol and doing beanies and bringing all this stolen stuff back (Interview 19, Boy, Age 16).

The children defined daily rhythms as stable or chaotic. In describing their stable rhythms, children cited bedtime and morning rituals which provided a sense of safety or a sense of certainty. This young girl described a fairly predictable daily rhythm to her family life.

Well. First, we wake up and then have breakfast and then get ready for school and then we go in the bathroom and brush our teeth and then we get our bikes ready and then we go to school. . . Usually my Mom does, but I usually get my own breakfast when I don’t have to rush to school . . . Well, the weekend is I go with my dad. Sometimes on the

weekend and we buy chips, we buy pop corn, we buy drinks, we buy my favorites things and we watch me get movies, and then we get to watch Goosebumps or Mr. Bean because that's my favorite one, the Church one (Interview 01, Girl, Age 7).

Other children experienced more chaotic daily rhythms in their formative years. One boy described how his mother was unable to act due to her depression.

We just knew. She wasn't going to do anything about us if we didn't go to school, so we didn't. She was just tired. She doesn't want to do anything. She just wants to sit there and sleep. So we just pretty much go upstairs and act like we're not there. . . But she didn't answer the phone . . . well if that happens for a long time, a truant officer would come andI don't know. . . Eventually we got to know that guy pretty good. . . . Then we'd go to.... school for like a while and then, I don't know, me and my brother would want to screw around so we'd skip school. *(In grades 3 – 5 italics added)* But then eventually it got worse though. *When we were kids . . . we just like rebel against her. Like she'd say, 'go to school now' and we'd say, 'no'. But we didn't want to go to school, cause we'd get used to not going to school (italics added)* (Interview 19, Boy, Age 16).

For some children, the disruptions that occurred with more acute episodes of mental illness were a continuation of instability in the family home; for other children, the disruptions were a departure from stability.

Well, we wake up around 7:00 in the morning and we're at school around 8. And school starts around 8:30-9:00. It's alright. And I like my school; . . . me and J. go to the same school. *Before he (father) lost his driver's license, he drove us all the time. And he doesn't anymore. (italics added)* We just, me and J, we just take the bus now (Interview 11/1, Boy, Age 14).

The children's daily rhythms were affected by changes in their parents' abilities; for example, in the preceding quotation, losing a driving license. This was a loss that made the family problems public and that greatly disrupted the rhythms of children's lives and reduced their ability to "fit in".

The children also monitored disruptions in family rituals such as birthdays and holidays. They were aware of omissions and changes, such as missed birthdays or subdued or forgotten celebrations; "So, I don't know. This year, like the year, this coming up year, I didn't even do anything for my birthday. . . .No. I never had a party yet or anything. Well whatever, it doesn't matter" (Interview 15/1, Girl, Age 14).

Through watching, listening, and sensing the children monitored not only their parents, but also the daily rhythms of their lives and the effects of the mental illness on family dynamics. They were affected by the acuity of the mental illness, availability of information, contexts, and their developmental stages. After the children monitored and considered the meaning of what they had monitored, they adjusted their behaviours to find a rhythm with their parents.

Nature of Adjusting

"Adjusting" was the process by which the children responded to the meaning they assigned to the events and the behaviours they had monitored. In "adjusting", the children tried to change their behaviours to find the rhythm, which had been disrupted by their parents' behaviours and illnesses. "Adjusting" included the properties of acting, by helping directly and helping indirectly, and evaluating. "Adjusting" helped the children to find a rhythm in their relationships with their parents and in some cases to re-establish daily rhythms.

Acting

The children took action in response to the meanings they assigned after "monitoring" their parents' behaviours. Their actions were influenced by their beliefs and knowledge about mental illnesses and by actions of stable adults in their lives. Most of the children acted by

engaging in what they perceived as helping behaviours. These helping behaviours, helping directly and helping indirectly, enabled the children to respond to their parents' behaviours and to the disruptions in daily rhythms to try to mitigate the problems so they could find a rhythm. The children engaged in helping their ill parents, and their well parents, their other family members, and themselves. They also helped to re-establish rhythms with the daily routines. The actions the children took were restricted by the limitations in their power and control over their situations and their understanding of what was happening, arising from their developmental stages.

The children in the study selected their actions based on the options available to them. The older children had a wider range of choices available to them than younger children. If the well parents were psychologically and physically available, the children sometimes opted to approach them. The children based their actions, partly on their parents' past responses, and partially on what they wanted to accomplish. If the behaviour was novel, bizarre, or particularly unreasonable, the children sometimes used trial and error to select an action. The children often had few supportive adults to help them; therefore, many children struggled to select the most appropriate action.

Helping

Most of the children acted to try to help their ill parents, well parents and other family members. They tried to re-establish the daily rhythms, to protect themselves and their family members, and to prevent situations from escalating, in order to find a rhythm with their parents. They tried to help both directly and indirectly. When they helped their ill parents, children claimed that they knew what their parents wanted as a basis for choosing their actions.

Well. I think that. . . whoever it is that has depression. Know ... what they wanna do. Like if they want you to just leave them alone for a little... to have some rest or quiet

time. Or maybe other stuff like um, just stay and try to keep helping and try to make them feel better. All different kinds of things. (Interview 22, Boy, Age 7).

The children believed, if they could try to understand what their parents wanted, they had a better chance of helping the situation. Their beliefs were evident in how they used humour, touch, and offered their presence. They understood that the timing of their actions was important.

Helping Directly

The children selected specific actions that directly affected their ill parents, their well parents, and other family members. Their specific actions with their ill parents consisted of offering comfort and affection, talking to them, sharing humour, being compliant, taking control and offering suggestions. The children tried to help by choosing to comply with requests from their parents and family members, as evidenced by a young adolescent boy who tried to help with medication compliance; “Yeah, like when there’s one (pill) left . . . and there’s only Sunday night bedtime pills left, we (child and adult in the home) would refill them for the next day” (Interview 03, Boy, Age 13).

Although the children had some choices, their ability to act was circumscribed by the power allotted to them within their families and society, in accordance with their developmental stages. For example, older children could go to the store to buy groceries while younger children helped by putting groceries away for their parents. The children at different developmental stages also used humour differently. Two young siblings described making their parent feel better by telling them jokes and tickling their parent. Two pieces of art with the children’s accompanying explanations (Appendixes Z and A1) illustrate the children’s actions.

“(That’s) his dad. Um, a table, talking about it (being sad) and all that. And his dad got happy when he (the child) was telling him some funny stuff. . . . The dad could tell him jokes back (Interview 05, Boy, Age 9). (Appendix Z)

“And trying to make him laugh. That’s what I do to my dad. Ah. Tickle him. . . . I’d just tell them (other children)...go and tickle them sometimes if they wanna be tickled.

...they (children) will ask the parents, if they say yes, they will get tickled”

(Interview 04, Boy, Age 6). (Appendix A1)

Older children also used humour in different ways than younger children. An adolescent child used the computer to make cards for his father and aunt who lived in the family home, both of whom suffered with depression.

When my auntie’s having a bad day. . . I’d send her a card. There’s this one card that I sent her. There’s this one from www. . . . That’s So Funny dot com. I sent her a funny one. . . I went in (the computer) and created my own little card for him (father) and it had him and it’s like ‘you work so hard, take a break, get a vacation, leave town for a while, get away from it all for a while. Like sit back, relax. . . . (Interview 03, Boy, Age 13).

In helping directly, the children tried to demonstrate caring. Younger children offered affection by sharing their toys and favourite stuffed animals and offering to play with their parents. They believed that these actions would make their parents feel better.

Give her a hug and a kiss (Interview 20, Girl, Age 6).

I hugged him, I kissed him and I watched TV with him. . . . Hug him, kiss him and help him with everything that he needs (Interview 12/1, Boy, Age 9).

Well I try to make her happy. Give my monkey to her and give her a glass of water and give her “Monkey”, my little stuffie. . . I always feel happy when I hold him and squeeze him. . . I had him . . . since I was two (Interview 1/2, Girl, Age 7).

Sometimes I um, take him for a walk and all that. To the park. . . Yeah. And he watches me an all that. Sit down and watch me and “A” and sometimes I tell him to push me (on the swing) and he’s all happy then (Interview 05, Boy, Age 9).

Older children offered caring to their parents through concrete activities and affection.

Like if my dad comes home and he's feeling sad from work, like he's sore. . . . So I boot up the computer for both of them [dad and aunt]. And I make them a pot of coffee. I would go get flowers for my auntie. Like, if there would be flower patches outside people's yard. I'd go plop, and give them to my auntie. . . And then ...sometimes I'll go and give them a big hug. . . . Take care of them. . . . Help around the house and cheer them up a bit. . . . If you have younger brothers or sisters, take them outside for a little bit. Go buy your auntie, dad, go buy them a card. Or like when you have the money, go buy them a couple of candles to cheer them up. And I have this Folger's can and I pour all the wax into it to try and make a big candle for my auntie...*help one another understand how you can help and how you can figure things out without going cuckoo (italics added)* (Interview 03, Boy, Age 13).

When helping directly the children comforted and gave affection to their ill parents, by offering small gifts and cards and physically assisting their parents. "Help her. Yeah. To the couch. Sometimes, she just goes to the couch and has a sleep" (Interview 06, Boy, Age 14). The children also complied with their parents' requests. By doing as they were told, children hoped to mitigate their ill parents' problematic behaviours and to stop situations from getting worse. The children described how they took on extra chores to please their parents.

And bring my clothes down, she asks me to bring the clothes down. Usually she asks me if I can get a can of tomato or something, some soup. She asks me to go downstairs and I do it for her (Interview 17, Girl, Age 10).

Well, whenever she's like that. I usually just try to; I'll talk to her and ask her if she needs anything done around the house or something usually. . . I just be extra nice to her I guess (Interview 14, Boy, Age 13).

In addition to helping their ill parents, most children helped their well parents to try to prevent further family problems. They realized the importance of helping their well parents to

maintain family stability.

Hugging her (well parent) and telling her everything was gonna be alright with dad and, yeah, and it came true and dad came home safe (Interview 12/1, Boy, Age 9).

If your Mom's (well parent) feeling down, just like cook supper for her for like two times out of the week, just something you like and something they like. Just help her out a bit . . . whoever's not manic-depressive or whatever it is. . . And like clean the house, do the dishes, like some of that stuff, some of that little stuff . . . She had a lot. She gets tired of it and she just wanted to leave my dad and then I don't want that though (Interview 11/1, Boy, Age 14).

Actions the children took were intended to help find the rhythm with their parents, but the children had to act carefully if they noticed any behaviours indicating irritability. By their actions, the children were trying to keep the peace in their families and to smooth relations between themselves and their parents. The connections in the parent/child relationships were often strained during acute periods of illness and children acted in the hopes of finding rhythms with their parents.

Well usually if she seems sad . . . and if she's like not happy, yeah I leave her space and I talk to her. Yeah I leave her space to calm down... because if she's like bad I know that she might be a little bit grumpy and she wouldn't wanna talk or something. . . when she says she has a bad day. And I'm like okay, means that I might have to be really gentle and I must be nice...but usually I'm not that rough with her. *Yeah I'm careful. I'm careful, because if she's gonna be mad at me, I don't want her yelling (italics added).* No because I don't like hearing her yelling . . . I'll just be quiet and I won't bug her as much . . . Yeah watch what I'm doing (Interview 17, Girl, Age 10).

The children's actions were both in response to identifying problems and to preventing further problems in the household. They repeated actions that they felt had helped them and

their parents in the past. The children expended a considerable amount of energy responding to behaviours that they had monitored in their parents. Their actions were usually attempts at trying to use the interactions with their parents to develop a regular rhythm and to re-establish daily rhythms in their homes. At times, parents were incapable of responding and unable to consider the needs of their children. "Like sometimes I try, like with, do you wanna watch a movie or something, try to get her mind off of it? But sometimes like that doesn't even help" (Interview 15/2, Girl, Age 14). Despite their best efforts, the children were sometimes unable to find the rhythms with their parents. At other times, their actions prevented further escalation of trouble in their homes.

Taking over and offering suggestions. Helping directly also included taking over and offering suggestions. In situations, where the parents' abilities were compromised, these children assumed the advisor/protector role in an attempt find a rhythm with their parents. Generally the children took control as a last resort. The children took control in situations, such as, when parents were using drugs or when parents had difficulty in public situations. The children would offer advice and warnings when they assigned meaning that their parents' behaviours were out of the bounds they considered acceptable.

I think I drew this message not to smoke (pot) cause he has a low tolerance...I remember that picture now; it was like a good picture of a guy smoking a joint. And then it shows afterwards, it shows him, I think, it's like a rain cloud around him and . . . the guy's crying and it's raining on him and then it shows going to a hospital and then the hospital and that's it (Interview 09/1, Boy, Age 16).

When parents were fearful, some children took control, by talking to them, calming them down, and offering physical comfort and touch. One adolescent boy depicted this in his artwork.

And in the right, in the right hand side it says, after the panic attack, and I have, we're holding hands and then I'm telling her it's okay, mom (Appendix B2). So the only

advice I could really say is ah, just be, if you're around them, talk to them and calm them down (Interview 14/1, Boy, Age 13).

At times, children had to determine when to take control. During a panic attack, one child guided her parent out of a large crowd by reassuring the parent and leading her by the hand. In the situations where children took control, the rhythms of the parent/child relationship were changed with children assuming the lead.

Yeah. Like when she (mother) said about the crowd thing. Um I like had to take her hand and I was like weasling through everyone and she, she was getting all hot and I'm just like it's okay, it's okay. And then I finally got her out and she bought me a corndog (Interview 13/1, Girl, Age 11).

With like panic attacks, like if you don't have a dad or someone else you can turn to, to feel safe with, then I think the best thing to do is just try to tell them (ill parent) everything's okay. And like maybe if you're (the child) that scared, you can just, like, sit on a couch (Interview 13/2, Girl, Age 11).

The children also directed parents to care for themselves and attempted to look after their welfare; "Cause my mom's getting help right now. Like she goes to a lot of therapy and stuff so...uh. Try and convince them to get some help" (Interview 18, Boy, Age 14). They also gave advice to help their parents manage on a day-to-day basis, based on their previous experience with the problem; "Uh. I always tell him to go to sleep if he's like, I guess, getting cranky. I'm, like, if you just go to sleep you'll feel better (Interview 10/1, Boy, Age 14).

When parents were overwhelmed with feelings of sadness or agitation, children directed their parents to try and reduce those emotions; "Usually I tell her to go into one of the rooms for a while" (Interview 08, Girl, Age 10). A young girl described taking control when her parent was agitated; "Well, okay, I guess, tell her to settle down. If, like, she's getting mad over something that can easily be fixed or easily be done or something, *just tell her to settle down and*

then tell her I'll do the job or something (italics added)” (Interview 13/2, Girl, Age 11).

Younger children also sensed sadness and offered advice to their parents. This young boy helped by telling his father to talk to his friends; “I don’t know. Just hang around with him (dad). Talk to him and all of that. Yeah . . . (tell him). . . Go on the computer. Talk to your friends (the father’s) and all that” (Interview 05, Boy, Age 9).

Although the children tried their best to offer suggestions and to take control, they were sometimes unable to influence the situation in spite of their efforts. This was particularly true with manic behaviour when the parent had little insight and was not receptive to direction. The children also tried to take control to assist their families by restoring daily rhythms in the household, but recognized their limitations.

Well, the fact that the role model (dad) for the siblings I have, is in the hospital so you know, you’ve got to take another role model, to try to work, and I’m the oldest one beside my dad in the family...to show them what a father would actually be pretty much.

But not, like, I’m . . . I’m too young to. . . (Interview 09/2, Boy, Age 16).

When children attempted to take on too much, they could lose control of the situation. The young boy in the preceding quotation fulfilled his father’s roles within the household unsuccessfully.

As parents recovered from serious episodes of illness, the children tried to act in the best interest of their parents to find the rhythm in their relationships. They believed that the activities that they were offering would improve their parents’ outcomes.

Everyday I come home and we (mom and I), just, within the last three weeks, we’ve been going to the gym. Yeah. Everyday. Cause I’m really athletic. I always go but I try taking her with me...and...she’ll be sleeping at 11 o’clock and that’s not her, that’s not normal. So I wake her up and get her up and yes, and we go out, just make her feel

wanted. That's basically all that I can do for her, you know, when she feels like that
(Interview 16/1, Girl, Age 16).

Helping Indirectly

The children also acted indirectly to help their ill parents and, sometimes, the other family members. They cleaned their rooms and their houses, protected siblings, and generally decreased irritants for their parents. They were hopeful that these actions would restore both their daily rhythms and help them to find the rhythm in their relationships with their parents. Reducing irritations in the household often centered on cleaning the house. Some children realized that disorganized households could be a significant irritant for the parents and also for themselves.

Well, the different things I do, like for them, is like, when I know they're feeling down in the dumps, as my family puts it, I would: 1) cheer them up; 2) uh, take the kids outside when they're being a little too noisy. . . . Then I would get cleaning (Interview 03, Boy, Age 13).

I clean the basement cause . . . like . . . the basement is mine cause it's got all my stuff down there. And I always make messes down there cause I'm always playing
(Interview 22, Boy, Age 7).

I help take out (of the car) the groceries after grocery shopping. And I help take them in (the house) *When she asks me to clean up my mess I sometimes clean more up* (*italics added*) (Interview 20, Girl, Age 6).

Well, usually I just . . . try to do, clean my room sometimes (Interview 17, Girl, Age 10).
Make lunch. Clean the house. We (brothers) just help her out (Interview 06, Boy, Age 13).

Yeah, and I would go ballistic on the house. Um. And then I vacuumed the whole living room, washed where they (young brothers) splattered the oranges. . . Um, the kitchen was

still kinda a mess, there were dishes that were getting kinda old, old, with food in it. So I washed the dishes (Interview 03, Boy, Age 13).

I don't know. Do extra things. Clean up; go shopping for her, talk to her, or whatever (Interview 19, Boy, Age 16).

In order to reduce irritants for their parents, the children cleaned up, were more mindful of their toys and messes, and played quietly when their parents were ill. The children also rearranged furniture to reduce clutter and make the most of space in crowded conditions. All of these actions represented the children's attempts to find the rhythm with their parents by controlling their behaviour and environment as much as they were able. Even young children learned new skills to help their parents; "Well, cause my mom sometimes does laundry, I know how to do the laundry. I just need to do it a few more times. To know how to turn it on. Cause I don't really do it very much" (Interview 22, Boy, Age 7). They also played quietly away from the parent; in order not to irritate the parent or decreased noise by turning down the television or music; "I just, I don't know. Well, I just like play in the back room . . . Well, I do think about it (parent being ill and irritated), but I try not to think about it" (Interview 11/2, Boy, Age 11).

I'd be quiet. I go down to my room and just watch TV. . . . We don't fight when she's sad or, yeah. . . especially my sister and I. Yeah. Sometimes we like to play fight but we don't do it too hard (Interview 02/1, Boy, Age 10).

The children also helped the situation by choosing not to respond to their parents' irritating behaviours. There were occasions when some of the children evaluated situations as too difficult for them to help and felt powerless. At these times, the daily rhythms of family life and the rhythms in their own relationships with their ill parents were so fragmented that they were in danger of becoming lost. The children wanted to help their parents, but could not. When the children felt that there were no reasonable options, they deliberately became quiet and stayed out of their parents' way as illustrated by the following examples.

I don't know what I could do. Cause if he is, if he's going like that, I can't talk to him cause then he just gets more crazier. . . I don't really know . . . It's kinda hard to help him . . . Uh, when he is ill (manic) (Interview 09/1, Boy, Age 16).

Um-hum. Like I think, if he skips a day (medications), he gets pretty mean.

Uh, he's like, his eyes, his eyebrows go like down. And you just, sometimes, if you say the wrong thing, he just yells at you. I just like, I just keep to myself I guess (Interview 11/1, Boy, Age 14).

It's just like she doesn't listen so. I just kinda of leave her alone (Interview 21, Boy, Age 13).

When the children did not believe they had effective actions to change situations, they often chose to ignore troublesome parental behaviours; "She'd definitely like start fighting with me . . . I wouldn't be able to tolerate her, but I would" (Interview 16/2, Girl, Age 16). By doing so, they hoped to prevent further problems and strain in the rhythm of their relationships.

When they helped indirectly, some children prayed, often after they had exhausted more concrete strategies. The children prayed that their parents would get better, "I don't know (what to do). I just ask like God to help, help her out. I don't know" (Interview 15/ 2, Girl, Age 15). "Pray that dad won't be sad" (Interview 09/1, Boy, Age 16). "I hoped that my dad gets better, God, and I hope he comes home (from the hospital) soon" (Interview 12/1, Boy, Age 9). Children also changed their attitudes about helping to find the rhythms, by decreasing tensions within the relationships with their parents.

You should ...help them or make them happier or just try not to, say 'Mom, could I have this or Mom could I have that, Mom could I have this, Mom could I have that (Interview 17, Girl, Age 10)?

Yeah. Don't be mad at them. . . try and help them out as much as you can. Well, cause

they're already down enough, so you shouldn't make them more down than they already are (Interview 10/1, Boy, Age 14).

Try not to make them more depressed. . . . Yeah. Like don't screw around. . . .

If you're bad or whatever or you wanna be bad, I'd say don't do it cause it does make her more depressed like. Cause she obviously cares about you. And try and to help (Interview 19, Boy, Age 16).

The children also attempted to protect their parents from further difficulties such as overwork, and unpleasant events. For example:

Dad asked me nicely if I wouldn't mind coming in (to work) if he worked 5 days next week, um, he gets two days off, which is good, cause the past two weeks he's been working 6 days, only one day off which is Sunday (Interview 03, Boy, Age 13).

Protecting the parent took other forms, such as guarding them against harm from outsiders.

Sometimes I go on my auntie's computer and see what guys, like see if they tease him (father), and all that. Sometimes they do, sometimes they don't. Be nice to your parents. . . . Stick up for them (Interview 05, Boy, Age 9).

The children also acted to protect their younger siblings in situations where they were vulnerable. Older siblings were as young as seven and ten years old. Older children redirected younger children when their behaviours were annoying to their parents and were placing them in vulnerable situations; "I just try to keep my sister in the room . . . and I tell her (younger sister) that she's (mother) like upset and not to leave. . . . And then after we play" (Interview 08, Girl, Age 10). A seven-year-old child made plans to protect his infant sister.

When they're (parents) fighting, both of them get really angry. And I go in, if it's really bad, I go into the basement. Cause we made these little spots before. To know where we go and mine was in the basement. My dad's was in my room and my mom's was in her

room...If the fights just with my mom and my dad, *I think my little sister will come with me in the basement (italics added)* (Interview 22, Boy, Age 7).

If he's (younger brother) screwing around with his friends downstairs and they're doing drugs or something like that or being stupid, like, I'd say go do that outside, like go, just go away because, like, mom's sitting here. She's pissed off, she's depressed, and she doesn't want that crap going on (Interview 19, Boy, Age 16).

"Finding the rhythm" was more difficult when the environment was strained and caused parents distress. The children acted to adjust their environments in the hopes that their parents would become calm and predictable, thus facilitating "finding the rhythm". At times, the well parent assisted them, at other times, the children acted on their own. Some children were maintaining connections and rhythms in more than one household when their parents were separated.

Children took action in response to "monitoring" the ill parents' behaviours and the consequent effects of their behaviours on the children and their families. The children acted by helping mostly their ill parents, but also other family members. They helped directly by comforting and nurturing their ill parents, by talking to them, and by directing them. They helped their ill parents indirectly by removing irritants in the environment. This included cleaning, reducing noise levels, removing siblings, and choosing to ignore parental behaviour. The children also helped their well parents and attempted to protect their siblings, as best they could, while finding the rhythm with their ill parents.

Evaluating

Sometimes, the children's actions led to them feeling more comfortable about "finding the rhythm". Sometimes, the actions resulted in further disrupting the rhythm. Evaluating was the process whereby the children decided how effective their actions were, if they should continue with their actions, or if they should try another action. When the children decided that

their actions were not improving the situation, they experienced a current of emotions including feeling badly, sad and helpless.

I felt real bad for her because there's nothing really you can do because it's just her and her feelings like. Whatever you try it's just like... if you try talking, if she'll talk but then she might talk about things that are depressing, not even realizing. It just affects everything. And you can't really do anything. Like sometimes like if she wants to watch a movie she just can't even watch it. Like during the movie she'll be talking and she'll be depressed and like not be able to watch it. Or a movie will depress her (Interview 15/2, Girl, Age 14).

At times, the children felt that their behaviours had actually worsened the situation and it was better to withdraw.

I would say I try not to fight but sometimes when you're in a fight you just sorta fight. So I don't know, it'd be better if I was different and tried to help her. So then I'm different (after going out) and I feel different and I feel better and happier. I find that (going out) works for me (Interview 15/2, Girl, Age 15).

The children evaluated the effectiveness of their actions, not only for "finding the rhythm" with their ill parents, but also for themselves, and based their future decisions on the results. For themselves, the children evaluated how the action made them feel, "I feel safe" (Interview 01/2, Girl, Age 7). In that respect, there was some overlap between "finding the rhythm" and "maintaining the frame". Children desperately wanted to find a rhythm with their parents, but they could not do so at any cost to themselves. If a child evaluated the action as unsuccessful, he or she became anxious, did not feel safe, and was concerned for the parent and him or herself. The children evaluated their actions and, if they considered them ineffective, they reconsidered their options and next course of action. Their efforts were always aimed at "finding the rhythm" with their parents.

Goals of Finding the Rhythm

“Monitoring” and “adjusting” helped children to get along on a daily basis and to elicit positive responses from their parents in their relationships. The goals of “monitoring” and “adjusting” were, thus, at the level of getting along day-to-day in family routines and positive interactions with parents. The children attempted to reestablish previous acceptable levels of day-to-day rhythms in their lives. In “finding the rhythm” (“monitoring” and “adjusting”), children were looking for positive interactions with their parents and family stability on a daily basis. In their attempts to find a rhythm with their parents who had mental illnesses, the children were also searching for signs of stability in their family homes. Signs of stability helped them to feel secure. Trying to establish or re-establish day-to-day rhythms contributed to the children’s perception of family security. Families that were secure had predictable and regular routines.

When children could not find any signs of daily rhythms, they had no confidence in family stability. Exacerbations of mental illness were inherently unpredictable and affected the environment but for some children, other adults, who took over when their parents were ill, mitigated this. For other children, there were few helpers to take over, and the symptoms of the mental illnesses and lack of daily rhythms in their families made them regard their relationships with their parents and their families as extremely unstable over their formative years. Children who lived in chaotic circumstances generally had few resources available to them. In situations where the illnesses were not resolved or controlled, and contributed to other adverse circumstances such as marital discord, children were frequently on edge with little respite from instability.

He (father) seen more of me cause I lived with him longer than the two boys put together; *which I first only found out when we were leaving the next day (italics added).*

Like my mom found a place on H. Street (Interview 03, Boy, Age 13).

Cause I took a babysitting course in Grade 6. Like I didn't get the, I never got like the, little card like some babysitters get when they finish, like, they get the degree type thing. I never got that cause I was away. They (dad and family) were moving then (Interview 03, Boy, Age 13).

For some children, instability in daily rhythms was such that they did not know where they would be living, at times going from one parent to the other with little warning or involvement in the decisions. Instability in the daily rhythms that children valued complicated their lives and made it difficult to view their daily interactions with their parents or their families as stable. It also made it harder for them to engage with people and institutions outside of their families. These circumstances led to sustained duress, which exhausted all family members and sometimes led to child apprehension from the home. Other children had a sense of daily connections and of routine and stability.

And then um, when my Mom is off the computer then we do my spelling and my verbs and then after supper, we do, we read. Yeah and then . . . after that sometimes we have a little bit of time so I watch a little bit of TV. Um, usually I go (to bed) about 8:30. Well we usually . . . on the Saturday, usually I have my art classes at noon, like at lunchtime and then . . . I finish at like 1:30, I think. Yeah. And . . . then we, yeah then we go have lunch somewhere. Yeah usually we go out. But usually after that we go to my swimming lessons that start at 4. Yeah I do synchronized swimming like ballet swimming (Interview 17, Girl, Age 10).

Despite their best efforts to contribute to day-to-day rhythms, the children achieved varying levels of positive daily interactions with parents and family stability, with some children experiencing chaotic life styles and others experiencing consistency for the much of the time. Some children were haunted by the image of 'the ideal family' and some of the family rhythms they felt that they had missed.

I don't know. Like, I...the family. Like the ideal picture, you know, the house and the parents at work and they pick you up and drive you when they have to. You know, like I never really had that. And I don't know. I'd just like that. Like a dream you know. Yeah. Like just something. . . Like I don't want them never to fight, that's not how I want them, fake, happy families, but just like you know, just like the family (Interview 15/1, Girl, Age 14).

At whatever level of stability the children had, they experienced changes in their parents' behaviours. These changes were caused by exacerbations of the mental illnesses which disrupted relationship and family stability and any existing rhythms of daily life. The children tried to improve the quality of their daily rhythms. They wanted to spend time on a daily basis with their parents, talking to their parents and being with them. When parents were ill, they were psychologically and emotionally absent from their children, and, at times, physically absent. By "monitoring" and "adjusting" the children wanted to achieve the goals of getting along day-to-day, through new and stable family rhythms and relating positively to their parents on a daily basis.

And she goes up in her room and like talks to her friends and sometimes she cries cause it makes her upset. Sometimes she's just sad. For no reason. I'm sensitive. I'd be quiet. I go down to my room and just watch TV. . . . Try to make mom happier (Interview 02/1, Boy, Age 10).

This child attempted to find the rhythm with his parent in order to get along day-to-day by "monitoring" the parent's behaviours and making an adjustment in his own behaviour to restore a sense of relating positively to his parent.

Summary of Finding the Rhythm

When the children were "finding the rhythm" with their parents' during their daily lives,

they monitored and adjusted. "Monitoring" helped these children to track their parents' behaviours and the day-to-day situations. The children monitored by watching, listening, sensing and considering. When they felt their parents were stable and safe, they took respite from "monitoring". Contexts where "monitoring" became increasingly important were, when the parent was hospitalized, discharged home, and when the child was removed from the home. The children mostly monitored their ill parents, but also monitored the effects of the mental illnesses on other family members and family routines. The acuity of the illnesses, having only part of the story, the context of the situation, and the developmental stage of the child influenced "monitoring" behaviours. Other aspects of "finding the rhythm", wherein the children considered the meaning of what they monitored, and then "adjusted" to their parents' behaviours, were part of the children's efforts to find the rhythm with their parents.

When "adjusting", the children chose actions that helped directly or indirectly. The children evaluated their actions and chose other actions if their previous actions were unsuccessful. When the children's actions were unsuccessful, the children could not find a new rhythm with their parents. Being unable to find a rhythm negatively influenced their physical and psychological safety, and that of their family members. In severe illness episodes, parents were not capable of being present for their children. This made it more difficult to adjust and find the rhythm. In those situations where the parent lost insight, the child could be wrongly accused of misbehaviour or small actions could be blown out of proportion. In these situations, to find a rhythm with their parents, the children struggled to find the appropriate action. At other times, the children's actions were successful in de-escalating situations. The children's actions were intended to help them have positive interactions with their parents and daily family stability in their lives in order to get along day-to-day.

Emotional Currents in Finding the Rhythm and Maintaining the Frame

“Emotional currents” flowed through the children’s experiences of living with a parent with a mental illness. These “emotional currents” arose from all aspects of living with the children’s parents and flowed through both of the BSPPs, “finding the rhythm” and “maintaining the frame”. At times, the “emotional currents” were strong and negatively influenced the children’s experiences, threatening to sweep them away. At other times, the “emotional currents” flowed softly and smoothly, comforting and nourishing the children while they tried to find the rhythm and to maintain the frame.

Range of Emotions

The range of emotions that children encountered was vast – joy, love, pride, sadness, worry, frustration, anger, guilt, fear, despair, anxiety, grief, hurt, discouragement, embarrassment, relief, hope, and loathing. These children experienced the usual range of emotions associated with daily living, quite apart from living with their parents’ mental illnesses; however, the “emotional currents”, which flowed through “finding the rhythm” and “maintaining the frame”, were exacerbated by the mental illnesses of their parents. Often the parent’s affect would be altered and this would change the emotional climate for the whole family. These children witnessed a wide range of intense and erratic emotions in their parents, whose moods were often subject to highs and lows. The children also experienced fluctuating emotions as a result of their experiences with their parents. One child expressed his emotions this way:

I worry about, like, lots of things. What’s going to happen and things like that? To everybody. . . Yeah. Cause sometimes my mom’s up, sometimes my mom’s down, sometimes she’s normal. I’m always nervous. Um. Well, not always, but most of the time, and in the mornings yeah (Interview 21, Boy, Age 13).

The children varied in the intensities of emotional reactions to the effects of their parents’ illnesses, depending on the nature and severity of the illness and available support. The

“emotional currents” also varied in their effects on the children’s families and their daily rhythms. The “emotional currents” influenced their efforts to find a rhythm and maintain a frame with their ill parents and to find rhythms in their daily lives.

Intensity of Emotions

The children experienced varying intensities of emotions; some could be overpowering while others were muted. The children’s emotions were less intense when life was moving smoothly. Intense emotions were most commonly experienced during the acute phases of the illnesses, in response to the unreasonableness of their parents, feeling disconnected from their parents, and the powerlessness children felt about influencing their circumstances. Intense negative emotions drove older children out of their own homes and younger children to their rooms when they felt that the environment was too emotionally charged for them to remain peacefully. Intense positive emotions mainly occurred when the connections between the parents and the children were strong and the children were motivated to maintain their frames with their parents. The children also experienced intense concern and compassion for their parents when they were ill, which motivated them to find the rhythm and maintain the frame with parents.

While teens were more articulate in expressing their emotions, younger children also struggled to describe their intense emotions, while trying to find the rhythm and maintain the frame with their parents. Their emotions were most intense when they felt unsure about what would happen in their lives and their relationships with their parents. An example of the intensity of emotion that one child experienced follows:

... usually some nights I pray that they (mother and father) wouldn’t die and I, it’s just, I don’t want them to die because they’re really important to me. So (I) wouldn’t have to go to another family. Yeah, I really worry a lot about my family. Well...and if I go with someone else it wouldn’t be the same (Interview 17, Girl, Age 10).

Other properties of the of the children's emotional reactions included: opposing emotions and situations where positive emotions overcame negative emotions or negative emotions overcame positive ones.

Mix of Opposing Emotions: Positive and Negative Emotions

As the children tried to understand what was happening, they struggled with opposing emotions of love, fear, and confusion. Negative emotions took precedence when children did not have a supportive adult to buffer their circumstances. Those children described experiencing a preponderance of negative emotions because they were left to deal with them on their own.

Like this whole last year I've had *so many mixed emotions (italics added)* and *I'm just frustrated with everything. . . Oh, with everything, just so stressful. . . it's just a lot of stress (italics added).* . . . I wake up in the morning, no one is here. I come home no one is here (Interview 16, Girl, Age 16).

At the same time these children experienced love for their parents, which was expressed through their compassion towards them in the face of their parents' suffering. The children compared their experiences with their imagined experiences of their parents. For example, going through a haunted house with a friend was likened to the parent's struggles with mental illness.

So we were like really scared. We were like linking up arms really tight. So I wouldn't wanna be there but I felt it was kinda like the same thing if my mom's like going crazy (Interview 13/1, Girl, Age 11).

The older sibling agreed with the younger child and also expressed loving compassion toward the parent.

She could be having her own haunted house. . . . She could, she could be seeing things and stuff I guess. Having her own haunted house. And it's always helpful to have somebody around when you're scared (Interview 14/1, Boy, Age 13).

Children described situations where their feelings of love and compassion were mixed with hurt and anger towards their parents. Sometimes during attempts to help their parents, the children were psychologically hurt and frustrated by their parents.

She (mother) was saying stuff about me and . . . I didn't really want him (family therapist) to see . . . and I was like, . . . telling her, like don't, don't tell him (family therapist). . . . So I was just about to go, and like, leave, right, I was that mad. And I don't know. She, and then she'll start crying . . . in the room . . . Well it's like we're the cause of it and it makes us (siblings) feel bad I guess...And then I would like hug her and stuff and so she just cries over nothing though. It doesn't make any sense though. Yeah. Sometimes it's almost like, okay be quiet over there, it's not that big of a deal. But I don't like to see her cry like . . . it brings me down too (Interview 14/2, Boy, Age 13).

Most of the children tried to deal with their opposing emotions towards their parents' behaviour by overriding their feelings of sadness, anger, frustration, and hurt with loving compassion for their parents and by putting their parents' needs first. For example:

Uh well I guess that's just like um, don't let it blow up. Like, like don't really blow up on them cause it'll just make it more like sad and stuff. Make him more depressed or make him more mad, like manic and stuff (Interview 10/2, Boy, Age 14).

Some children tried to ignore their feelings of distress to find the rhythm and maintain the frame with their parents, "Suck it in. . . . Don't cry. Suck it in" (Interview 06, Boy, Age 13). These children simply did not allow themselves to describe painful emotions or to direct these emotions at their parents.

The children also described feelings of sadness, hurt and anger towards their parents when they believed the symptoms of the illnesses caused trouble for their families.

It (the family) just like, it just drops, I guess like. When my dad goes out, cause we're always like, we're tired of it and like sometimes we get kinda mad like (Interview 10/1, Boy, Age 14).

Because they appreciated their parents' vulnerability, the older children were more likely to describe opposing feelings of caring and concern for their parents mixed with anger, hurt, sadness, guilt, and bitterness. The child, in the following quotation, experienced opposing emotions as she wanted to protect her parent who did not want to be hospitalized, but was also in need of help for herself. By asking for help for herself, she felt her mother would be hospitalized against her will.

Cause it (going to the hospital) would be embarrassing for her and like they, they'd want her to go to a hospital right away and she does not wanna go and it would just, like, I just couldn't really do anything even if I wanted to. . . And then there's her . . . depressed.... It was just, it was just so bad, like it was like late and night and I don't know, I just started crying, . . . Why would you do that (suicide attempt)? Why would you do that, don't you think what would happen? *Like what about me, what am I supposed to do or where do I go? (italics added)* (Interview 15/2, Girl, Age 14).

Younger children experienced negative and positive emotions at different times. In the situation described below, discharge home from the hospital, the younger child was initially relieved to have his parent home but later concerned with the slow process to recovery. In the same family, the older child was very negative about his parent's condition. For the older child this situation led to experiencing mixed emotions together. This quotation illustrates the younger child's focus on his father's return after being hospitalized characterized by positive feelings.

Uh. Everything's going great and fine and my mom's working hard... I was glad the first day he got out of the hospital. I didn't even think of all the sick people around him. . .

Cause my dad's just a nice guy and he's a nice dad and he's great. . . Happy and great

that my dad's well and he's doing great and he's a nice guy (Interview 12/2, Boy, Age 9).

The older brother in this family was disturbed that routines in his home were disintegrating and blamed his parent; "He should actually learn how to be like a better parent at least with his kids. Like more authority" (Interview 09/2, Boy, Age 16).

Despite experiencing conflicting emotions in response to their parents' illnesses and consequent situations that arose, the children tried to remain hopeful that their parents would recover and become themselves again. They tried to avoid blaming their parents for the problems the illnesses created.

Um. That it's not their, that it's not them (parents) that are doing that, that it's an illness and they won't be like that forever. That some day they're gonna find a cure for that . . . (Interview 21, Boy, Age 13).

These children tried to remain hopeful that their own situations would improve and tried to control their emotional reactions to the frustrations and confusion the illnesses often created.

"Emotional currents", which the children experienced at home, could also spill over to their relationships with their peers, causing the children additional distress. This child described his reaction to his friends.

I can see it in myself, I'm a bit more rough, so. Yeah. Like with my friends. When that happens I notice that they're a bit more far away from me, so. A bit more argumentative, just like my dad (well parent) (Interview 21, Boy, Age 13).

These children were faced with acute and chronic situations, wherein they experienced conflicting emotions. In some situations, their positive emotions overcame their negative emotions, which helped them to find the rhythm and maintain the frame with their parents.

Conditions where Positive Emotions Overcame Negative Emotions

The children generally experienced relief and pride when their parents were again well. Positive emotions overcame negative emotions when the children's parents with the mental illnesses had survived a crisis. Then, when the children were aware that they were not to blame for their parents' illnesses, it was easier for them to have positive emotions.

Well that's. Yeah. Well, I didn't want her (mother) to feel like I was losing her. . . .

Like, she was not succeeding being a mother, because, I know, that's the only thing that she really cares about in her life is being a good mom. . . . Like I have an awesome mom (Interview 16/1, Girl, Age 16).

When the children experienced intense positive emotions toward their parents, they sustained their efforts to find the rhythm and maintain the frame with their parents. Most of the children were able to love their parents in spite of the mental illness. For example in describing her art, (Appendix C2), a young child offered this explanation.

Well um, it's just a whole bunch of blue stick people that represent, like, the parents of my friends. And then there's one orange which makes them, her, the odd ball and that happens to be my mom. And I put '*mental illness makes my mom unique*' and I drew a heart around her cause I love her (*italics added*) . . . Well it just means she's different than other parents and, yeah . . . *Different good* (*italics added*) (Interview 13/2, Girl, Age 11).

The children were proud of their parents when they witnessed them overcoming problems and challenges successfully. Some children were proud when their parents had improved, the parents made efforts for them, or when their friends liked their parents. Older children were aware of sacrifices that parents made for them and younger children noted the kindness and love that they received. When children saw the mental illness as a unique characteristic of the parent, they were proud that the parent was different and saw this as something that could be helpful to

them as sometimes it was good to be different; "She's not your average ordinary mom" (Interview 13/2, Girl, Age 11).

Positive interactions with their parents were associated with the children's positive emotions. They valued fun in the family home and spoke of it as an important aspect of their family lives. "(We have) fun everyday in my family; like everyday in my family" (Interview 06, Boy, Age 13). The children were pleased when their parents did special things for them, provided fun activities and interacted with them spontaneously.

(I feel) Happy and great that my dad's well and he's doing great and he's a nice guy.

And he's a good dad . . . Like every sunny day he . . . his fun like side just takes over.

Yep. His fun side is fun, his fun body like. . . Uh, brings us shopping, swimming and all that (Interview 12/1, Boy, Age 9).

When new rhythms were found that were characterized by positive interactions the children experienced more positive emotions. When the children described the "emotional currents" that ran through their lives most felt the positive emotions outweighed the negative ones. They wanted to be where they were, i. e., in the family home. On the other hand, they neither escaped from negative emotions and nor were unaware of the painful emotions associated with their situations.

Conditions where Negative Emotions Overcame Positive Emotions

When negative emotions overrode positive emotions, the children felt they could not influence the outcomes of the situation, the rhythms were unpredictable, and the frame was too difficult to maintain. Negative emotions also overrode other emotions when the children could not determine if their parents' behaviours were attributable to the illnesses. Parental behaviour that was contradictory to what the parent had taught the child and behaviour that was of a chronic nature with little resolution culminated in negative emotions overriding positive emotions. Some of the children experienced anger and blamed their parents for their family

problems. The children experienced fear when their home lives were threatened, i. e. apprehension or marital discord. The children experienced sadness and grief when they saw little resolution for their situations. In the situations with limited support, many children could feel confused and abandoned; negative emotions of fear, sadness, confusion, loathing and anger dominated.

In most families, the children's feelings of apprehension, fear and confusion were tempered by feelings of love, loyalty, and respect for their parents' wishes. On the other hand, the children could feel despair when they felt trapped in their situations. This happened in situations, with limited support, where the children felt they had no where to turn.

There was this one time, like I, she was really, really bad, . . . I didn't know what to do, like I started, I just, I just, I don't know, I like, I like broke, broke down like. . . Like, I don't know if she was . . . just so, so bad like talking about . . . wanting to like slit her wrists or something and like. . . I didn't know what to do. Where to go . . . if I should leave or if I should stay or what, what, about if I left, and who I should call . . . Cause I wanted to talk to someone . . . I was scared . . . *Like I wanted to help her and I wanted to help me (italics added)*. And, but I didn't, I didn't know who to call or anything like that (Interview 15/2, Girl, Age 15).

In situations where the children were removed from their homes, they experienced fear, anger, and anxiety, until they were reunited with their families. Their emotions were fueled by their perceived lack of control over their situations and the unpredictable rhythms of their lives. The children felt alone and discouraged. When they perceived minimal adult support, their discouragement was overwhelming; they stopped trying to "find the rhythm" with their parents.

Um. Alone and just don't want to be there (in the home)...My dad doesn't speak Ukrainian so he can't help me and my mom just, she (ill parent) just doesn't want to help me (with school work) so. Pretty discouraging (Interview 21, Boy, Age 13).

In situations where children did not understand the reason for their parents' behaviour, or were becoming tired because of the chronicity of the illness, negative emotions of anger, guilt, sadness, and loathing predominated. Even in situations where children felt supported, at times, they worried about the long-term effects of mental illness on their parent.

[Mental illness is] like frightening, like uh kinda, it scares me sometimes. Yeah. Scary or frightened or whatever... Like how my mom's gonna be after she... has her mental illness. Like once in a while I, I think of, like, *what happens if she snaps this time, is it gonna like, like really snap her, so she's gonna be like, really bad for like her whole life (italics added)*. But I don't know. Then I see, I don't think that's gonna happen but, so I sometimes am scared of how is she's gonna be after (Interview 14/2, Boy, Age 13).

When the children did not understand why their parents were behaving erratically, they sometimes felt betrayed by their parents and, consequently, devalued them. Negative emotions also overrode positive emotions when the children blamed their parents for situations and felt limited support from other adults. One child was very vocal about his hostility and contempt for his father while reporting some guilt regarding his judgment of his father; "Um....Just thinking about what everything is in my family pretty much. *'That I shouldn't be judging them' (italics added)*" (Interview 09/2, Boy, Age 16). At the same time, he blamed his father for his behaviour and described his anger and contempt towards his father.

Well, yeah, I totally understand that, I know, that he has a mental illness, so like I realize everything that drags him down that he can't do because of mental illness. So he can at least try to do something about it, like help himself get better... Right. Doesn't work. So pretty much scratch him out of the picture financially. And then my mom, my dad will drain my mom half, so it's like half a person that has to take care of everything. So you know it's just like really weird. *It's my Mom, my Dad's pretty much, I'm not going to say useless, cause it makes him sound like a dog or something* (Interview 09/2, Boy, Age 16).

Younger children often had limited supports from adults and few resources, so they described intense emotions around less definite, but meaningful concerns in their lives; “And scared that something bad was going to happen to me” (*Soft voice*) (Interview 20, Girl, Age 6). When family stability and survival was at stake, negative emotions tended to take over. One young girl also worried about her family being separated and losing a parent and a sibling.

It’s just we might move to Kelowna. That’s what I’m scared of... My dad said he’s not going to let me go so I’m going to have to be with my dad if they (mother and brother) move to Kelowna...It’s only when people drive me somewhere I get scared, without my mom (Interview 01/2, Girl, Age 7).

While trying to find the rhythm and maintain the frame with their parents, the range and intensity of children’s negative emotions were influenced by other factors.

Factors Influencing Emotions: Acuity and Hospitalization

Emotional reactions to the mental illness of a parent were influenced by the acuity of the illness and parents’ hospitalizations. These situations were emotionally charged. In acute illness, the children did not always understand what was happening. They experienced intense emotions of anger, fear, love, frustration, and hopelessness. They felt that they were trying to find a rhythm with strangers rather than their parents.

Um. It’s just scary...It’s kinda scary cause it’s not your dad. It’s just the illness....Yeah. And like when he was in the hospital, (he said) I want to leave the family; I don’t want to be with them. My mom knew right away that was just the illness and she talked to us about it (Interview 11/1, Boy, Age 11).

With minimal support during acute illness, the children experienced intense emotions where even the daily routine of coming home from school generated emotional turmoil.

When things got bad I was scared to come home, like I didn’t really wanna come home. Because...I didn’t know what I was coming home too....What if she was...I

don't know, sitting there bleeding on the couch or crying...In the bedroom or in the bathroom or, or how bad she was, what she was gonna say to me, if we were gonna fight or like, like so many different things (Interview 15/2, Girl, Age 15).

Even when some children were academically successful at school and able to temporarily forget about their home situations, returning home to an acute episode of mental illness caused extreme emotional distress. Acute illness could generate fear, apprehension, confusion, and love. Some acute symptoms were more vivid and frightening than others, particularly to children who may never have previously seen the behaviors or not been able to successfully intervene.

She is getting better, with night terrors and everything, screaming. Cause when she did, it like freaked me out...she said don't be afraid to wake me up...And I like poked her and like she went whipping around. I got so scared. So now I always get my dad to come and wake her up (Interview 13/2, Girl, Age 11).

Children perceived having a supportive adult available as helpful and reassuring, particularly at times they were fearful.

Acute illness often necessitated the parents' hospitalization. The children associated the hospital with extreme illness and were concerned about their parents' prognoses. They worried that their parents would die. This young adolescent commented on his reactions to a past suicide attempt by his parent.

And we (well parent and child) came back home and my mom was locked up in her room and she was sick, she was in her bed, she couldn't get out. So my dad like struggles, open the door and then we brought her to the hospital. (I was) scared. I didn't know what was happening; I thought she was dying or something. Um. Well after a bit my dad told me but, I kinda had to like figure it out for myself (Interview 21, Boy, Age 13).

When the children contemplated their parents' attempts at suicide, they experienced intense fear and anxiety lest their parents complete the suicide and be lost to them.

I was like really scared. It scared me. But then I was, like, thinking about all these things and I, and then it finally clicked in....She, I, she could have been gone, like we could have lost her and I just said that's never gonna happen. I never wanted that to happen (Interview 16/1, Girl, Age 16).

Having a parent hospitalized sometimes meant that the children had to be removed from their family homes. Those children experienced fear as their daily rhythms were severely disrupted. They were fearful about both themselves and their parents. One of the children quoted below referred to suicide for herself.

That nothing bad's gonna happen to her (mother). Or me....That mommy will get really sick and die. Um. That the same thing will happen to their (other children's) mommies but they don't probably feel safe....(I worry) That something bad is gonna happen (Interview 20, Girl, Age 6).

Oh probably like every emotion possible. Like frustration...I don't know, everything....I actually remember questioning what I was doing, like in my life...I wonder if I should kill myself, like nothing like that, but...I remember questioning a lot of stuff that I was doing and stuff like, which got me frustrated, and then it just got me...confused.

Everything was just like a blur to you and you don't know what's going on and it's like hard to be happy. But that's me. Like I'm really close to my mom and that's why everything affected me a lot more. That's the way I was. *Oh yeah it's like every emotion...Everything, except for like pure happiness. Every, like, bad emotion (italics added)* (Interview 16, Girl, Age 16).

During extended hospitalizations, the children experienced extreme confusion, frustration and sustained anxiety. Hospitalization severely disrupted the daily rhythms of children's home lives and made finding the rhythm and maintaining the frame with their parents more difficult. Although the children could visit the psychiatric ward, they were afraid about what might happen

to them; “Yeah, (it was scary) so they’re (patients) just like crazy or something. Like go berserk on somebody and maybe like even hurt us ” (Interview 10/1, Boy, Age 14). They did not know what to expect and the unknown was frightening.

Because the children were uncertain about the acute episodes of mental illness and how they would resolve, they experienced heightened emotions. When their parent returned home from the hospital, the children initially experienced happiness, “feel good inside” (Interview 12/2, Boy, Age 9).

Emotional Effects of Transitions

The daily rhythms of the children’s lives were changed as a result of many transitions. Transitions consisted of moving to new neighborhoods; changing schools, friends, helpers, and, sometimes, living with a different parent. Those transitions intensified the “emotional currents” that the children were experiencing. When children moved their lives and their daily rhythms were disrupted, because they changed homes, schools, support systems, and friends. At times, the overall effects of the moves were beneficial for the children; at other times, the moves were costly in terms of their emotional impact. Transitions had negative emotional effects on children who had little power or choice, or who had cumulative changes with many transitions occurring simultaneously. As a result of moves, some children experienced hard times in their school lives and missed familiar places where they had been given extra resources to assist them.

Uh. It was very hard. Sometimes I didn’t get things, sometimes I did...I, like sometimes I don’t understand things. Yeah. But I loved...my old school. Yeah. I had a lot of people helping me out. And they was around too (Interview 04, Boy, Age 6).

Transitions could also bring mixed emotions for the children. Some of them were happy to be reunited with siblings, felt safer in their new homes, and felt a move represented a new beginning. At the same time they were forced to realign with new helpers and support systems.

Well, I didn't have any choice; I . . . told my auntie, the night before they took me in to get me started at B. School. Auntie, I'll go to B. School cause I have no other choice. So, in there I had some trouble there in Grade 7, which was the work and some of the kids, cause in Grade 7 and 8. . . *the kids are harder on you. (italics added)* So, I was living with her (mom) for a couple of years, never seen my dad for a while. I'm glad I'm living with him . . . We moved here. I didn't know anyone. So I sat in the house when my dad went to work. On the computer.... *all my other friends were in school. (italics added)*. . . . So I would sit in the house...*I forgot where all my friends lived besides one. (italics added)* I go to visit him once in a while (Interview 03, Boy, Age 13).

In addition to contending with the mental illnesses of their parents, children experienced a sense of loss related to the changes in the daily rhythms of their lives which sometimes interfered with school work, "Yeah, kinda cause you think about and...you can't get it, (mental illness of the parent) off your mind sometimes and you just can't focus on what subject and sometimes class" (Interview 11/2, Boy, Age 11). The children could become preoccupied with their parents' problems and feel overwhelmed by them. Cumulative losses around family interactions, general stability in their lives, and friends had significant emotional effects. The children despaired when they were unable to solve their problems at home and at school. The cumulative losses and consequences of mental illness and resultant transitions in the families' lives interfered with the children's abilities to find a rhythm with their parents and to maintain the frame with them in terms of preserving themselves and their identities.

*Summary: Emotional Currents and their Relationship to Finding the Rhythm
and Maintaining the Frame*

Throughout their attempts to find the rhythm and to maintain the frame with their parents, the children experienced "emotional currents". Their emotions fluctuated in intensity and duration. For the majority of the children, "emotional currents" ran over a solid bedrock of

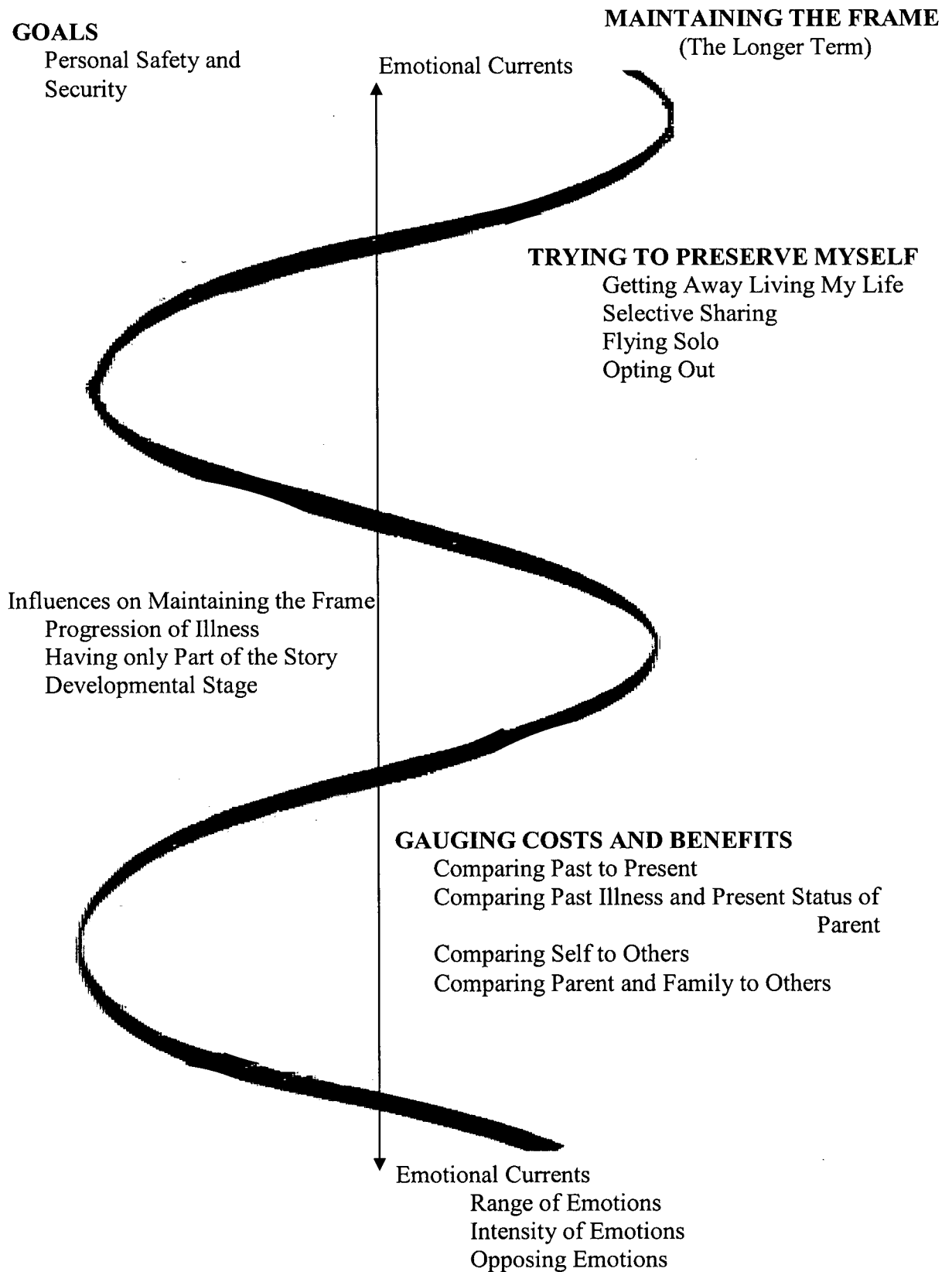
affection between the parents and the children. It was this bedrock of affection that sustained children's desires to find the rhythm with their parents, as well as to maintain the frame. The bedrock of affection could buffer some of the conflicting emotions that children experienced in response to the mental illnesses of their parents. Children, who by outward behaviour during participant observation, looked like they were handling things well, nonetheless described feeling emotionally drained and distressed while navigating these "emotional currents". Those children were able to hide their anger and look calm, while often feeling overwhelmed. The children experienced painful emotions related to unsuccessful attempts to find the rhythm and maintain the frame within their parent/child relationships.

Some of the children, however, were able to balance the positive and negative emotions in their daily lives, within the rhythm of their parent/child relationships. These children were better able to manage their intense emotional reactions while "finding the rhythm" with their parents often because of additional support. Intense feelings of love motivated children to find the rhythm, while anger and confusion impeded the process, sometimes fostering disconnection and strain within the frame of the parent/child relationship.

Maintaining the Frame

"Maintaining the frame" was the process that captured children's efforts to keep a frame with their parents, which allowed them to be connected while feeling safe and comfortable. Safety included physical and psychological safety for themselves, their parents and siblings. Comfort referred to their sense that the frame could be maintained without too much difficulty. "Maintaining the frame" referred to their attempts to support and develop their identities while living with parental mental illnesses (the bigger picture), rather than the specifics of getting along day-to-day in response to acute illness. The children's frames with their parents had to be adjusted in response to the parents' illnesses and their consequences for family life (physical

Figure 5.3 The Basic Social Psychological Process of Maintaining the Frame



moves, loss of jobs, hospitalization, financial burdens). Episodes of the illnesses or other events resulted in the children shifting the frame, in response to their parents becoming distant, unavailable, and non-receptive or when they became overly demonstrative, needy, and intrusive. The children had to shift the frame to compensate for their parents being unable to invest in them or to help them, while an episode of mental illness was occurring. Maintaining the frame was composed of the two stages: “trying to preserve myself” and “gauging”.

“Trying to preserve myself” was the process these children used to maintain ‘lives of their own’, and the sense that they were separate from their parents. Children were in relationship with their parents, but they also needed to be clear about boundaries so that they did not become consumed by the mental illness. By using the strategies in “trying to preserve myself” children were attempting to gain respite from the illness, self-affirmation, connections with others, solutions to problems, and space for themselves. “Gauging” was a stage of “maintaining the frame” where children determined how they were managing. These children weighed if they were doing better or worse as they “tried to preserve themselves”. Goals associated with “maintaining the frame” were personal safety and security. Attaining these goals helped children maintain and develop a sense of who they were within their parent/child relationships while remaining connected to their parents.

Trying to Preserve Myself

While “monitoring” and “adjusting” was concerned with getting along day-to-day and finding a rhythm with their parents, “trying to preserve myself” focused on the children managing living with parental mental illnesses over the long term through maintaining a safe and comfortable distance from their parents. “Trying to preserve myself” represented the children’s efforts to stay safe and secure while, maintaining a comfortable distance from their parents but without becoming disconnected from their parents. It placed the children in the broader life

context of school, peer relationships and community interactions. When “trying to preserve myself”, children used strategies to maintain the frame with their parents, without losing themselves in the process. They had to walk a fine line between keeping themselves separate from their parents while staying connected. The strategies described in “trying to preserve myself” were aimed at what the children needed to do for the longer term.

In trying to preserve themselves, the children used the strategies of getting away, living my life, selective sharing, flying solo, and opting out. A discussion of each strategy, its relationship to the stage of “trying to preserve myself” and to “maintaining the frame” follows.

Getting Away

To preserve themselves, these children needed to temporarily get away from the burdens of living with parental mental illnesses and to periodically step away from their parent/child relationships. Getting away was more than managing emotions; it was temporarily forgetting the whole experience of parental mental illness. This gave these children respite and restored their energy. Their temporary withdrawal provided them with opportunities to develop, such as socially with peers, and physically and mentally with sports, games, and academics.

In getting away, the children created distance from their parents by physically or mentally leaving the scene. The children either left their homes or distanced themselves by not thinking about the situation and psychologically putting it aside. Older children had increased independence to physically get away. They were able to ‘hang out and chill’ with friends, go to sleepovers, the mall or work and, sometimes, to drive a car. Younger children got away by sleeping, going to their rooms, playing, making up games, choosing to think of happy times not problems, reading, and taking comfort in stuffed animals and pets.

I calm my own body down and I think happy things when I’m sad. Yeah.

Just calm myself down. I read. . . but sometimes I take a story and I read it cause it gets interesting sometimes (Interview 01/2, Girl, Age 7).

Yes. I cuddle with my toys. To make me feel a little better...one day I um took a nap. I took a nap that day. Cause I thought, oh I need one, cause I thought of one time that I had to take a nap...And I took a nap (Interview 20, Girl, Age 6).

Sometimes I get sad, but usually when I'm sad I either just take deep breaths or go to my room...And uh, the video tape on Yoga...Sometimes at night for uh relaxing. Um. I haven't been doing it lately. I've only did it a few times. Just for a little stretch. Um. I just found it in uh, one of the movie cupboards (Interview 02/2, Boy, Age 10).

Younger children could only temporarily get away from problems within the frame of the relationship with their parents because their strategies were limited. Parents (ill and well) attempted to involve some children in extracurricular activities outside the home to help them "get away". These activities helped the children to create distance from the tensions of their circumstances, to develop a sense of self-separate from the home, and to create opportunities for making friends.

But it, so he (dad) just signed me up for karate. It's good. Cause one of the kids from Catechism it's their hobby. Um-hum. Somebody, another kid that goes to the YMCA is from my Catechism (Interview 22, Boy, Age 7).

The children who lived in two homes could have fewer resources to get away from their problems. One child described his life style in the ill parent's home:

Probably sleep more. Not much to do. Cause there isn't much to do. All there is would be to argue with me. I probably play on the computer a bit. Well, yeah, I have...I don't have much friends around here (Interview 02/1, Boy, Age 10).

Older siblings sometimes noticed how younger siblings got away from problems associated with parental mental illness.

I think it was, I don't know when it was, I think it was a while ago and they (younger siblings) were really worried about him (parent) so, like they always tried to; they always played with their little toys, so (Interview 09/1, Boy, Age 16).

Because the younger children were less able to remove themselves physically, they were more subject to the intrusion of their parents; they still developed strategies to gain respite from their parents' illnesses.

Games and play helped younger children manage difficult situations such as a foster home placement necessitated by their parents' mental illnesses. One younger child described using games to get away from her unhappy experiences in foster care.

And me and "C" (sister), like, we made up lots of games cause when we went to bed it was really boring... We um made up a game called "What". Well, if I put up my hand and then I go what, then she puts up her hand then goes what, then I go what, then she goes what, then when we go faster and faster, when we got too fast... Then we made up these clapping games. Yeah. We made up a Miss Mary had a cat, Miss Mary had a clock (Interview 08, Girl, Age 10).

These games provided distraction, humour, and fun which children found helpful. The children suggested that adults could use humour to help children: "I know one that's never used. Tell them jokes. Sometimes do funny faces" (Interview 04, Boy, Age 6). One child also identified games as an important aspect of a support group for children living with parents with mental illnesses; "Yeah. And there's fun games, too" (Interview 20, Girl, Age 6).

For older children, extracurricular activities provided a means of getting away so they could manage the tensions associated with "maintaining the frame" with their parents and feel more secure. "Yep. So I get it (parental mental illness) off my mind sometimes [when playing sports] (Interview 11/1, Boy, Age 11).

Friends were increasingly more important for older children, and offered opportunities to get away.

Just go out, like, with friends and just, like, kinda forget about it for a bit. Some days you just want to forget about it. Just do that. And like it'll probably help you out a bit... Yeah. You just kinda stay home and just sit down and feel sorry for yourself or blame other people. You just go out with other people and just, like, have a good time with your friends. And just, like, forget *about everything (italics added)* (Interview 10/1, Boy, Age 14).

The older children also used deliberate forgetting through distraction when with their friends, as a means of getting away.

Yeah. I didn't really think about it (mental illness of parent) too much. Like...except for when I guess going, like when I was on my way home. It would be in the back of my mind because you know school, like friends, homework, whatever....Well I guess it got my mind off of it, didn't make me worry (Interview 15/2, Girl, Age 14).

But now that my dad's out [of hospital] and he's actually getting something to do, I don't actually worry about it that much anymore....*Like just put your mind on like something else (italics added)*. Like go and play road hockey... you'll forget about it and it'll be alright...fun like that....If I'm getting too frustrated here...I have to go see my buddies. So I just go out and hang out with them and either I'll come back or I'll sleep over there (Interview 10/2, Boy, Age 14).

Some of the older children deliberately stayed away from home when situations were too difficult for them; they physically removed themselves from their homes by using other activities.

I go for a bike ride to the library and things like that. I usually come back at around 3 o'clock (Interview 21, Boy, Age 13).

Uh. I don't know like. If it's sad, like if we're in a fight or something I usually like go out or something. And it gets better. Yeah, like, go out with my friends. Go to my cousin's house....Yeah. Sometimes I go there, or I...go out with any of my friends, just something to do (Interview 15/1, Girl, Age 14).

At times, even older children were unable to get away physically, so they chose to remove themselves mentally from their situations. Often sleep was their only way of doing so.

Well, like in the summer vacation, I just try to kind of doze off when I can't just kind of leave...*it takes time, like it, it takes time off, like. I don't have to be worrying about it when I'm sleeping (italics added)* (Interview 21, Boy, Age 13).

When the chronicity of their parents' illnesses became too much for some of the children they described getting away to the point where they moved out of the frames.

And just hanging out with your friends...they like help you out and stuff. You can have fun with them. (Not think about) Family stuff; it just builds up and you get frustrated and stuff. *It just makes you want to punch a pillow. That's why you have to, like, go out with your friends and just hang out with them. That's what I do. (italics added)* (Interview 10, Boy, Age 14).

The strategy of getting away helped the children in other areas of their lives. They described trying to walk away from conflict and playing along in order to deescalate situations with peers at school.

Well the main thing is, if there's any problems you have, like with kids bothering you if they find out that your parents, have a mental illness and they make fun of you...just say laugh it off...like play along with them, so they know they're not getting you. It's like bullies. Like they keep bugging you and bugging you until you actually like play along with them...and just let it go in one ear, out the other. It's like, just ignore them type of things and laugh along (Interview 03, Boy, Age 13).

Um. Sometimes kids at my school will pick on me. Oh, I don't know because they're older. I blow it off, I get through it...Cause I'm going to be in a different class and I might have the bullies again...Let, just let them be. Let them be (Interview 02/2, Boy, Age 10).

All children varied in the opportunities available to them to get away. The children who had resources, such as money, supportive people, and some stability in their lives, had more opportunities to find places where they could get away from the problems of living with parental mental illnesses. Some parents were able to give the children money for extracurricular activities and some children had family members who were able to spend time with them.

Living My Life

Another strategy the children used in "trying to preserve themselves" within the frame of their parent/child relationships was to live their own lives by exerting as much control as possible. Living my life was different from getting away. While getting away provided temporary relief, living my life involved the children accepting they had a right to pursue their own interests and their own lives and to let go of inappropriate responsibility for their parents. "I guess like, try and like live life to the fullest, I guess" (Interview 10/1, Boy, Age 14). The children often felt pulled in their parents' direction, particularly when the needs of their parents were chronic and unresolved; however, living my life affirmed the children's worth as separate people with their own identities and helped them feel safer and more secure.

Younger children, whose lives were more centered on the home and whose activities were under supervision of the family, were less able to articulate how to live their own lives. Despite their limitations, some children still learned to see themselves as separate at an early age "Yep. I love myself....I practice trying to like myself" (Interview 01/1, Girl, Age 7). They made conscious efforts to care for themselves. Some of the younger children were articulate about how they described keeping themselves separate to develop an identity.

I think that kids should know, that yourself isn't the bad one, yourself is the good one.

So I think that yourself is really special. You make sure that yourself is happy so. . .

(Interview 01/1, Girl, Age 7).

All of the children took what control they could of their lives, in an attempt to preserve themselves, develop their identities and be successful within their developmental tasks; "I stay until (in for) recess. Only at lunch recess, I go outside. So I can get my spelling done" (Interview 05, Boy, Age 9). The developmental stages of the younger children and their places within society and their families limited how much influence they had over their lives. They attempted to take whatever control they could to live their lives on their terms. Even the younger children had a sense of what their lives should be.

Um...It's (father's past hospitalization) nothing. It's a memory...And just for my mom too. *I went on to my real, real life. (italics added)* Yep. My life instead of just thinking about the days that happened to my dad....Um. Just think of happy stuff instead of uh, the hospital and stuff, where my dad is right now (home)....Um. Just think of your family when you have a good time, and just don't think of the bad times what happened to your family. Just think of other stuff, I just do that on my own (Interview 12/2, Boy, Age 9).

The younger children wanted their parents to be well and when they were, they were better able to preserve a sense of self in their family homes. School, day care, and family could help or hinder them in living their own lives somewhat separately from the parents' mental illnesses. Their attempts to live their own lives were facilitated by validation from nuclear and extended family, community, and a sense of routine.

But usually after school, well I have all those fun stuff. They call my name on the radio and say that it's my birthday and then I go to, to the Principal's office and then they give me a sucker and...pencil. Yeah, just for a little treat. And sometimes the class says

Happy Birthday...after school, well at my babysitter's, usually she makes a cake...and she gives a present to the kid if it's their birthday...She's really loose and...she's a good babysitter. Yes. I'm really lucky to have a babysitter like that...she lives really near to the school...Yeah I just walk there and my Mom, when she's done work she comes and picks me up and go home and we do all the rest of our stuff....

Usually I come home, we wait for my Dad and then um, we eat what I wanna eat for supper (Interview 17, Girl, Age 10).

Um. Now this is something funny. On my grandpa's birthday, I was born. So we both have it on September 18....When I come home from school. He picks me up, from his work and every year, I think, we're always gonna go to a special restaurant. We, we eat supper...Yep, just me and him. We have some pizza and then we go play some games. Together (Interview 22, Boy, Age 7).

The older children were definite about expressing the need to live their own lives. They set boundaries and limits. This adolescent described her need to have her own life and to stay healthy.

He (mother's boyfriend) can relate to her (mother) more than I can. Like, because they both have depression and like, I guess like, *sometimes I'm too busy with my own life. (Italics added)* And I don't really want to like talk about love and like...*You just can't stop yours (life) (Italics added)*. Yeah. Like I'm not just gonna sit around...It's a lot healthier, I think if I go out and do my own thing. I think so. But *always be there for her, but just not every moment (italics added)* (Interview 15/2, Girl, Age 15).

The older children also indicated that pursuing their own interests helped them develop themselves. The children lived their lives by developing friendships, interests in sports, theatre and other extracurricular activities, forging a sense of who they were through these activities.

I'm serious about basketball and I gave up everything to play it because you know, it was a huge commitment. So that's all I do is play basketball and I work out every day. I can't work during basketball season...cause there's no time at all...I have a tournament almost every weekend...I had to quit my job for the three months that I'm playing basketball, my parents might give me money and might give me like a hundred bucks a month for allowance...cause they're gonna support me. But, I commit myself to it so. Like I wanna be the best so (Interview 16/1, Girl, Age 16).

There were costs to the older children trying to maintain a distance and boundaries. Some described fatigue when they pushed themselves to stay away from home.

I made myself because I knew that if I isolated myself from everything...then I, would not be happy either. Maybe that's why I was really tired, cause like, maybe I should have been staying home, but I forced myself to go out and do stuff just because...I knew that I needed it...It didn't actually make me feel better but...then it probably would have been like a hundred times more worse. Just sitting there by myself all the time. Cause that's what I wanted to do...(Interview 16/2, Girl, Age 16).

Some children received support from adults to help them live their own lives. This child described how her well parent assisted her to withdraw from the ill parent's problems. She reluctantly described leaving her parent in the hospital over the weekend.

We (well parent and child), left for a weekend, which I did not wanna do at all. I didn't wanna leave her, but it was something we needed and it helped. And sometimes...I didn't wanna go to school but he'd (father) make me. Sometimes he'd let me stay home you know, but you can't get used to that. You can't used to always like, well this is a problem so, you know I, I have the right to do whatever I want, like *you have to stay focused on other things in your life*, (italics added)...And know I can still play sports . . . nothing in my life had changed cause *I didn't let it take over my life. It changed my life*

but I didn't let it control it. (italics added) It's a hard thing. Hard to accept...*This is my life, (italics added)* this is what's happening, so make the best of it cause you can't change it (Interview 16/1, Girl, Age 16).

It was easier for the children who had people like the well father in the previous quotation who supported and encouraged them in their efforts to preserve themselves while they were still trying to maintain the frame with their parents with mental illnesses.

Selective Sharing

As part of preserving themselves, the children sometimes selectively shared their experiences with trusted others. Trusted others included their parents, peers, friends, and helpers, such as counselors and teachers. Sharing intimate information helped children to preserve themselves by validating their experiences and helping them feel more secure, and decreasing their feelings of isolation as they connected meaningfully with others. Trust was the most crucial element in deciding with whom to share personal information; the children chose carefully. For younger children, the family was their dominant point of reference for life events. The younger children were less likely to share information outside of the family; "Actually I don't tell my friends about it. Because I don't just, I don't share with people...that are not family" (Interview 11/1, Boy, Age 11).

Some of the children were instructed by their parents not to share information so that the option of selective sharing was not available to them. For example: "My parents tell me to keep it hush hush so. But he (father) tries a bit to keep it a bit hush hush. Because he doesn't want me to worry" (Interview 21, Boy, Age 13). Restrictions about sharing information made it difficult for children to preserve themselves within their parent/child relationships and engage with the outside world. They were forced to keep secrets causing some children to feel less secure.

Some of the children had extended family members with whom they would selectively share their experiences and feelings. While extended family was more visible in acute illness,

the wisdom they shared with the children helped the children to understand the chronic problems associated with the illnesses. They provided the children with a safe place to voice their concerns and questions.

My grandma, she helps us. My dad's side, my grandma helps us. They talk to us about it. That he's gonna get better, but he might have to stay in there (hospital), but he's gonna get better. It's just his illness, don't worry, it's just his illness, it's not him talking (Interview 11/1, Boy, Age 11).

Encounters with family members helped the children feel less alone. The younger children, however, had fewer resources and opportunities outside their families and were more dependent on others reaching out to them. Thus, they were more likely to share their experiences and feelings with their parents, if the parents made themselves available.

Some parents guided and encouraged their children to tell them how they were managing. The children sometimes saw sharing their feelings as a way to help both themselves and their parents. One young child described how she was nervous about the interview with the researcher until she learned it would be in the family home. She described how sharing her feelings with her mother, a strategy that she routinely used, helped the mother understand her and made both of them feel better.

Make sure they're (parents) doing good...By telling them (parent) what they (children) feel about them. That's what I do...Like today. I told my mom about how I was nervous.

Yeah. I talk about those things, because sometimes it's just going in front of other people makes me nervous and scared. I really don't know. I feel scared...sometimes, I only went a couple times in my life with people that I didn't know. I get scared cause I never go somewhere, without my Mom. So I'm used to that (Interview 01/2, Girl, Age 7).

At times, parents helped the children express their feelings after difficult family situations. In this quotation a child describes discussing their experiences as the family attempted to regroup.

And we, we'll call a big family meeting...Usually it's in the living room.

...It's just so we can all, like talk about different things that happened. Sometimes we'll have it after...I go to school and something happened...I, I like to have the meeting cause we all get to get together and just talk about the different things that happened (Interview 22, Boy, Age 7).

When children developed confiding relationships with their ill parents, it was helpful to preserve themselves, as long as their parents were able to focus on their children's needs.

I, I talk to my mom (ill parent). Like I talk to my parents about everything. There's really nothing that I can't tell them about. So. It's good talking to my mom about that kinda stuff so (Interview 14/2, Boy, Age 13).

A parent's or family member's receptiveness to talking about the illness helped the children to preserve themselves within the frame of their parent/child relationships, because they felt supported around sharing their observations.

Like my dad (well parent), we talk, we're close. Like we, we became really close. And if I talked to anyone, *it was him and without hesitation (italics added)* (Interview 16/1, Girl, Age 16).

Selective sharing could occur outside the family home, with counselors, teachers, and other adults in the community. Selective sharing in those situations involved some risk because the children were not entirely certain how other adults would respond. Contact with counselors was frequently initiated by the ill parents and provided by the school system; however, not all the children found counselors helpful. For those who did, counseling provided a means where the children could selectively share information, within a safe and confidential environment.

Confidentiality was important because they did not want to be seen as different from their peers.

Um, one of my teachers actually...I talked to her about a lot of stuff. And she...was someone that I came to, when I was like stressing out. And just you know crying, just

really stressed out and, she was just there. She talked to me about anything. Like we'd be talking about my mom and then she'd just be like, well how's everything else going, and just right there, that just made me feel so much better for some reason. I started to talk to her about like basketball and things like that and, I just felt better. Yeah. I don't know why...I know it made me feel better just talking to her, cause we didn't talk about like one main thing (Interview 16/1, Girl, Age 16).

And the counselor (school) is like really nice and...she knows what's going on here (at home) Cause my mom talks to her...You just like, talk to someone about it...It won't get all around...It's like I guess confidential...You don't want like everybody...to feel sorry for you... so then everybody is treated the same way that it used to be... counseling's like; I think is the best way. Yeah. And then you just let everything out, they won't tell anybody (Interview 10/1, Boy, Age 14).

Although counseling made some of the children feel less alone and more hopeful, some of the children did not know why counseling stopped when it did.

So I was like 13...she's (counselor) been like a friend of the family's for a long time. We talked about my dad (absent well parent) It was almost a year ago...We only talked a little bit. Like an hour a day, every Thursday for like 3 weeks, I think. I don't know what happened, can't remember. Well. I could just ask her when she's (mother) um, (cuckoo) you know. I already know what's wrong with her, pretty much (Interview 18, Boy, Age 14).

On occasion, children found other adults in the community, with whom they connected and could share their experiences. The children sensed when people genuinely cared about them and when it was awkward for others to respond to them.

I was telling her (adult woman) everything and that was fine. Everything was going fine and then like, but he (boyfriend) was sitting there, so I just wanted to finish the

conversation cause I felt kinda bad cause I knew he was uncomfortable. But, if he wasn't there and I talked to her about it, I probably would have felt a lot, you know I would have ended the conversation and just felt better. Cause I always feel better when I tell someone about it. It always sort of makes me feel better. But that like particular situation was kinda weird cause he was there. It wasn't weird for me, but I knew that it was weird for him (Interview 16/2, Girl, Age 16).

Friends were important confidants, particularly for the older children. Some of the boys in the study had girlfriends who listened and helped them.

I told...my best friend "D" (girl). I'm always with her. So she knows my mom...she wouldn't treat her any different or anything...We're just so close like...there's no way she couldn't understand it (Interview 14/2, Boy, Age 13).

Having peer confidants gave the children a safe place to discuss what was happening in their homes and, if the confidant was empathic, helped the children manage their situations. The children were cautious about confidences, because they wanted commonalities with their peers so they could 'understand' their experiences. When selectively sharing with peers who had similar experiences the children were both validated and confronted with the reality of the illness. At times, the reality could add to their concerns.

That's my best friend "F"...Well we could actually talk about it cause like we actually had something in common with the families...like manic depression. So I guess we're not shy about it, we just don't tell anybody about it. It's just between us. Uh, cause we're best friends and I don't really want to tell everyone that our dad has manic depression and stuff. That was kinda bad cause she'd (friend's aunt who completed suicide) actually go to that. . . she'd make, actually went to that level and actually committed suicide. That's pretty intense and stuff. She must have been really sick I guess. Yeah. Like sometimes like if he's (father) actually, like manic I guess...Well I

don't think he'd commit suicide. But like, I don't know. I don't think he'd actually go to that level but sometimes I just worry just in case (Interview 10/2, Boy, Age 14).

Even when the illnesses were different, the experiences around the illnesses provided commonalities for selective sharing. This adolescent described the commonalities in experiences with parents who have physical and mental illnesses.

So I actually went to her (friend with physically ill parent) because I just like, I told her everything that was going on. Like how many people does she meet that understand, like the stress you know... *We're a support group for each other (italics added)* (Interview 16/1, Girl, Age 16).

Selective sharing helped children preserve their sense of self and to connect with others when they were met with comforting and positive responses. Friends were important confidants, particularly for the older children. At times, these were children who had common experiences, with illness of an adult in their families. Selectively sharing with peers could also be disappointing for children. If unsatisfactory responses occurred, selective sharing had the potential to hurt the children. Therefore, children used discretion, because they were aware of the potential risk that friends might gossip about their situations. They trusted that their friends would not do so, but sometimes had concerns.

I just told them (friends) he (father) has a mental illness, that's about it. And they're like, that's not good. They help me out though, my friends...Cause if I'm feeling down, they already know. So they, well, we gotta make him feel better...Just chilling with me. Having a good time. Cause I can trust them and if they wanna go blab that...Like what's the big deal if they wanna go blab that to everyone, it's not really a big, *well, it is a big deal to me (italics added)*. But to them I don't think it would be a big deal to go blab it out to everyone so. (they would not) Well...cause it's like they knew there was family problems and they know what's going on (Interview 09/1, Boy Age 16).

As the children gained more insight into their parents' illnesses, some children had difficulty continuing to share with friends on an intimate level. At times, their friends were not consistent in their support. At the same time, some of the children realized that opening up to others was helpful.

I tended to push away all my friends...I didn't want them to know about it just because, they wouldn't really understand. My close friends knew about it. A lot, a lot of people know. Cause like, it's hard to keep that your mom's in the hospital for like 7 months, you know. . . Well they all kind of knew but, I never really had like in-depth conversations with anybody. She (my best friend) really let me down...She was just, it's gonna be okay don't worry, but *she never actually like talked to me, like I would have wanted to talk to someone about it (italics added)* (Interview 16/1, Girl, Age 16).

Like not to keep everything inside. I know from experience that is just not the way to handle things. Well for me, it's not...like I kept things in, like since Grade 7. Kept it in. Yeah. So I just finally opened myself up to people and now I let people in my life and I, used to push people away and I would not let anyone like do anything for me. Then finally I just opened myself up and I felt, like a hundred percent better...It's hard...I just learnt that myself (Interview 16/1, Girl, Age 16).

Not being able to open up to other people could be difficult for the children who could not share as they were more likely to try to solve problems independently.

Flying Solo

In attempting to preserve themselves within the frame of their relationships with their parents, many of the children tried to fly solo. Flying solo meant that children were dealing with problems on their own. When asked who helped them to manage the experience of living with a parent with a mental illness, they often said no one. They used flying solo to combat their loneliness and to solve their problems by developing other ways to help themselves. The

children took on the responsibility to make things right. Although the children attempted to come up with solutions on their own, both younger and older children often experienced emotional distress, because of the enormity of their problems; “Who’s gonna get me? (pending custody battle). You know cause I don’t know which one to stay at. Cause I’ll miss both of them. Maybe, they, *maybe I’ll come up with something (italics added)*” (Interview 01/2, Girl, Age 7).

Despite limited resources, the younger children could be resourceful in problem solving.

I’m making myself feel happy and I talk nice stuff to myself....Well, it means that I’m saying sorry to myself about when I was really sad. Like sorry you’re sad or something. It helps solve my problems. I don’t know about you...*I just do it myself (italics added)* because it’s, I think myself is very special *(italics added)* (Interview 01/2, Girl, Age 7).

The young children often felt that they had to come up with their own solutions; “I just do that on my own [think of the happy times] (Interview 12/2, Boy, Age 9).

The children often solved their problems, with unpredictable support from others. Having helpful teachers made their attempts to solve problems less difficult; however, they could not always maintain those connections.

Well I had a real, a really helpful teacher last year that really helped me but other than that, nope. (No one helped with schoolwork). Next year my homeroom teacher isn’t really, most helpful (Interview 21, Boy, Age 13).

Having no options but to rely on themselves forced children into self preservation mode. This child talked about his feelings of aloneness in both interviews. This did not mean that children were not affected by feelings of aloneness; “Oh yeah you have to be (mature) pretty much. In this family anyway” (Interview 09/2, Boy, Age 16).

Nobody really (helps me). My mom calls the school and tells the counsellors to come talk to me. But I don't really like going to see the counsellors all the time. Try to deal with it by myself. Be your own self, that's like basically being cool....

(Interview 09/1, Boy, Age 16).

Even when other adults were present, the children often flew solo. In a family where there were several workers in the home on a daily basis, a child found them unhelpful during a crisis situation; "I guess cause they, they help her [mother]. *They [workers in the home] don't really have to help me (Italics added)*" (Interview 15/2, Girl, Age 15). The child was left to manage the situation on her own. The children who did not have consistent support available in their lives felt alone in solving their problems.

[Parents should] just like talk to them (children) about...like how to do things, or...ask them about stuff...in school, like if they have homework...the parent should help out and stuff like that. . . Like my parents probably won't know cause when it comes to science...So I don't think my parents would really know. *So I guess I'm on my own when it comes to homework (italics added)* (Interview 10/2, Boy, Age 14).

Like really he (father) never teaches me that much. You know how fathers would teach their kids that, pretty much a lot that they know about all this other stuff, and then they learn about it. Well, I don't think he does that much with the kids. You know, that'll make them smarter when they're older....There's things I don't know. Yeah...So that means that *I just gotta try to teach myself all that stuff. (italics added)* And I just want it to be like, I just want him to be like that with my brothers. (Interview 09/2, Boy, Age 16).

Flying solo involved children learning how to solve problems on their own or trying to find people to help them. Where there were no consistent, supportive adults to buffer the effects of parental mental illness, the children had to rely on their own efforts to solve problems. When the children had to almost totally rely on solving their own problems, it was difficult to maintain

a safe and comfortable frame with their parents. For some children, flying solo was more likely to progress to opting out because they saw opting out, as the only way to preserve themselves.

Opting Out

In preserving themselves, two boys had to put so much distance between them and their parents in the home, that they opted out of their relationships. Opting out occurred when children had reached their limits of endurance and were unable to invest more energy to try to maintain a safe and comfortable frame. The children felt that their situations were not open to resolution and their best choice was to opt out of the relationships with their parents. They needed to create space for themselves to survive. Opting out, involved increasing their distance so that they exceeded the limits of any frame with their parents. This boy had witnessed his family having continual difficulties and perceived his well parent as less concerned about the family. His strain in his relationship with both of his parents caused him to focus solely on his own needs and to begin the process of opting out of what he saw as an irresolvable situation.

I don't know. It (having an ill parent) makes me more independent. Yeah. That's what I find. Makes me want to do my own thing. Work hard and do what I want to do. And I know my mom, she's a grown adult. She'll be able to fix herself up, so might as well not drag me in the hole with her too. Uh. I think *it's just me cracking down on what I want to do (italics added)* (Interview 09/2, Boy, Age 16).

This boy opted out of putting energy into "maintaining the frame" with the compromised parent and eventually also with the well parent; instead, he put his energy into his own activities.

Um. Try to stay strong, focused and uh, that's about it. Well I have a job right now, so that keeps me busy. Keeping me busy really made me like focus on what I'm doing. So really just focus on whatever you're doing...But staying focused is the main one for me (Interview 09/1, Boy, Age 16).

Opting out could be expressed through risky behaviour that was costly to the children. In order to opt out, some children used alcohol and drugs and became embroiled with psychiatric and legal authorities. Others avoided situations where they had to deal with other people. One adolescent boy had developed a school phobia, had not been in school for one year, and had social anxiety, which severely limited his activities. In addition to his parent having a mental illness, his life circumstances had been continually chaotic in his developmental years. He was overwhelmed with his circumstances and unable to manage his situation. While reflecting on his current situation he described the following.

I don't know cause my sleep pattern got really messed up. I sleep too late... Last night I went to bed at like 5 in the morning. Had this problem since I was nine. Since the beginning of the year (not been to school). Last year I went but they held me back. They didn't tell me over the summer... I was held back in grade 8. I was supposed to be in grade 9 this year. I don't know. I was doing well before when it was just me and one teacher in a separate classroom, with no kids in there (Interview 18, Boy, Age 14).

This boy's anxiety contributed to his opting out of normative activities with his peers and school. He had few friends and strained relations with his family. Another adolescent boy became entangled with the legal system and had opted out of school and investing energy in the frame with his parent. He "tried to preserve himself" by opting out through focusing solely on his needs, and ending up in legal trouble. When the children found that trying to maintain a frame with their parents was too emotionally draining the only way that some could preserve themselves was to step out of the frame. Some children did this temporarily, others for the longer term. Those children were at a loss as to how to maintain safe boundaries. The boundaries had become so uncomfortable that they couldn't connect across them anymore. While few children chose this extreme option, two adolescent boys saw this as their only reasonable choice. One focused on activities that improved his situation while the other used

behaviours that resulted in his removal from his home and brought him into contact with the law. A third child was struggling significantly with “maintaining the frame” with his parent.

Gauging Costs and Benefits of Maintaining the Frame

The second stage of “maintaining the frame” was the process wherein the children gauged the costs and benefits of “maintaining the frame” with their parents. In “gauging”, they weighed whether they doing better or worse in their efforts to preserve themselves in the context of their families. While the goals of “finding the rhythm” (daily family stability, getting along day-to-day, daily positive connections with their parents) contributed to children’s goals, “gauging” was specifically related to children’s efforts to maintain a safe and comfortable frame with their parents. “Gauging” allowed the children to think about the bigger picture. In preserving themselves, the children worked at “maintaining the frame” with their parents without becoming engulfed by the parental mental illnesses in order to develop and maintain a sense of self. The strategies the children used to preserve themselves and the respective outcomes including respite, self-affirmation, solutions to problems, connections to others and space for self, were achieved, by most children to varying degrees of comfort. In gauging, the children thought about whether they were gaining or losing ground in their efforts to preserve themselves and to maintain a comfortable frame. In order to weigh their situations, the children compared the past to the present, the self to others, and their parents and families to other parents and families. In this study, most of the children (19/22) felt that their frames with their parents were comfortable enough to maintain in terms of psychological and physical safety.

Comparing Past to Present

The children gauged whether “maintaining the frame” was working by comparing how they and their families were currently doing to how they had been doing in the past. They did this at the appropriate levels for their developmental stages. The younger children drew on their experiences, which were mainly accessed through their families. The older children, who were

becoming independent and developing external relationships, drew on their family experiences, as well as other families' experiences as a basis of comparison. They were able to engage in more abstract thinking about their circumstances and were more aware of norms in terms of family life and parental behaviour.

Children compared their ability to preserve themselves in the context of past significant events, which sometimes consisted of changing schools and family configurations, crisis events, such as parental hospitalization, loss of a job and/or driver's license, and the way family holidays and rituals were celebrated, to their current abilities to preserve themselves. Children, whose family lives had been stable and predictable for a while were better able to effectively use the strategies to preserve themselves. The children weighed whether their circumstances for preserving themselves were better or worse.

For some children, living with their parents with the mental illnesses, was preferable to past living arrangements with their well parents as stated by a younger child, "Very good . . . and awesome (new living arrangement with dad). Cause when I was living with my Mom I used to get spankings and all that for no reason" (Interview 05, Boy, Age 9). This child felt more comfortable and safe in the home with the parent with the mental illness. This teenage girl noted her better school performance was largely due to her improved living situation with her parent with a mental illness. The well parent's life choices had compromised the girl's sense of security in her former home.

I am actually. I would say I am good at school. Like, um, last year I went the whole year in honors. Um ... And then first term this year I had honors. So it's actually changed since, since I moved here from P. In P, I wasn't a very good student. *My marks were not as good in P. (because of the) household. The people I was living with. The whole situation. Yeah. Cause my step dad's an alcoholic (italics added)* (Interview 07, Girl, Age 16).

For these children, the frame felt safer with their parents and it was easier to preserve themselves with more opportunities for personal development.

The children incorporated memories of past family celebrations and rituals into “gauging” their situations. On occasion, celebrations were not planned, or spoiled, due to parental mental illness. These experiences were hurtful to the children, made it more difficult for them to preserve themselves and diminished their sense of security with their parents. The children attempted to overlook these losses but often felt disappointed. These events did not help children feel that they were affirmed by their parents. One adolescent boy described his memories of past birthdays.

Like my birthday one year, she (mother) didn’t even want to celebrate it. She just wanted to bring me to the doctor. I really didn’t like that. Another year, she started an argument with my dad over at the restaurant. . . I treat it like a normal day. The only thing that’s special about it is I get presents. Because my mom treats it like this, like the same thing. She doesn’t really, doesn’t really change anything on that day. Sometimes (have cake) yeah (Interview 21, Boy, Age 13).

Connections with extended family members could help to create rituals where ill parents would otherwise have difficulty. When rituals were missing, the children found it harder to preserve themselves and to maintain the frame with their parents. Rituals assisted the children to live their lives within the context of their families and to feel affirmed. Rituals and celebrations helped children feel safe and valued.

Umm, we get to open presents. Umm, well, really Christmas Eve is a good time too. Yeah. Christmas Eve we do the...the whole supper thing. We have turkey; we have corn, er, like um cream corn. We have potatoes, we have all those stuff and then after we get to open only one present. Around the Christmas tree (Interview 02/1, Boy, Age 10).

She (grandmother) bakes. She makes like these taffy, like um, caramel toffee. Um, she makes those and they're really good. But there's something you'd die for. Her borscht. . . . She gets those (vegetables) in me. But she makes excellent borscht. Most grandmas yeah, most grandmas don't make borscht this good. Not even the stores can make it this good (Interview 02/1, Boy, Age 10).

Oh they're (birthdays) great. Well, we go to gram's because that's the birthday place. Yeah. And, then, she, cause she has the big pool to play around and she lives in an apartment...So we get to go in it and we get to play in it and...Oh yeah. We get grandma's famous food. Sometimes Chinese, sometimes chicken, sometimes stew... But my other grandma is really famous. Well, she's famous for making food. She's the best. And she buys me lots of things. She bought me that Barbie camera and it was \$20 ...it was \$24 bucks, and she bought it for me. And I didn't do any chores for her or anything (Interview 01/1, Girl, Age 7).

The children gauged family rituals as positive experiences outside of their relationships with their parents which helped the children feel affirmed and connected. These experiences helped children maintain the frame with their parents and families. As stated by an adolescent boy who had experienced multiple changes: "We were one big happy family. My dad would goof around lots. Like on turkey day when we're having Christmas dinner..." (Interview 03, Boy, Age 13).

For children without extended family to help, celebrations were more erratic. Lack of celebrations contributed to the children feeling like they were flying solo; the children felt alienated and devalued. An adolescent girl recalled her sweet 16 birthday when her mother was hospitalized.

Well for my 16th birthday, she was in the hospital. So she came home, cause she got a weekend pass and...gave me presents and stuff and it was fine... we didn't go out for

dinner... And like the saddest part was...we were talking about it, she was like, 'Well where did we go, like I forget, where did we go for dinner on your 16th birthday?' We didn't (go anywhere) and it just broke her heart but like she was home, she was with me. And they gave me...some pretty good presents. *Plus it was my 'Sweet 16' so...I really wish that she actually was really healthy...For me that was a really big birthday. But that's the way it went, so (italics added)* (Interview 16/1, Girl, Age 16).

Past Illness and Present Status of Parent

The children compared past episodes of illness to their parents' present conditions. This gave them a sense of whether the parent was progressing or deteriorating over time. If the parent was progressing well, children felt optimistic that they could continue to use the strategies to preserve themselves and to maintain the frame. The children could see their parents' lives developing so that they did not have to relinquish their own lives in order to keep them well.

. . . My dad basically recovered from it. He's basically been my hero forever. . . Yep. Definitely. He's always been there for me. . . He's awesome. Um-hum. Actually I heard him speaking once to a bunch of people. Yeah. At a church. And he talked about the kind of stuff that he'd been through . . . like standing on the bridge thinking of committing suicide, seeing mine and his faces. He was just thinking of us and that's what stopped him. . . . But it was awesome to see how far he's come. . . . You know he's got this great job now. . . . *And it's amazing to me, because he goes from being in a hospital, because of not being able to take care of himself, to being in a group home, and you know, now he's teaching (italics added).* He's teaching people about, about, you know, mental illness and all the stuff that, you know, what he used to have. . . (Interview 07, Girl, Age 16).

When comparisons were favourable, the children gained a sense of stability and regarded maintaining the frame as contributing to their security. They were more easily able to preserve

themselves safely within their parent/child relationships. If their parents were deteriorating, the children's lives became more difficult; they gauged their experiences negatively, because they had more difficulty feeling safe and secure. In comparing the past to the present, some children had come to the realization that the exacerbations of the illnesses were part of their lives. They saw little hope for constantly maintaining frames that felt comfortable. While some of the children accepted this and did not gauge their situations harshly, other children could not accept this and gauged their situations negatively. For example, one adolescent girl accepted her situation; "You have to accept it before you can feel better about it. That's what I had to learn to do" (Interview 16, Girl, Age 16).

Other children compared how they were doing when their parents were ill and could not accept their situations. Where the father was not improving, an adolescent boy described his perceptions as follows:

Well it's kinda obvious with (at) school; I'm not really talking that much. I'm just mad sort of, kinda bitter (about my father's illness) sometimes, and then I get frustrated cause I have work and I have school and I have hockey and I get all frustrated sometimes about that (Interview 09/1, Boy, Age 16).

Comparing Self to Others

The children varied in how they gauged their circumstances when they compared themselves to others; some thought this difference made them more interesting and others felt frustrated with the associated problems of the illnesses. When children compared themselves to others they were "gauging" how they measured up to their peers, whether they were affirmed and accepted, and how safe and secure they could feel under those circumstances. The older children were more likely to realize that they were different, not only because of their parents' illnesses, but also because of their circumstances. Some children were not affirmed by their peers;

“Sometimes I get in fights by accident. Cause, its some people call me names. They tease me cause I can’t kick the ball an all that” (Interview 05, Boy, Age 9).

One adolescent boy, who had developed social anxiety, described how he was unable to make friends easily. He realized that this was much more difficult for him than for his peers who found it easier to make friends and be sociable. He was not successful at preserving himself while finding a rhythm with his parent; he was unable to make connections outside of his family.

Uh. No. I don’t think so. I’m not really good at making friends or being social so. Yeah. When I’m around a lot of people I, I just get nervous. My mom says I get a mean face on. Like I don’t mean to, I don’t know that’s happening but, it does. Like I can’t go out in public and smile, it’s just hard for me. Um... It might have something to do with “L” going to jail. Cause that’s what might happen to “L”, going to jail. (Interview 18, Boy, Age 14).

Other children noted that their experience with mental illness had given them different qualities than their friends. One girl described her differences in maintaining the frame with her parents which she perceived as positive.

Like my friends complain. . .I just hate it when my friends are, like, I hate my parents. . . .They always fight with them for like stupid reasons and its understandable, *but I just see things like a little bit differently (italics added)* (Interview 16/1, Girl, Age 16).

Comparing Parents and Families to Others

The children gauged their efforts to preserve themselves by comparing the safety, security, and comfort of their families with other families with which they came in contact and their parents to other parents. The younger children had limited bases for comparisons; they were less likely to compare their families to an ideal but gave considerable thought to their comparisons. Children who felt that their families compared favourably in terms of security and comfort were more likely to feel safe and secure.

Well, think of Cinderella and think of, hum, you know how she has the mean stepsisters?

And not nice Mom, and between them and mine, ours (family) would be a lot better

(Interview 02/1, Boy, Age 9).

Children learned that their parents' behaviours could be different from their friends' parents. These behaviours served as part of the basis on which they gauged their families. The younger children often only had extended family experiences as a point of reference initially, but after they were in the school system they compared their parents and families to those of their classmates. The younger children were primarily concerned with personal and family safety. They sought self-affirmation and respite from the symptoms of the illnesses. These children gauged their families' abilities to provide comfort (resources, fun, and help) and to support their efforts to preserve themselves.

They help me with stuff, like my math homework. Yeah and my brothers too. And my mom and dad get me somewhere where I wanna go. Hockey practice, school

(Interview 12/1, Boy, Age 9).

Well, my mom does. My mom helps me with my homework because if I don't get something right, she helps me make it correct (Interview 01/1, Girl, Age 7).

When families contributed to the children's efforts to preserve themselves, the children gauged their experiences favourably. They felt that their efforts were supported, and their parents and families were capable and stable, which compared favourably to other families.

The children valued fun and their parents' efforts to provide fun filled opportunities. Fun contributed to their positive feelings about their families and provided relief from hardships. The children viewed fun as a quality in family life which helped the frame with their parents to feel safe and secure. Impromptu surprises also validated children's self worth; "And I came back and I went in my room, looked up and on my, I saw it (remote control car) on my shelf and I'm like, oh, and I start thanking my parents" (Interview 17, Girl, Age 10). This child also identified

her families' abilities to affirm her interests and engage in her activities so that flying solo was not so necessary and living her life was comfortably facilitated at home.

Cause they're (parents) really fun. My mom loves crafts and I love that too. And ... if she's drawing, I would look and I say, can I draw too?. . . She takes a paper off and she gives it to me and I start drawing too with her. . . And with my dad, he's like a brother to me because he would want to play with me. He plays on the computer. . . Well they're not like just normal parents that are boring usually. That's what people say. They're more like, they're interesting (Interview 17, Girl, Age 10).

In homes where there was little fun, the children did not feel comfortable "maintaining the frame" with their parents. "It's (my house) no fun" (Interview 21, Boy, Age 13) and viewed being outside of the family as necessary for positive experiences and relief from their situations.

When parents were separated, some children had two families and drew comparisons between them. The children gauged their family lives on the basis of whether they could be together comfortably with their family members and feel safe.

It's a lot of fun . . . a lot of the time; it's just us having fun together. And even at the dinner table. Like, at least once a week we'll have one dinner where we just talk and, well, we'll laugh. . . And, of course, once a week I have to get my giggles out and get all my frustrations out. And so I do that by laughing. So . . . my brother and I would go through this big laughing spell and we all have a great fun time with that. So much more fun than in S.... (other home). Yep. So much better (Interview 07, Girl, Age 16).

In homes where there was reciprocal warm interaction, the children were able to get respite from the illnesses and to feel safe and secure. Other forms of family interaction did not contribute to children feeling safe or secure.

Cause my mom (well parent) would tell me that he (step father) would come in and check in on us at night while we were sleeping. And I'm just wahh. So he usually ends the night drunk so. But it sometimes freaks me out though (Interview 07, Girl, Age 16).

The children valued their parents' support for their efforts to live their lives, for example, when playing community sports in a new neighbourhood; "... He (father) came and watched. And yeah he was really supportive of that and so was my mom. Yeah. So, and they were really supportive" (Interview 07, Girl, Age 16). They felt more comfortable in families that presented to the outside world as healthy. Once the mental illness became public, because it affected what parents could do, some children felt embarrassed about relying on others for what family members 'should' do to help them feel secure. This caused them to gauge "maintaining the frame" with their parents more negatively.

My dad drives us but then he lost his license from when his mental illness or something. [He is getting his license back] in another week or something. . . I have one of my friends comes picks me up from . . . way over there. . . Kinda sucks. . . not fun (Interview 11/2, Boy, Age 9).

As the children got older, they routinely compared their families to other families. Some families supported the children's efforts to get away, live their lives, and to share selectively with friends. Children, whose parents did not work, drive, have friends or go out, did not view their families as able to support them. Some children thought about how they would like to be able to live their own lives, so that there were some limits and that they could feel safe.

Yeah. . . I'm probably going to be really strict with my kids. But, like, I'm going to be like, lenient but really strict when it comes down to other things. *But that's not really how it is here. (italics added)* We don't really have rules here, but they expect us to not be, like, crazy rebellious or whatever (Interview 09/2, Boy, Age 16).

Some of the children were confronted with harsh realities, compared to what they viewed as ideal, which caused them to view their situations wistfully.

Well yeah. Like, my mom can't pick me up cause, to take me to school or drive me to school. We don't usually like eat supper at a table, supper table or anything like that.

It's just casual, whenever we're hungry. . . I don't know, we just don't eat meals together. . . I don't think I've ever like done that on a regular basis. I wish I had that. . .

I can't say I miss it, because I never had it. . . I think we did (ate family meals) when we were little. But I don't remember. . . (Interview 15/1, Girl, Age 14).

Such comparisons caused some children to distance themselves within the frame of their relationships with their parents, while other children became closer to their parents, because they viewed them with more compassion and admiration. The standards children used to compare their families differed depending on what the children's life experiences were and their terms of reference from their social circles. Most of the children expected occasional family fights, to do some chores, and to have limits set so they felt safe and secure. They also expected respect for all members of the family including themselves.

I think of it. . . mostly everyone has like an average family. . . All I have to say is that I have an average family. . . A few little fights, everything,. Fighting, fighting and name calling, that's all. Kids argue. Yeah. I do dishes or laundry. My mom assigns them. Yeah. I don't like fights. I don't know one family that doesn't fight. . . My mom stops it. (heh heh). . . Um. A lot of other families, um, they, have, they have *kids in the other families and they steal from the moms and everything. . . People won't even have respect for their mom (italics added)*. Bad. It's not right. . . Bet even you try and respect your mom sometimes. . . But sometimes you just can't. It's hard (Interview 06, Boy, Age 13). Like some, C's parents care for him a little bit. K's parents . . . they care for him but not a whole lot. And then my family cares for me and my brothers a whole lot. Like they

want us to be safe. . . Say if I got to C's place for example, I'll have to call when I get there and leave before 8. . . and then, the discipline. . . . *We don't get hit or anything; (italics added)* we just get things taken away, like toys. Like K. . . . if he goes and skips school, they don't care. . . . It's like, oh yeah; he's not going to school. They (school) will call they'll ask if K's at home. They're (family) all, (saying) guess he doesn't wanna go to school. Most kids don't have the choice if they wanna go or not. Nope. I would have to go to school if I liked it or not (Interview 03, Boy, Age 13).

The children gauged strict limit setting and boundaries as a benefit, as long as they contributed to them feeling safe and secure. Reasonable limit setting was interpreted as family caring; "My family is stricter which I can understand cause they care for us" (Interview 03, Boy, Age 13).

Goals of Maintaining the Frame

In "maintaining the frame", the children were trying to find the appropriate distance that would allow them to have comfortable relationships with their parents and families which allowed them to have personal safety and security. They gauged their efforts to "preserve themselves" in terms of the costs and benefits of "maintaining the frame" with their parents. In "trying to preserve themselves" they used the strategies of getting away, living my life, selective sharing, flying solo, and opting out. They achieved varying levels of their desired goals of respite from the illness; self affirmation, connections to others, solutions to problems, and creation of space for themselves. The attainment of these goals contributed to their efforts to "preserve themselves" while "maintaining the frame" with their parents.

In "gauging" the children determined the costs and benefits of trying to maintain the frame in terms of their safety and their security. The children described varying degrees of safety and security, both physical and psychological while "maintaining the frame". The children were looking for safe boundaries and some distance while maintaining a connection

with their parents. They attempted to create space in the family setting by moving out to the wider world. When they compared the past to the present, themselves to others, and their parents and families to other parents and families favorably, the children gauged their ability to preserve themselves as having more benefits than costs. When the children felt safe and secure with their parents and their families, they were more easily able to move out to embrace the broader context of their lives and to fit in with societal expectations. Feeling safe and secure, not only meant that the children's basic needs were met, but also that they perceived their parents, as generally able to support, validate and guide them.

Yes. They're (my family) really kind. They're really nice to me. Um, well they get me a lot of stuff. Um-hum. And when I'm hungry, they let me eat (Interview 02/1, Boy, Age 10).

My family and me and everyone in my family and me are just special...they listen when I'm trying to say something (Interview 1/1, Girl, Age 7).

When the children felt safe and secure, they wanted to be in their family homes. When lacking feelings of safety and security, they sometimes chose to leave the family home or to remove themselves from the frame. Some children had circumstances in their lives that allowed for minimal feelings of safety. They were unable to carve out time and space for themselves and felt uncomfortable with the frame that they had with their parents. For others, feeling safe was achievable because there was consistent support and care. When the children were able to achieve the goals of personal safety and security in their family homes and within their parent/child relationships, they were likely to develop a sense of safety and security within the broader aspects of their lives external to their families.

Influences on Maintaining the Frame

"Maintaining the frame" was influenced by the progression of the parent's mental illness and the difficulties that occurred within the parent/child relationships. The length of the illness

exacerbations compared with the length of time the parent was well, the success or failure of treatment, and the residual effects of the illness on the parents contributed to how the children were able to “maintain the frame over time”. When the exacerbations of the illness were longer than the periods of wellness, the children had more difficulty “maintaining the frame”, particularly with unreasonable parental behaviour. These difficulties were increased when children had only part of the story with little factual information about the illness, did not understand what was wrong with their parents, and no other consistent adult support. “Maintaining the frame” was also influenced by the developmental stage of the child, as younger children had more restricted options to preserve themselves and also were less able to consider the implications of chronic mental illness. Thus, “maintaining the frame” was influenced by the progression of the mental illness, having only part of the story, and the developmental stage of the child.

Summary of Maintaining the Frame

“Maintaining the frame” explained how children managed the longer term effects of their parent/child relationships. It was composed of the stages of “trying to preserve myself” and “gauging”. In “trying to preserving myself”, the children attempted to develop a sense of their identity within the bigger picture of their lives; younger children were more dependent on their families to do so, while older children had more independence and opportunities to do so.

As part of “maintaining the frame” with their parents, children tried to create healthy boundaries to develop their own lives rather than becoming consumed by their parents’ illnesses. Through getting away, living their lives, flying solo, selective sharing, and opting out, the children strove to preserve and develop themselves in the context of their relationships with their parents. By getting away, they had respite from their circumstances. By living their lives, they gained self-affirmation. When they selectively shared with others, they reduced their isolation and made connections. In flying solo, they attempted to generate solutions to problems. The

children used their strategies in ways that were creative and accepting of their parents as well as angry and rebellious towards them. In opting out, they created space for themselves in the only ways they could, feeling that they had no choice but to step out of the frame with their parents. They could preserve themselves by focusing only on themselves for the short or longer term.

“Gauging” was the process whereby children determined whether their efforts in “trying to preserve themselves” within their families and within the frame of their parent/child relationships were generally successful in creating feelings of safety and security for them. The children gauged whether their feelings of safety and security were increasing in their relationships with their parents and their life circumstances or decreasing. How they gauged this, determined how much they were willing to invest in their parent/child relationships to maintain the frame with their parents. Most children described their frames with their parents as contributing to their safety and security; however, three adolescent boys gauged their situations as unsafe and insecure and felt that their efforts to preserve themselves were not sustained within their family homes. For two of them, “maintaining the frame” had become too difficult, and the third was struggling significantly.

The next section of this chapter describes the overall outcomes of “finding the rhythm” and “maintaining the frame”. The outcomes represent the extent to which the children stayed connected with their parents or became disengaged, if their efforts to stay connected had become too burdensome; and the extent to which their identities were developed in their efforts to find the rhythm and maintain the frame with their parents.

Overall Outcomes of Finding the Rhythm and Maintaining the Frame

The process of “finding the rhythm” consisted of “monitoring” and “adjusting”, in efforts to get along day-to-day and to have acceptable rhythms with their ill parents and stable family routines. The process of “maintaining the frame” consisted of “trying to preserve myself” and “gauging” the costs and benefits of maintaining the frame in the longer term. The goals of

“trying to preserve myself” contributed to how children gauged their circumstances. If the costs of “maintaining the frame” outweighed the benefits, and the children saw little resolution for their problems, they gauged their situations as worsening and viewed themselves as unsafe and insecure. If the benefits outweighed the costs, children gauged their situations as improving or stable. Both BSPPs were influenced by the “emotional currents”, which affected how children responded to changes in their lives.

How well children were able to achieve the goals of the two BSPPs (daily family stability and daily positive interactions with their parents; and personal safety and security) affected the overall outcomes of the two BSPPs. The overall outcomes were development of a sense of identity and connections with the children’s parents and families. These outcomes represented a range of the children’s connectedness with parents and family members and the strength of their identities. The children commented on the culmination of their efforts to manage in terms of their identities and their connection with their parents.

Identity

While they were living with parents with mental illnesses, the goals children were trying to achieve in “finding the rhythm” and “maintaining the frame” contributed to the ongoing development of their identities. Some children described elements of their identities that were positive, while others were described as less positive. The children varied in their levels of confidence and their descriptions of the robustness of self-images or identities. Some of the children had strong identities. They had enjoyed extra curricular activities, such as drama, singing and sports with their friends. They were enthused about their future plans. Others had a mix of positive and negative views of themselves. This girl enthused about her plans, but also expressed some concerns about her future identity and whether it would include the label of mental illness.

Oh for sure, for sure. I plan on going to Europe, when, once I get money...

I didn't audition for the play or anything at school last year cause I was just kind of trying to fit into the school and everything like that...But this year I auditioned and got in and now I'm auditioning for a musical and I've pretty much passed. I'm gonna be in there, cause I'm in choir...I have a feeling if I don't get like a main part, I'll at least get a chorus part. Like I have a solo for the Christmas concert this year (Interview 07, Girl, Age 16).

Well...in Grade 7, like, my mom thought I had depression cause I was having a really bad year. I wanted to kill myself in Grade 7...That's when I started smoking. . . I quit. . . and so my mom explained...what it (mental illness) was about . . . got tests and ended up coming out with some other disability. . . I don't even know what it is. . . . *Still is. (scary) (italics added)* . . . I had a like a breakdown a while ago. . . Yeah it was earlier this year . . . like it was when I was still working. But I think it was still probably due to stress. . . I was having a really bad day and I started um crying in math class, just cause I was you know, falling behind in assignments and whatever. Yeah. *And kinda, kinda haunting in a way. Cause you know, you look at like your parents, and then you think you really don't wanna go through that (italics added)* (Interview 07, Girl, Age 16).

This child's view of her identity was less positive after she had described having a breakdown and had been labeled as having a learning disability. When she was able to find the rhythm and maintain the frame with her parent, she was better able to sustain her views of a positive identity. At such times, her parents were better able to support her endeavours to develop herself.

Some children described aspects of their personal identities as cynicism towards life and about their power to effect change. They described feelings of bitterness, apathy, and uncertainty. The children who developed these feelings perceived that they were unsuccessful in their efforts to find the rhythm and to maintain the frame with their parents and those efforts had

negatively affected their identities. They viewed themselves as less able to be successful in the larger world. For example, one child was struggling with identifying himself further with a criminal subculture that had become part of his life. He was unsure if he would escape from this lifestyle.

Cause she thought I'd be the good one and stuff and I'd always you know, stay at home and go to school and get a job. . . There's things make me want to change, then there's other things that make me wanna just screw up and not really care about anything. I don't really want to do crime as much, just start my own life. Do what I want. But then if I do what I want, then I'll come back in here (youth detention center) and screw up. Probation and all that crap. . . . No once you're in probation, you'll be back. It's that simple. Like they make it so you come back. It's called job security. Yeah. It's true. . . . No warning, no nothing, just, you're breeched, go to jail. That's what it's like for a lot of people. . . . But the maximum they can give you for breach is 3 months so. . . I wouldn't care if I got breeched. If I did, I would just like go on the run and then try not to do any crimes, just try like stay out for as long as I can. And then, when they do catch me, it'll just give me one breach and then, I'll get out the next day or whatever so (Interview 19, Boy, Age 16).

When the children had limited affirmation from their parents and had received limited opportunities, they were more negative about their identities and their future development. They realized they may have missed opportunities that would not be available again.

Yeah . . . usually. . . when you get into Grade 11 and 12, you gonna start pretty much looking at your future. . . *All I know my future is gonna, is me, trying to survive pretty much. (Italics added)* Like I won't have a really, really good job cause I'm not that smart at certain subjects. I just know that I'm going to make money and try to keep myself happy and. . . raise a family when I'm older and all that stuff so. . . I guess

I'm just not motivated enough. Well, see I'm not in applied or pre-cal or anything like that. But I do really good in consumer (math) . . . I got finished with a 91 in consumer. But, like, I didn't realize in that Grade 9 when I had to do good to get into applied. I didn't really care about it or know about it then. Now I realize do (Interview 09/2, Boy, Age 16).

On the other hand, the children also described developing elements of their identities that were different from children who did not live with parents with mental illnesses. They saw themselves as being more tolerant and putting small events into perspective.

Uh. Nothing is as bad as it seems. Like *don't sweat the small stuff* (italics added) because so much worse could happen to you . . . like. Well, they (your parents) could die tomorrow, you know, and my friends they'd regret saying that (wishing their parents were dead) . . . you can't get through to them (friends), because. . . they don't really understand that. . . I'm always like, you think it's a big deal right now, but in a couple of days everything's gonna be fine again, *so what's the point of even worrying about it* (italics added) (Interview 16/1, Girl, Age 16).

The children also noted that children who experienced other difficulties, such as a parental death or a parent suffering from a physical illness, had similar identities to them.

My, other best friend um, her Mom's dying actually. She has cancer. And ah, we've gotten along great there. Just because *we know the stress that, like coming from the really sick and it's just so stressful.* (Italics added) So we're kinda of, we've really related to each other. (Interview 16/1, Girl, Age 16).

Some of the children felt they developed aspects of their identities such as patience, sensitivity, sympathy, strength, and an ability to live in the moment, as a result of their exposure to their parents' mental illnesses. A 14 year old boy noted the positive aspects of his personality that had developed as a result of the mental illness of his father; "Maybe how to deal with stuff. I

don't know. Maybe patience and stuff like that how to deal with things, how to do things better." (Interview 10/2, Boy, Age 14). Many of the children described forgiving their parents for their shortcomings. Most of the children viewed themselves as compassionate people. These children were compassionate towards their parents and were there for them. The children described learning from their experiences with their parents with mental illnesses.

Of course, and then you know . . . *everything can't go well all the time (italics added)*. I mean of course there's gonna be some bad and you're just gonna have to deal with it when it comes. . . *You learn from it. (italics added)* So I don't know *maybe it makes you better, maybe a little smarter, (italics added)* like more aware what to do and what could happen (Interview 15/2, Girl, Age 14).

Several of the younger children also expressed empathy and compassion for their parents. In describing what depression must be like for his parent, a young child drew an insightful parallel from his own experience. This young boy thought that when his mother was depressed, her behaviours was out of her control, similar to his lack of control over his behaviour when he was on medication for asthma.

And she (mother) gets very, very sad and . . . she says that she kinda gets angry sometimes. And *I know what that feels like (italics added)* cause before when I took these certain pills. . . I got angry from the pills. . . For . . . asthma, I think. And I get really mad, if something makes me mad. Yeah. If I'm a little hyper, I get really hyper . . . after I took the pills. Like I take them. Or sometimes at lunch, and then after I'd be wild for a little and then calm down, and sad. When, like I wasn't angry at the time but, it, it also makes me hyper, so then it makes me really hyper. Cause I don't take the pills anymore (Interview 22, Boy, Age 7).

Younger children who had opportunities to develop their identities in extracurricular events and hobbies and who received help when they were struggling at school were more able

to develop positive aspects of their identities. In the second interview, this young girl identified an improvement in her reading skills and a more positive attitude about her performance after receiving additional timely help; “ Very good. Yep. (My reading is) Way better. I can read chapter books. Yep, but now I’m not [going to private resource school]” (Interview 01/2, Girl, Age 7).

Some children, who had a consistent supportive adult in their lives, described rising above challenges, being strong, and developing a new perspective.

Like, like, it’s happening so, like, I can’t change what’s happening, you just have to be flexible and run with it so I...turned it around like the positive way out of it. Cause that’s just the way I think. Like I could have been upset and I could have...lost all my marks and been like really depressed. Or I could have started drinking...taking the easy way out but um, I wasn’t, I wasn’t brought up to be like that you know. *I’m brought up to be strong so I kind of look at everything in a different way (italics added)* (Interview 16/1, Girl, Age 16).

When living with a parent with mental illness, the children described opportunities to develop sensitivity to the needs of people who had challenges in their lives. Their life experiences led several older children to view themselves as people who had elements of their identities that would make them successful in a career helping others.

I see what they’re (my parents) doing and I think, I would so love to do that. Like it’s, it’s so awesome what they’re doing (mental health workers) that would be such a cool job, but I don’t know anything about it. And I think to have somebody (at school career fair) to say well this is, you know, what it entails and like the different fields that you can get into (Interview 07, Girl, Age 16).

As illustrated in the preceding section, the children experienced differences in their views of their identities. The nature of parental mental illness exposed the children to life events

that made them realize the fragility of their circumstances at an early age. This led some children to view themselves as more mature and able to discriminate between trivial and significant events in their lives. Other children did not view themselves positively and were in doubt about their abilities. For some children, components of their identity included conserving their energy for important events and not wasting their energy on trivial matters. Because these children had high demands on their energy, they could not afford to waste it.

Connection to Parents and Families

As an outcome of “finding the rhythm” and “maintaining the frame”, the children achieved different levels of connectedness to their parents and families ranging from being totally engaged with them or totally disengaged from them. The children who stayed engaged with their parents and families, as long as they could have a safe frame, felt connected and loved. The children who disengaged from their parents, because they did not feel safe or secure in their frames, felt unloved and disconnected. At times, the parents were incapable of engaging with their children, due to the effects of their illnesses; despite children’s best attempts to engage their parents, they were unable to do so. The children who were able to stay connected to their parents were able to develop empathic understanding of their parents’ struggles.

It would be, well, like once, I would think once you’re like, you’re not sad or angry anymore and it’s (depression) not happening, you’d feel a little bit sad from, like when you’re angry what you’ve done like in arguments. . . (Interview 22, Boy, Age 7).

Even the younger children described awareness of the multi-faceted effects of depression on their parents and families, and their awareness and ability to make allowances for that helped them to maintain connections to their parents. The seven-year-old child in the previous quotation recognized the remorse that his parent felt after her behaviour was upsetting to the child and the family. Efforts by parents and family members to communicate with children around the problem helped the children to find a rhythm in a safe and secure frame and to

maintain their connections. One adolescent girl described her thoughts after an acute episode of her parent's mental illness, which had caused this child to feel extremely upset. Sharing and talking about the experience helped her to remain connected with her parent.

Um. Maybe made it (relationship between mother and child) a little stronger I guess. It didn't really lessen anything. Uh, I don't know. I guess when you have a bad thing (mental illness) like that happen; *it sort of makes you stronger I guess sometimes (italics added)*. I guess like both (mother and myself) in this case, I...and then maybe getting over it helped us together I guess. Talking about it and sorting things out (Interview 15/2, Girl, Age 15).

For some of the children, living with a parent with a mental illness provided opportunities where they were able to know their parents on a different level than they otherwise would have known them. They described being totally connected to their parents; for example, "Yeah. And I don't think if my mom was uh, I don't think if my mom [did not] have these problems, I don't think I would be this close with her" (Interview 14/2, Boy, Age 13). In efforts to engage their parents, some children took on unique roles with their parents that were unusual for their developmental stage: "Yeah, well I like, I like being the one that I know she (mother) can trust and talk to" (Interview 14/1, Boy, Age 13). Many of these children valued the closeness that they shared with their parents as a result of the mental illness because they felt able to maintain that level of connection without losing themselves. They indicated that they 'knew' their ill parents in a different way than their well parents.

Well. Uh. We're really close. It's brought us really close. Like my mom's my best friend. Like I come home and I come home from being out with my friends, just cause I wanna be here. And I just wanna like, I tell her everything. She tells me everything and she's like my best friend and I'm like really close with my dad. Like they're really important to me. . . like a lot of people like realize that when they get older, (than me)

like but, but I've realized it way sooner and I'm happy that that happened and that's

changed my outlook on things a lot... Just on life. . . . (Interview 16/1, Girl, Age 16).

Another adolescent girl described how her mother's experience with mental illness made her relationship with her mother more positive and close. Some children seemed able to feel that sense of closeness while also feeling that they could preserve themselves.

I don't think we would have *as big of a bond*, (*italics added*) because, like, you know what they're going through (mental illness). *It's more like you know them as a person, not like a parent*. Like I don't have the same relationship with my dad (well parent) as I do with my mom. . . like I know about my mom, I know how she's feeling, I don't know my dad, I don't know if he has depressed times or anything like that...I probably wouldn't know her. I wouldn't know her like that if she didn't have (mental illness). It's a point. *Like a positive thing* (*italics added*) (Interview 15/1, Girl, Age 14).

If the children received messages that their welfare was important to their parents, they felt connected with their parents. The children noted that even in acute illness, some parents remained concerned about the children; "Or, or, just like, are you okay? And even when she's panicking, she's worrying more about us" (Interview 14, Boy, Age 13). Obvious expressions of caring helped the children feel more connected to their parents. For some of these children, exposure to their parents' lives and troubles facilitated their abilities to manage their circumstances, to understand the nature of their parents' problems, and to forgive them for some of their behaviours.

But now I understand and...I never realized before, but she's right about a lot of things and I can understand that because she had a really bad childhood and like she probably was the same way...when she was my age, she's probably the same way I think right now so...Um. It (knowing this) makes me more forgiving and sensitive to her . . . (Interview 16/1, Girl, Age 16).

When feeling connected to parents, the children needed to negotiate safe boundaries in their parent/child relationships so that they could both preserve themselves and sustain reciprocal relationships with their parents.

My mom tucks me in and I get to watch TV a little more and I like it because I get my very own room. She kisses me good night and she hugs me. So then I feel really safe. Oh, and the other thing that I like is when I get nightmares, I get to go in her room to sleep with her (Interview 01/1, Girl, Age 7).

Yeah but I talk to my Mom (ill parent) and my Dad mostly about problems that I have at school. That some kids are mean to me and all that. And I explain to them and they, and my Dad said, he jokes around, like before he says, kick their asses. And I'm like well "no-oo". He likes to joke around usually. Yeah, and probably because he wants to make me feel better (Interview 17, Girl, Age 10).

The children sometimes saw their parents and families as exceptional in terms of their level of comfort with one another and trust and respect for each other, which enabled the children to feel connected but separate while feeling safe and comfortable

Cause a lot of my friends...don't have good relationships with their parents. . . It's like they have one parent that they kind of connect with but they don't connect with both parents . . . You know they'll yell at each other and you know throw swear words at each other. It's just not a very healthy family. *I think that's the main difference between my family (italics added)* (Interview 07, Girl, Age 16).

Yeah. I think of this (blended family) as more of my family. . . Oh my gosh...the one thing I like....Um. Probably, um, the fact that we're all really comfortable around each other. And we all, like, we pretty much connected right away. *I think that's the main difference between my family; is that we're all very comfortable with each other, we trust each other, and we're very loving (italics added)* (Interview 07, Girl, Age 16).

Some children saw the experience of mental illness in the family as something, which set their parents and families apart in a positive manner. In feeling connected to their parents and safe, these children were able to recognize the positive contributions of their families in a challenging context.

. . . We live a different life. In terms of handling things, you know...like when my mom was in the hospital, all the support that we all give each other...And the closeness. We're just, we're so close . . . actually like I come home cause I wanna be with them. . . It just like makes me happy. They're really important to me. Um. That's probably the best thing. We laugh. . . Like we laugh together. Like I'm lucky. I'm glad. *And I don't know like how many families are actually like that. (italics added)* We don't fight. . . Like a good fight's healthy. But like we don't fight constantly like all my friends fight with their parents. . . but we understand each other . . . we're all on the same level kinda (Interview 16/1, Girl, Age 16).

The children in this study varied in their abilities to view their parents as making a unique and positive contribution to their lives and thus to feel connected to them. Most of the children had the capacity to see beyond the mental illnesses of their parents and to view their parents and their family lives as making a positive contribution to their efforts to preserve themselves. Others could not view their parents as making a contribution to their efforts to preserve themselves. They felt threatened by their connections.

When the children could not safely stay connected to their ill parents, they reduced their connection or disconnected from their parents. Disengagement was generally temporary until their parents were able to resume the relationships in a more appropriate manner. Disengagement could help the children maintain their boundaries and feel safe, by keeping part of themselves separate from their parents and the illnesses. The strategies children used to preserve themselves helped the children to change their levels of connectedness to manage their

situations. For example, in flying solo, some children did not choose to disengage but felt this was imposed on them as far as solving certain problems, such as homework, in their lives. When some of the children found their efforts to stay connected were not successful or too costly, they withdrew from their parents and no longer invested energy in “finding the rhythm” and “maintaining the frame”.

She’s (mother–ill parent) always sticking her nose in everyone’s business. . . .

We’d (brother and he) start joking around and stuff, (at church) making fun of the priest.

My mom would get really pissed off. . . . I wouldn’t really care, cause, well I was carefree. . . I’d only think about going out and having fun, going to screw around with my friends (Interview 19, Boy, Age 16).

When the children felt that their parents’ problems were too burdensome, particularly if the problems were chronic, they disconnected. These children gauged their situations as too unsafe and overwhelming. To preserve themselves, the children created physical and psychological space between themselves, their parents, and their families. These children disconnected when parents habitually did not respond or responded in an irrational manner, when they could not get along with their parents, or when they were under duress in their family homes. This boy described how the family dynamics forced him to disconnect from his parents in order to survive in his home.

Pretty much drives the whole thing (family) down. It (illness) gets my dad (well parent) very mad. Then he comes and he unloads it on me. And my mom unloads it on me.

Well my dad really has no choice he has to unload it on somebody and he can’t unload it on my mother because then it’s just gonna get worse. He’s very argumentative and things like that. *Pretty much the same thing I do with my mom. I just kind of ignore it (italics added)* (Interview 21, Boy, Age 13).

Another adolescent boy described his disconnection and his lack of respect for his parent.

I don't know. . . we (siblings) keep on bugging her (mother) or whatever, then doing something to piss her off. I don't know she's always trying to get into other peoples' business. *It (counseling) was good because I could get away from my house. I'd kinda take advantage of it* (parent's depression and inability to act) (*italics added*) Interview 19, Boy, Age 16).

When children had difficulty connecting with their parents and had minimal support maintaining a comfortable and safe frame, became increasingly difficult; "But my friends never put me down usually. Only my family would so" (Interview 09/2, Boy, Age 16). Disconnecting could start as a temporary solution, but it could progress to rebellion, taking advantage of the parent, and permanent disconnection from the parent. Generally, children temporarily pulled away from the intensity of the relationship because they were unable and unwilling to maintain the frame within the discordant rhythm of the relationship. In order to survive, two adolescent boys had disconnected from the parent/child relationship. They gauged their connections with their parents as unsafe and insecure. They could not remain heavily connected and invested in the frame without losing themselves. A third boy struggled to maintain a relationship with his parent.

In "finding the rhythm" and "maintaining the frame" with their parents, all of these children had various levels of connection and disconnection which varied over time. The ability of the parent to reciprocate was an influencing factor in whether children remained connected, sought to improve the connection, or were unable to sustain the connection to their parents. Most children realized that their parents were much more than the illness and continued their efforts to connect with their parents. For others, living with their parents and their mental illnesses, was too difficult.

Summary of Outcomes of Finding the Rhythm and Maintaining the Frame

The overall outcomes of “finding the rhythm” and “maintaining the frame” were variations in connections to parents and views of identity. The children’s goals from “finding the rhythm” (daily family stability and daily positive interactions with their parents) and “maintaining the frame” (personal safety and security) contributed to the overall outcomes as both BSPPs were intricately intertwined. The children experienced varying levels of attainment of the outcomes (connections to parents and identity), at different times, often related to the progression of the mental illnesses.

Social Structural Condition: Fitting In

The outcomes of “finding the rhythm” and “maintaining the frame” were situated within the social structural condition of “fitting in” to the world that existed outside the family home. “Fitting in” was the social structural condition which influenced how the children considered they were measuring up in the outside world. “Fitting in” referred to how children viewed themselves and how others saw them as managing at school, getting along with their peers, developing friendships, engaging in extra curricular activities, and not standing out because of their clothes and appearance. The children had to examine, not only in terms of family life, but also how they were doing in terms of external criteria; were they “surviving” in the outside world, were they “getting along” or were they “flourishing”? They had to make those decisions in the context of the definitions held by the people in the school, community, and those involved in extra curricular activities. “Fitting in” was facilitated when the children’s parents were able to work, drive, provide adequate income to purchase items prized by their peers, to support extracurricular activities, and to have adequate social skills. As the children got older, and their peer groups became more influential, “fitting in” became increasingly important and, for some, increasingly difficult.

The younger children appraised their ability to “fit in” by looking at contributions of family celebrations and daily rhythms to their lives outside of the family and by comparing themselves to their classmates in school. The older children placed increasing emphasis on how their peers and on how others saw them “fitting in” with societal expectations; “You need survival when you’re older, yeah” (Interview 09/2, Boy, Age 16).

The children were attempting to find the rhythm and to maintain the frame with their parents, while expected by others to fit into larger societal expectations they encountered. These children realized that their parents did not fit into the mainstream society when they did not work, participate in social activities or did not have friends in their lives. The children realized that their parents had difficulty “fitting in” with the societal expectations of securing a good job.

I think that if my mom, like had a job and didn't have that mental illness), like she'd be working (italics added) . . . and we really wouldn't talk about how she's feeling and stuff like that. . . She, would have other people to talk to (italics added)

(Interview 15/2, Girl, Age 14).

The children experienced a range of difficulties in attempting to “fit in” with societal expectations. Family circumstances sometimes necessitated that the children enter the school system late in the year. This put the children out of sync with the rhythms of the school year and their schoolmates while adding to their anxiety resulting from the major transitions in their lives. Nine of the children were living with minimal resources to purchase clothing, fund lessons or extra-curricular activities, and buy food. Those children were struggling to “fit in” with the community, the school, and their peers. Their limited resources made it difficult for them to participate in extra curricular activities other than school-based activities. For these children, the limited resources available were used for basic sustenance and not for any ‘extras’.

We went to go get food from a food bank. Had to stay (there) cause there was no room in the car cause there was the car seat, C., F. and the two boxes of food (Interview 03, Boy, Age 13).

I think it's good that he (father) can actually make money now. I think it's good. So it will help with the family as well. Like I, if I was an old adult, I would consider that a side job (delivering newspapers) (Interview 09/2, Boy, Age 16).

On the other hand, some children, who were living below the poverty line, did not regard themselves as poor compared to some of their even more impoverished friends.

K's parents are Native and have treaty numbers and . . . C. gets a high amount of allowance every two pay cheques. . . He has lots of games. K doesn't have barely any. *I have like in the center. Some parents get more money than others (italics added).* So that's another way our family's different from some others. (Interview 03, Boy, Age 13).
It's a nice house and we always clean it up. Yeah and we live by some of our friends. Yeah and we can . . . it's fun living in a house, *then like living on the streets. That's not fun. You can't like buy anything, you just gotta live somewhere on the streets (italics added)* (Interview 12/1, Boy, Age 9).

When peers saw them as equal, it helped some children to feel they and their families "fit in" better than some other families. Thus how well children perceived themselves as "fitting in" also affected how children gauged their circumstances. As they grew older, the children described expectations placed on them to "fit in" at school by arriving on time, not missing classes, doing homework to the standard, and participating in extra curricular activities as increasing over time. Even in situations where children had more resources and were able to "fit in" with their clothes, some of the children described the pressures of trying to "fit in" at school. For some children not "fitting in" meant that others bullied them. While bullying was not always related to the parent having a mental illness, some of the negative effects of living with parental

mental illness prompted bullying. Children of different ages described being teased and bullied at school. In this quotation, an adolescent boy commented about the general pressures of trying to “fit in”. He described pressure to “fit in” in terms of clothing, access to games and entertainment, and parental involvement.

Like teasing and being complete . . . like, rude . . . yep. (kids at school) Well, some of the stuff was cause *I’m not quite in the style (italics added)*. Like I wouldn’t wear so tight, I wouldn’t wear clothes . . . I’ll feel like I’m swimming in my clothes. So I wasn’t too much in style and then one kid came up to me one day and ‘Wanna know what “M”? *You’re not in style with clothes anymore.*’ (italics added). ‘Look at me; does it look like I care? It’s like as long as I have two rear-ends (chuckle) well one rear-end instead of two, um, I’ll wear as I like’. . . . And then the kid’s just like, well okay, ‘He’s (child narrator) strange’, and then just walked off. . . (Interview 03, Boy, Age 13).

The adolescent boy in the previous quotation obtained clothing, which was not the latest style, from a community-clothing bank. The children described peers as having the potential to be particularly hurtful to them.

So. I’d have to say a lot of kids just get stressed out from school. One of the major things. Yeah *being accepted (italics added)* (Interview 16/1, Girl, Age 16).

Younger children also experienced bullying. A ten year old boy, who had moved to a new school to escape bullying, was again bullied at the new school. He described his experiences:

And uh there’s a lot of meanies in that class. Yep. Like I got some nicer people in my class and I got a split class, Grade 4’s and 5’s. And I used to play with the Grade 4’s. I’m not sure how it’s gonna turn out this year coming up. Cause I’m gonna be in a different class and *I might have the bullies again. Cause they’re still around (italics added)* (Interview 02/2, Boy, Age 10).

Family circumstances necessitated that the child, in the preceding quotation, live in two different homes on a weekly basis. This added to the problems of “fitting in” with peers.

Some children had lifestyles, influenced by the mental illness of their parents, which altered their body images or views of their abilities and presented further challenges for “fitting in”. This seven-year-old girl described the effects of changes in her life on her reading.

I can't read very good and I'm not catching up because before when I was at half of two schools. . . we had to move because a whole bunch of bad kids were being really bad to me and E. (brother). Because they put poison on me and E.; all over my hair and my arms and stuff. . . Well, it was like a bottle of a whole bunch of glue and paint and stuff and they poured (it on us). That's why we moved here. . . we had to move

(Interview 01/1, Girl, Age 7).

The mental illness of the parent had contributed to the some of the structural changes, moves, changing school, affordable neighbourhoods, which had influenced the girl's reading difficulties and acceptance at school.

School had the potential to be a place where the children could escape from the mental illnesses of their parents, however, the children's experiences varied at school. “Fitting in” at school in terms of performance and peer relations caused some children concern; they compared themselves to other children and were compared by others academically and socially. All of the children were aware if they were not doing well in school. The children were concerned if they could not keep up in their studies, as this marked them as not “fitting in” academically. Some had mixed feelings about trying to fit in. One adolescent boy saw school as a place of respite; however, he saw his grades slipping and was concerned about his performance.

No, (school is not stressful) because, you get away from home. You do, sometimes you do fun stuff. . .In my situation, I'm really afraid of my grades and stuff. *Cause my grades*

have been going down now so, cause I don't get any help from my mom anymore (italics added) (Interview 21, Boy, Age 13).

Moving to different locations made it difficult for the children to maintain ties with their friends and added to their feelings of not being part of the group, not “fitting in” completely. Changing schools challenged children to fit into the existing environments and peer groups in addition to dealing with their parents’ mental illnesses.

The location like. Well, cause we (brothers) have hockey in X and we go to school in X and all our friends are in X. And then we live out here and like we sometimes can't get that much rides out there. *So we kinda miss out on stuff (italics added)* (Interview 10/1, Boy, Age 14).

In situations where families had few resources, participant observation and field notes substantiated these children's descriptions of difficulties with “fitting in”. I observed there were few resources available for the children outside of their family homes. In the poorest families, where the children's circumstances were more visible, i.e. their clothes were different, and for some children, their academic performance was lower, they saw themselves and believed others saw them as different from other children. Some children became aware of the societal stigma associated with mental illness. This affected how they viewed themselves and families as “fitting in”:

(Embarrassed) Cause most dads are healthy and not ill. . . Kinda bad. Cause we would have to ask for other people for rides. (Interview 11/2, Boy, Age 11).

Some families had marginally more resources and were able to sacrifice to provide opportunities for their children. Other families with financial advantages provided many opportunities for their children making it easier for the children and the families to “fit in”.

Brother: My parents want us to have lots of experiences. Ah, just in May, they took us to Mount B. by car.

Sister: We saw Mount B. They took us on a Caribbean cruise a few years ago. They just do a whole bunch of things for us that most of the other kids haven't done.

B. Cause they said they didn't have it when they were kids so they thought it would be nice for us to have (Interview 13/1, Girl, Age 11, and 14/1, Boy, Age 13).

Resources helped children to fit in by providing opportunities for them to develop skills, which contributed to positive identities. The children who had more resources in their families, in terms of money, social support from other family members, and parents who were able to seek outside help, were better able to "fit in" because they could develop positive identities and skills that they viewed as important. These children had opportunities such as travel, lessons in dance, martial arts and theatre, which helped them "fit in" with societal expectations. While these children were more fortunate than the nine children who struggled to subsist and with chronic instability in their lives, even these more fortunate children had concerns about "fitting in". The children did not always feel that they fit into the larger society of community, school, and their peers. As they got older they noted differences that made them stand out.

Oh. I think it's when I think what all that could have been if he (father) didn't have this mental illness. Like it probably sure would have been a different lifestyle I think.

. . . Well like most of my friends have really nice houses, and their parents have pretty nice cars. I'm not saying our vans aren't nice, but they're older vans you know. And the house is kinda old too and well it's not as big and new. I just wish. . . like how it would have all came out if he didn't have the mental illness (Interview 09/2, Boy, Age 16).

Because the children in this study had different experiences than children whose parents did not have mental illnesses, they were aware of their differences and some children felt misunderstood by their peers. The following quotation by an adolescent girl, whose appearance and behaviour would suggest that she did "fit in" with her peers, describes her perceptions.

And the one like main thing is like no one understands, like none of my friends, like I did tell them, and they'll be like, it's okay, but like the most frustrating thing is they don't actually know like (Interview 16/1, Girl, Age 16).

The child in the preceding quotation did not feel that she "fit in" with her peers as a result of her experiences with her parent with a mental illness. Seeking help from the institution, in the form of the school counselor, could be risky because it could mark someone as being different and endanger their abilities to "fit in". One boy who found the counselors helpful stated:

Because like, you just like, talk to someone about it. And you know that like, it won't get all around and all that. It's like I guess confidential. Yeah. Like, you don't want like *everybody just, like, to feel sorry for you cause, like, so then everybody is treated the same way that it used to be (italics added)*. (Interview 10/2, Boy, Age 14).

"Fitting in" was important for children; therefore they were sensitive to any differences their peers perceived in them, such as needing to see the counselor or not performing adequately in their schoolwork. Even the children who were able to superficially blend in more easily than some of the less fortunate children were cautious about discussing their parents' mental illnesses, as they were fearful that they would be treated differently and no longer "fit in" with their groups. With the exception of a few children, children generally did not like to be seen as different.

The children who liked to be seen as different were attempting to define their families without the stigma of mental illness, in an effort to be accepted and valued as unique.

...Well. I like being different from other people. I don't want to be the same as everyone else. (italics added) Well, it just means she's different than other parents and, yeah. *Different good (italics added)*. Well, just *because like someone has mental illness doesn't mean it's bad. That's what I have to add [to the interview] (italics added)* (Interview 13/2, Girl, Age 11).

These children struggled to find a way to understand mental illness without accepting the stigma attached to it.

It's (living with my mother) interesting. It's not really boring. Uh. Well you know I mean . . . it's something different. Um sometimes it's good. Like sometimes it's interesting to talk to her about it and stuff like that. Um, but when it actually happens, like the depression and that stuff, it, it's tough sometimes (Interview 15/2, Girl, Age 14).

The children who had difficulty "fitting in" more had difficulty identifying with the school and had parents who were less able to support them, both in terms of finances and support. For some children, the nature of their lives and a lack of positive role models made it even more difficult to "fit in" with societal expectations. At times, the mental illnesses of the parents created barriers making it difficult to provide safe ground rules and limits for the children and to intervene to assist children.

He's (brother) gonna be in jail for the rest of his life. We figured that out a couple of years ago. . . . I've barely been with him actually. . . . He moved in from Alberta when he was like 13 and then . . . he just went and stole cars. His actual first charge was when he was 13, was gun charge. . . . Yeah. All my other brothers, both my other brothers been in jail all their lives. They spent . . . three years of their lives in this place (youth center) and then they got raised and they're both in a Federal Penitentiary (Interview 19, Boy, Age 16).

Long standing difficulties of "fitting in" also made it more difficult. This older child recalled difficulties from the time of elementary school.

But we (brother and himself) didn't want to go to school, because we'd get used to not going to school. And when we did go to school, we'd be behind. *Like people, kids would make fun of us, oh you're not going to school, your dumb blah blah blah. (italics added)*

So we just said screw it then. That'd be a lot better than to get in a fight or get kicked out or get caught selling drugs or something like that (Interview 19, Boy, Age 16).

When the children did not "fit in", they struggled to find positive alternatives to their situations to help them "fit in". Societal structures did not facilitate their efforts or those of their families to find a way to fit in by making any allowances for their lack of consistent family rhythms.

They (school breakfast program) make toast and have cereal. Yeah. But I go on the bus so I go a little later and most of the kids are there by 8. When I'm there, I'm usually the only kid there (Interview 08, Girl, Age 10).

Because the children were more aware of the stigma of mental illness when they were older, they would try to manage it by trying to ignore it and making light of it.

Say someone says 'Oh your mom and dad are, have mental illnesses, oh, they're so stupid'. '...Oh really, thank you. I'll be sure to tell them that' and just be sure to play along with their little game so they get tricked instead of the other people (Interview 03, Boy, Age 13).

The children in this study developed the sense that having a mental illness was marked by secrecy and shame within their families and in the larger society. Keeping things "hush hush" was part of the children and families' efforts to maintain the outward appearances of "fitting in". The older children sometimes stated they were not ashamed of the mental illnesses of their parents and trusted their friends as confidants, then paradoxically worried who their friends might tell. They were concerned about how they and their families would be viewed as "fitting in" with the larger society. Siblings discussed their concerns regarding their friends knowing about their mother's mental illness.

Sister: I don't know if they'd like treat us or mom different.

Brother: Maybe some of them. Cause maybe they don't understand like what it is or whatever. I don't know. There's some uh, I guess, jerks, you could say, out there and (they) would kinda make fun of you but, none of my friends would, *I don't think (italics added)* (Interview 13, Girl, Age 11 and 14, Boy, Age 13).

This uncertainty of how others would react to themselves and their families kept children guarded about their circumstances. Thus children's perceptions of how they "fit in" affected how they gauged their circumstances and how their sense of identity developed; i.e. how they saw themselves and if they saw themselves as fitting in with other families and the community.

Some children were able to accept their difficulty of "fitting in" while others were unable to accept their circumstances within the larger societal systems or to find helpful resources. These comparisons left the children feeling that something was missing in their lives and they didn't fit in with the norms. Their families were different and didn't "fit in". They couldn't get usual services like insurance and their families were defined by the mental illness as opposed to physical illness, where people don't usually talk about "cancer" families.

Um. It's not that fun because you don't get uh life insurance. That's kinda a bad thing I think. So that kinda like sucks, for my Dad. Like, I'm not sure what ah life insurance is though (Interview 11/1, Boy, Age 11).

The older children tended to compare their life circumstances to those of their peers and by doing so; they became more aware of inequities and the difficulties of "fitting in" with the larger societal expectations. They found themselves identifying with "mental illness" as a child in a family "with mental illness" rather than as a child who was struggling with a set of circumstances.

Well sometimes I compare my family to my friends' families. And in my mind I think about it. My friends have way better lifestyles with their families and everything. But I think it's because *my father has a mental illness and my mother comes from a family*

with mental illness as well so it's kinda, it's all about mental illness in the family pretty much (italics added) Well, yeah, cause her mother (grandmother) has it too (Interview 09/2, Boy, Age 16).

The children in this study, who perceived difficulty in “fitting in” had difficulties in the school system, lacked daily rhythms which meshed with structures, and did not qualify for sufficient support. They struggled to meet basic expectations. Children in families with more resources were better able to fit in or appear to do so. For the children in families with limited resources, often a result of the hardships of living with parental mental illness, “fitting in” to societal expectations was an ongoing struggle.

Summary

This chapter has presented a detailed account of the findings from the study.

The demographic characteristics of the children and their families have been documented.

The substantive theory that explains the children’s perceptions of living with parents with mental illnesses and how these children managed their circumstances has been thoroughly discussed.

The two BSPPs of “finding the rhythm” and “maintaining the frame” with the respective stages of “monitoring” and “adjusting” and “trying to preserve myself” and “gauging”, and the theoretical categories of the “emotional currents”, and overall outcomes provide an understanding of the processes by which children managed their circumstances. The children were managing their circumstances by “finding the rhythm” within their day-to-day activities and by “maintaining the frame” of their relationships with their parents over the longer term. The social structural condition of “fitting in” provided insights into the larger context of children’s lives outside of their family homes. This larger context both influenced children’s lives and was influenced by their experiences of parental mental illness. Chapter Six, the Discussion Chapter, will discuss the significance of the findings, how they are situated within the existing literature,

and their implications for nursing practice, education, and research, as well as policy changes to promote the well being of the children living with a parent with mental illness.

CHAPTER SIX

DISCUSSION

In this chapter, I will discuss the key findings of my study and how they fit with the existing knowledge base and literature. The purpose of the study was to understand the perceptions of children living with a parent with mental illness, in terms of how they managed this experience, specifically what was helpful and what was not helpful. The substantive theory, which explained the children's experiences, included the BSPPs: "finding the rhythm" and "maintaining the frame", as well as the social structural condition of "fitting in". I will discuss the findings in terms of the theoretical framework, symbolic interactionism, and the literature. I will also address the implications of the findings for clinical practice, education, research, and health policy. Finally, I will discuss the limitations of the study and my plans for the dissemination of the findings followed by a chapter summary and the conclusion of the thesis.

Overview of the Key Findings

How children managed living with a parent with a mental illness was explained by two BSPPs: "finding the rhythm" and "maintaining the frame", and the social structural condition: "fitting in". Both of the BSPPs were influenced by "emotional currents" which were pervasive. I found that children living with parents with mental illnesses managing and struggling. "Finding the rhythm" captures the children's experiences of struggling while managing to find daily positive interactions with their parents and a sense of routine in their households. "Maintaining the frame" explains how the children strove to preserve a sense of themselves while maintaining some physical and psychological security in their relationships with their parents. The children acknowledged the positive contributions their parents made to their lives. Most of the children described mutuality within their relationships with their parent, as they experienced many positive emotions.

When the children attempted to “find the rhythm” with their parents, they were “monitoring” their parents’ behaviour and “adjusting” their own behaviour and the environment to try to get along with their parents on a daily basis. The rhythms included the daily patterns and interactions with their parents that provided context to the children’s lives. The children were trying interact positively with their parents while keeping the rhythms of their daily lives as stable as possible. Intertwined with “finding the rhythm”, was “maintaining the frame”. This was the process whereby the children attempted to keep a safe and comfortable distance between themselves and their parents, while remaining connected to their parents. This allowed them to maintain a sense of personal safety and security. The children “tried to preserve themselves” and “gauged” how well they were managing in terms of feeling safe and secure. To preserve themselves, the children used strategies of “getting away”, “living my life”, “selective sharing”, “flying solo,” and “opting out”. These strategies helped children to find respite and self-validation, solve problems, connect to others, and to find some space of their own. Children gauged their situation, by weighing their costs and benefits, to determine how well they were managing to find personal security and safety.

Throughout the processes of “maintaining the frame” and “finding the rhythm”, the children’s lives were strongly affected by “emotional currents”. Those currents were characterized by varying intensities of diverse and sometimes opposing emotions. The “emotional currents” influenced how the children managed through the processes and contributed to the children’s assessments of their success. The children’s experiences took place in the context of the social structural condition of “fitting in”. In “fitting in”, the children considered how they were measuring up in the outside world. They thought about whether they were surviving, “getting along”, or flourishing in terms of their peers and their interactions with the school system and the authorities. The overall outcomes associated with “finding the

rhythm” and “maintaining the frame” were the children’s sense of the quality of their connections with their parents and their identities.

Within a burgeoning interest in children’s perceptions who are living with a parent with mental illness (Ackerson, 2003; Orel, Groves & Shannon, 2003; Ortega, 2003; Smith, 2004; Stallard, Normand, Huline-Dickens, Salton, & Crib, 2004; Valiakalayil, Paulson, & Tibbo, 2004), my study makes a significant contribution to understanding children’s perspectives about attempting to manage their circumstances. Qualitative findings about children’s perspectives have rarely been reported in the literature. The relationship of the study to the literature will be discussed from the perspective of the BSPPs and other key components of the theory.

Finding the Rhythm

In “finding the rhythm”, the children responded to the actions of their parents after interpreting their parents’ actions and intent. Symbolic interactionism emphasizes the importance of such a process, based on interactions between the parent and the child. Children assigned meaning to their parents’ behaviours by “monitoring” them and then chose actions that they believed would help them and their parents. In other words, they fit their actions to the acts of their parents. In “finding the rhythm” with their parents, as Perinbanayagam (1985), a symbolic interaction theorist described, the children were building up lines of conduct by ongoing interpretations of their parents’ actions. These children were active participants in their parent/child relationships and took action by choosing to help directly and indirectly. In helping indirectly, they were less overtly active, but still took action by choosing to retreat and do nothing in response to their parents’ actions. Important aspects of “finding the rhythm” were the children’s strategies (“monitoring” and “adjusting”). Those strategies enabled them to affect daily family stability and their interactions with their parents. In the process of those actions, the children indicated that they lacked sufficient information about their parents’ illnesses, which made it difficult for them to interpret what was happening and to assign meaning to behaviours.

Monitoring and Adjusting

Despite the challenges that mental illness, with its exacerbations and remissions, presented in getting along day-to-day, the children attempted to construct meaning from the patterns of behaviour which they monitored in their parents. Symbolic interactionism places primary importance on how social interaction affects the self (Harter, 1999). It views self as a social construction developed through linguistic exchanges with others. Symbolic interactionism has contributed to ideas about how the self is developed in childhood. Language is one of the primary symbols upon which meaning is assigned and interpretations formed (Harter). The concepts provided by symbolic interactionism are important in understanding the children's experiences. Mental illness is often not named or openly discussed within the family home and thus the symbols representing mental illness may not be clear to the children. Perinbanayagam (1985) states that articulating a symbol and meanings which surround it indicates that discourse around symbols has been accomplished. While mental illness of a parent may be central to family life, open discourse on this topic often does not occur, leaving children to develop their own interpretations of behaviours. The literature on stigma recognizes that the silence surrounding mental illness prevents acknowledgement and open discussion of mental illness (Ekdahl et al., 1962; Marsh & Dickens, 1997; Miller, 1996; Thomas & Kaucy, 2003). My findings extend this literature, to describe how stigma prevents children from being informed about their parents' illness. My study suggests that even within their family homes, some children perceived the effects of stigma because their families were unable to openly discuss the nature of their parents' illnesses. As a consequence, these children perceived that having a mental illness was shameful.

Children's parents and families are the major daily influential contacts in children's lives and their primary reference group. Many of the children received strong validation about their personhood from their parents, but this was more explicit when the parents were well. Some of

the children described experiencing concern and caring from their parents even when their parents were unwell. Cooley's (1902) discussion of the "looking glass self; "Each to each a looking glass, reflects the other that doth pass" p.17) emphasized the influence of daily contacts in people's lives. In my study, the nature of contact children had with their parents influenced the children's identities. When children had positive interactions with their parents, they became integrated into their reality and contributed to positive perceptions of self. A high degree of mutuality between parent and child has been found to be a protective factor for the child's healthy development (Anthony, 1974; Kauffman et al., 1979; Rutter, 1978). My study extends the research on mutuality between parent and child by presenting children's perceptions of their efforts to maintain relationships with their parents, and extends the literature by emphasizing the importance of their connections with their parents. Meanings, which children constructed from positive interactions with parents, assisted the children to manage their parents' less nurturing behaviours and, at times, to be forgiving of their parents' deficits. If children had a pattern of positive interactions with their parents, they were more likely to be empathic towards their parents and construct more benevolent meanings of their parents' behaviours. I found that most children who were managing well were emotionally involved with their parents rather than detached and analytical. These findings concur with Kauffman et al. (1979) who found that children, with warm and supportive parents, were more compassionate towards their parents and their mental illnesses; but are in opposition to Anthony's (1974) findings that suggested that the children who manage well, are detached and objective about their parents' illnesses.

In "finding the rhythm", the children changed their perspectives in ways that were dependent on the evolving patterns of their interactions with their parents and the acuity of their parents' illnesses. They changed their perspectives based on their evaluations of whether their efforts to help directly and indirectly were accomplishing what they had hoped. Within the traditions of symbolic interactionism, actors are continually creating meaning (Charon, 1989).

When children were unable to understand their parents' behaviours, they constructed meanings, such as erroneous beliefs that their parents would die, that caused them unnecessary concern. Those meanings were partly based on a lack of adequate information about their parents' illnesses.

Recent research on children's perceptions concurs with my findings. Riebschleger (2004) conducted a qualitative study with 22 children, between the ages of 5 to 17 years, whose parents had mental illnesses; she sought the children's perceptions of daily life with their parents. The children in her study were similarly concerned that their parents would die when ill and associated hospitalization with death. They intertwined comments about physical and mental illness, sometimes not being able to sort out the differences. The majority of the children had not been told about their parents' illnesses and had received no information about the mental illnesses (Riebschleger). The children in her study described reacting and "adjusting" to behaviours associated with their parents' mental illnesses; the children in my study described similar behaviours to make adjustments; for example, ignoring, avoiding and attempting to reduce the family stress by helping behaviours; however, my study extended Riebschleger's findings by describing the strategies children used to monitor their parents' behaviours, the purposes that "monitoring" served and by placing the children's strategies in a larger process of "finding the rhythm" with their parents.

Because mental illness is expressed through irrational behaviour, mood, thought, and speech, symbols to which the child and parent had previously assigned meaning could change during an exacerbation of the mental illness (American Psychiatric Association, 2000; Elgin Holley, 1997; Hinshaw, 2004; Lyden, 1997). When parents were acutely ill, the children had difficulty "finding the rhythm", particularly when symptoms were bizarre, incongruent with their parents' usual behaviours and values, had not previously been observed, and were not positively influenced by the children's efforts to adjust their behaviour to find the rhythm. These

conditions made it more difficult for children to assign meaning to their parent/child interactions. The early work of Bleuler (1974) recognized the efforts the children of parents with schizophrenia made within their daily lives and interactions with their parents. This work recognized the children's strengths, suffering, and sacrifices in the context of their adverse circumstances to maintain a sense of daily rhythms. The findings from my study not only indicated the centrality of "finding the rhythm" as a process by which children managed their experiences, but also the effects on their sense of identity. The experiential retrospective accounts of adults' childhood experiences of living with a parent with a mental illness, also support the centrality of the parent/child relationships to children, and the efforts they made to establish daily family stability (Atkins, 1992; Dunn, 1993; Elgin Holley, 1997; Hinshaw, 2004; Lyden, 1997; Marsh & Dickens, 1997). Due to the illness, children were also required to assign new meaning to old symbols and to reinterpret the meaning of the situation according to the present moment.

Effects of Information about Mental Illness

When the children in my study had little knowledge of mental illness, the meanings that the children constructed around their parents' behaviours were restricted. Valaikalayil et al. (2004) found that adolescents had varied understanding of their parents' mental illnesses which interfered with their interpretations of their parents' behaviours. A narrow set of meanings attributed to the behaviours made it more difficult for these adolescent children to choose an effective action. These children indicated that knowing little about mental illness affected how they were able to manage their circumstances. Despite their limited information, their children in my study had ideas on what they considered important information to share with other children who had parents with mental illnesses. These findings are significant in that the children themselves described what they felt was important for other children. Their ideas clustered around the following points: how to act when your parent is ill; what information is

needed to understand and acknowledge mental illness, how adults can help children, and tips to manage mental illness. In describing how to act when their parents were ill, children wanted other children to know many of the specific strategies described in “adjusting” and “trying to preserve myself”; such as moving to a safe place and not worrying about the illness all the time. They described strategies that they found helpful, within the range of their available options. For example, younger children suggested simple strategies, such as telling jokes, in attempts to change their parents’ moods. In addition, the children thought it was important that other children know that there are others living with parents with mental illnesses. They thought this was important because other children will not tell you that their parents have a mental illness. It was also important for children to tell other children that mental illness is an accident and that it is no one’s fault. Sometimes there is nothing that you can do and at these times you need to wait it out. My findings indicated that children wanted to talk to other children about their parents, but that they did not know how to do this safely and further suggested that providing children with a safe place in which to share their perceptions is helpful to them.

Older children stated that they needed more information about mental illness as it was not openly discussed at home or at school. Children felt that that they and their peers knew little about it. The children thought that their peers equated mental illness with developmental delays, such as mental retardation. To some of the children, the silence around mental illness signified that it was not important. Even when not openly acknowledged, children knew that something was wrong. This secrecy and silence made some children think that the family was lying to them and that perhaps lying was ‘alright’. Older children thought adolescents should have information about mental illness and recreational drug use. This could help them to resist peer pressure.

The children thought that adults could talk to children more about what was happening. Nicholson and Henry (2003) and Wang and Goldschmidt (1996) reported that mothers identified

concerns regarding how to talk to their children about their mental illnesses and recognized a need to do so. My findings indicated that children felt they had limited information on what was wrong with their parents and generally wanted more accurate information. These findings extend the work undertaken with parents and emphasize a need to consider how and when information is given to children. Barnes et al. (2000) found that parents, living with cancer, were surprised that children knew about cancer despite not having discussed their illness with their children. Upon reflection, these parents felt that not telling children made the situation more difficult. My study demonstrates that children living with a parent with a mental illness were aware that something was wrong despite not being told and most wanted further information. While there are some similarities to children's reactions to parental mental illness and cancer, children whose parents experience cancer have more resources to assist them to manage their situations in that more family supportive services are organized around the cancer experience (personal communication, J. Taylor-Brown, February, 2004).

The younger children particularly valued adults using some kind of humour and fun with them. The children did not want the mental illness of their parents to consume their lives, and saw fun and humour as something that adults could provide to assist them in managing. My study demonstrated that children perceived the use of humour as an important general strategy for helping their parents and themselves. These findings extend the literature on the importance of humour in children's well being. Garnezy et al. (1984) and Werner and Smith (1982) found that humour and a good natured disposition assisted children to develop harmonious relationships with others. This study demonstrated how children of all ages also used humour as a strategy to help their parents.

Younger children indicated that other children should know it is important to stick up for your parents and not to place demands on the parents when they are ill. You need to help them and try not to worry as they will get better. You can't worry about it all the time. Someday, a

cure will be found. Having a parent with mental illness is not all bad, as sometimes you get closer to your parent and your family becomes closer. These findings significantly contribute to the existing knowledge by emphasizing what children value in assisting them to live with their parents with a mental illness. They support the importance of enhancing the competencies of children who are comfortable in their relationship with their parents by strengthening the parent/child bond (Tebes, Kaufman, Adnopo & Racusin, 2001). My study demonstrates that understanding what children value about their well being can contribute to more accurate measurements of resilience. Such measurements must include children's perceptions of what they find helpful in managing their circumstances and promoting their well being.

Recent studies about parenting with mental illness and with children of parents with mental illnesses concur with my findings that children possess little knowledge about mental illness and that they perceive this as difficult. Such studies indicate that children have little factual information about mental illness, even though they are living with parents who suffer with these illnesses and that this causes increased burden (Orel et al., 2003; Stallard et al., 2004; Valiakalayil et al., 2004).

When the children had knowledge to classify parental behaviours as part of the mental illnesses, they assigned different meanings to their experiences and their perceptions of their roles. Cooley (1902) believed that children internalize opinions of others about the self, so that the attitudes of others become incorporated into the self. Findings from my study suggest that the children perceived that often when their parents were ill, they devalued their role as parents and, consequently, they devalued their children. When children had help to interpret the parents' behaviours as part of the mental illness, they interpreted disparaging remarks differently. Some of the children who had information about the illness indicated they knew when 'it was the illness talking' and, that as their parents became well, they returned to being themselves. The literature about parents with mental illnesses demonstrates that many parents are concerned

about the well being of their children and aware of the strain associated with being a good parent and dealing with a mental illness (Nicholson & Henry, 2003; Mowbray et al., 2000). The children in my study perceived their parents were different when ill and required strategies to help them manage these differences. This extends the literature to include how children perceived and experienced parental deficits related to illness and children's inability, at times, to manage these differences.

When the children had limited information on what was happening to their parents, their attributions about parents' behaviours were based on only possessing part of the story; they constructed explanations based on limited knowledge and some children ascribed negative meanings to their situations and to themselves. While children's perspectives stress the importance of having information about their parents' mental illnesses, little attention has been paid to this in the literature. In studies of invulnerable, resilient children there is minimal acknowledgment of what children understand about the mental illness of their parent and how they acquire this information (Luthar & Zigler, 1991; Kauffman et al., 1979). Children's desires to know what was wrong with their parents were prominent in my study. The growing body of knowledge on parents with mental illness identifies parents as wanting more information on how to discuss mental illness with their children (Nicholson et al., 2001; Nicholson & Biebel, 2002; Stallard et al., 2004). Research, about how children whose mothers experienced cancer are informed about their parents' illnesses, suggests that these mothers have similar difficulties in disclosing information about their diagnoses (Hilton & Gustavson, 2002). The scarce research on children's perceptions supports their desire for more information on mental illness (Handley et al., 2001; Hinshaw, 2004; Riebschleger, 2004; Stallard et al.). Children in my study stated that they knew something was wrong. This supports ideas that children have more potential to understand complex concepts of illness than previously thought and that, even if they are not told of the illnesses, they are sensitive to changes in their environments and parents' health similar to

children in the study conducted by Barnes et al. (2000). The literature has shown that adolescent children of parents with mood disorders, who were best able to manage their circumstances, were the children who were aware that their parents' behaviours were due to their illness (Beardslee & Podorefsky; 1988).

Findings from my study also indicated that, when children do not have factual information about mental illness, and medication side effects, they attribute parental behaviour to personal characteristics and feel more hostility towards their parents. Their lack of factual information influenced the process of "finding the rhythm", making it more difficult to interpret behaviours, to choose effective actions and to stay connected to their parents. Valiakalayil et al. (2004) found that adolescent children of parents with schizophrenia were uninformed about their parents' illnesses. That lack of information caused children to erroneously attribute their parents' behaviour to being under the parents' control and to personal characteristics, for example, "laziness", versus recognizing the behaviour as a symptom of the illness. In a small qualitative component ($n = 4$ children) of a larger study by Handley et al. (2001), the children identified their struggle to understand and recognize their parents' illnesses and to manage the illnesses. Their findings mirrored my study findings, in that the children struggled to make sense of what had happened and found it more difficult to manage when they did not know what was happening. My study, however, explains how the children continually worked at their connection with their parents, regardless of their developmental stage.

My findings indicated that the developmental stage of children influenced their ability to monitor and make adjustments. In other words, older children were more sophisticated in their abilities to assign meanings to their parents' behaviour and had a wider range of behaviours available to them when they were making adjustments. Developmental stage was not the sole determining factor. Other factors, such as the availability of supportive adults, information about medications and mental illness, and how often the child had witnessed the symptoms, all

influenced how the child monitored and adjusted. While recognizing the emotional and cognitive limits associated with the children's development, the findings would suggest that age was not the predominant variable that determined how the children reacted to their situations. For example, I found that, as some children got older, they did not necessarily have more accurate information about mental illness. Tebes et al. (2001) also found limited effects of age as a determinant of children's adaptation to their circumstances.

There is a well-established body of literature on attachment theory; attachment being defined as a socio-emotional bond between the child and parent, usually the mother. In essence, the attachment literature suggests that children form an enduring socio-emotional bond with their primary caretakers as they develop cognitive and perceptual skills (Bowlby 1969). Ainsworth (1978, 1973) argued that most children (60 – 65%) are securely attached to the mother; less secure attachment patterns make it more difficult for the child to develop a sense of trust and confidence in the parent, and to develop satisfying social interactions. Attachment theory suggests that attachments are formed within the earliest childhood relationships which permanently shape the child's development (Bowlby, 1969). My findings indicated that the children's attachment to their parents in the context of a mental illness is an ongoing process over many developmental stages, based on their interactions with their parents on a daily basis and the rhythms and rituals of their families' lives. Moreover, the children, in "finding the rhythm" and in "maintaining the frame", used strategies to work at connecting to their parents and sustaining their relationships and rhythms in a safe and comfortable frame over time. Therapeutic interventions are now acknowledging the ongoing nature of attachment and suggest a focus on the enhancement of attachment between child and parent over the life span (Herring & Kaslow, 2002). These ideas concur with the findings from my study in that they suggest that attachment is an ongoing process throughout the relationship of the parent and the child. While recognizing the contributions of the classic attachment literature, more recent literature has

questioned whether other aspects of family life are important for children's security. Leon & Jacobitz (2003) found that family rituals also contributed to a sense of stability, created shared memories, and fostered emotional ties within families.

On the other hand, the children in my study also used strategies of "living my life", "getting away", "selective sharing" and "flying solo"; these findings indicated that they were maintaining their relationships while creating lives of their own outside of their connection to their parents. In doing so, they were attempting to develop autonomy in the context of their sense of relatedness to their parents. The findings from my study support the idea of reciprocal interactions between parents and children and also the awareness of complex interactions between family and extra familial systems (Anthony, 1974; Burbach & Borduin, 1986; Hinshaw, 2004; Rutter, 1978). Literature on children's experiences of maternal cancer has noted similar themes (Hilton & Gustavson, 2002).

The children in my study made it clear that their families were their primary reference, especially the younger children. The younger children were more restricted in their abilities to contact and seek out other reference groups. They relied on their parents for mobility and were less involved in extracurricular activities. In "finding the rhythm", all of the children monitored their ill parents, but also attended to their well parents and other family members in the household.

"Finding the rhythm" was a dynamic process where the children were trying to engage their parents in reciprocal parent/child relationships. Previous studies also suggest that child/parent interactions are reciprocal in nature and that the characteristics and behaviours of the parent influence the child's behaviour, which in turn influences the parent's behaviour (Anthony, 1974; Burbach & Borduin, 1986; Kauffman et al., 1979; Rutter, 1978). "Finding the rhythm" was motivated, in part, by the children's desire to maintain positive interactions with

their parents and a regular routine in their households for themselves and their families. Most of the children were motivated by their positive regard for their parents.

In my study, most of the children described their relationships with their parents with mental illnesses favourably. The literature on the parents' perspectives of their relationships with their children suggests that many parents value their parenting role and attempt to respond to their children's needs as best they are able (Bender, 2004; Mowbray et al., 2000; Nicholson & Biebel, 2002). The majority of studies on children with parents with a mental illness have focused on the deficits associated with growing up with a parent with a mental illness (Ackerson, 2003). Within the literature there has been little acknowledgement of the positive aspects of parenting for women with mental illness, the positive aspects of the child/parent relationship and the significance of its meaning for children (Nicholson et al., 2001)

Symbolic interactionism attributes understanding actors' behaviours based on thoughts, not only overt behaviours (Charon, 1989). These children's perceptions of how they get along in their daily lives contributes substantial knowledge to the existing knowledge base. The children in my study monitored daily routines (rhythms) in their homes and adjusted their behaviours to restore these rhythms and gain daily family stability. The children welcomed and appreciated the daily rhythms of their homes. They tried to re-establish or assist with routines and household chores and spoke nostalgically about times when regular routines were in place. My study demonstrated that children devoted a considerable amount of energy to "monitoring" and "adjusting" in order to elicit positive reactions from their parents and to contribute to daily family stability. The literature generally has not referred to children's efforts to maintain some order and predictability in their family lives by first attending to what was happening and then "adjusting" their behaviours to try to facilitate the goals of positive connections to the parents and daily family stability. Family routines, identified as patterned activities which occur with predictable regularity in family live provide order in the course of daily events (Denham, 2002).

Routines provide structural integrity to daily family life and are important components of family health (Denham). Children in my study monitored the family routines to assess how parental mental illness was affecting their daily lives. Assessment of family routines has been identified in the literature as a concrete way to identify family stresses and strengths (Denham). The children thought these routines were important in contributing to the integrity of the family and to the benefits of maintaining the frame with their parents.

Maintaining the Frame

The children in my study attempted to maintain the frame with their parents by “trying to preserve themselves” as separate from their parents’ illnesses but also to remain connected to their parents. They also gauged the effects of their efforts to preserve themselves and whether they contributed to feelings of personal safety and security.

Countering Engulfment

Anthony’s (1970; 1974) early work recognized that one of the characteristics of children, who were better able to manage their circumstances, was their resistance to being engulfed by the illness. Beardslee & Podorefsky (1988) identified that resilient adolescent children were able to be realistic about their capacity to act, the consequences of their actions, and described themselves as separate from their parents’ illness. Because the children in my study perceived a need to “try to preserve themselves”, by “living their own lives”, “getting away”, “selective sharing”, “flying solo”, and at times “opting out”, my findings extend previous findings, because the children provided strategies that helped them to avoid being engulfed by the illness. My findings also indicated that the children valued remaining connected to their parents while “trying to preserve themselves”. My theory contributes to the knowledge base about children living with a parent with a mental illness, because it indicates that children generally wanted to participate in “maintaining the frame” with their parents and perceived that their parents were making a positive contribution to their lives. Previous research has focused on the separation of

the parent from the child, with little attention to the positive connections that children feel towards their parents. Some studies have identified that children who can resist being engulfed by the illness and who have warm connections with their parents have fewer problems (Anthony, 1974; Kauffman et al.; 1979; Rutter, 1978). The majority of the literature, however, has focused on the more negative aspects of the parent/child relationship (Ackerson, 2003). Little attention has been paid to the strategies children use to live with a parent with mental illness (Garley et al, 1997) and even less on their parents' positive contributions to their lives (Ackerson; Nicholson et al., 2001).

The children in my study, who gauged their efforts to "maintain the frame" with their parents negatively, viewed opting out as their only reasonable strategy. Using opting out to the exclusion of other strategies created more distance between themselves and their parents, but was their only alternative to what they viewed as unsafe environments. The children who opted out constructed less satisfactory meanings from their interactions with their parents. The children who seemed to have the most difficulty remaining connected to their parent were older boys, between the ages of 13 to 16 years. These boys were developing diverse perspectives as they spent more time outside the family home and with different reference groups. While diverse perspectives and social worlds can exist simultaneously, (Charon, 1989) the differences that the children noted in their social worlds impacted negatively on their desire to maintain the frame with their parents.

The literature on the influence of gender as a moderating factor in the relationship between parental mental illness and children's reactions is complex with conflicting results (Nicholson et al., 2001; Wang & Goldschmidt, 1994). Studies, determining gender differences on mental health outcomes, have been limited by one or two measures of mental health problems and may have suggested that sex differences are more widespread than recent studies suggest (Stephens, Dulberg & Joubert, 2005). While boys tend to develop conduct problems and girls

develop depression; gender, however, may interact with family functioning and conduct problems may also occur in girls (Nicholson et al., 2001). In my study, the three children who were having the most difficulty with their parents were teenage boys. One of the boys had developed serious conduct problems, while the remaining two were going to school and living at home, but identified significant distress about their situations and saw no way to resolve them. Previous findings on gender differences support that boys experience more emotional problems (Wang & Goldschmidt, 1994). Boys in my study also experienced difficulties within the school system. This concurs with Tebes et al. (2001) who found that boys exhibited more problems in adaptation such as problem behaviours and psychiatric impairment. My study findings suggest that managing living with a parent with mental illness is more difficult for teenage boys but also that there are other complex interactional factors, other than gender, that affect their lives to create difficulties. Thus while, gender may be implicated, other issues, such as poverty, availability of support inside and outside the family, and success in other areas of life, influenced these children's management strategies and outcomes.

The discussion of mutuality and the ability to parent in a warm and supportive manner has not been well developed in the literature about living with parental mental illness. Kauffman et al. (1979) noted that the degree of mutuality between parent and child was an important consideration for children's positive outcomes. Anthony (1974) hypothesized that, in situations where the parents with the mental illnesses were able to provide support and empathy to their children without being intrusive, the children were better able to manage their circumstances. Rutter (1978) also noted that even serious pathology in the parent did not always eliminate the parents' abilities to parent in a warm and supportive manner, which was beneficial for the children's development. My theory emphasized the importance of the connection that children had with their parents. Their valuing of this connection motivated them to "find the rhythm", by "monitoring" and "adjusting", but only if they were comfortable, and maintain the frame" by

“preserving themselves” and “gauging” how they saw themselves managing overall. My findings suggest that although this connection with the parent is central to the children, the children were not able to maintain it at any cost. They invest in the parent/child relationships and their connections with their parents are significant in their lives, but so is safety and security. The literature, while sporadically acknowledging the mutuality of the parent/child relationship and the potential for positive parenting even when parents are suffering with a mental illness, is not well developed. There is beginning recognition of the importance of strengthening parenting performance to enhance the well being of children (Nicholson et al., 2001; Sanders, 2002; Tebes et al., 2001). My study contributes the children’s perspectives on the significance and value that they placed on their relationships with their parents and, as such, demonstrates the importance of considering their parents not only as patients, but also as parents.

The Emotional Currents that Affected Children’s Lives

Ongoing “emotional currents” were pervasive in the children’s lives and influenced their abilities to find the rhythm and to maintain the frame with their parents. The children experienced a range of emotions and differing levels of intensity of these emotions. The “emotional currents” influenced the children’s abilities to navigate the processes and, ultimately, the outcomes of connection to their parents and the nature of their identities. The findings emphasized the children’s attributions of emotional reactions to the events in their lives and the significant positive emotions that children felt towards their parents. My findings are consistent within the lay literature, which documents adult reflections on childhood experiences of parental mental illness. These adults described the intensity and variety of emotions they experienced as children, and their connections to their parents (Crosby, 1989; Graziano, 1998).

Children’s Emotional Experiences

All of the children in the study experienced a range of emotions with varying levels of intensity. Both groups of children, who externally appeared to be functioning well and those

who did not, experienced emotional distress. Some of these children described painful emotional reactions to "monitoring" the behaviours demonstrated by a parent with a mental illness and the children's success or failure at "adjusting" their behaviours. Those feelings could include anger, hostility, sadness, and anxiety. The children, who appeared to be functioning well, were doing well at school and were active with friends and extracurricular activities. While some of these children may have been described as having resilience, "a dynamic process encompassing positive adaptation within the context of significant adversity," (p. 543; Luthar et al., 2000) the children nonetheless described painful emotions which were not indicative of unqualified resilience in the face of adversity. Beardslee and Podorefsky (1988) described the painful emotions that adolescents experienced while living with parental mental illness but failed to consider these emotions as indicators of children's levels of adaptation. My study highlights the subjective distress that children felt and the significance of this distress in assigning labels to children's adaptation to their circumstances. The discrepancy between outward functioning and inward affect has not been duly considered in the literature on resilience in children living with parents with mental illness. On the other hand, retrospective lay accounts of adults who grew up in homes with parental mental illnesses have described experiencing emotional duress, which significantly influenced their experiences, while appearing competent in other domains (Dickens, 1996; Elgin Holley, 1997; Graziano, 1998; Lyden, 1997; Marsh & Dickens, 1997).

Claims of resilience in children have often overlooked children's subjective reactions, failed to consider that resilience is not stable and changes over time, failed to consider the multiple contexts in children's development, and failed to adequately consider the possibility of significant problems within other spheres (Luthar et al., 2000). The literature encompassing resilience includes ambiguous definitions and measures and a lack of consensus around central terms; as well, the multidimensional nature of resilience may find children competent in some areas but struggling in others (Atkins, 1992; Dunn, 1993; Luthar et al., 2000; Marsh & Dickens,

1997; Robinson, 2000). Children in my study described painful experiences within the context of their lives and everyday experiences. Within the classic work on resilience in children (Garmezy, 1974; 1981; 1985; 1987; Garmezy et al., 1984; Werner & Smith, 1982) there is limited recognition of children's feelings about their experiences. Kolbo (1996) noted that previous research on children's outcomes in adverse circumstances has relied heavily on behavioural indicators of development. My study suggests that children's experiences are more fully captured with diverse methods of inquiry which incorporate their perceptions of their lives.

While most of the children in my study experienced a range of positive emotions, which sustained them, they also experienced painful negative emotions related to their circumstances. Living with parents with mental illnesses was emotionally draining for these children. They often did not have a safe place to discuss their emotional reactions to their parents' illnesses. Some of the children in my study, who by outward appearance and functioning appeared to be thriving, frequently spoke of emotional upheaval in response to their situations. Some of these children suffered in silence as they went through the motions of managing their lives without difficulties. Outward competence (doing well at school, being involved with extracurricular activities, having friends) masked their emotional upheaval and negative feelings. These findings are significant in that they contribute to our understanding about the nature of emotions and resilient behaviours in the lives of children who are living with parents with mental illness. Farber and Egeland (1987) distinguished between competent behaviour and emotional health in their longitudinal work with abused children demonstrating that outward competence did not necessarily indicate emotional well being. While existing research on resilience in children at risk has made a significant contribution to this body of knowledge, my findings strongly suggest that, unless children's perceptions are actively sought, their distress is at risk of being overlooked. Their perceptions must be incorporated in important constructs, like resilience, which claim to measure children's adaptation.

Significant Positive Emotions Directed Towards Parents

Most of the children in my study consistently expressed positive emotions towards their parents and recognition of their parents' positive contributions to their lives. With the exception of four children, these children strongly stated that they cared for and appreciated their parents. Their positive emotions of love and caring toward their parents influenced how children constructed meaning of the behaviours of their parents when they were ill. When parents had episodes of acute mental illness, the children received diverse reactions from their parents, some of which caused them emotional distress. When parents were acutely ill, they were often irritable and acted "weird" which confused, worried, and angered the children. Parents would engage in behaviours that they had told their children were not acceptable. The children identified heightened emotional states when their parents were acutely ill, particularly when their parents had to be hospitalized. Riebschleger (2004) reported similar findings. In my study, the children's positive emotions could influence them to forgive slights and disrespect directed toward them by their parents. Of the four children who did not express caring and appreciation for their parents, three of them were able to express compassion toward their parents and the fourth expressed a desire to be with the parent. The children described their feelings of fear, anger, and contempt which negatively influenced the children's interpretation of parental behaviours associated with mental illnesses, sometimes only temporarily, but for some of the children, for a long time.

In my study, the children identified intense "emotional currents" which consisted of both positive emotions towards their parents and distress and emotional pain. In describing how their illnesses affected their children, women suffering from mental illness, described their relationships becoming closer and stronger because of the illness (Nicholson et al., 2001). Several children in my study identified that their relationships with their parents were stronger because of the illness. These children were female and helped their parents by caring for them

when ill. Given that both parents in the literature and children in this study have identified positive influences from parent-child relationships further study of their perspectives about the relationship is warranted which incorporate gender differences within the experience of living with a parent with a mental illness.

Fitting In

As children talked about their lives, it became clear that other factors, such as, poverty, crime, lack of supports, and the stigma surrounding mental illness, impeded their efforts to find the rhythm and maintain the frame with their parents and to “fit in” with the larger society. “Fitting in” is a social structural condition wherein the children had to consider how they were viewed by those in the outside world. Children were not only attempting to find the rhythm and maintain the frame within their parent/child relationships, they were also trying to fit into larger societal expectations that they encountered. For some children, the family rhythms often did not fit well with external systems such as school. Having no routines for breakfast, getting up in the morning, going to bed at night, and not doing homework did not help the children to “fit in” with their classmates. Mental illness of a parent, how a family functions and parenting style have been identified as strong predictors of vulnerable children within the context of systemic barriers of poverty, racism, a diminishing sense of community/social responsibility, the need for affordable housing and the effects of family breakdown (Child Guidance Center, 2003).

While children in my study came from varied income levels, many were living in poverty. All of the children were aware of the stigma that surrounded mental illness. Poverty and stigma were additional burdens that children had to manage while living with a parent with a mental illness, because they affected how children perceived themselves as “fitting in”. These findings concur with Bronfenbrenner’s ecological theory which proposes that people are exposed to inter-connected contexts that interact in complex ways and influence their development (Bronfenbrenner, 1979).

In my study children were managing living with parents with mental illnesses amidst the influences of the multi-systems that interconnected and affected their experience. For example, the exosystem, the socio-economic context of children's lives and government institutions, (access to services for children and their families) the mesosystem, the immediate context of family, school, and neighbourhoods, (gangs, lack of supportive counselors and teachers and school bullying, changing family configurations) and the macrosystem, of beliefs, and values concerning mental illness, all interacted to affect the children's experiences of "fitting in" outside of the family home. The experience of living with a parent with a mental illness did not occur in isolation from the influence of these systems. My findings also support Bronfenbrenner's assertion that measures of children's resilience cannot exclude the context of their lives but must incorporate their reality. These ideas support the work of Rutter (1985) on multi-causal influences of children's behaviour. Generally the children from more affluent households were more able to preserve themselves and achieve personal safety and security. These children had more resources that allowed them to develop in diverse areas through sports, theatre, dance and travel.

Living in Poverty

Using the definition from Statistics Canada, eleven out of twenty-two of the children in this study were living in poverty; however, these children did not always perceive that they were poor. If they lived in neighbourhoods that were homogeneous in regards to life styles, they were less likely to be aware of their poverty, particularly when the children were younger. The older children who were living in poverty were more aware of differences in their lives. Older children were more likely to come into contact with diverse people and situations, to which they compared themselves.

When these children were in schools and in neighbourhoods with a mix of children from families with different income levels, they became more aware of differences. They were

sometimes teased because of their clothes or life circumstances. In some families, children and parents described struggling to finance their children's participation in extracurricular activities. Children were not always aware of their parents' struggles. When an exacerbation of the mental illness caused further strain and economic hardship children were faced with the fact that their families did not have as much as other families. This was embarrassing for them. My finding concur with Werner's (1989) classic work on protective factors wherein affectional ties and emotional support within the family, and community support systems that reward the children's competencies, assist children to manage their circumstances. Children who were able to develop competencies in extra curricular activities or at school had a stronger sense of identity. Children, who had cumulative stressors in their lives, such as their ill parents, unplanned moves, and limited supports at home or at school, had more difficulty managing their circumstances. Lower economic status is associated with poorer academic outcomes and when coupled with parental depression puts children at increased risk for academic difficulties (Ryan & Adams, 1999). My findings that children with cumulative stressors had increased difficulty managing their circumstances concur with Garmezy's work on cumulative stressors and increased risk (1993).

While Tebes et al. (2001) found no significant relationship between children's adaptation and socioeconomic conditions, it is generally accepted that chronic poverty is associated with cumulative adverse events in life (Garmezy, 1993). Poverty is associated with additional hardship for children, and increases the likelihood of behavioural and emotional problems in children of parents with mental illness (Nicholson et al., 2001). In my study, children, who lived in poverty, sometimes saw that other children had less than they and regarded those children as 'poor' but did not identify themselves as poor. One child who was poor went to private school and another child was privately tutored for remedial schoolwork. The children perceived these events as generally positive. Providing extra opportunities for the children took them out of their immediate environments and exposed them to other ways of living. For the older children, being

exposed to other circumstances made them aware of their economic conditions and general situations. For example, the child in the private school was aware that her parent was unable to participate like other parents and that her home life was different than that of most of her peers. Although a number of the children in my study were poor, only two of the children commented on being poor. This was in opposition to the recent study by Riebschleger (2004) where children expressed concern about poverty, bills not being paid, and being regarded as poor.

The Stigma of Mental Illness

Most of the children were aware of the stigma and silence surrounding mental illness. This was often evident in their family homes, because parents and family did not explain or acknowledge the illness. Some children perceived the silence surrounding the illness as meaning that the illness was not important. Within the symbolic interactionist perspective, the meaning of an object is constructed by the meaning that others have for it, as well as the meaning that the self constructs (Blumer, 1969). These children were trying to determine the meaning of mental illness, but they were influenced by other's attitudes towards mental illness. If an object is not named and goes unacknowledged, there is no discourse about that object. Meaning becomes obscure (Perinbanayagam, 1985). Most of the children were aware of the stigma that surrounded mental illness despite their family members failure to discuss it, because they were aware of the negative perceptions within their diverse reference groups, at school, and within the community. The children were aware that people often thought of mental illness as "bad". Not all children experienced overt stigma, but some of these children wondered how their friends would react if they knew about their parents. Most of them were sensitive to the fact that having a mental illness marked you as different. Some of the children spoke of keeping things within the family and only talking about the mental illness to family members.

The stigma around mental illness in Canadian society prohibits open discussion and leads to feelings of shame for those afflicted with mental illness and also their family members.

Kenny (2001) suggested that while society professes to be more open regarding mental illness, there continues to be lack of acceptance of people with mental illness. The children in my study were aware of this at an early age and knew that there was an element of shame associated with mental illness; that this was not to be freely discussed; and that this might prevent them from “fitting in”. In addition, they were often aware that they had only part of the story, or limited information about what was happening to their parents. The stigma and lack of information added to the complexity of monitoring their parents’ behaviours as well as to the intensity of emotions that the children experienced. Valiakalayil and al. (2004) also reported that adolescent children of parents with schizophrenia erroneously attributed their parents’ illnesses and behaviours to character flaws. Their attributions were based on their limited factual information about schizophrenia. The stigma that surrounds mental illness serves to isolate and create a formidable barrier for families and individuals suffering with mental illness (Allender & Spradley, 2001; Willinsky & Pape, 2002). My findings on children’s perceptions of stigma contribute to the growing body of knowledge on stigma which must incorporate the children’s perceptions.

Outcomes of Finding the Rhythm and Maintaining the Frame

The overall outcomes of “finding the rhythm” and “maintaining the frame” were the children’s connection to their parents and the development of their identities. In attempting to find the rhythm and to maintain the frame, the children attained varying degrees of connectedness to their parents. While doing so, they also developed diverse kinds of identity, depending on how they achieved the goals associated with trying to move through their developmental stages. The following discussion will provide a summary of the significant findings related to these outcomes.

Connection to Parents

A critical finding of this study was the children's feeling of connection to their parents with the mental illnesses. Most children were closely connected to their parents and used diverse strategies to maintain a safe and comfortable distance with their parents in "finding the rhythm" and "maintaining the frame". Only when the children were overwhelmed and unable to see any solutions did they opt out of their relationships with their parents. A few children, three adolescent boys, struggled in their efforts to connect and experienced tenuous, strained connections with their parents. The data from my study, however, clearly suggests that most of the children were invested in their parent/child relationships and wanted to be in their family homes.

Traditional western theories have focused on individuals gaining autonomy as a developmental goal. Individuals' need for connectedness in relationships has been less well investigated. Independence is admired in Western culture and is ingrained in many of the developmental theories (Harter, 1999). My study highlights the strategies that children used to develop their autonomy while remaining connected to their parents. By engaging in "maintaining the frame" while simultaneously "finding the rhythm", the children were attesting to the importance of their parent/child relationships in their lives. Children's strategies that contributed to autonomy ("getting away, living my life, selective sharing, flying solo, and opting out") helped to "preserve themselves" within the frame of their parent/child relationships. They gauged their experiences partly on the basis of their desire to remain connected to their parents in a safe and comfortable manner.

While there is a considerable amount of research on the influence of family discord, hostile parenting styles, and lack of maternal warmth in families with parents suffering from mental illness, (Fisher et al., 1987; Rutter, 1979; 1980; Rutter et al., 1975; Sameroff et al., 1982) there appears to be little investigation of the positive aspects of the parent/ child relationships

particularly from the children's perspectives. My findings indicated that parents' positive contributions to the welfare of their children were highly valued by children. Those findings need to be incorporated in discussions of children living with a parent with a mental illness. Research is moving from an exclusive focus on the mental illness to an incorporation of the multi-dimensional lives of parents and their families (Handley et al; 2001; Hinshaw, 2004; Mowbray et al; 2004; Nicholson et al., 2001; Nicholson et al., 1998a; 1998 b; Riebschleger, 2004; Ritsher et al., 1997; Savvidov et al., 2003). Children's perceptions about their parents' importance are an essential component of this move to a more inclusive approach in research studies.

Developing autonomy and maintaining a connection. Using strategies to preserve themselves, the children were attempting to maintain the frame of their relationships with their parents. My study strongly suggests that while the majority of the children were invested in preserving themselves, adolescents had more opportunities to do so. The adolescents had more flexibility and resources for activities outside of their homes with peers and extra-curricular activities. Harter (1999) suggested that children require ongoing connection with their parents and their peers and that connectedness develops in tandem with autonomy. Therefore the concepts of autonomy and connectedness are not dichotomized as adolescents attempt to meet the goals of individuality and connectedness simultaneously (Cooper, Grotevant & Condon, 1983). Grotevant and Cooper (1986) suggested that adolescents' identity formation is facilitated by their connection to their family. The reciprocal connection between the parent and the child can positively influence both the child's development of autonomy and relatedness with the parent. Conversely when absent, it may impede the process. Attachment theory posits that the major attachments between parent and children are made in the early years of life, resulting in variations of insecure or secure attachments (Ainsworth, 1973; 1978; Bowlby 1969). My study suggests that connection with parents is an ongoing dynamic process which continues over the

developmental stages. Children described connections with parents that continued to develop. Some children formed, what they described as unique positive bonds with their parents, which developed out of the circumstances of parental mental illness. A similar finding was reported in a study that focused on adolescent children living with parents who had schizophrenia (Valiakalayil et al., 2004).

The meanings that children constructed of their experiences determined how they established connections with their parents. Meanings were derived from multiple interactions with their parents, some of which were based on times when the parent was well, not only on interactions associated with the symptoms of mental illness. The family was the first reference group for all of these children, where their social interactions occurred. Those findings fit with the interpretation of behaviour and reactions to their behaviours to jointly create meaning around and participate in their relationships (Perinbanayagam, 1985). As well, meanings were also obtained from other reference groups, such as extended family, peers and community groups. Those meanings assisted children to construct meanings about the significance of their relationships with their parents.

As these children ventured forth into the larger world, i.e. school, they encountered varied experiences and influences. Some of these experiences reinforced children's positive connections to their parents; others, such as their parents' obvious inability to function as well as other parents, alienated the children from their parents. If children had difficulty fitting into the larger social expectations, the family home, even if unpredictable due to the mental illness of the parent, could provide them with some sense of security. For these children, relationships with their parents represented a measure of security in spite of the mental illnesses, particularly if children had few favourable alternatives. Other children, despite difficulties in navigating in the outside world distanced themselves from their home and parents. Other children constructed

more positive meanings in the outside world, which were reinforced by their parents and reinforced their connections with their parents, particularly when their parents were well.

My study strongly supports that the children felt they had valuable connections with their parents and that those connections made positive contributions to their lives. Most of these children did not see the mental illnesses of their parents as overwhelming their sense of connection with their parents. Many children described their parents valuing them as children. They felt they were important to their parents. Some children described being the most important thing in their parents' lives, how children made their parents happy, and that it was good for them to have a child. Others described their parents' sacrifices to make life better for them. This aspect of the children's experiences, despite its apparent significance to the children is not well documented in the literature. Instead the majority of the literature focuses on illness and deficits of the parents with minimal discussion on their positive attributes. This finding demonstrates that children incorporated these validating perceptions of parental care and love into their perceptions of themselves and constructed positive meanings around their connections to their parents. The more recent literature is calling for interventions that will promote the parent/child bond and parenting strengths of parents with mental illnesses (Hartley & Phelan, 2003; Mowbray et al., 2000; Nicholson & Biebel, 2002; Stanley & et al., 2003; Tebes et al., 2001). My findings demonstrate the significance that children place on their relationship with their parents and reinforce the need to support families experiencing mental illness.

While the children spent considerable time and energy in "finding the rhythm" and "maintaining the frame", many children perceived that their parents also contributed to the connections between parents and children. A critical finding of this study is that most children perceived their connections with their parents as positive reciprocal interactions. The connection with their parents was important to the children and foundational to their lives. Multiple factors such as the severity of mental illness, the lack of availability of supportive others, confusion

about what was happening, and the inability to see any resolution to their problems, could contribute to children feeling disconnected from their parents. For some children, although the connection to the parent was valued, it became too troublesome and difficult to sustain. This concurs with the literature that states cumulative factors place children at increased risk for difficulties (Garnezy, 1993; Werner, 1989). Most children, however, were able to maintain a connection with their parents, which they appeared to strongly value.

Identity

To begin, I will provide a brief overview of the key points of the symbolic interactionist perspective as it relates to childhood development and the findings of my study. The key contributions of the symbolic interactionists to the child development field are that children imitate significant others' values, attitudes and behaviours, adopt behaviours to get approval from social sources, and adopt the opinions that significant others hold of them (Harter, 1999). In my study findings, in order to manage their circumstances, the children tried to "find the rhythm and maintain the frame" with their parents. In doing so, they both sought approval and affirmation from their parents and a sense of who they were outside of their relationships with their parents. The appraisals that they received from their parents influenced how they saw themselves and their situations. As the family is the first reference group for developing perspective (Shibutani, 1955) much of this self-development occurs within the parent/child relationship. It is later modified by other reference groups as the child ventures into the world outside the family and multiple perspectives and social worlds may exist (Shibutani, 1955).

In the development of their identities, the children who received harsh negative appraisals, felt less hopeful about their circumstances, unless they encountered more positive interactions from other sources, often school, extracurricular activities, or peers. Positive interactions with supportive other adults or peers fostered positive identities. Symbolic interactionism recognizes that the construction of self occurs in multiple social contexts and that

the appraisals that one perceives, define one's sense of self as a person (Harter, 1999). In my study, the children who received positive self-appraisal from parents and outside sources appeared to develop a better sense of self. Children, who did not generally perceive appraisals as positive, i.e. within the school system and at home, struggled more to exhibit as positive a sense of self.

Cooley (1902) believed that children developed their sense of self through a very social process. This social process was integrated with affective reactions that arose in response to perceptions that others had of the child and influenced the child's sense of self (Cooley, 1902). Fitting in demonstrated that identity was affected by how children were accepted by their peers, i.e. whether they were bullied, able to keep up with their studies, and whether there were opportunities to excel in or enjoy activities.

As children developed a sense of self within their multiple social worlds, they were also dealing with the presentation of mental illnesses within their families. At times, the symptoms of mental illness made the parent seem like a different person to which the children had to respond. Mental illness changes the thinking, behaviour, and affect of the afflicted person (American Psychiatric Association, 2000; Elgin Holley, 1997; Hinshaw, 2004; Lyden, 1997). The children in my study described their parents, when they had an exacerbation of their illness, as not being themselves. This finding suggests that in the development of self, children had demands placed on them that required them to respond to the demands of multiple relationships within the context of their relationship with a parent. In other words, as the illnesses drastically changed the personalities of the parents, the children were challenged to respond to what some children called a different person. Children who live with parents with mental illnesses are challenged to adapt to diverse presentations of their parents. In a sense, while "finding the rhythm" and "maintaining the frame", they are navigating multiple relationships but with the same person,

their parent. In developing a sense of self, these children are facing multiple demands within their parent/child relationships, which may not always reinforce positive images of them.

Gergen (1991) suggested that the demands individuals now have on them in the postmodern era have the potential to erode an authentic sense of self. While Gergen (1991) has posited that marked advances in technology, with multiple modes of communication and access to information, have placed demands associated with multiple relationships on individuals; his ideas may offer some understanding to the demands on children living with parents with mental illnesses. For these children, demands from multiple relationships, due to diverse presentations of mental illness, may make it more difficult for children to develop a sense of self. Diverse presentations of the parent force the child to conform to the particular relationship at hand, as in the process of "monitoring" and "adjusting". The demands of diverse relationships have the potential to cause emotional distress for some individuals but, for others, may represent possibilities (Lifton, 1993). Children, living with parents with mental illnesses, may experience these feelings. The children are required to contend with increasing reference groups in the world outside of their homes, as well as the demands of multiple presentations of their parents with mental illnesses. When the children have to respond to the diverse unpredictable ways their parents are present, it may be more difficult to form an authentic sense of self. On the other hand, when the adaptations to the diverse presentations of their parents are successful, children may feel that their power is increased and become optimistic about their situations, and develop a stronger sense of themselves. Identity development is an ongoing process for children (Harter, 1999; Waterman, 1985) and the findings from this study not only represent the children's development of identity at the time of the study, but also the nature of that development.

The children in this study indicated that extracurricular activities provided opportunities for social interactions and diverse input to be incorporated into the construction of self. For the children who had more limited opportunities within their family homes, social interactions from

outside sources became increasingly important to develop a healthy sense of self. As children aged, they were exposed to more social contexts outside of the home. Some of the children had their exposure to outside sources enhanced by their parents' abilities to support their interests while other children were exposed to fewer social contexts, other than within their school and peer relationships. Younger children were more dependent on parents or extended families to provide opportunities outside the home for development of self-identity.

Maslow's theory of Self Actualization is based on deficiency motives that maintain physical and emotional homeostasis, and being motives that involve the need to understand and to grow. Parts of his theory relate to the experience of the children in this study. In "finding the rhythm" and "maintaining the frame", the children were driven to find physical and psychological security and safety, a sense of love and belonging and a need to develop their own identities paralleling Maslow's being motives for self respect and esteem (Maslow, 1968). While this study did not confirm a hierarchical flow of needs, the BSPPs appear to be driven by some of the deficiency and being motives described by Maslow and psychological safety and security appeared to be central to maintaining connections.

I have described the study findings from the perspective of the BSPPs, their relationship to the existing literature, and the unique contributions of this study to the existing knowledge on children living with a parent with a mental illness. I now turn to implications for nursing practice, education, research and health policy.

Implications for Nursing Practice, Education, Research and Health Policy

The findings from this study have implications for the areas of nursing practice, education and research as well as for health policy development. A discussion of these implications follows.

Implications for Nursing Practice

The findings from my theory have important implications for nursing, particularly psychiatric/mental health nursing within hospital and community settings, and public health nursing practice. The significant findings that affect nursing practice are the invisibility of children of parents with mental illness within the mental health system, the children's lack of knowledge about mental illness, strategies that children used to manage their circumstances, and the value that children placed on their relationship with their parents.

Invisibility of Children within the Psychiatric/Mental Health System

In the two years previous to the interviews with the children, 6 of the parents had been hospitalized, which represented multiple admissions and contacts with the mental health system. Only one child in the study identified coming into contact with a nurse. This may have occurred for several reasons. Children may not have visited their parents in the hospital, children may not have recognized the nurses, particularly as psychiatric/mental health nurses generally do not wear uniforms, or nurses may have had little interaction with the children. The organization of psychiatric/ mental health services may limit nurses' interaction with children (Bender, 2004; Hartley & Phelan, 2003; Mowbray et al., 2004; Nicholson et al., 2001).

Although children of parents with mental illness have been identified as at risk, they remain largely invisible within the mental health system (Garley et al., 1997; Handley et al., 2001; Hinshaw, 2004). Assessment data forms may not routinely solicit information on children of hospitalized patients or consistently refer to this data within the treatment plan. Nurses, as well as other health care professionals within the mental health care system, may not think of patients as parents and thus not solicit data on children (Mowbray et al., 2004; Nicholson et al., 2001; Riebschleger, 2004). Adult mental health professionals usually have minimal contact with family members and may view the patient as the only one requiring help (Blanch et al., 1994; Devlin & O'Brien, 1999; Handley et al., 2001). Nurses, however, must assess for factors in

children's lives that predispose the children living with a parent with mental illness to harm. My study suggested that these factors include: living in poverty with limited opportunities for respite from the illness, feeling alienated and not having trusted caregivers to confide in, particularly in acute exacerbations of the illness where children were unsure what was happening to their parents. These factors generally concur with previous work on risk and protective factors for children considered at risk for developmental problems (Anthony, 1974; Kauffman et al., 1979; Rutter, 1978; Werner & Smith, 1992). My study suggests that teenage boys in these circumstances had the most difficulty and also that nurses must consider that even children who appear to be managing well, must be directly asked about their experiences.

This invisibility of children within the mental health system is also complicated by the issues of stigma and fear (Hearle et al; 1999; Nicholson et al., 1998a; 1998b). Patients who are not regarded as parents may perceive stigma and negative attitudes from the mental health care system about them becoming parents (Nicholson & Biebel 2002). As such, they may be ashamed to disclose that they are parents and be concerned that their children will be removed from them (Nicholson et al., 2001). Thus, the parents may be hesitant to disclose information about their children. Given that qualitative studies of women with serious mental illness have consistently found they valued their role as parents and experienced child apprehension related to their mental illnesses, it is understandable why parents may be hesitant to disclose information on children. While children of parents with mental illness have long been considered at risk, missed opportunities within the psychiatric mental health system continue to occur (Nicholson & Biebel, 2002; Philips, 1983). Thus, these factors accumulate and nursing may not regularly intervene with the children of parents with mental illnesses. My findings suggest that nurses were largely invisible to children despite the number of hospitalizations of their parents and as such missed opportunities to intervene with children and with patients as parents. Nurses must increase their awareness of parents with mental illness and their children and how they are

managing their circumstances. Nurses may then play a key role in bridging services that are often fragmented and not in communication with each other.

Children's Perceptions of Lack of Information on Mental Illness

A persistent theme in this study was that the children did not know what was wrong with their parents and had little information about mental illness, despite their efforts to manage living with a parent with mental illness. Most children (other than one child) wanted more information and felt that this would help them to understand what was happening with their parent. It is important to consider how much information should be given to the child, what information would be helpful, and to respect the parents' wishes about information to be shared (Stallard et al., 2004). Many of the children stated that they knew something was wrong and that not having information made things worse for them. Recent studies have also reported that children have little information about mental illness and want additional information (Hinshaw, 2004; Stallard et al., 2004; Valiakalayil, et al., 2004). There are some psycho-educational and support programs that assist children living with a parent with a mental illness. Beginning research on these endeavours suggests that such interventions are helpful to children (Handley et al., 2001; Orel et al., 2003).

Based on the findings from my study and the supporting current research, practicing nurses can work towards a more proactive approach with children living with a parent with mental illness. Nurses need to consider that parents' hospitalizations present an opportunity to assist their children. Nicholson and Biebel (2002) suggested several strategies for general health care providers, which can be adapted to nursing practice. Nurses can examine their own assumptions about parenting with a mental illness to ensure that their attitudes do not create barriers for children, within the mental health care system. It is important that nurses ask questions about dependent children when in contact with patients suffering from mental illnesses. Similar to history taking with abuse issues, nurses will only get this information if they

ask the appropriate questions. Nurses will also need to follow up on issues with children and attempt to secure services for children beyond their basic survival needs. When children visit on the psychiatric wards, nurses can be proactive and speak with children to ensure that they are included in treatment, as needed, and also to share appropriate information with the children. Nurses can also educate the public and the health care system on mental illnesses, its treatment, prognosis, and effects on families and advocate for expanded services and system changes that will allow them to meet the needs of children and families. These efforts will assist children who suffer with parental mental illness by creating an environment of social support. Social support contributes to good mental health of the community in general and particularly for vulnerable populations (Willinsky & Pape, 2002).

Strategies that Children used to Manage their Situations

The strategies that children used to manage their experiences of living with parents with mental illness offer concepts useful for planning interventions services for children. Learning from children what they do while “trying to preserve themselves” within their parent/child relationships is important, as it provides a realistic array of strategies that could be available to children, depending on their circumstances. While older children may have more access to diverse strategies, younger children also described strategies, such as telling jokes, reading, going to their rooms, playing, that were helpful. The findings from this study can be used to develop age-appropriate strategies that may be helpful to children. The children felt that it would be important to share these strategies with other children. Nurses can incorporate some of these strategies into services that help children to manage their situations. Of note, the strategies that the children in Riebschleger’s (2004) study identified as helpful were similar to strategies that children identified in my study. While these strategies require further development, they provide nurses with a beginning understanding of the options that children find helpful to assist them in living with parents with mental illnesses. Difficulties with living my life, having to fly solo,

relying on getting away and opting out, are signs that children perceived themselves to be in risky situations.

Children's Perceptions of their Relationships with their Parents

A significant finding of my study is that most of the children perceived their parents as contributing positively to their lives. Parents' contributions are an important consideration in that nurses may also be vulnerable to the societal stigma against parenting with mental illness (Nicholson et al., 2001) and may not readily anticipate the children's perceptions. Moreover, they may actively discourage parents from discussing their efforts to parent their children or children from exploring their feelings about their parents. In a recent pilot study with adolescents living with a parent with schizophrenia, the children identified diverse aspects of their relationships with their parents as positive. This included feeling closer to the parents, developing tolerance towards disabilities, and feeling a stronger sense of self (Valiakalayil et al., 2004). Similar sentiments were expressed by some of the children in my study. Findings such as these are helpful for nurses to understand children's perceptions and to build on their positive attributions towards their parents while helping them put their parents' behaviours in context.

The significant findings from my study highlight practice areas for psychiatric/mental health nurses and public health nurses who have clients with mental illnesses. The findings suggest that nurses need to be aware of the invisibility of children living with a parent with a mental illness within the mental health system, to examine their own assumptions about parenting with a mental illness, to become proactive in intervening with these children, and to assist them to understand and manage their circumstances. Within these endeavors, nurses must ensure that children are safe in their homes by reporting abusive and unsafe circumstances, and developing accurate ways of determining children's safety while assisting them to maintain their connections with their parents.

Implications for Nursing Education

My study findings have implications for nursing education in that they suggest that educators have a responsibility to make visible the invisible children of parents with mental illness. Nursing curricula can educate students about this population and the issues that are associated with being a child living with a parent with a mental illness. As the child does not live in isolation, the issues related to parenting with a mental illness must also be incorporated into nursing education. Educators must incorporate research that includes children's voices and their unique perceptions. Educators can provide nurses with skills to communicate with and to assess children and parents in a sensitive manner. The population of children of parents with mental illness has long been identified as at risk, with few specific services to address these children's needs (Hearle et al., 1999; Mowbray et al., 2004; Nicholson et al., 2001; Stanley, Penhale, Riordan, Barbour, & Holden, 2003). Educators can incorporate this issue in curricula. They can emphasize skills for advocacy for more resources for children living with stigma and poverty and make changes within practice settings. Advanced practice nurses can be educated to specialize in children's issues related to growing up with a parent with a mental illness and to effect change in inter-professional agencies as services to these children may require inter-agency collaboration (Stanley et al.). As the number of parents with mental illnesses who are parenting, appears to be rising (Mowbray et al., 2000; Ostman & Hansson, 2002) it is likely that this area will take on increasing importance for nursing education.

Implications for Nursing Research

My findings have revealed a substantive theory that presents intriguing future questions for investigating children's perceptions. Children who participated in this study were mainly children of parents with mood disorders, some of whom were diagnosed with comorbid disorders of anxiety and personality disorders. It is critical to note that only one child whose parent had schizophrenia participated and that it was not possible to locate this family for a second

interview. There are several reasons why the number of parents with schizophrenia represented in the study is low. Schizophrenia has a lower prevalence rate than mood disorders within the general population. The nature of the illness (delusions, hallucinations, feelings of suspicion and paranoia) and the realistic fear that children may be apprehended may prevent parents from participating in a research study. People with schizophrenia also may not have their children living with them (Jacobsen & Miller, 1998; Nicholson et al., 2001). Nonetheless, future research efforts must include children living with parents with schizophrenia.

Future research is also needed to determine what children know about mental illness, where they receive their information, and the most appropriate times to discuss mental illness with them. Such information will help nurses identify how and when to best help children acquire the information they say they need in order to manage their parents' illnesses. Children identified sensing that something was wrong with their parents, but they were unable to explain how they knew this. Further investigations into this phenomenon may provide insights about how children incorporate information and make decisions about "adjusting" to their situations.

There is scant research on fathers who are parenting with a mental illness. Children's perceptions of living with a father with a mental illness are needed to understand this experience, throughout children's developmental stages. How is having a father with a mental illness perceived differently by children? In my study, three of the parents were fathers, two of whom were stable. One father was very ill and that situation accounted for the child who was least able to find a rhythm and maintain the frame in his relationship with his parent. A key area of research with children who live with parents with mental illness is to track what interventions are provided for them while their parents are hospitalized. Research could include chart reviews, which track how children are treated. Intervention studies using both qualitative and quantitative measures may determine how knowledge about mental illness assists children to manage their circumstances. Future research should also further explore the nature of children's positive

connections with their parents. What external factors do children perceive as leading to a positive connection with parents?

In sum, there are many unanswered questions regarding children's experiences that require future qualitative research. Qualitative and quantitative research is needed to inform meaningful services that can assist children.

Implications for Health Care Policy

Two major policy implications arise from the study's findings. Firstly, policies that govern the care of and services for parents with mental illnesses must acknowledge the potential needs of the children. Such policies would help children to become visible within the mental health care system; otherwise, they will continue to be underserved, despite being identified as at risk. The children's voices must be incorporated into the policies that influence services provided for them in order to ensure that their needs are met. Secondly, parents who suffer with mental illness need to be recognized within the health care system as parents. Most of the initial contacts for my study were made by the parents with the mental illnesses who were concerned about how their children were managing. Their concerns are supported in the literature on parents with mental illnesses (Mowbray et al., 2004; Nicholson et al, 2001). Often parental roles and the difficulties of parenting with a mental illness go unnoticed. Thus policies need to focus on families experiencing mental illness to provide children and parents with services based on their needs.

Such policies need to include proper assessment of children's needs and consideration of children's safety, while not stigmatizing children who live with a parent with a mental illness. The scope of practice for public health nurses and psychiatric/ mental health nurses working in the community now needs to address not only the needs of the mentally ill, but also the development of mental illness prevention strategies and the promotion of community mental health (Allender & Spradley, 2001; WHO, 2003). The principles of mental health promotion

call for health public policy inclusive of a reorientation of services to provide appropriate and timely services for mental health not only illness; capacity building efforts to strengthen individuals, families and communities, and efforts to foster social justice and social support while recognizing that not all factors, (i.e. socioeconomic status, access to resources, taxation structure), influencing mental health are within the control of the individual or family (Willinsky & Pape, 2002). To address the findings about “fitting in”, policy changes in the areas of healthy child development are important. Public policy that promotes mental health with complementary approaches such as fiscal and taxation policy, that incorporate advocacy, the development of healthy families, and empowerment interventions, which increase a sense of control over one’s life, increase people’s ability to meet life’s challenges (Willinsky & Pape). The issues that children and their families faced in attempting to “fit in” with societal expectations would be better managed with public policies which ensure adequate housing, respite and recreational opportunities to children and their families. These policies would assist families and children to be on a level economic playing field to sustain and enhance their well being.

The current trends in psychiatric services favour shorter hospitalizations and care in the community. Families are left with minimal resources as parents resume their parenting roles while recovering from mental illness. Children in these families are generally without formal resources to help them manage their situations. Recent literature suggests that parents are interested in helping their children, concerned about the effects of parental mental illness on their children’s development, and perceive few available resources to assist them and their children (Mowbray et al., 2004; Wang & Goldschmidt, 1994, 1996). The Canadian Standards of Psychiatric and Mental Health Nursing Practice (Buchanan, Harris, Greene, Newton & Austin, 1998) have emphasized community-based care, improved access to services and expanding views of the health care team to include partnership/collaborative relationships with professional and self help/advocacy groups (Buchanan et. al.). Ongoing work is needed to give nurses the

opportunity to effect change in the health care system for these children. Both psychiatric mental health nurses and public health nurses are well situated to take on a broader role with children living with mental illness of a family member. Nurses working with acute psychiatric illness may also consider expanding their practice to be more inclusive of children and families during illnesses.

Summary of Implications of Findings

The findings from this study have significant implications for nursing practice, education, research and policy development. It is imperative that children's needs be recognized and addressed within the mental health care system. Nurses can begin to address this by seeking out children who come in contact with the mental health system because of their parents. Nurses must also recognize that patients can also be parents and understand parents' reasons for hesitancy to disclose information on children. Nurses can be proactive in assisting children by interacting with them in acute and community settings, developing appropriate safety assessments and assisting children to understand and manage their experiences. Nurses must be educated to assist children and to advocate for resources for children. Nursing research endeavours can continue to explore children's perceptions on living with parents with mental illnesses and the specific issues that this study suggests. Policy must make these children more visible within the mental health system in order that their needs may be met.

Limitations of the Study

While the study has contributed significant findings, there are several limitations to the study that warrant discussion. The sample was gathered from a variety of sources, which included referral from professionals and self-referrals from word of mouth and advertisements. Those parents who self referred, reported their diagnoses and were taken at their word. Thus the diagnosis of all participants was not verified by a mental health professional. This limitation was tempered by the researcher's clinical experience with mental illness that allowed her to be aware

of any gross discrepancies between self-report of diagnosis and behaviours. Self-report diagnoses appeared to be accurate. However, some parents may have described their illness as depression versus psychotic episodes, because depression is more socially acceptable. I did not get the sense that this had happened judging from the parent's presentation at the time of the interviews.

The study sample was composed of children whose parents were concerned about how their children were managing while living with parental mental illness. This would suggest that these parents had some level of insight into their illness, that they valued their role as parents and that they were willing to let their children discuss their experiences. Thus this sample may represent children who have parents who are more able to be involved with their care and to be proactive for their children. Other children in the community may have parents who are unable or unwilling to participate in research and their situations may be different. For example, only one parent in the study had schizophrenia. The symptoms of schizophrenia, paranoia and avolition, hinder parents' participation in studies discussing their children's experiences.

While all children described subjective distress related to their circumstances, it is possible that they may not have fully disclosed painful experiences due to loyalty to their parents and/or fear of apprehension. Some children may have learned what was safe to reveal to adults outside of the family and shared only this part of their experiences. While this is an important consideration, it should not override what children shared about their experiences and what they considered important. Thirteen of the children who participated in the study were siblings. As such they represented five of the fourteen families. This may have limited the variation of experiences but allowed for in-depth understanding of family dynamics and the uniqueness of each child's experience within the family.

It was difficult to use theoretical sampling throughout the study due to the complicated nature of obtaining participants and their availability to participate in follow up interviews.

Despite these limitations, the study adhered to a rigorous analysis of the data which constructed the processes that children used to manage their experiences.

Summary

The implications chapter has demonstrated the contribution of my study to the literature about children living with parents with mental illness. Children had little contact with nurses, despite their parents coming into contact with the mental health care system where nurses practice. This suggests that while nursing is invisible to the children, the children are also invisible to the health care system, despite being identified as at risk. The chapter has illustrated important implications for nursing practice, education, research, and policy development that will enhance proactive practice with this population, begin to address these concerns, and move to a health promotion perspective.

Conclusions

This study has increased our understanding of the perceptions of children living with a parent with a mental illness. The study method was grounded theory, which was well suited to explore this phenomenon. Twenty-two children were interviewed once, with ten of the children re-interviewed. The children were between the ages of 6 to 16 years. The major conclusions from the study indicated that children spent considerable time and effort trying to “find the rhythm” with their parents and “maintaining the frame” of that relationship with them. In doing so, most of the children developed strategies that helped them remain connected to their parents and to develop their own identities. Not all children were able to do this.

The children valued their connections to their parents. Even so, most children experienced intense negative emotions associated with their experience. The children reported having little information on mental illness while trying to live with parental mental illness. They recognized the stigma that surrounds mental illness. Despite this, most children described feeling comfortable in their homes and wanting to be there. The study suggested that nurses are

not highly visible to this population despite being active in services for the children's parents. The study implications include the recommendation that nursing become proactive in practice, education, and research endeavours in order to help children in these circumstances. Policies that recognize the needs of children and that allow nurses to practice in a manner that will meet children's needs are required.

These findings emphasize the importance of the increasing recognition of the globally rising burden of mental illness, which has identified the need for mental health promotion efforts within the health care system (Allender & Spradley, 2001; WHO, 2001, 2003). While traditional mental health services have focused on the mentally ill, current thinking recognizes the importance of mental health promotion and prevention. Children of parents who have a mental illness will be well served if nursing can operationalize the principles of mental health promotion. Children of parents with mental illness may well be in a position that is akin to the position children of parents suffering from cancer were several years ago. At one time, there were few resources for these children, but now there are resources designed specifically to assist the children to manage the illness of their parents. Within the past three years there has been a plethora of books, pamphlets, web sites and chat lines to help children and families living with cancer. In addition, beside support groups for children, parallel parenting groups exist to more holistically manage the cancer experience (J. Taylor-Brown, personal communication, March 1, 2005). Similar to the current status of mental illness, cancer in the recent past was much less openly discussed with few resources available to children. The services now offered to children and families living with cancer may serve as guide to providing more holistic services to children and families living with mental illnesses. As nurses become more aware of children's needs in relation to parental mental illness, they are challenged to provide information, services, and support to children of parents with mental illness.

The children's perspectives are of key importance to nurses who may practice in a system of health care delivery that does not always allow them to consider a holistic perspective. The children's perceptions serve as a reminder to consider the whole person not just the illness. Their perceptions are important considerations in decisions made by health care professionals concerning their welfare and promoting their well being. As such, the study results will be disseminated at psychiatric nursing conferences and health care conferences addressing the issues raised within this study. The findings will also be published within nursing research journals; and made available to the parents and the children involved in the study. The children will receive a child friendly version of the findings geared to their developmental level. It becomes important to understand children's perceptions of their situations to plan effective services, to help children manage with the least amount of difficulty, and to assist children to preserve themselves in a healthy manner while maintaining the connections that they value with their parents.

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Appendix A

University Of British Columbia Ethical Approval



The University of British Columbia
Office of Research Services and Administration
Behavioural Research Ethics Board

Certificate of Approval

PRINCIPAL INVESTIGATOR Hall, W.A.	DEPARTMENT Nursing	NUMBER B02-0097
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT 		
CO-INVESTIGATORS: Mordoch, Elaine, Nursing		
SPONSORING AGENCIES Canadian Nurses Foundation		
TITLE Perceptions of Children Living with a Parent with Mental Illness		
APPROVAL RENEWED DATE MAR -1 2004	TERM (YEARS) 1	
CERTIFICATION: <p style="text-align: center;">The protocol describing the above-named project has been reviewed by the Committee and the experimental procedures were found to be acceptable on ethical grounds for research involving human subjects.</p> <p style="text-align: center;"><i>Approval of the Behavioural Research Ethics Board by one of the following:</i></p> <p style="text-align: center;">Dr. James Frankish, Chair, Dr. Cay Holbrook, Associate Chair, Dr. Susan Rowley, Associate Chair</p> <p style="text-align: center;">This Certificate of Approval is valid for the above term provided there is no change in the experimental procedures</p>		

Appendix B

University Of Manitoba Ethical Approval



**RESEARCH SERVICES &
PROGRAMS**
Office of the Vice-President (Research)

244 Engineering Bldg.
Winnipeg, MB R3T 5V6
Telephone: (204) 474-8418
Fax: (204) 261-0325
www.umanitoba.ca/research

RENEWAL APPROVAL

02 July 2004

TO: Elaine Mordoch
Principal Investigator

FROM: Stan Straw, Chair
Education/Nursing Research Ethics Board (ENREB)

Re: Protocol #E2001:079
"Perceptions of Children Living with a Parent with Mental Illness"

Please be advised that your above-referenced protocol has received approval for renewal by the **Education/Nursing Research Ethics Board**. This approval is valid for one year only.

Any significant changes of the protocol and/or informed consent form should be reported to the Human Ethics Secretariat in advance of implementation of such changes.

Please be advised that this is the final renewal allowed. Subsequently a full application must be submitted.

Appendix C

Information Sheet For Parents/Legal Guardians Of The Child

**Children Living With A Parent With Mental Illness
Information Sheet For Parents/Legal Guardians Of The Child**

Your child is invited to participate in a study titled **Perceptions of Children Living with a Parent with Mental Illness**. The aim of the study is to understand how children experience parental mental illness in order that children and their families can be helped to manage this experience. Children within the ages of six and sixteen years are invited to take part in the study. For the purposes of the study, mental illness is defined as depression, bipolar disorder, and schizophrenia.

The study is undertaken as part of my graduate work within the Ph.D. nursing program of the University of British Columbia and is under the direction of Dr. Wendy Hall, Associate Professor, School of Nursing, University of British Columbia. I have been both a nurse and a nurse educator in the field of mental health nursing since 1987 and been active on community boards working to obtain services for those suffering with mental illness.

If you would like your child to participate in the study and your child also wishes to participate, your child will be interviewed in a location, which is acceptable to both you and your child. You will be asked to sign a consent form for your child's participation and your child will have the opportunity to sign an assent form if your child wishes to be in the study. An assent form provides the child with the opportunity to voluntarily agree or disagree to be in the study. At any time in the study, should your child choose, he/she may withdraw from the study or not answer specific questions in the study. Your child may tell the researcher or yourself that he/she does not wish to continue. The child's wishes will be respected. The interview will focus on questions about your child's day-to-day life in your family. During the interview, your child may be asked to draw and write a response to a story that the researcher may tell them. This technique is recognized as helpful in interviewing children. The length of the interview may depend on the age of the child. It is anticipated that most interviews will take from ½ hour to 1 ½ hours. The interviews will be tape-recorded. Your child may be asked to participate in a second interview. The reason for this will be it may take some time for the child to know me and/or there may be information that I will need to be sure I understand correctly. Your child may choose not to participate in the second interview.

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Prior to the interview, both you and your child will be asked a series of short questions on the size and structure of your family. You may see a copy of these questions prior to granting consent. I will also be making observations of family life before the interview and may make notes on these observations. You may see the guideline for observations prior to signing the consent form. Only the researcher will have access to your name and the name of your child.

During the study, the original interview data and information sheets will be kept in a locked drawer to which only the researcher will have access. Upon completion of the study, the data will be stored in a locked cabinet for a period of seven years, after which it will be destroyed in a confidential manner. Data that is kept on the computer will be accessible only by password and removed from the hard drive of the computer at the end of the study. At the end of the study, you may request a copy of the group findings. You will not have access to your child's personal data.

The decision to participate in the study is voluntary for both you and your child. If you or your child do not agree to participate, it will in no way interfere with the care either you or your child currently receive. The study will provide children an opportunity to discuss their perceptions. A potential risk of involvement in the study is that some children may become emotionally upset. If a child is seriously distressed (overwhelmed with excessive sadness or anger, threatens to harm self or others), the researcher will stop the interview and attempt to find appropriate resources for the child. Findings from this study have the potential to improve services for children and their families. As a way of thanking your child for participating in the study, your child will receive a movie pass for two. If the child is unable to complete the interview, the child will still receive the movie pass.

All information obtained will be for the purpose of my graduate work. The results may be published in variety of places. Neither your identity nor the identity of your child will be revealed at any time. No personally identifiable information will be included in any presentations or publications. A summary of the results of the study based on group findings, not individual child reports, will be provided upon request.

If you have any further questions, I may be reached at xxx - xxxx). Please do not hesitate to call with any questions. Also Dr. Wendy Hall, (Ph.D. chair), Associate Professor, School of Nursing, University of British Columbia can be reached at xxx – xxx -xxxx and Dr. Wanda Chernomas, (PhD committee member) Associate Dean, Faculty of Nursing, University of Manitoba, can be reached at xxx – xxxx.

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Thank you for your consideration of this request. Please note if you have any concerns about your rights or treatment as a research subject, for either yourself or your child, you may contact the Director of the Office of Research Services, University of British Columbia, telephone (xxx – xxx -xxxx). Concerns regarding either your or your child's rights and treatment as a research subject may be also be directed to the University of Manitoba Human Ethics Secretariat at xxx – xxxx.

Kindest regards,

Elaine Mordoch RN PhD (c)

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Appendix D

Parental Informed Consent For Child To Participate In The Study

**CHILDREN LIVING WITH A PARENT WITH MENTAL ILLNESS
PARENTAL INFORMED CONSENT FOR CHILD TO PARTICIPATE IN THE STUDY**

I,-----, allow my child,-----, to participate in the study entitled “ Perceptions of Children Living with a Parent with Mental Illness”. The study is conducted by Elaine Mordoch, RN, Ph.D (c), student in the University of British Columbia, School of Nursing. The study examines how children (ages 6 – 16 years) experience day to day family living with a parent who has a mental illness. I understand that my child will have the opportunity to assent to participate in the study. Assent implies that my child voluntarily agrees to participate in the study, understands that he/she has the right to not answer questions and to withdraw from the study at any time without consequences. My child may withdraw from the study by telling myself or Elaine that he/she does not wish to continue. The child’s wishes will be respected. I understand that Elaine Mordoch will interview my child for approximately 1/2 to 1½ half hours. Elaine will ask the child basic questions about family life. The questions will focus on how the child perceives the family life, feelings related to the experience, and what the child finds both helpful and unhelpful in managing these circumstances. All the questions will be asked in a gentle and sensitive manner. Elaine may ask my child to draw and write a response and to respond to a story she may tell them.

The interview will be audio taped and the recorded information will be transcribed at a later date. Generally, children will be interviewed only once. If Elaine needs to clarify information, she may ask the child to participate in a second interview. The child may choose to decline the second interview. The information will be analyzed along with the interviews of other children in similar circumstances. Elaine will also engage in some observations of family life at the time of the interview and may write some notes after she leaves to remind her of what she has seen. I may see the observation guideline prior to consenting to the study. When the project is written up, the information will be grouped in such a manner that no one will be able to identify either my child or myself. Elaine will also ask me some basic questions prior to the interview with my child. My child will also be asked some basic questions prior to the interview. Both my child and I may see these questions prior to signing the consent and assent forms.

Participant’s Initials _____

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Continuation of Informed Consent

Children Living with a Parent with Mental Illness

identifying information. Neither my name nor my child's name will be used in the transcribing of the data or in any future discussions or publications of the study. Number will identify interview data only. I understand that the information obtained will be kept strictly confidential. The only exceptions to this confidentiality are that the researcher is required by law to report any incidents of child abuse. I understand that Elaine's teachers may have access to the data without any identifying names on the data. A transcriber, who has taken an oath of confidentiality, may listen to the original tapes. I understand that I and my child may receive a summary of the results of the study upon request but that I will not have access to my child's interview data.

I understand that this study is not expected to have any direct benefits to my child or myself, however, the study will provide an opportunity for children to discuss their perceptions and validate their experience. The risk that could be involved is that some children may become upset when discussing their experience. If my child is seriously distressed (overwhelmed with excessive sadness or anger, threatens to harm self or others) during the interview process, the researcher will stop the interview and attempt to secure appropriate resources.

I understand that participation in the study is voluntary and that I can withdraw my child from the study at any time. I understand that my child has the right to withdraw from the study at any time. My child has the right to refuse to answer any questions he/she chooses to omit without prejudice or consequence. I understand that if I refuse to participate in the study neither the health care of myself nor my child will be affected. The results of the study will hopefully assist health care providers to better understand the children's experiences and to improve care for both them and their families. I understand that my child will be offered a movie pass for two as a token of appreciation for participation in the study. In the event that the child wants to withdraw from the study prior to completion, I understand that the movie pass for two will still be offered to my child.

If I have any questions about the study, I may call the researcher, Elaine Mordoch at xxx – xxxx or the researcher's dissertation chair Dr. Wendy Hall, Associate Professor, School of Nursing, University of British Columbia at xxx – xxx – xxxx. Dr. Wanda Chernomas, Associate Dean, Faculty of Nursing, University of Manitoba, may be reached at xxx – xxx – xxxx. If at any time during this research project, I have any concerns about the rights or treatment of myself or my child, I may contact the Director of the Office of Research Services, University of British Columbia at xxx – xxx – xxxx. I may also contact the University of Manitoba Human Ethics Secretariat at xxx – xxxx. Please note your personal health information will be treated as confidential in accordance with the Personal Health Information Act of Manitoba.

Participant's Initials _____

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Continuation of Informed Consent
Children Living with a Parent with Mental Illness

I consent/ I do not consent to my child's participation in this study.
I have received a copy of the consent form and the information sheet for my personal records.

Parent's Signature..... (mother)

Parent's Signature(father)

Legal Guardian.....

Researcher's Signature

Date

Appendix E

Information Sheet For School Age Children 6-12 Years

CHILDREN LIVING WITH A PARENT WITH MENTAL ILLNESS**INFORMATION SHEET FOR SCHOOL AGE CHILDREN AGES 6 – 12 YEARS**

Hello, my name is Elaine Mordoch and I am a nurse. I am going to school at the University of British Columbia. For my school, I am working on a project to learn what it is like for children in families like your family. I would like you to tell me what it is like for you in your family.

I would like to visit with you for about ½ hour to 1½ hours. I may ask you to draw pictures and listen to a story when we talk. I may ask to visit you again. I will also make some notes on how you and your family act and look before and after we talk. I will tape record our talk. I will only come to talk to you if you want me to come. If you want to stop our talk or do not want to answer questions, you may tell your parent or me and we will stop talking. If you do not want me to come back to talk to you, you may tell your parent or me. I am hoping that what you and other children tell me will help children who live in families like yours. If you like, you may have your parent with you in the interview. I would like to thank you for helping me with this project. I would like to give you a movie pass for two people. If for some reason you do not finish the talk with me, you will still get the movie pass.

If you have any questions that you would like to ask me about this study, you may phone me at xxx - xxxx. Also my teacher, Dr. Wanda Chernomas can answer questions. You may reach her at xxx - xxxx.

Thank you for thinking about this study.

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Appendix F

Information Sheet For Adolescent Children 13-16 Years

Information Sheet for Adolescent Children 13 – 16 Years

Hello, my name is Elaine Mordoch and I am both a nurse and a student. I am studying at the University of British Columbia, Graduate studies. I would like to learn what it is like to live in a family such as yours. I am interviewing children and adolescents from 6 years to 16 years of age about their experiences within their families.

I would like you to tell me what this experience is like for you as a teenager. The interview will take approximately ½ to 1½ hours and will be audio taped. In the interview, you may be asked to draw and write, listen to a short story and to answer questions. If you chose not to participate in any of these activities, you may tell either myself or your parent. Your wishes will be respected. You may be asked to take part in a second interview. The second interview is voluntary and you may chose if you would like to participate. If you chose not to participate, please tell either your parent or myself. Your parent may be with you in the interviews if you would like your parent to be there. Before and after the interview, I will be observing you and will make notes on my observations. I will be noting my general impressions of how you look and act, and of the environment. You may see the observation guide prior to deciding if you would like to be in the study.

The information that you share with me is confidential. Your name or your family's name will not appear on any written information. Any information that is published or presented will not include any names or personal information that can be identified. Elaine and her teachers are the only people who may read Elaine's notes or the transcribed tapes.

You are invited to be in the study. Your participation is voluntary, you may choose not to answer questions and you may quit the study at any time. You may stop the interview at any time by telling me you do not want to continue or telling your parent that you do not want to be involved. The information that you and other children and adolescents share will help others who live in families like yours. If you have any questions about the study, you may phone me at xxx-xxxx or my teacher Dr. Wanda Chernomas at xxx-xxxx. As a way of saying thank you for helping me with this study, I would like to give you a movie pass for two. If you do not finish the interview, you will still receive the movie pass. Thank you for taking time to read about this study

Appendix G

Interview Questions For School Aged Children 6-12 Years

Children Living With A Parent With A Mental Illness

Interview Questions for School Aged Children 6 –12 Years

Verbally discuss confidentiality limits as per assent prior to interview.

I would like to learn about what it is like for children to live in families like your family. I will ask you some questions. If you don't understand the question, please tell me and I will explain it. Is that okay with you? Do you want to ask me anything before we start? Okay, we will start now.

1. What is it like to live at your house?

Probes: Tell me about your home.
 What is it like for you?

2. What do you do every day?

Probes: What do you do when you get up in the morning?
 After school?
 On the weekends? Saturday morning?

3. How does your family celebrate holidays, special events?

Probes: When do you have a party?
 Birthdays?
 Whose birthdays do you celebrate?
 What other holidays?
 Christmas? Hanukkah? Other?

4. Do you have special food for parties and holidays?

Probes: Who makes that food?

 Tell me what you have.

 What is your favourite holiday food?

 How is that different from every day food?

5. How do you feel about what you are doing?

Probes: Helping at home?
 What is the part of the day you like best?
 What makes you feel happy?
 What makes you feel sad?
 What other feelings do you have?

6. What things do you like about your family?

Probes: What do you think is the best thing about your family?
 How do you have fun with your family?
 What makes you feel good (happy) with your family?

7. What things don't you like about your family?

Probes: Sometimes there are things we don't like about our family...
 What is hard for you in your family?
 What would you like to change?

8. Do you think your family is different from other families in any way?

Probes: In what way?
 Is there anything you can think of?
 What do you think about that?

9. How are things different when your mom/dad is ill ? has to go to the hospital or the crisis stabilization unit (special unit) ?

Probes: How do you feel ?
 What do you do?
 Does anyone help you?
 How do they help?
 What is unhelpful to you?

10. What would you like to tell other children whose family is like yours?

Probes: What do they need to know?
 What would help them?

11. Is there anything else that you would like to tell me about your family?

Anything else you want to say?

Thank you for telling me what it is like for you. I would like to give you a movie pass for two people as a way of thanking you for helping me.

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Apr. 11/02 (University of British Columbia)

Appendix H

Interview Questions For Adolescent Children 13-16 Years

Children Living With A Parent With A Mental Illness

Interview Questions For Adolescent Children 13-16 Years

Verbally discuss confidentiality as per assent - prior to interview.

I would like to learn about what it is like for teenagers to live in families like yours.

I would like to talk to you about your experiences in your family. To begin, I will ask you some questions. If you do not understand the question, just let me know and I will explain it. Do you have any questions before we start? Okay, let's begin now.

1. Could you please tell me what it is like to live at your house?

Probes: Tell me about your home and what it is like.

What is it like for you?

2. Please describe what you do everyday.

Probes: Home? School? Work? Friends?

How do you spend the weekend?

What chores are your responsibility?

3. How does your family celebrate holidays?

Probes: What holidays do you celebrate...birthday? Thanksgiving? Other

What do you do?

Take pictures? Presents? Guests

Traditions?

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4. What food do you have on special occasions?

Probes: What is your favourite holiday food?

Who makes that food?

How is that different from everyday meals?

5. How do you feel about what you are doing?Probes: **Happy? Pleased? Contented?**

Stressed? Frustrated?

How do you express these emotions?

Would you like to change anything?

6. Do you think that your family is different in some way from other families?

Probes: In what way?

Tell me about that.

How does that make you feel?

Does that bother you?

How do you manage that?

Who helps you with that?

What is the most difficult thing about this situation?

7. What things do you like about your family?

Probes: What do you think makes your family a strong family?

How do you have fun together?

What makes you feel good about your family?

8. What don't you like about your family?

Probes: Everyone usually has something they do not like about their family....

What would you like to change about your family?

How does that affect you?

How do you manage that?

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9. What is different when your mom/dad is ill? Has to go to the hospital or Crisis Stabilization Unit?

Probes: What do you do when that happens?
 How do you feel when your mom/dad is there?
 How do you help your family?
 Who helps you at that time?
 What is unhelpful for you at that time?

10. What would you like to tell other children and teens who live in families like yours?

Probes: What do you think they should know ?
 What would help them?

11. Is there anything else you would like to tell me regarding this experience?

Anything that you can think of and want to share?

Thank you very much for helping me with this study.

I would like to offer you a movie pass for two people as a way of thanking you for assisting me with this study.

Version: Nov. 27/01 (University of Manitoba)

Apr. 11/02 (University of British Columbia)

Appendix I

Assent Form For Children Aged 6-12 Years

Children Living With A Parent With A Mental Illness

Assent Form For Children Aged 6-12 Years

I,, agree (want) to take part in this project. The project is about what children think about their family life. Elaine Mordoch is a nurse and goes to school at the University of British Columbia. She will ask me questions about my family. Elaine may ask me to draw some pictures and listen to a story when she talks to me. She will talk to me for approximately ½ to 1 ½ hours and will audio tape our talk. She may ask to talk to me a second time. I can say no to Elaine if I do not want to talk to her the second time. If I want to stop the talk that Elaine and I are having, I can tell Elaine or my parent that I want to stop. I do not have to answer any questions that I do not want to answer. If I want my parent to be with me while I talk to Elaine, I may have my parent with me. Elaine will also write notes about what she sees before and after our talk. The notes will be about things she notices about me, my family and the place where we talk. I may see the guide Elaine will use to write notes about things she notices.

When this project is over, no one will know that my family and I have been in the project. My name or my family's name will not be on any of the information. No one other than Elaine and her teachers may listen to the audiotapes or read the notes that Elaine may make. When Elaine writes about this project she will not mention my name or my family's name. Elaine will offer me a movie pass for two as a way of thanking me for being in the study. I can quit the interview at any time. If I quit the interview, I will still get the movie pass. Elaine will keep all our talk confidential. This means she will not tell people my name or that I said something. My mommy/daddy (dad/ mom) and my family will continue to receive care when they need it. Elaine is required by the law to report if someone was hurting me or if she was worried about my safety. She would share that information in order to get someone to help me.

If I have any questions, I may call Elaine at xxx-xxxx or her teacher, Dr. Wendy Hall. Dr. Hall is Elaine's supervisor. If I would like to call someone in Manitoba, I can call Dr. Wanda Chernomas at xxx-xxxx. If I do not like the way I am treated in the project, I

Participant's Initials _____

Children Living with a Parent with Mental Illness

can call the Director of the UBC office of Research Services and Administration at xxx-xxx-xxxx. If I do not like the way I am treated in the project, I can also call the Human Ethics Secretariat, University of Manitoba, at xxx-xxxx.

I understand that this is an assent form. Assent means that I agree/want to be in the project. The project is voluntary. This means that I will join the project only if I want to join it. I understand that I may quit the project at any time and that my parent's signature is also needed to allow me to be in the project. I understand this information and that I can ask questions at any time.

I assent / do not assent to be in the project. I have received an information sheet and a copy of this assent form.

Child's Signature -----

Parent's or Legal Guardian's Signature -----Date-----

Researcher's Signature ----- Date.....

Version: **Jan. 30/02 (University of Manitoba)**
 Apr. 11/02 (University of British Columbia)

Appendix J

Assent Form For Adolescent Children Aged 13-16 Years

CHILDREN LIVING WITH A PARENT WITH MENTAL ILLNESS

ASSENT FORM FOR ADOLESCENT CHILDREN 13 – 16 YEARS

I,-----, agree to participate in the study conducted by Elaine Mordoch, Graduate Studies, School of Nursing, University of British Columbia. The purpose of the study is to help health care professionals understand children's and adolescents' experiences in their family home. This information may also help other children and adolescents. Elaine would like to talk to me about my family and my life at home. She will ask me questions for approximately ½ hour to 1½ hours and will audio tape the interview. Elaine may ask me to participate in a second interview. I may say no to the second interview if I chose. I may be asked to draw and write in response to questions and listen to a story and comment upon it. Elaine will make notes on what she observes before and after the interview. She will observe how I look and act and the environment where we talk. I may see the observation guide she will use before I decide to be in the study.

I can quit the study at any time and I may choose not to answer certain questions. I can tell Elaine or my parent that I do not want to continue. Elaine will respect my wishes. My participation in the study is voluntary. I may choose to have my parent with me at the time of the interview. Elaine will offer me a movie pass for two people as a way of thanking me for being in the study. If I chose to withdraw from the study before it is over, Elaine will still offer me the movie pass. My participating or not participating in the study will affect no future care for my family or myself. All the information in the tape-recorded interviews is confidential. Only Elaine and her teachers may listen to the tapes and read Elaine's notes. My name and my family's name will not be on any of the interviews. No one will be able to identify what I say or who I am. If Elaine writes an article or presents a talk about this study, no names or personal information will be included. Elaine is required by law to report any incidents of child abuse to the proper authorities. She would do this to help me.

I may call Elaine at xxx - xxxx if I have any questions or concerns. I also may call one of Elaine's teachers if I have questions or concerns. In British Columbia, Dr. Wendy Hall,

Participant's Initials _____

Children Living with a Parent with Mental Illness

Associate Professor, School of Nursing, University of British Columbia is Elaine's supervisor. In Manitoba, Dr. Wanda Chernomas, Associate Dean, Faculty of Nursing, University of Manitoba, can be reached at xxx-xxx-xxxx. If I have any concerns about how I am treated in the study, I may call the Director of the UBC Office of Research Services and Administration at xxx-xxx-xxxx. I may also call the Human Ethics Secretariat of the University of Manitoba at xxx-xxxx.

I understand this information and that the study is voluntary. I am aware that I may withdraw at any time and that I may choose not to answer questions without any consequences. I also understand that all information will be kept confidential and that the results of the study are presented as group results. The information will be stored in a locked cabinet and my name will not appear on any documentation. The interviews will be coded. Also I may request a copy of the study results.

I understand that this is an assent form. Assent means that I agree to be in the study and understand the details in this form. I can ask questions about this form if I do not understand all of it and Elaine will answer them. My signature below indicates I want to be in the study. I understand what has been presented to me. I understand that my parent/legal guardian's signature is required.

I (assent) (do not assent) to be in this study. I have received a copy of this assent form and the information sheet.

Adolescent Child's Signature -----

Parent's or Legal Guardian's Signature -----

Researcher's Signature ----- Date-----

Version: Jan.30/02 (University of Manitoba)

Apr. 11/02 (University of British Columbia)

Appendix K
Participant Observation Guide

Children Living With A Parent With Mental Illness Participant Observation Guidelines

The following guidelines will be used to direct the researcher's observations pre and post interview sessions. The researcher will write notes on these observations.

Initial Impressions

Appearance of Child/Adolescent:

Physical descriptors

Clothing

Affect: outward expression of mood, happy, tired, sad etc.

Behaviour of Child/Adolescent

Actions of child pre and post interview

Voice: tone, volume, rate of speech

Interaction with Parent

Nature of interaction: details of interaction

Style of interaction: cooperative, defiant, humorous, caring, etc.

Environment

Interview location

Descriptors of the location: noise, appearance, space

Other people present

Interaction with Interviewer

Open, guarded, cautious, talkative, friendly etc.

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Appendix L

Parental Consent Form For Participant Observation

1/2

Children Living With A Parent With A Mental Illness

Parental Consent Form For Participant Observation

I,....., consent to participate in the study, Perceptions of Children Living with a Parent with a Mental Illness. This study is for a doctoral thesis. The study will help nurses understand how children perceive living with a parent with a mental illness in order to assist children and families to manage this experience. The researcher will interview children and make observations of family life pre and post interview. The faculty advisor is Dr. Wendy Hall, Associate Professor, School of Nursing , University of British Columbia. She can be contacted at xxx-xxx -xxxx. In Manitoba, I may contact Dr. Wanda Chernomas, Associate Dean, Faculty of Nursing at xxx-xxxx. I agree to allow the researcher to observe me before and after my child's interview (s) and document these observations in field notes. If my child would like me to be present in the interview, I am aware that the researcher will observe my behaviour in the interview. The interview will last from ½ to 1 1/2 hours. Some children may be interviewed twice. I am aware that I may see the Participant Observation Guideline before agreeing to participate in the study. It is anticipated that the pre and post interview observation time and completion of the forms, will take approximately 45 minutes in total.

I agree to answer questions on the size and structure of my family. The questionnaire will take approximately 15 minutes to complete. I am aware that I may see the questions the researcher will ask me prior to agreeing to be in the study. If I have any questions, about the Participant Observation Guideline and/or the family questions, I am aware that I may ask the researcher for clarification. I am also aware that I may choose not to answer specific questions. I may withdraw from this study at any time without penalty to my family's or my personal future care.

Participant's Initials _____

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Children Living with a Parent with Mental Illness

If I have concerns about my rights or treatment as a research subject, I may contact the Director at the University of British Columbia Office of Research Services at xxx-xxx-xxxx. I may also contact the University of Manitoba Human Ethics Secretariat at xxx-xxxx.

I consent/ I do not consent to participation in the study.

I have received a copy of this consent form and the study information sheet for my personal records.

Parent's Signature

Legal Guardian.....

Researcher's Signature.....Date.....

Appendix M

Family Member’s Consent Form For Participant Observation

Children Living With A Parent With A Mental Illness

Family Member's Consent Form For Participant Observation

I,....., consent to participate in the study, Perceptions of Children Living with a Parent with a Mental Illness. This study is for a doctoral thesis. The study will help nurses understand how children perceive living with a parent with a mental illness in order to assist children and families to manage this experience. The researcher will interview children and make observations of family life pre and post interview. The faculty advisor is Dr. Wendy Hall, Associate Professor, School of Nursing, University of British Columbia. She can be contacted at xxx-xxx-xxxx. In Manitoba, I may contact Dr. Wanda Chernomas, Associate Dean, Faculty of Nursing at xxx-xxxx. I agree to allow the researcher to observe me before and after my family member's interview (s) and document these observations in field notes. I am aware that I may see the Participant Observation Guideline before agreeing to participate in the study. It is anticipated that the pre and post interview observation time, will take approximately 45 minutes in total.

If I have any questions, about the Participant Observation Guideline and/or the family questions, I am aware that I may ask the researcher for clarification. I may withdraw from this study at any time without penalty to my family's or my personal future care.

If I have concerns about my rights or treatment as a research subject, I may contact the Director at the University of British Columbia Office of Research Services at xxx-xxx-xxxx. I may also contact the University of Manitoba Human Ethics Secretariat at xxx-xxxx.

I consent/ I do not consent to participation in the study.

I have received a copy of this consent form and the study information sheet for my personal records.

Parent's Signature

Legal Guardian.....

Researcher's Signature.....Date.....

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Appendix N
Confidentiality Waiver For Transcriber

Children Living With A Parent With A Mental Illness

Confidentiality Waiver For Transcriber

I understand that the tapes given to me to transcribe are data from a research project and that according to ethical principles of the research process, I am bound to uphold the confidentiality of the research process. This means that I will keep confidential all matters pertaining to the identity of the subjects involved in the project. I will discuss the research project only with the researcher and keep confidential all matters associated with this process.

During the course of the transcription of the interview tapes, I will refer to the participants and any other individuals mentioned by initial only in order to maintain confidentiality. I understand that participants' names are not to appear on any transcribed data.

Transcriber.....

Witnessed by Researcher.....

Date.....

Appendix O

Poster



Perceptions of Children Living with a Parent with a Mental Illness

Funded by the Canadian Nursing Foundation and the

Institute of Urban Studies, Center of Excellence for Child and Youth Centered Prairie

Communities

My name is Elaine Mordoch and I am a nurse studying in the Doctoral program, Department of Nursing, University of British Columbia. I am interested in children who live with a parent with schizophrenia, depression or bipolar illness. I would like to interview children/adolescents about their experience, to understand what is helpful and what is unhelpful to them. The interviews will be audio taped and are expected to take from ½ to 1 ½ hours. Some children may be asked to participate in a second interview. Both parent and child will be asked to complete a short questionnaire, which will take 10 minutes. I would also like to observe you and your child before and after the interview. This study will help nurses in hospitals and communities promote the well being of children and their families who live with mental illness. Children will receive movie passes for their time and efforts.

To be in the study, the child/adolescent must:

Be between 6-16 years of age

Speak English

Voluntarily agree (assent) to be in the study

Have the consent of the parent/legal guardian to participate

Live either full or part time with their parent who has a mental illness

The parent with the mental illness must

Have been diagnosed with schizophrenia, depression, or bipolar illness

Receive ongoing treatment/support from the health care system

If you would like further information, please contact Elaine Mordoch, RN Ph D (c) at xxx-xxxx where you may leave a confidential message. Thank you for considering this study.



Appendix P

Letter Requesting Access As A Nurse Researcher To Study Setting

Children Living With A Parent With A Mental Illness

Letter Requesting Access As A Nurse Researcher To Study Setting

My name is Elaine Mordoch and I am a nurse engaged in Ph. D studies with the University of British Columbia, School of Nursing. My dissertation work is entitled **Perceptions of Children Living with a Parent with Mental Illness**. I have worked in the mental health field as a nurse and nurse educator since 1987. My interest in the study topic arose from my nursing experiences in the emergency room and psychiatric wards of hospitals. This experience will assist me to be sensitive to issues associated with mental illness. Within the research process, I will be respectful of children at all times. Every effort will be made to ensure that the research process does not create disharmony within the family unit. I am writing to request your assistance in the recruitment of the sample for this study.

The aim of the study is to understand and describe the subjective experience of children who are living with a parent who has a mental illness. For the purposes of the study, the child will be living (either full or part time) with a parent who has a diagnosed DSM IV mental illness of schizophrenia, depression or bipolar illness. It is hoped that the study will provide insight into the unique needs and experiences of children and inform future interventions to assist children and families in managing their circumstances.

The population of interest is children from the ages of six years to sixteen years who live with a parent with mental illness either on a full time or part time basis. I am hoping to obtain a sample of 30 children. Both the consent of the parent who is the legal guardian of the child, and assent of the child will be sought. Either the well parent or the parent with the mental illness may be the legal guardian. If the parent with the mental illness is the legal guardian, consent will be sought only if the parent is competent. Only children whose parent consents to the study will be interviewed. In the situation, wherein both parents live with the child, the researcher will attempt to ensure that both parents are agreeable to their child's participation in the study. If both parents are not in agreement, the researcher will not recruit that child. This strategy will be used to prevent any untoward possible future distress to the child as a result of participating in the study.

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Within the assent process, care will be taken to ensure that age appropriate language is used to describe the study and to uphold the rights of the child. Every effort will be made to ensure that the child understands he/she may withdraw from the study at any time, may refuse to answer any question in the study, and that neither the care of themselves nor their parents will be compromised as a result of these actions.

The study is a qualitative study using the grounded theory method. As such the main strategies of gathering data will be from interview and participant observation. Children may also be asked to draw and write in response to a question and story. Before and following the interviews opportunities will be taken to observe family dynamics and the child's environment. Field notes will be written about these observations. The researcher will request permission to interview the child in a location that is agreeable to both the parent and the child. The interviews will be audio-taped and follow a semi structured interview guide. Younger children may be asked to draw their responses to facilitate discussion of the interview questions. Some children may be interviewed more than once. The child may choose to refuse the second interview. It is anticipated that younger children may require familiarization with the researcher prior to the discussion of sensitive subjects. The interview will likely take between ½ hour to 1 ½ hours. All data will be stored in a confidential manner and dissemination of the data will also uphold the child's and family's confidentiality.

If you require further clarification, I can be reached at xxx-xxxx. Dr. Wendy Hall, (Ph D Committee Chair) Associate Professor, School of Nursing, University of British Columbia, can be contacted at xxx-xxx-xxxx. Dr. Wanda Chernomas, Associate Dean, Faculty of Nursing, University of Manitoba, (member of my dissertation committee), can be reached at xxx-xxx-xxxx. Participants may contact the Director of the UBC Office of Research Services and Administration at telephone number xxx-xxx-xxxx, if they have concerns about their rights or treatment as research subjects. Any concerns regarding rights and treatment as research subjects may also be forwarded to the Human Ethics Secretariat, University of Manitoba, at xxx-xxxx.

Thank you for your consideration of this request. I look forward to your reply.

Kindest Regards,

Elaine Mordoch, RN, PhD (c)

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Appendix Q

Script For Intermediary To Introduce The Study

Script For Intermediary To Introduce The Study: Children Living With A Parent With A Mental Illness

Hello,

I have been asked to introduce the study: Perceptions of Children Living with a Parent with Mental Illness. The researcher, Elaine Mordoch, is a nurse who is a student at the University of British Columbia, in the PhD nursing program. She is interested in knowing how children between the ages of 6 and 16 years perceive the experience of living with a parent with a mental illness of depression, bipolar disorder or schizophrenia. She would like to interview children in these circumstances. The child may live full or part time with the parent with the mental illness.

The study consists of interviews with the children and participant observation. Generally, one interview will be conducted with the possibility of a second interview. In the interview, the child may be asked to draw and write in response to a question or to comment on a story told by the researcher. The researcher will also observe you and your child prior to and after the interview and will make notes on her observations. Prior to consenting for your child to be in the study, you are welcome to see the interview questions and the observation guide and clarify any concerns you may have.

The researcher will ask parents/ legal guardians for informed consent to allow their child to participate. The parent who will consent to the child's participation in the study will be the legal guardian of the child. This could be the parent with the mental illness, the well parent or a designated other. If the parent with the mental illness is the child's legal guardian, the researcher will ensure, to the best of her ability, that the parent is competent to provide consent for the child. The child also will be asked to sign an assent form. Assent implies that the child has voluntarily agreed to the study. Within the assent process, the researcher will stress that the child has the right to withdraw from the study at any time, ask questions about the study and the assent form. The child has the right to refuse the second interview. All interviews with children will be conducted in a sensitive, caring and ethical manner, respecting the rights of children as individuals.

The results of the study will provide information that will be helpful to program planning for children and their families. The risk involved in the study may be that the child will become excessively emotionally upset. In these circumstances, the researcher will stop the interview and will endeavour to find appropriate resources for the child. If you are interested in this study and would like more information, please call Elaine Mordoch at xxx-xxxx. You may also leave your number with me (the person who has introduced the study).

With your permission, your number will be forwarded to Elaine who will call you for further discussion. The study is voluntary and participants may withdraw at any time without consequence to any health care provided to the parent/legal guardian and/or the child.

Thank you for considering this study.

Appendix R
Parents'/Legal Guardians' Demographic Form

Children Living With A Parent With A Mental Illness

Parents'/Legal Guardians' Demographic Form

Your interest in this project is much appreciated. All information is confidential. You are **not** required to put your name on this form.

Elaine Mordoch, RN Ph.D. student, School of Nursing, University of British Columbia.

Please indicate whether you are:

Spouse/Partner..... Parent with the mental illness

Other.....

Age of child Sex.....

Siblings Age..... Sex.....

 Age..... Sex.....

 Age..... Sex.....

Your age Partner's Age.....

Diagnosis

Parent's Age of Onset of illness

Child's Age at Onset of Parental Illness.....

Number of hospitalizations in the past 2 years.....

Number of admittances to the CSU.....

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Present Marital Relationship.....

Educational Level.....

Income: under \$10, 000 _____ \$10,000 – 20,000 _____
 \$21,000 – 30, 000 _____ \$31,000 - 40,000 _____
 \$41,000 – 50,000 _____ \$51,000- 60,000 _____
 \$61, 000 and up _____

Please indicate who helps you with your children when you are ill?.....

.....
.....
.....

Please note any other comments you wish to make.....

.....
.....
.....
.....

Thank you

Appendix S

Children's'/Adolescents' Demographic Form

Children Living With A Parent With A Mental Illness

Children's/Adolescents' Demographic Form

Your help with this project is appreciated. All information is confidential.
You are not required to put your name on this form.

Elaine Mordoch, RN PhD (c)

Age.....

School Grade.....

Siblings: Sisters:.....Ages:.....
 Brothers.....Ages.....
 Half Sisters.....Ages.....
 Half Brothers.....Ages.....

Who lives in your house with you?.....

.....

What is the reason you decided to be in the study?.....

.....

Please add any other comments you would like to include.....

.....

.....

Thank You

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Appendix T
Revised Interview Questions

Revised Interview Questions**September 25/03**

1. What does your parent tell you about their illness?
2. What do you think about that (what they have told you)?
3. Please tell me what it is like to live in your house,
in the week, on the weekend?
4. How do you celebrate holidays – birthdays?
5. How do you know when your parent gets sick?
Tell me what is like when your parent gets sick (i.e. depression etc.; use language of the parent).
6. How do you manage when your parent is sick?
What makes you do that? Does it help? Who does it help?
7. How do you feel when your parent is sick?
Is there anything that helps with how you are feeling?
How does it help?
8. Some of the kids that I talked to say that they should have done things differently so that their
parent would not get sick. Do you ever think that?
Tell me about that.
9. Does anyone help you to understand what is happening to your parent?
How do they do that?
10. What happens in your family when your parent is having problems with their illness?
Pull apart? Come together? Anyone come to help?
11. What is like for kids to have a parent with a mental illness?
12. What is the most important thing that you would like to tell other kids about having a parent
with a mental illness (depression etc.) ?
13. What else would you like to tell me?

Thank you for helping me with this study. I would like to give you two movie passes as a way of saying thank you.

Appendix U

Vignette

Children Living With A Parent With A Mental Illness

Vignette (Mom With Typical Depressive Symptoms)

This is a story of a brother and a sister who were talking about their mom. They were worried that their mother was sick. She did not have a runny nose or a cough. She did not have a rash or a fever. The children were still worried because their mom did not seem like the usual mom they knew. Sometimes she cried and they could hear her up in the night. Their mom did not do the things that she always loved to do. The children noticed she did not eat much anymore and they sometimes heard their dad telling mom to “snap out of it”. Sometimes the dad would be cranky with the children.

What do you think about this story?
How do you think the children feel?
What do you think they could do?
What do you think would help kids in this situation?

This vignette is based on the book: *What Happened to Mommy?* By R. Fran, Eastman Publishing Inc, N.Y. 1994. The author is a parent who has suffered with mental illness.

Hypothetical questions, third party questions, props and story can assist children to participate in the research process. Children may not have had much experience conversing with adults in other than structured settings and improvisations that may assist them to converse are often needed in the interview process (Graue & Walsh, 1998).

Appendix V**Early Memo**

Getting Along With Parents April 6/03

Reciprocity –to move backward and forward, give and take, mutual exchange

When the girl says that the m.i. has made my parents and I respect each other, what does she mean by that? Sometimes fighting or the heated exchange of views is healthier than silence.

Does she mean that they stay silent when things happen or does she mean that they have other ways of resolving things? Are kids worried about their parents dying because of the relationship they have with the parents? It seems from reading the interviews that parents are more present at some times in their illness. Does that create a greater sense of uncertainty for the children? Are they less likely to take their parents for granted? Are parents who need reassurance about parenting only ones with mental illness? (Likely not – but the intensity of the reassurance would likely be different)

Perhaps they are more forthright about expressing their needs than other parents?(or more needy??) When you said “pain based silence” in this memo what did you mean by that? Maybe that child had learned to be less engaged when the parents had an exacerbation. Was the child over identifying when he said it kills to see her sad or was the child feeling a sense of responsibility and guilt about having failed her? Is reciprocity about figuring out what contribute to harmony both my parent and children? When parents let children off the hook in terms of the illness does that provide space for the children and parents to get closer or to feel that things are more reciprocal? ****

The mental illness has made my parents and I respect each other – don’t fight – is this related to fragility- keeping the peace so that mom will remain ok? Would it be different if the parent was not ill – girl wonders – girl stated that the parents could die tomorrow-

And kids could have regrets – (interview #16) – also interview (#17) worried that her parents would die – is this specific to mental illness? Maybe heightened because the fragility of the

parent is more obvious? Is this different than if a parent has a chronic physical illness - or from kids in general - ?

It is important for the girl to be sure that mom knows how important she is to her- that the daughter credits the mom with helping her to be who she is – the child is troubled as when the mom gets ill – the mom believes that she has failed as a mom – the child does not think so – sees the mom as valuable in her life, besides the mental illness – other qualities that have helped child – besides the good things that the parent supplied to the child – child also realized that the mom could take “it out” on the family – when ill. To manage this, the child became silent (??pain based silence) and rationalized the mom’s behaviour as due to illness. The child becomes very sad when the mom is sad – almost “kills me to see her sad” – over identification with parent? Is the child so concerned that she over identifies with the parent – feels her misery? There is a relationship between the child and the parent – there is some give and take-

Mom and dad support child in her efforts – extra curricular activities – have dinner together – values this. Taking on chores – groceries/laundry/cleaning (interview #3, 16) in an effort to keep the peace or when parent hospitalized – reciprocated by calmer less stressed parent.

Interview 17 – parent supplies the child with information, talks to the child about the illness and also about other problems – for example mom’s childhood experience with bullies – father also helps the child manage problems in her life, have discussions- aware that she can turn to mom for assistance and information—“when kids are mean to me” - mom provides structure, day to day assistance, holiday celebrations etc. Reciprocity – mom provided explanation that child not to blame for illness and assisted child to understand this – not take on blame – this helps the child understand the illness and gain a different perspective regarding the parent- within this reciprocity the child described being/feeling very close to her parents, both the ill and the well parent – similar to #16 and also #15- who said the illness made them talk more.

Kids also aware that the parent wanted the best for them (16, 17, 15, 13, 14, 7, 3).

Interview # 15 child stated that if mom did not have a mental illness they would not have such a close relationship and have such discussions. For example, she felt that she knew her mom as a person and not her dad – knew him as a dad. This is interesting in light of the fact that some people never know their parents as people only in their parental roles. Child saw this as a strength –

So parents who can be open or feel obligated to be open (?) may be helping their child to manage the illness – giving information, explanations helped the child understand.

Parent also provided private school and attempted to celebrate birthdays and holidays. These holidays sometimes were disorganized and filled with uncertainty due to circumstances of life – new partners of adults (dad). Because of the small apartment with little available room, birthdays with friends were held at a relatives – child described mom trying to organize a surprise

Party which she did and then not celebrating the next birthday – child seem hurt by this – unclear why there was no celebration – this mom was trying to stay out of the hospital –

?hospitalization at that time? Ill. Mom also allowed child freedom with friends (limits also) and pet in the apartment. Child had own space with all her treasures around. Computer in the hall for child's use. Mom ordered special magazine for her. Mom likes to hug me – child – ambivalent about them – however did mention that if mom worked and had a job – she would come home and kiss me – ambivalent about mom and physical contact – or maybe stifling at times???

Girl found explanations from the parent helpful – and discussions that they had around the mental illness – wanted more of that at times- felt this is what would be the most helpful to other kids- to understand what is going on. when you have a parent with a mental illness you talk to them more and understand them –know them like a person – parent shares information – is it always appropriate info for the child or is perhaps good that the parent can be open about problems - ?? pull together to manage???

April 21, 2003

While children realize that their mother had a mental illness – they also appreciated what the parent did for them. My mom tries to understand sports (interview 14) even though she really doesn't like them – she asks me questions – she is nice to my friends. Both children in this family (13 & 14) knew that the parents tried to give them opportunities and experiences as best they could – they realized that not all kids had these opportunities – therefore they saw the parent with the mental illness as a good parent for most of the time. The older boy admired the mom for being able to do all the things she did for them – he stated that he did not know how she managed this – and that he was sure that he could not do this.

Parents also got their kids in touch with counselors/teachers at school – both these children had talked to the school counselor because their parents had approached the counselor – kids founds this helpful – especially the older boy – the younger girl said it was short – nothing much happened.

So even when the parent has a mental illness, the parent still provides some things to the child – which makes it feel like a reciprocal relationship – in fact these children were aware of the bounty that the parents provided and the older child of the difficulty the mom had doing so at times.

April 27/03 Interview 09/10 Reciprocity

These boys were aware that they had nice things and activities because of their parents' efforts. They had their space downstairs with music, movies and had extra curricular sports that were supported by the parents. Even though in this home, the family seemed unable to talk about the m.i. of the dad and its effect on everyone, they boys both felt that the parents cared about them, would want them to have information on m.i..

May 17/03 Interview #8 getting along with the parent appeared to involve a certain amount of wariness on behalf of the child. This child seemed to scan the environment to see where mom was and to be sure what she was saying was not overheard. Seemed hesitant at times to answer possibly based on close quarters of interview site and mom's location in apartment??

What is the data a study of?

The complexity of the relationship between the child and the parent who has a mental illness. There is a give and take – the parent continues to make contributions to the child's well being.

What is the data really saying?

Children are able to see the contributions that the parent makes. They still see the goodness and the sacrifices the parent makes for the child's well being. Is there an integration of the mixed emotions that a child may have, conflicting thoughts re the parent? Children tend to speak positively about their parents and accept them as they are. ??? too Pollyanna???

What category does this incident represent?

While #8 had wary guarded ?fearful reactions around her parent, still voiced concerns and caring about her mom; valued family, saw family as contributing to her well being. With #9 the boy acknowledged that “we don't talk about it but I know they want me to have information” – even though the subject of m.i. was not openly discussed in the family – he knew that the parents would want him to have info on m.i. (which I mailed with their consent – he was correct). So there may be an unspoken knowing around some of these issues – the child knew his parents cared for him and would want him to get help anyway he could – even without these being verbally expressed. The subtlety of reciprocity – and knowing that the parent is there for the child at some level.

Appendix W

Late Memo

The Core Category and Related Concepts

Following Discussion with Dr. Hall, Feb. 3, 2004

The Core Category: Finding the Rhythm

Finding the Rhythm appears to describe the process by which the children perceive and manage the experience of living with a parent with a mental illness. Finding the rhythm suggests that the children are actively engaged in finding out/discerning the rhythm, the ebb and flow, of their relationship with the parent. This searching for the rhythm may take place daily (int.# 21) wherein the child gets up in the morning and attempts to find the rhythm of the day – how will the parent act today, what is the mood of the parent this morning and what is the child's best response to this mood. The best response may serve several purposes: to keep peace in the house; to restore the rhythm to a more harmonious beat, to minimize the effects of the behaviour on the child and family. In finding the rhythm, the trajectory of the illness is important. This is always underlying the reason, the need for the child to engage in finding the rhythm. When the parent has a mental illness, there is a fair amount of uncertainty and change as to how the parent will behave. The parents' behaviour may change suddenly or insidiously due to acute exacerbations of the mental illness. The environment of the child, and most particularly, the relationship of the child to the parent and to the family, changes. The rhythm of the relationships is disrupted and the beat has changed. The change in behaviour of the parent affects the whole family and may also affect how the family and child are viewed in the world outside of the family. The child may become more visible as having a different parent or unusual circumstance (mental illness) in the family. The child attempts to find the now changed rhythm of the relationship by monitoring the parent's behaviour, which in turn, helps the child to determine actions which will hopefully minimize the immediate effects of the behaviours (illness) on the child.

The children are finding the rhythm because they care for the parent. They value the parent /child relationship, recognize the parent's contributions to their well being outside of the illness, as well as their parent's limitations and hence do their best to sustain the relationship. Children often stated that their parents were doing their best. This valuing and regard for the parent appears to be a strong motivator for children to expend energy into finding and sustaining the rhythm - to restore and preserve their relationship with the parent and the integrity of their family. The act of finding the rhythm is complex as the illness trajectory has a range of

behaviours, which may cause from minor to major disruptions in the rhythm. The child becomes adept at monitoring the situation and watching for the signs and symptoms of the mental illness. Over time, and with the sharing and or gathering of information from outside sources, i.e. the well parent, extended family members, overhearing conversations, the child recognizes the patterns of behaviour that indicate an interruption in the rhythm of their relationship with the parent.

As children monitor and watch for signs of change, they are not only aware of the significance of the behaviour and what it may imply for daily life, but become acutely aware of the disruption of their relationship with the parent. Children then make adjustments to minimize this disruption; they make adjustments to their environment, to their general behaviour, and to their way of interacting with the parent. In making adjustments children first note and monitor the behaviour, then consider, select, evaluate and readjust the adaptation in what ever manner the child views as appropriate; whatever works best.

Within both acute exacerbations and in the chronicity of the illness, the ability to monitor and to consider, select, chose act and evaluate adjustments, enables the child to find the rhythm and restore it as best they can. In dealing with the chronicity of the illness, the child may make fewer less intense adjustments to sustain the rhythm of the relationship as compared to the more intense adjustments that may be needed in the acute stages of the illness. At times when the parent is well, finding the rhythm flows easily and becomes effortless, easy like riding a bicycle (int. 16). At other times, when the illness is acute, finding the rhythm can be excruciatingly exhausting.

The Core Category: Maintaining the Frame

In dance, maintaining the frame refers to keeping the right distance between you and your partner. For children, finding this right distance revolves around the core experience of finding the rhythm which is driven by the gauntlet of emotions that the child experiences related to their circumstances. The idea of maintaining the frame is similar to the concept of maintaining healthy boundaries in relationships, which allow both participants in a relationship to interact in a manner that supports their individuality as well as their connectedness. The frame may fluctuate with the intensity of the illness and its consequences (family disruptions, hospitalization, stressful relationships, loss of jobs and financial burdens). As the parent becomes ill, the child may feel that the frame has shifted. The parent may be too distant, unavailable, non-receptive. The parent may be physically unavailable, i.e., hospitalization, and/or psychologically

unavailable to the child. Children describe the parent as being overly demonstrative, needy, and intrusive

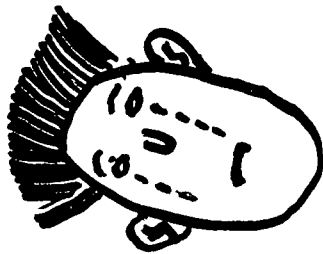
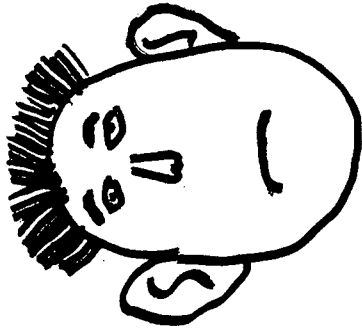
(#15/1; 16/1/2/). For example, two female teens described the needs of the parent as overwhelming at certain points within the illness trajectory. The children felt called upon to structure the frame in a manner that could be both supportive of the parent and themselves. This was a complex undertaking made more so by the range of emotions that the child felt inclusive of fear, confusion, frustration, sadness and resignation. In the acuity of the parents' illness, both girls restructured the frame and in response to their parents' unavailability created solutions that would sustain the frame at the distance which allowed the girls to manage the situation. The girls made efforts to maintain the frame in some semblance of the desired child/ relationship, tried to find the comfort zone within the frame that would accommodate the discordant rhythm as defined by the symptoms of the illness. The parent was no longer able to orchestrate the dimensions of the frame in a harmonious manner. The emotional gauntlet that children traveled while doing so was immense as identified by their personal accounts of these experiences. While both girls may have appeared to be functioning well (school/work/friends), each described an emotional havoc central to their experience at that time. In maintaining the frame of the parent child interaction, the girls improvised how to maintain the frame in the face of acute illness; one by compartmentalizing the diverse aspects of her life, the other by changing her attitude to the situation.

Note: Both finding the rhythm and maintaining the frame were originally conceptualized as core categories, but with further analysis, were more accurately conceptualized as BSPPs, as each consisted of distinct stages (monitoring and adjusting; trying to preserve myself and gauging).

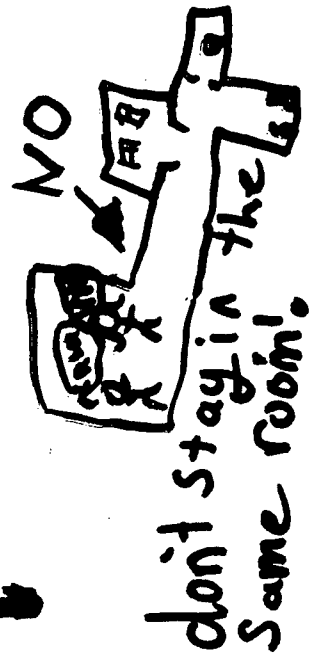
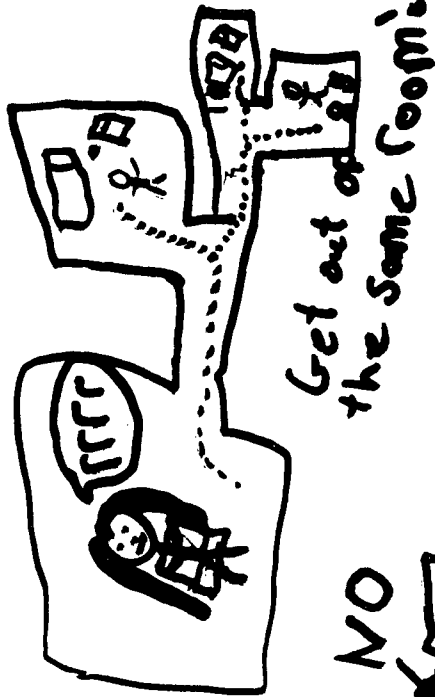
Appendix X

Interview 08, Girl, Age 10

Artwork: Identifying Signs of Depression and What to Do



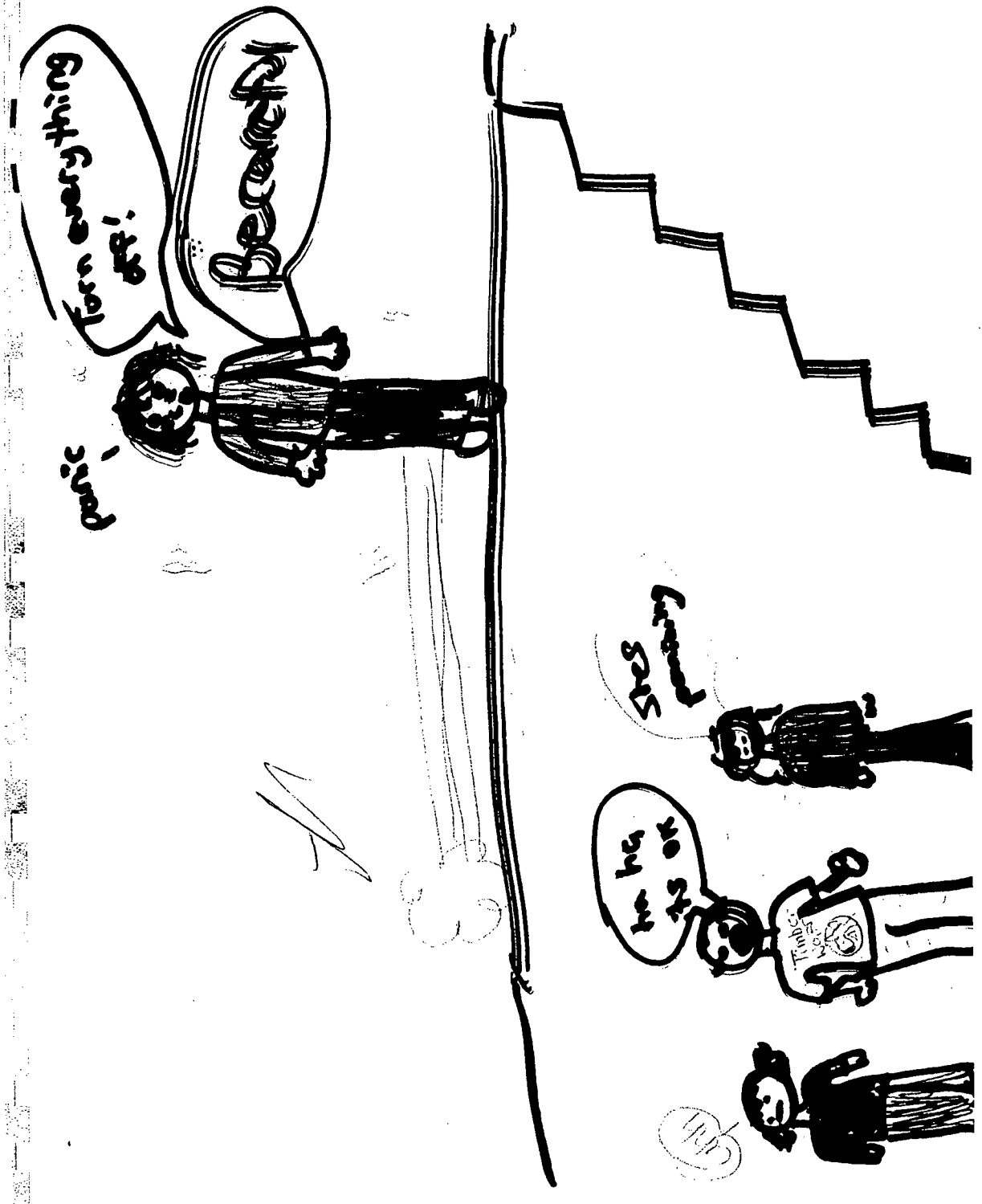
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Appendix Y

Interview 13/1, Girl, Age 11

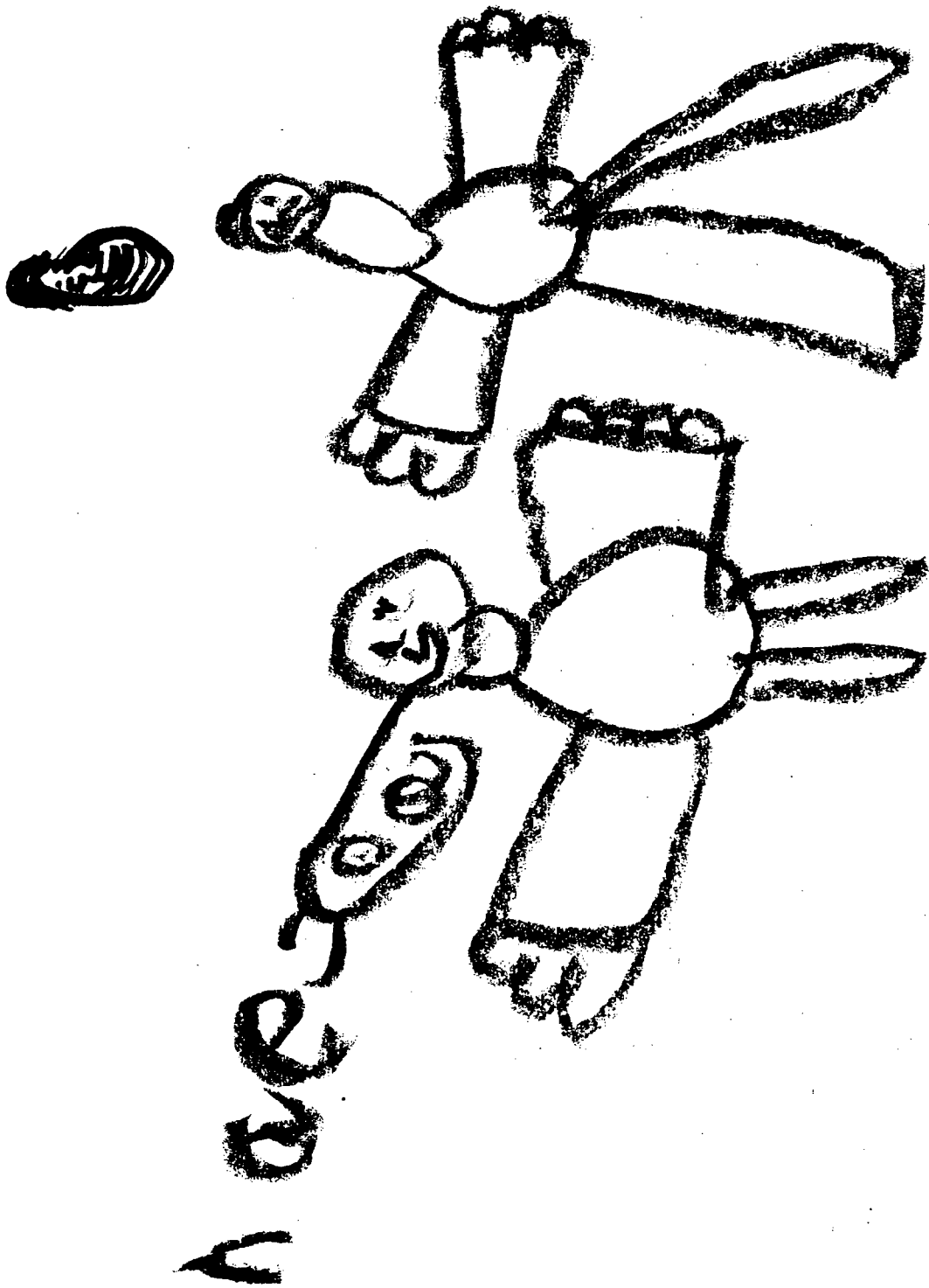
Artwork: Managing A Panic Attack With Help From The Well Parent



Appendix Z**Interview 05, Boy, Age 9****Artwork: Using Humour To Help The Depressed Parent**



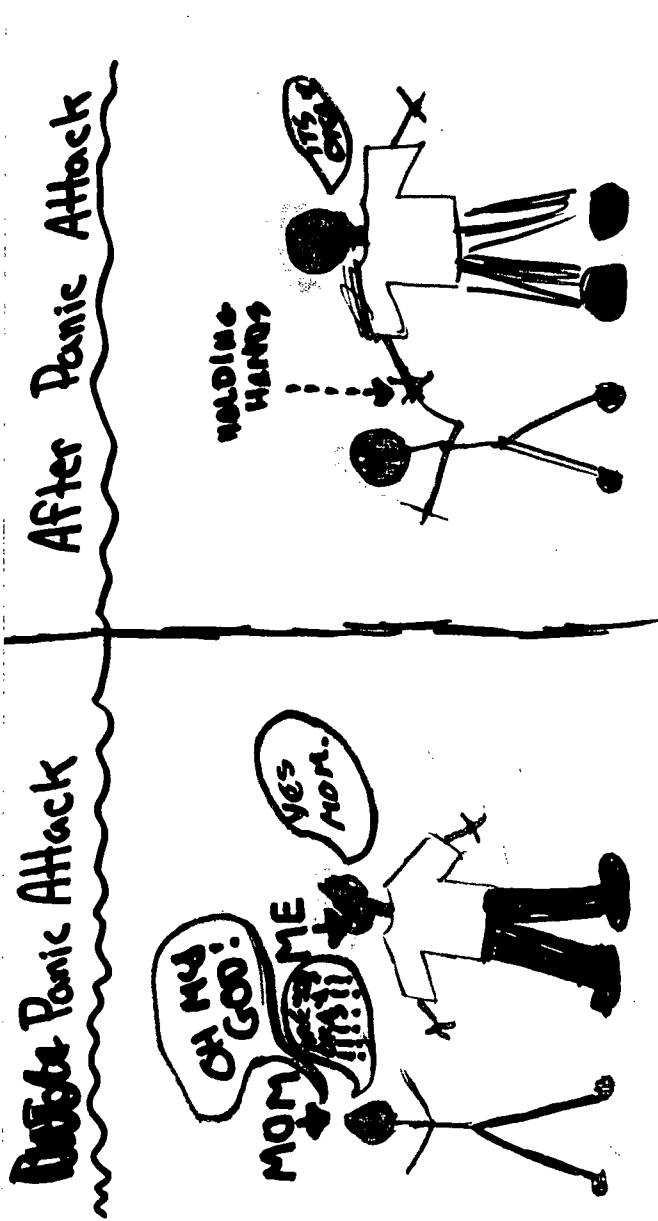
Appendix A1**Interview 04, Boy, Age 7****Artwork: Using Humour Telling Jokes To Help The Depressed Parent**



Appendix B1

Interview 14/1, Boy, Age 13

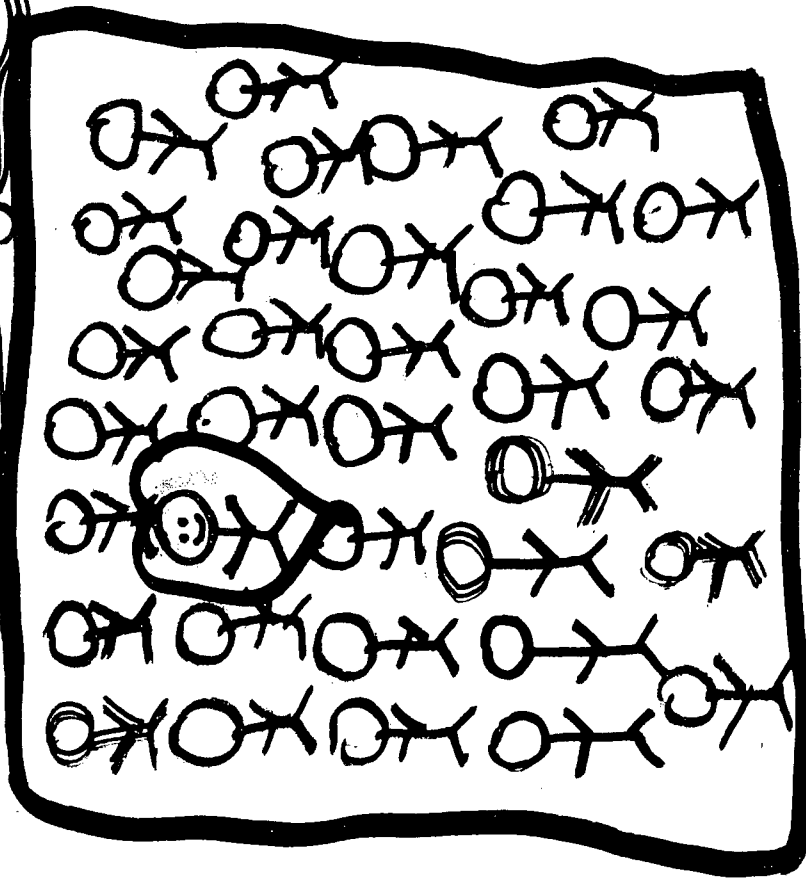
Artwork: Before And After The Panic Attack



MOM'S PANIC ATTACKS
BRING US CLOSER AS
FRIENDS.

Appendix C1**Interview 13/2, Girl, Age 11****Artwork: Putting Mental Illness In Perspective**

Parents of My Friends



Mental illness makes my Mom unique!