

**EXPERIENCES OF ADULT OFFSPRING OF PARENTS WITH A MENTAL ILLNESS:
PUTTING TOGETHER THE PIECES AND MAKING MEANING OF EXPERIENCES**

by

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ABSTRACT

According to a 2009 Canadian national health survey approximately 12% of children under the age of 12 live in a household where the survey respondent reported one or more mood, anxiety or substance use disorder (Bassani, Padoin, Philipp & Veldhuizen, 2009). In fact, one out of every five individuals will experience a mental illness during their lifetime. It is widely accepted that people who experience mental illness parent at the same rate as the general population. Numerous studies have explored the topic of children of parents with a mental illness. Early research focused on understanding the adverse effects on children and specifically on identifying risk for childhood psychopathy. More recently researchers have begun to explore the positive aspects of growing up with parental mental illness in light of children who are seen as demonstrating considerable resiliency. Strength-based aspects to the experiences of growing up as a child of parental mental illness have been included in some studies.

The goal of this exploratory qualitative study was to explore the experiences of adults, who as children, grew up with a mentally ill mother and/or father. The method used included recruiting study participants using purposive sampling. The data collection and analysis was informed by grounded theory including a constant comparison of interview data and data analysis. Findings in this study supported previous research related to growing up with parental mental illness. Experiences of study participants were also similar to findings in existing research. Unique findings that would be worthy of further exploration included experiences of growing up in a two parent family with a father with a mental illness. Significant challenges with transitioning from adolescence to young adulthood were found across many of the interviews. The process of making meaning of experiences growing up in a family with parental mental illness as study participants experience their own significant life events was also found. These findings can

inform policy and practice working with individuals and families who experience parental mental illness.

TABLE OF CONTENTS

ABSTRACT	ii
TABLE OF CONTENTS	iv
LIST OF TABLES	x
ACKNOWLEDGEMENT	xi
DEDICATION	xiii
INTRODUCTION	1
Children of parents with mental illness.....	1
Defining mental illness.....	1
Prevalence of parental mental illness	3
Fathers with mental illness.....	4
Alternative theoretical approaches in parental mental illness research.....	8
Parent-child relationships and agency.....	8
The family perspective	10
LITERATURE REVIEW	12
Mental illness and children of parents with mental illness	12
<i>Impacts of serious mental illness on parenting</i>	12
Prospective studies of children of parents with mental illness.....	13
<i>Positive aspects and negative consequences for children of parents with mental illness</i>	13
<i>Children of parents with anxiety and depressive disorders</i>	14
<i>Children of parents living with bipolar disorder</i>	16

<i>Children of parents who live with schizophrenia</i>	16
<i>Lived experiences of children of parents with mental illness</i>	17
<i>Young people who provide care</i>	24
<i>Who is providing caregiving and why</i>	25
<i>Parentification versus young caring</i>	26
<i>Multiply disadvantaged families who experience parental mental illness</i>	27
Retrospective studies of children of parents with mental illness	28
<i>Adult children of parents with mental illness</i>	28
<i>Adult offspring of parents with severe mental illness</i>	29
<i>Adult offspring of parents with bipolar and depression</i>	32
<i>Adult offspring of parents with bipolar or schizophrenia</i>	33
Making meaning of experiences as an adult	35
<i>Grief and loss</i>	35
<i>Childhood maltreatment</i>	37
<i>Felt obligation</i>	38
<i>Adult offspring caring for parents with a mental illness</i>	40
<i>Transition to adulthood and life course events</i>	41
<i>Making meaning of childhood experiences</i>	43
Risk, protective factors and resilience.....	44
RE-CONCEPTUALIZING: BEYOND RISK AND RESILIENCE	46
RATIONALE FOR STUDY	49
RESEARCH QUESTIONS	50
METHOD	51

Research design.....	51
Selection and recruitment.....	53
<i>Sampling design</i>	53
<i>Method of recruitment</i>	53
<i>Criteria for participation in this study</i>	54
Data collection and analysis.....	55
<i>Interviews</i>	55
<i>Coding in data analysis</i>	57
Credibility and usefulness of inquiry	59
<i>Credibility</i>	59
<i>Saturation</i>	60
Ethical issues.....	61
Establishing validity.....	61
FINDINGS.....	62
Theme one: Growing up with a mentally ill parent	64
<i>Parental mental illness</i>	64
<i>Living in a family with parental mental illness</i>	64
<i>Acute periods of illness and times of wellness</i>	66
<i>Denial of parental mental illness</i>	66
<i>Paternal mental illness</i>	67
Theme two: Family life.....	67
<i>Family values</i>	68
<i>Siblings</i>	68
<i>Well parent</i>	69

<i>Talking about mental illness</i>	70
<i>Family support system</i>	72
<i>Uncertainty, unpredictability and chaos</i>	73
<i>Marital discord and family violence</i>	74
<i>Rituals and special memories</i>	75
Theme three: Childhood experiences growing up with a mentally ill parent	76
<i>Abuse</i>	76
<i>Alternate caring arrangements as a child</i>	78
<i>Emotions felt as a child</i>	78
<i>Appearances of outward competent</i>	80
<i>Monitoring parents behaviour and coping strategies</i>	82
<i>Young caring and parentification</i>	82
<i>Support and coping strategies as a child</i>	84
<i>Perceived strengths as a child</i>	85
<i>Childhood mental illness</i>	86
Theme four: Transitions into adulthood.....	87
<i>Creating boundaries</i>	88
<i>Delayed adolescence</i>	88
<i>Not having the skills or experience</i>	89
<i>Leaving the family home</i>	89
<i>Continued caregiving</i>	90
<i>Interruption in education</i>	91
Theme five: Experiences of adults and parental mental illness	91
<i>Grief and loss</i>	92

<i>Mental health troubles as an adult child</i>	93
<i>Adult child caregiving</i>	93
<i>Perceived strengths as an adult</i>	96
<i>Becoming a parent</i>	96
<i>Influences on choice of occupation</i>	97
<i>Family involvement with criminal justice and mental health systems</i>	98
Theme six: Making meaning of experiences growing up with a mentally ill parent	99
<i>Acceptance of parent’s mental illness</i>	100
<i>Finding balance</i>	101
<i>Dreams</i>	101
<i>Death of a parent</i>	102
<i>Becoming a parent</i>	102
<i>Self reflection and healing</i>	103
<i>Things could have been worse</i>	105
<i>Spirituality</i>	105
<i>Reconnecting with extended family and friends</i>	106
<i>Humour</i>	107
Theme seven: Wishes for children growing up with parental mental illness.....	107
<i>Working with children and families who experience parental mental illness</i>	108
<i>Using superficial measures when assessing children of parents with mental illness</i>	110
DISCUSSION	111
Parental mental illness and the child welfare system.....	120
Parental mental illness and mental health systems.....	122
Best practices.....	123

<i>B.C.'s provincial working group supporting families with parental mental illness.....</i>	<i>123</i>
<i>Family centered practice and focused interventions.....</i>	<i>124</i>
<i>What the findings of this study suggest.....</i>	<i>125</i>
STUDY LIMITATIONS AND IMPLICATION FOR FUTURE RESEARCH.....	127
CONCLUSION	129
REFERENCES.....	131
APPENDICES.....	153
Appendix A: Recruitment poster.....	153
Appendix B: Consent form	155
Appendix C: Interview guide	158
Appendix D: Resources.....	159
Appendix E: BREB certificate of approval.....	160

LIST OF TABLES

Table 1	Participant Demographic.....	55
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DEDICATION

*To those children and their
families who continue to
live in silence.*

INTRODUCTION

Children of parents with mental illness

Researchers and practitioners who are versed in the topic of parental mental illness acknowledge that both consequences and strengths are seen in children who grow up in families with one or more parent who experiences a mental illness. Findings of studies also suggest that offspring of parents with mental illness often figure out a way to stay connected to their family and their ill parent, while at the same time construct boundaries that are perceived to keep them safe and allow them to function within the family unit (Mordoch & Hall, 2008; Riebschleger, 2004). Although there are a limited number of studies that have explored the experiences of adult offspring of parents with a mental illness those that exist suggest that this type of family functioning and parent-child relationship often continue into adulthood (Marsh, 2009; Mowbray & Mowbray, 2006; Kinsella, Anderson & Anderson, 1996). There is little known about the mechanisms that play a role in the occurrence of negative and/or positive consequences for children that result from living with parental mental illness. However, retrospective studies that look at the subjective experiences of adult children may provide a glimpse into some of the influences that shape the lives of these offspring.

Defining mental illness

The World Health Organization (2005) reports that there is no single consensus on the definition of mental disorder/illness and that the phrasing used for description depends on the social, cultural, and legal context in different countries and in different societies. The Canadian Alliance on Mental Illness and Mental Health (2009) defines mental illness as a collection of disorders characterized by symptoms such as extreme mood swings, disturbances in thought or perception, overwhelming obsessions or fears, or high levels of debilitating anxiety. There is no

objective medical test that determines whether an individual has a mental illness. Diagnosis is based on self-report, observations by family and friends, disturbances in behaviour and the judgment and experience of a medical practitioner such as a family doctor and for more serious mental illness, a psychiatrist. In North America, the current diagnostic tool used is the Diagnostic and Statistical Manual of Mental Disorders, 4th Edition (DSM-IV). The DSM-IV is published by the American Psychiatric Association and is considered by health care professionals as the standard for diagnosing all mental disorders in adults and children. The DSM-IV takes into consideration the diagnosis of a mental illness, as well as considers the influences of physical illness, psychosocial stressors and levels of functioning on mental health (American Psychiatric Association, 2000). It is used to diagnose mental disorders such as depression, anxiety disorders, bipolar, schizophrenia, eating and personality disorders and post traumatic stress in adults and children.

There are times when the use of standardized assessments to diagnose mental illness is problematic to parents and their families. Professionals may vary in their interpretation, which can lead to parents with multiple diagnoses from different professionals; diagnoses that at times are at odds with each other. For example, a professional may diagnose a patient with depression, but previous trauma or life stressors may be overlooked. The stigma associated with a specific diagnosis such as borderline personality disorder, schizophrenia or bipolar disorder can have a significant impact on a family. Moreover, a parent is likely to experience periods of both wellness and episodes of acute illness and any diagnoses can, and often does, change over a parent's lifetime (Somers, 2007).

Mental illness is not thought of by everyone as a psychiatric diagnosis as defined by the DSM-IV or other standardized assessments. In some cases, a parent may simply deny they have a mental illness. Some cultures may differ in the way they conceptualize mental illness and/or

may interpret a mentally ill parent's behaviours entirely different from mainstream interpretations (Bhugra, 2006; World Health Organization, 2005). Cree (2003) suggests that there is always a continuum between mental well-being and mental disorder or mental illness, and it is difficult to define the cutoff for what is considered normal. Assessing an individual is complicated because of the considerable stigma and discrimination attached to mental illness in many societies. Consequently, families who live with parental mental illness often experience high levels of secrecy and shame as a result (Foster, O'Brien, & McAllister, 2005). Young people living in families affected by mental illness often experience the added stress of knowing mental disorders have a genetic component. However, having a parent with a mental illness does not mean that an offspring will necessarily be diagnosed with a mental illness, and if mental illness occurs the diagnosis may be different. Literature suggests that as many as 50% of mentally ill patients live with children (Gopfert, Webster & Seeman, 1996), but it is quite likely many more parents who experience mental illness at some time in their lives are not included in this statistic. Parents fear child protection services will become involved with their family and/or fear the stigma associated with having a mental illness and may not access health care services for themselves or for their children.

Prevalence of parental mental illness

Mental illness occurs in approximately one out of five individuals in a lifetime with major depression being the leading cause of disability (Foster, O'Brien & McAllister, 2005; Government of Canada, 2006). Adults with mental illness are known to have children at least as often as adults in the general population (Gopfert, Webster, & Seeman, 1996; Reupert & Maybery, 2009). In the United States, Oates (1997) estimates that approximately 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. In Canada, a recent health survey conducted by Bassani et al, (2009) found that

approximately 12% of children under the age of 12 years old lives in a family where a parent has one or more mood, anxiety or substance disorders.

A recent survey conducted in the Fraser, Northern and Interior Health regions of British Columbia revealed some interesting statistics related to families who live with mental illness (Provincial Working Group, 2010). A total of 3,423 cases were reviewed across the three regions. On average 35% of adults who access mental health services reported having children, with approximately one third of those individuals reporting having preschool children, under the age of five. In addition, just over one third of the children were school aged and approximately one third were high school aged. On average 67% of parents reported that their children lived with them all the time; 15% reported children lived with them some of the time and 28% reported that their children did not live with them. Finally, 46% of adult clients who use services for addiction/concurrent disorders reported having children. This data is based on nine surveys used to compile information regarding the type of services adult clients were using. The surveys included mental health services, addictions and concurrent disorders.

Fathers with mental illness

There are no reliable estimates for the number of men with serious mental illness (SMI), but it has been reported that more than one in five men with SMI indicate they have children (Nicholson, Nason, Calabresi & Yando, 1999). Wilson & Durbin (2010) suggest that lifetime rates of major depressive disorder in men ranges from 3.6% to 9.0% indicating a sizeable number of men experience depression over the course of a lifetime. Although women experience depression at twice the rate as men (Hasin, Goodwin, Stinson & Grant, 2005), rates of depression in men under the age of 45 years are greater than men 45 years or older (Blazer, Kessler, McGonagle, & Swartz, 1994). In fact, it is reported that those in the age of greatest risk for depression are also those most likely to have children (Blazer et al, 1994). This trend also

appeared to be consistent across different ethnic and socio-economic groups (Blazer et al., 1994). Depression was found to be more common in males with lower levels education and income (Kane & Garber, 2004).

Unfortunately, a scarcity of literature exists about fathers with mental illness as they are regularly left out of the research on parental mental illness and children of parents with mental illness (Kane & Garber, 2004; Phares & Compas, 1992). Studies that do exist primarily focus on father's characteristics or experiences (Nicholson et al., 1999; Styron, Pruet, McMahon & Davidson, 2002). A literature review conducted by Phares and Compas (1992) explored, in part, outcomes of children whose father had sought or been referred to clinical services or received a psychiatric diagnosis. One study examined the functioning of children whose parents committed criminal or antisocial acts. Kandel, Mednick, Kirkegaard-Sorensen, Hutchings, Knop, Rosenberg & Schulsinger (1988) focused on the role of IQ as a protective factor for offspring at high risk for antisocial behaviour. They found that adolescents who avoided criminal behaviours were found to have higher IQs than offspring of fathers who had been identified for serious criminal behaviour. Higher IQ has also been found to be protective in children who grow up with parental mental illness (Worland, Weeks & Janes, 1987). Furthermore, Jacob and Leonard (1986) conducted a study that compared children whose fathers were alcoholic with children whose fathers were diagnosed with other forms of psychiatric disorders. They found that fathers who abused alcohol and fathers with depression did not differ and both rated higher than the control group by both mothers and fathers on negative child behaviour ratings. In addition, Goodman and Gotlib (1999) suggest that mental health of fathers may exacerbate the effects of maternal depression on child outcomes. The effects of both paternal and maternal depression may combine with worse outcomes for children (Goodman & Gotlib, 1999). Studies that explored the functioning of children of depressed fathers found children to be at increased risk of behaviour

and psychological adjustment compared to control groups (Beardslee, Schultz & Selman, 1987). Gender of the depressed parent has been reported as not being related to children's functioning, with children of parents who experience depression having more physical, emotional, behavioural, school and peer problems than control children (Billings & Moos, 1985). However, it has also been reported that paternal psychological symptoms were related to children's anxiety, but not depression, while mothers' psychological symptoms were significantly related to children's self report of depression and anxiety (Jensen, Bloedau, Degroot, Ussery & Davis, 1990). Fathers of children diagnosed with depression were more likely than mothers to have a history of substance abuse and antisocial behaviour (Mitchell, McCauley, Burke, Calderon & Schloredt, 1989).

Despite the lack of research about paternal mental illness and potential consequences for offspring it is still unclear what the mechanisms underlying paternal effects of child and adolescent maladjustment, when maladjustment occurs (Phares & Compas, 1992). Some suggestions about possible mechanisms include genetic effects and gene-environment interactions, interactions between fathers and their children, parenting practices and behaviours, and modeling and social learning, which can provide guidance and nurturing in social environments (Phares & Compas, 1992). Overall, paternal depression appears to be influential in the development of higher levels of emotional and behavioural problems and lower levels of competence in children and adolescents (Kane & Garber, 2004; Phares, Duhig, & Watkins, 2002).

McLoyd (1989) reported significant indirect effects on children of paternal job loss and economic loss. The indirect model suggests that paternal economic loss leads to greater negativity and pessimism in the father, which leads to deterioration in the father-child relationship. The author of this study suggests that this deterioration may lead to socioemotional

problems, reduced personal expectations and aspirations in offspring. Studies have also found that father's psychological symptoms were associated with their children's reports of maladaptation, but father's symptoms did not predict maladaptation in prospective or longitudinal analysis (Phares & Compas, 1992).

Very few studies have explored father's experiences of parenting with a mental illness. Reupert & Maybery (2009) interviewed 11 men with a mental illness about their parenting experiences and needs. None of the men were living full time with their children. All men were Caucasian and between the ages of 30 and 39 years old. All but one was separated from their spouse. Three of the men had adult children. Seven themes were identified: "fatherhood self image, access to children, relationship with children, stigma associated with men and mental illness, overemphasis on pathology, isolation, and parenting needs and supports" (Reupert & Maybery, 2009, p. 63). Some men in this study reported not being able to talk to others such as their doctor about their mental illness as they were fearful of the impact it may have on access to their children. The men described being involved in their adult and dependent children's lives, even if it was only over the telephone. Some men talked about how having children is a positive influence on their mental illness. Men with older and adult children described how their relationships with their children had changed and that for some men their children's ability to confront them about their illness was helpful. The stigma associated with being a man and having a mental illness was reported as difficult by all of the men. They described a belief that being a man meant that they were supposed to do certain things like suffer in silence or be tough and strong and take pain and bear it. This suggested that coming to terms with their illness was complicated and made accessing help or treatment problematic. The men in this study reported difficulties with relationships, especially during episodes of acute illness that resulted in isolation when they most needed support. One man stated that when his ex-wife was pregnant with their

first child there was no education or support to assist them with any possible impacts on his mental illness as a result of having a child. Fathers in this study reported “fatherhood as central to the image they had of themselves” and “even when they had minimal contact with their children, fatherhood was still an important, defining feature of who they were and how they presented themselves to society” (Reupert & Maybery, 2009, p. 66).

Alternative theoretical approaches in parental mental illness research

Gladstone, Boydell and McKeever (2006) call for a redressing of the dominate casting in research of children of parents with mental illness as at risk and invisible; alternative theoretical approaches that are not deeply rooted in developmental and socialization models. The criticism of developmental models is that they can be seen as endorsing a claim about how and why ‘normal’ children think, feel and behave, neglecting to recognize that parental mental illness may be experienced in different ways by individual children (Gladstone, Boydell & McKeever, 2006). Parental mental illness and its ramifications could be illuminated, along with their needs and vulnerabilities, through research that focuses on children’s perspectives of their experiences growing up with parental mental illness (Gladstone, Boydell & McKeever, 2006). Cohler (1987) concurs with this assumption and adds that there is no reason to assume that parental mental illness will necessarily lead to low levels of psychosocial functioning or that children will necessarily be unable to cope with problems that may result from living with a mentally ill parent. Predicting outcomes of risk or resilience needs to be considered in the social context in children’s lives (Cohler, 1987).

Parent-child relationships and agency

Research on the topic of the experiences of children of parents with mental illness (COPMI) has shifted in recent years to include not only adverse consequences, but also perceived strengths

and positive aspects of growing up in a family with parental mental illness. This shift from an individualistic, deficit-based medical model that focuses on parental pathology has also shifted the focus of research to include the family. Rather than assuming negative impacts on children who experience parental mental illness this focus assumes that children are not passive, but active participants in families. Much of the early literature on parent-child relationships views children as passive recipients of their parent's actions and takes the perspective that adults are solely responsible for preparing children for their future roles in society (Kuczynski, 2003). This standpoint of children's agency neglects to consider children's social lives, experiences and perspectives that are independent of their parents (Mayall, 1994). A strong assumption of the bilateral model of parent-child relationships is that the parent and the child are equal agents (Kuczynski, 2003). Furthermore, each interaction between a parent and a child occurs in the context of the relationship, which includes a past that in turn informs future interactions (Lollis & Kuczynski, 1997). This action perspective of human development does not imply that individuals are the sole producers of their biography. Activities that relate to personal development are subject to cultural, socio-historical and physical constraints that lie outside of a child's control, but influence the range of behaviour and developmental options (Brandtstader, 2006, p. 517). Commonly, children of parents with mental illness experience stigma and isolation from family members, their community and the broader society. Certainly, the context in which these children grow up both within their family and outside of their family influences their opportunities and choices for action.

A sense of control over the environment is seen as important to an individual's feelings of competence and well-being (Kuczynski, 2003). Bandura (2006) suggests that among the mechanisms of human agency the most central is the core belief that one has the power to effect changes by their actions. Children who grow up with parental mental illness frequently

experience unpredictability and chaos at home. Some children will gain a sense of control in some aspects of their lives through positive experiences at school, participation in community activities or a supportive adult. Other children who are isolated and live in enmeshed families will experience a lack of control. Understanding or meaning of each child's unique experiences is important. According to Kuczynski (2003), children actively interpret information in their environment and respond to the interpretation rather than the event itself. Messages, values and other information that comes from parents or the culture are interpreted and transformed as children attempt to "understand their social environment in terms of their personal experiences and ways of knowing" (p. 11).

The family perspective

Byrne (2003) advocates for placing mental illness within a family perspective, which differs from the perspective of placing blame on the individual with a mental illness for causing troubles within the family. The assumptions of this family perspective include: parents and children as active agents in establishing relationships within the family; that processes occurring within the family can affect outcomes, and that relationships are bidirectional in nature. The idea that mental illness is more than a biological disorder of an individual has encouraged researchers and clinicians to explore the impacts of mental illness on families (Byrne, 2003). Research in the area of parental mental illness and children of parents with mental illness typically focus on genetics and outcomes for children. A relational perspective focuses on how a parent's mental illness interferes with his or her relationship with their child and the resulting impacts. This view considers how a parent's illness affects the environment in which the family lives and the possible implications for children and the family as a whole (Byrne, 2003). One example would be the impact of parental mental illness on parenting, which in turn may lead to confusion for children and significant stress for a "well" spouse. The agentic perspective of human

development could assist in further understanding the processes that occur that may place children at risk or mitigate adverse consequences. Information regarding how children construct meaning and act on their experiences of living with a mentally ill parent could be useful in helping families reduce risk and assist clinicians when planning family centered interventions to reduce risk (Byrne, 2003). It is also important to consider that experiences are interpreted, meaning constructed and actions are taken on an ongoing basis throughout a person's life (Byrne, 2003).

LITERATURE REVIEW

The following is a review of existing literature that has examined the topic of children of parents with mental illness. I will begin by reviewing literature about the impacts of parental mental illness on parenting. I will continue by reviewing some of the prospective literature that explores the experiences, negative consequences, and strengths and positive aspects of living with a parent who experiences mental illness. Some retrospective studies that have explored the experiences of adult children who grew up in families with one or more mentally ill parents will be reviewed. Then, I will consider the concepts of risks, protective factors and resilience in relation to families that live with parental mental illness. Finally, I will discuss possible ways to consider subjective experiences of children of mentally ill parents including exploring conceptualizing these experiences beyond the prevailing discourse of risk and resilience traditionally seen from a stage by stage developmental perspective.

Mental illness and children of parents with mental illness

Impacts of serious mental illness on parenting

Parenting is a complex form of social interaction that can create significant challenges for parents with mental illness (Phares & Compas, 1992). However, it is important to recognize that parents with serious mental illness are a diverse group. While some parents will struggle with parenting others may only require support such as assistance with caregiving, which is helpful to families with and without parental mental illness (Marsh, 2009). Some parents may need additional support during periods of acute illness or hospitalization, but are able to successfully parent during periods of wellness (Marsh, 2009). Chronic mental health problems will usually lead to challenges in parenting such as interference from psychotic symptoms such as hallucinations and delusions; negative symptoms such as low energy, lack of motivation,

social withdrawal and lack of emotional expression. Interference from mood symptoms may also occur, which include manic and depressive episodes; trouble with concentration; difficulty dealing with the stresses of parenting, and stigmatization and isolation due to hospitalizations (Marsh, 2009).

Overcontrolling or overprotective parenting styles, which are often seen in parents with anxiety and depression, may be especially important to the development and maintenance of affective disorders as it sets the “emotional climate” (Degnan, Almas & Fox, 2010, p. 503) for the parent-child relationship. Cummings, Keller and Davies (2005) suggest that comparable effects of maternal and paternal depression on mothers’ and fathers’ parenting behaviour. Parental mental illness may contribute to a parent’s inability to interact with an infant and young child in a way that reduces stress and allows for the formation of a secure attachment between a parent and a child (Schore, 2003). At times, side effects of medication may also create or exacerbate symptoms of mental illness. Although research studies suggests that the potential effects of specific severe mental illnesses on parenting is important to assess, the severity and chronicity of a parent’s illness is more important than the diagnosis (Ackerson, 2003).

Prospective studies of children of parents with mental illness

Positive aspects and negative consequences for children of parents with mental illness

Numerous studies have explored the adverse consequences and some studies the perceived strengths that may result from growing up with a mentally ill parent. Many studies suggest that children of parents with mental illness are often at risk of emotional, social and physical outcomes (Singleton, 2007; Thomas, Stainton, Jackson, Cheung, Doubtfire & Webb, 2003). Adverse consequences reported frequently include poor mental and physical health, academic

problems and social and relationship troubles (Micco, Henin, Mick, Kim, Hopkins, Beiderman & Hirschfeld-Becker, 2009; Moore, McArthur & Morrow, 2009; Mordoch & Hall, 2002; Peisah, Brodaty, Luscombe & Anstey, 2005; Schubert & McNeil, 2003; Somers, 2007) that often persist into adulthood. Conversely, some grown-up children of mentally ill parents cope well and report high levels of success in areas such as perceived personal strengths and social, educational and occupational well-being (Kinsella, Anderson & Anderson, 1996; Knutsson-Medin, Edlund & Ramklint, 2007; Mowbray, Bybee, Oyserman, MacFarlane & Bowersox, 2006; Polkki, Ervast, & Huupponen, 2004).

Children of parents with anxiety and depressive disorders

Anxiety disorders are generally characterized by excessive, uncontrollable and often irrational worry about everyday things that is disproportionate to the actual source of worry (American Psychiatry Association, 2000). According to Harvison, Chapman, Ballash & Woodruff-Borden (2008) children of anxious parents are more than seven times more likely to be diagnosed with an anxiety disorder than those of non-anxious parents. However, genetics are likely to account for less than half of the variance in familial transmission and having an anxious parent does not mean that offspring of these parents will become clinically anxious (Harvison et al., 2008). In contrast, feelings of worthlessness and self-blame, sadness, disappointment and emptiness are normal feelings felt by individuals at some point during their lives. However, depression becomes an illness, or clinical depression, when these feelings are severe, last for several weeks, and begin to interfere with one's life (Canadian Mental Health Association, 2010). Children of parents with depression, the most common parental mental illness, have similar outcomes as children of parents with anxiety. Depression has been associated with impairment in parenting and in the quality of parent-child interactions resulting in potential dysfunction in a wide range of social and

interpersonal aspects of life (Beardslee, Versage & Gladstone, 1998). Infants of parents who experience depression are found to have more sleep problems and crying; are more tense, fussy and less active than parents of infants without depression (Gladstone & Beardslee, 2002, p.279). Furthermore, findings of a study conducted by Klein, Depue, & Slater (1985) suggest that children of depressed fathers appeared to display similar levels of problems as children of depressed mothers.

Children of parents with depression and parents with anxiety have been found to experience significant levels of parental intrusiveness, parental distancing and marital conflict (Langrock, Compas, Keller, Merchant & Copeland, 2002; Rapee, Schniering & Hudson, 2009). Gladstone and Beardslee (2002) suggest that parental depression has been associated with insecure attachment; negative self-concept and poor interpersonal coping strategies in children. According to Cunningham, Harris, Vostanis, Oyeboode, & Blissett, (2004), attachment is “an affectional tie that endures over space and time” (p. 639) and its primary functions for a child are protection and security. Children of mothers with major depression have been found to more commonly have insecure patterns of attachment compared to mothers with minor depression (Cunningham et al., 2004). Insecure attachment was found to be more frequent in children of mothers with bipolar depression than unipolar depression (Cunningham et al., 2004). Manassis, Bradley, Goldberg, Hood & Swinson (1994) found that 80% of children of parents with severe anxiety were insecurely attached. Although for some children insecure attachment may predict higher levels of problems, the pathways between attachment and any negative consequences are unclear. Attachment in itself is not a measure of mental illness, but it may set a trajectory that interplays with other risk factors and increases the risk in children for internalizing or externalizing mental disorders (Cunningham et al., 2004).

Paternal depression has been associated with lower levels of positive and higher levels of negative parenting behaviours (Wilson & Durbin, 2010). A meta-analysis on the effects of negative and positive parenting conducted by Wilson and Durbin (2010) suggest that child's age and father's age may have a moderating effect on the association between paternal depression and father's negative parenting. The authors suggest that the strain of dealing with the high demands of younger children; the inexperience of younger fathers, and the interaction between these factors and a father's age may result in the higher levels of negative parenting found in this group of fathers. The findings of this study indicated that paternal depression had a significant effect on parenting behaviours of fathers that is equal or greater than that seen in study of mothers with depression (Wilson & Durbin, 2010).

Children of parents living with bipolar disorder

Bipolar disorder is characterized as a severe and episodic mood disorder, which is often associated with suicidality and substance abuse (Frans, Sandin, Reichenberg, Lichtenstein, Långström & Hultman, 2008). Findings of a study conducted by Klein et al., (1985) found that a greater number of children of mothers with bipolar disorder received a mental illness diagnosis (69%) compared to children of fathers with bipolar (27%). In addition, findings of a study by Klein, Clark, Dansky & Margolis (1988) suggest that the effects of unipolar versus bipolar depression may differ for fathers and mothers. Overall, findings of this study indicated that children of depressed fathers were at an increased risk for a variety of emotional and behaviour problems.

Children of parents who live with schizophrenia

Schizophrenia is a mental disorder that affects the brain and is often characterized by symptoms such as disordered thinking, delusions, paranoia, hallucinations, changes in

emotions and behaviour. Schizophrenia afflicts approximately one in one hundred individuals (British Columbia Schizophrenia Society, 2010). Mueser and Gingerich (2006) describe some of the problems that children may experience living with a parent who is diagnosed with schizophrenia in their family guide to schizophrenia. Furthermore, according to Webster (1992), children who are exposed to violence or get caught up in their parent's delusional ideas may be vulnerable to psychological problems. Parents diagnosed with schizophrenia who refuse treatment are likely to have their children removed by child protection services (Webster, 1992). Some children of parents with schizophrenia may experience confusion in response to a parent's symptoms or behaviours and may feel embarrassed and/or isolation. Children may also experience neglect, may assume a caring role and be told by family members to keep the family secrets. A study conducted by Weintraub and Neal (1984) suggested that mothers with schizophrenia are perceived by their children as "more involved and more child-centered" than non-diagnosed mothers. In comparison, this study found that fathers with schizophrenia were seen more negative by their children including being unaccepting and uninvolved. Children of lone parents who live with schizophrenia appear to be most vulnerable (Somers, 2007). Findings in this study suggested that these children had mental health problems of their own; one child appeared to be raising himself and these children experienced lack of contact with relatives. Furthermore, children in this study wanted to be involved in their parent's treatment planning and wanted to know how they could best help their parent (Somers, 2007).

Lived experiences of children of parents with mental illness

Few studies have involved children's subjective experiences. As a result, children's voices are rarely heard in the current discourse of risk and resilience of young people who live in families experiencing parental mental illness. Mordoch and Hall (2008) conducted a study to

explore how children managed living with a parent with mental illness. Twenty two children between the ages of six and sixteen years, who lived with a parent diagnosed with depression, schizophrenia or bipolar illness, were interviewed. Parents in this study were reported as having insight into their mental illness and valued their parenting role. Three of the parents were fathers with mental illness, while the remaining were mothers. Findings suggest that these children attempted to find a “rhythm” (p. 1130) as a way of managing in their day-to-day lives living with a mentally ill parent. This rhythm was seen as a way of staying connected and included monitoring a parent’s illness and behaviour and adjusting their own behaviour as a result. “Maintaining the frame” (p. 1130) was a longer term strategy that included children trying to preserve a sense of self by gauging the costs and benefits of living with a mentally ill parent. Mordoch and Hall (2008) reported that children described a love for their parent that sustained their efforts to “find the rhythm with their parents and to maintain their frame” (p. 1130).

Some children who participated in this study stated that they found it difficult to find a rhythm in daily interactions with their parent because of their parent’s symptoms. However, one strategy to find a rhythm was managing their own daily activities such as attending school. Mordoch and Hall (2008) reported that children monitored their surroundings for change and were able to see a shift in the household when a parent became ill. Children in this study reported feeling joy and happiness when parental behaviours were perceived as comfortable, while they were angry and frustrated when their lives were chaotic and they were not able to connect with their parent. Children who had a well parent who helped with monitoring were considered to be more capable of interpreting parent’s behaviour. In addition, children described behaving in ways that they hoped would minimize the effects of their parents’ illnesses on their parent, the family and themselves. Simply getting out of the

way of their ill parent and finding somewhere safe in the home to stay was described as one strategy. Mordoch and Hall (2008) suggest that these types of strategies were used by children to reduce the stressors that they experience. When a parent was hospitalized children worry about what will happen to themselves and their parent. Children in this study reported experiencing feelings of fear and anxiety when their daily rhythm was disrupted.

Leon and Jacobitz (2003) suggest that family rituals are reported to be important and can contribute to shared memories and foster family ties. The authors of this study found that mothers tended to have more routine related to daily tasks such as domestic chores, while fathers tended to be more involved in rituals associated with leisure time in which they enjoyed a more relaxed time with family. Mordoch and Hall (2008), suggest that strong connections and daily patterns helped children in their study to feel safe and secure within their families, which in turn may make them more willing to invest in the parent-child relationship. Young people who reported knowing more about their parent's mental illness appeared to be better equipped to adjust their behaviour. Direct adjustments were perceived by the young participants of this study to be useful in managing their situation, included comforting their parenting, taking control, talking to their parent, sharing humor, and offering suggestions (Mordoch & Hall, 2008). Indirect actions such as helping with household chores, protecting themselves and siblings, and reducing stressors for their parent were also used by children (Mordoch & Hall, 2008, p. 1132). The authors suggest that an important contribution to literature is the description of the strategies that children used to try to manage their environment and their relationship with their parent (Mordoch & Hall, 2008).

Mordoch and Hall (2008) also explored the concept they called "maintaining the frame" (p.1132), which focused on longer term goals of children living with parents with mental illness that seemed to be related to staying connected with a parent, while developing their

sense of self over time. Young people described a need to have clear boundaries with their parents, so they could have lives of their own. Maintaining a connection to their parent was considered in the context of “preserving myself” and “gauging” (p. 1133). Some strategies used to preserve the self included getting away, flying solo and opting out (p. 1133). Physically getting away and spending time with friends or playing sports allows children some respite from their family situation. Children who had money to pay for activities or a family member that spent time with them had more opportunities than children without resources. Living life was also described by children as letting go of inappropriate responsibilities for their parents. They took control where they could. In fact, even younger children expressed a wish to be separate from their parent’s illness. In order to preserve themselves, the children sometimes selectively shared their experiences, which helped them “validate their experiences” and “decrease their feelings of isolation” (Mordoch & Hall, 2008, p. 1134). However, children reported that when they were told by their family not to talk about their experiences their options for sharing were limited. Some children were able to confide in extended family members and felt that this was a safe way to voice concerns and ask questions. When selective sharing occurred outside of the home with teachers or counselors it was considered somewhat risky as children were not sure how adults would respond, felt their parent’s illness was their responsibility and were fearful of child protection services. Some children reported “flying solo” (p. 1135) when no one was available for them to talk to, but described feelings of emotional distress, including feelings of loneliness, when this occurred. Opting out of the relationship with their sick parent was another strategy for preserving self described by children. They were unable to invest energy and regarded the connection with their parent as putting them at risk. Unfortunately, some children described this strategy also negatively impacted their relationship with their well parent.

Young people who lived in families experiencing parental mental illness also reported gauging “their costs and benefits” when considering what energy to expend on staying connected to their parent. If children saw the benefits outweighed the costs they continued to persevere. However, if they felt that the costs outweighed the benefits they gave up trying strategies that allowed them to continue with their day-to-day activities within their family (Mordoch & Hall, 2008). According to Mordoch and Hall (2008), children gauged their situations by comparing “their present to their past, their self to others, and their parents and families to other parents and families” (p. 1136). Older children were more aware about how they compared to other families and were less forgiving of major deficiencies. Younger children were reported to focus more on things getting better and their different, but special relationship with their parent. The authors of this study reported that all of the children in this study assessed their personal and family lives from the point of view of safety and stability and by the rhythm they had with their parent. Significant differences were reported in relation to changes in school, family configurations, family celebrations and rituals and crisis events (p. 1137). Mordoch and Hall (2008) found that most of the children in their study had the capacity to view their parent and their family life beyond their parent’s mental illness, which was seen as positively contributing to the children’s efforts to preserve themselves. Children perceived that positive outcomes were felt when they believed that their present circumstances were better than their past; when they compared favourably to their peers; and when they perceived their family provided as much support, love and fun as other families (p. 1139).

Children in this study reported that periods of acute illness of a parent were most difficult. They did not always understand what was happening and they described experiencing conflicting emotions such as anger, fear, love and frustration. Children in this study expressed compassion for their parents and acknowledged their suffering. Moreover, having a supportive

adult was considered by children as being reassuring, but not all children were willing or able to reach out. Children reported experiencing distress when they were unable to express their negative feelings (Mordoch & Hall, 2008). Even children who were successful in school and saw school as respite from their parent reported experiencing confusing emotions during a parent's acute episode of mental illness. Some of the children in this study worried about whether they would be removed from their home when their parent was hospitalized.

Mordoch (2010) conducted a secondary analysis of the data compiled in the 2008 study with the focus on exploring how children understood parental mental illness. The findings suggest that children are trying to “fit the puzzle together” (p. 21) while only having part of the story. Children tried to make sense of information they received or they had come across. All children reported that they did not have enough information about mental illness and that the topic was not openly discussed. Some children reported overhearing conversations between family members or obtaining information via the media. Mordoch (2010) concluded that this suggested to children that mental illness was not important. As a result the hazy explanations and efforts to protect children escalated these young people's concerns. Children who understood more about parental mental illness felt that their family had managed to stay together and that the children had learned to depend on themselves (p. 21). Mordoch (2010) concludes that the findings of this study provide an important contribution to the literature on working with families who experience parental mental illness and the importance of incorporating the perceptions of children in best practices and interventions.

Mowbray et al., (2006) found that many of the adolescent participants in their study had support from an adult other than their parent, which is often considered protective for this group of young people. Furthermore, the largest clusters of adolescents in this study demonstrated a high level of competence and were reported as high functioning and without

significant psychological distress. This group also scored high on positive coping and school competence. Mowbray et al., (2006) posits that the findings of this study suggest the importance of including “strength-oriented” (p. 217) measures in studies of children of parents with mental illness. Riebschleger (2004) also conducted a prospective study of children’s experiences living with parental mental illness. The study included children aged 5 to 17 years old, with a mean age of 9.36. An equal number of boys and girls participated. Most of the children lived in single parent families who were reported to have limited household income. Parental diagnosis varied and included bipolar affective disorder, major depression, schizophrenia and post traumatic stress disorder. The resulting children’s view of living with a parent with mental illness included themes such as good days and bad days and views about parental mental illness. Children in this study, reported good days as being when their parent was doing well, which included times when a parent would interact more frequently with them including watching TV, helping with homework and going on outings. During these times children reported that their parent was able to complete more daily tasks including doing housecleaning, cooking and going to work. On bad days, parents were described as less attentive and having more withdrawn behaviours. Parents would spend more time in bed, be grumpy, yell and have a temper. One 15 year old described being scared of a parent because “any little thing would set him off” (Riebschleger, 2004, p. 27). On bad days children described their responses to parents as “ignoring, avoiding, and/or engaging in caregiving to reduce family/parental stress” (p. 27). During times when parent’s behaviour escalated children described being afraid of hospitalization and/or suicidal behaviour.

In this study, children who had some understanding of their parent’s mental illness mostly gave behavioural descriptions of their parent when asked about what they knew about and how they found out about their parent’s illness (Riebschleger, 2004, p. 27). Most of the children

reported never being told about their parent's mental illness until they became involved in a community operated mental health prevention program. Five of the children in the study said that they learned about their parent's illness slowly over time as they began to compare their own family to their friend's family. Children also reported that their parent's behaviour was a "family secret" (p. 28). Interestingly, children in this study felt that parental mental illness was only one of a number of concerns in their lives. They reported that stressors such as poverty and parental divorce were more worrisome. Being teased, being angry, associating hospitalization with death, being placed in foster care, moving frequently, blaming themselves for their parent's illness, and "getting" a mental illness were also reported by children and young people in this study (Riebschleger, 2004).

Young people who provide care

It is estimated that approximately one-third of all young people living with a mentally ill parent provide a level of care beyond what would be considered 'normal' within their family (Aldridge, 2006; Dearden & Becker, 2004). These children and adolescents are often referred to as *young carers*. Young carers are generally defined as those under the age of 18 years old, although some studies include young people up to the age of 24 years, who become the primary caregivers in their families due to parental illness, disability or addiction (Aldridge & Becker, 1993; Cree, 2003; Joseph, Becker, Becker, & Regel, 2009). Children and young people become caregivers for many reasons, but usually caring is due to multiple factors that impact the family unit. Frequently children and adolescents take on caring roles because one or both parents are ill; they live in a lone parent family; family members make themselves unavailable; the family has a low level of income and they experience poverty, and there is a lack of adequate accessible parental and family services (Aldridge, 2008; Butler & Astbury, 2005; Thomas et al., 2003; Moore, McArthur & Morrow, 2009).

Who is providing caregiving and why

A trigger such as an acute episode of psychosis or hospitalization of a parent does not allow a child to gradually assume responsibilities that may be more appropriate for their age (Aldridge, 2008). A significant impact on these children may be attributed to the inclination for families to isolate themselves, in part, due to the stigma and shame that is often associated with mental illness (Lees, 2004). Young people often have little choice in the onset, type and extent of their caring duties because of the lack of sufficient support services and because their role either goes unrecognized or they are invisible to the outside world (Aldridge, 2008; Charles, Stainton & Marshall, 2008). Other influences reported to be related to children taking on a caring role include a children's gender, specifically being female, and having a mother who is ill (Aldridge, 2006). The Young Carer study conducted by Aldridge (2006) found that female offspring of a single mother who was not in paid work was most likely to take on a caring role that was long term and disproportionate to her age. In this study the findings indicated that 87% of the sample of parents were mothers with depression or bipolar who were being cared for mainly by their daughters (92%). The average age of the young carers in this study was 12 years old (Aldridge, 2006). A study of young carers in Cornwall identified the age 5 to 10 year old to be a growing cohort, not originally anticipated and a group that is not targeted by young carer support services (Butler & Astbury, 2005). The nature of caring provided by young carers of parents with mental illness is highly dependent on the nature of the parent's illness, which influences the duration and level of caring required.

Children of parents with mental illness are growing in numbers as young carers take on responsibility of caring for a parent with a serious mental illness (Aldridge, 2006). While this group of young people may undertake similar tasks to other young carers such as household chores and caring for siblings they also often provide crisis and ongoing emotional support

(Harstone, Bergen & Sweetgrass, 2010). They frequently monitor the mental health of a parent and assist with administration of medication (Gray, Robinson & Seddon, 2007).

Parentification versus young caring

In North America, young carers are sometimes referred to as parentified children (Charles, Stainton & Marshall, 2009). The young carer definition assumes that young people take on a caring role as a result of their family circumstances (Charles, Stainton & Marshall, 2009). In contrast, parentification assumes “a narcissistic demand being placed upon the young person by the adult” (Charles, Stainton & Marshall, p. 39). According to Peris, Goeke-Morey, Cummings & Emery (2008) emotional parentification is described as “a parent-child dynamic wherein children come to provide ongoing emotional support for parents” (p. 633). Parentification occurs when a parent abdicates their responsibility, which may include support for emotional and physical well being of siblings or a spouse (Gladstone, Boydell & McKeever, 2006). Fitzgerald, Schneider, Salstrom, Zinzow, Jackson & Fossel (2008) suggest that parentification often occurs within families that experience significant stress and family dysfunction as a result of parental mental illness, divorce and marital conflict. In addition, they found a relationship between parentification and childhood sexual abuse that appears to be specific to father-daughter intrafamilial abuse (Fitzgerald et al., 2008). Although the authors suggest further research into how childhood sexual abuse and the nature of the victim-perpetrator relationship may influence parentification, they do suggest that parentification is more common when abuse is chronic (Fitzgerald et al., 2008). Children of parents who experience mental illness may experience role reversal when a parent with mental illness or a healthy spouse leans on them for emotional support, particularly during times of acute mental illness. Conversely, a well parent may abdicate their emotional responsibilities towards their sick partner leaving the child to step into their role.

Findings of a recent study suggests that for parents parentification is linked to high levels of marital conflict, but for youth, it is linked to a greater perception of threat when conflict occurs (Peris et al., 2008). The authors of this study posit that if viewed from the lens of the emotional security theory this suggests that the youth acts by providing emotional support in order to maintain a sense of safety. A number of children of parents with mental illness, like children of divorce or young people who live in families with high levels of marital discord, appear outwardly competent and are seen as resilient. Hetherington and Kelly (2002) report that parentified youth typically grow up as competent and well adjusted adults, although they do tend to feel unsure of themselves and are vulnerable to persistent symptoms of mild depression.

Multiply disadvantaged families who experience parental mental illness

A range of childhood adversity is associated with children of mentally ill parents. Bifulco, Moran, Jacobs, Bains, Bunn & Cavagin, (2002) examined the linkages between maternal and offspring vulnerability, and maternal and offspring disorders. Specifically, they tested the hypothesis that mother's psychosocial vulnerability also transmits risk to her child even when controlled for her depressive disorder. In this study, the authors explored mother-offspring pairs in a relatively poor area of inner-city London that experienced high rates of lone parenthood and socio-economic disadvantages. The mothers in this study experienced recurrent depressive disorders. The authors concluded that children and adolescents in these mother-offspring pairs had a fourfold higher rate of depressive disorder when compared to the comparison series. Furthermore, the children were twice as likely to experience severe physical, emotional or sexual abuse before the age of 17 as the comparison group. It was found that the effects of offspring neglect and abuse contributed to offspring depressive disorder, but simply living with a mother who had depression was not a significant risk factor. The psychosocial disadvantages compounded the effects of parental mental illness adding a significant increase of risk that the

children would develop a depressive disorder. The strength of this study is that the findings highlight the fact that the pattern of transmission of mother's vulnerability to mental illness in children and adolescents is complex and depend on a number of contextual features of family and its circumstances. The limitations of this study included the use of mothers as the primary source of information. Evidence for the father's role in transmission of risks was not explored.

Rutter (1985) also suggests that chronic family adversities such as parental mental illness, marital discord, and overcrowding had less effect on psychiatric risk to children when occurring in isolation, but when several adversities co-existed risk went up sharply. In addition, he concludes that interactive processes need to be considered over time and not just at the single point in time when an individual encounters stress or adversity. These studies are important because they suggest that psychosocial and environmental factors clearly account for a substantial amount of the variance.

Retrospective studies of children of parents with mental illness

Adult children of parents with mental illness

Retrospective studies that explore the experiences of adults, who as children, lived with a mentally ill mother and/or father can make a unique contribution to the body of literature on the topic of children of parents with mental illness. Prospective studies traditionally focus on positive and negative outcomes and the subjective experiences of young people under the age of 19 who live with at least one mentally ill parent (Mordoch & Hall, 2008; Riebschleger, 2004). Understanding the outcomes, possible mechanisms for transmission and experiences of these children is critical to assisting families living with parental mental illness. However, young people over the age of 19 appear to be a somewhat neglected group in literature. Regularly these young people, now in their early to late twenties, have been experiencing parental mental illness

for many years. In their twenties they may still be living with their ill parent and/or are providing a significant amount of support, while at the same time experiencing their own significant life events such as moving away from home. They are beginning the process of separating from their families and starting their own lives. For some children of parents with mental illness this is also a time when they may experience mental health problems. According to Mowbray and Mowbray (2006) the peak age of onset of many mental illnesses occur in young and middle adulthood. However, the type of mental illness experienced by adult offspring during this time is not necessarily the same as their parents (Mowbray & Mowbray, 2006) and having a parent with a mental illness does not mean that all offspring will develop a form of mental illness. Depending on their lived experiences up to this point in their life they may have more or less difficulty transitioning from adolescence into adulthood. As with most children, as adult offspring of parents with mental illness grow older they move through various periods of life and bring with them their childhood experiences. Retrospective studies may help gain a better understanding of the experiences of offspring of parents with mental illness and how they make meaning of their experiences as they move through their lives.

Adult offspring of parents with severe mental illness

Studies that have explored outcomes of grown-up offspring of mentally ill parents suggest as young people while some will experience adversity many are reported to cope well and experience high levels of success in areas such as perceived personal strengths; and social, educational and occupational well-being (Kinsella, Anderson & Anderson, 1996; Knutsson-Medin et al., 2007; Mowbray, et al., 2006; Polkki, Ervast & Huupponen, 2004) both as children and as adults. Mowbray et al., (2006) studied the psychosocial outcomes for adult children of parents with severe mental illnesses who ranged in age from 18 to 30 years old. The results of this quantitative study found that some adult offspring of parents with severe

mental illness reported problems with schooling, psychological problems, poor social adjustment, learning difficulties, trouble with police, legal problems and more persistent emotional and behavioural difficulties than children of parents who were not mentally ill. The authors inferred that adult offspring in their study had relationship problems as only one in nine was in a committed relationship. An important finding of this study suggests that a mother's bipolar diagnosis was a significant independent predictor of negative outcomes in adult child. This study did not identify any mechanisms by which a bipolar diagnosis may have such negative and long term effects on children. In contrast, positive life outcomes were also identified, which included high levels of postsecondary education or training and working in adult offspring of mentally ill parents. More than 70 percent of adult offspring lived nearby and had contact with their mothers. Contrary to other studies, the authors found relatively few adult offspring had drug or alcohol problems and most reported being satisfied with their parent-child relationship. In fact, the authors found that older adult offspring were reported to have problems in fewer life domains and for each year of age there was a marked reduction in the number of problems.

A limitation of this study was the narrow sampling of mothers who were recruited from a USA public health system. The sample may not be representative of the adult offspring of all women with severe mental illness. Furthermore, only mothers' reports were used to compile the data in this study. However, most of the mothers were in frequent contact with their children. The authors noted that based on other data, these mothers had been found to be accurate reporters of child and adolescent behaviours and problems.

Knutsson-Medin et al., (2007) used a questionnaire to gather data from 36 grown-up children of previous psychiatric inpatients. Study participants ranged in age from 19 to 38 years old. The aim of this study was to follow-up with adult children to examine their

experiences of growing up with a mentally ill parent. Questions related to social adjustments including education, employment, morbidity, sick-leave, and contact with health care systems, residential status, marital status and social network. Participants were asked both standardized and open-ended questions, “both good and bad” (p.746), of their parents’ mental illness and its impact on them as children. Similar to a study conducted by Mowbray et al., (2006) about one third of the participants had completed higher education. Positive experiences reported include feelings of relief when they were supported during their parent’s hospitalization and when treatment was effective the experience was positive. All of the participants were reported as being very well adjusted based on education and employment status and none were without a residence. A surprising finding in this study was that 25% of adult offspring of a mentally ill parent reported previous contact with child and adolescent psychiatry. This was higher than the general population. Furthermore, approximately 20% of participants had been in contact with adult psychiatry, a higher proportion than the expected rate of 6-7% in society (Knutsson-Medin et al., 2007). Despite reports of seeking support for some level of mental illness these adult offspring all had a high level of social adjustment. The authors could not account for the discrepancy between higher levels of psychological distress in adult offspring of mentally ill parents in this study with the high levels of social adjustment.

Adult offspring also reported negative experiences as children growing up with a mentally ill parent. These included lack of support; lack of information or explanation from psychiatric staff about their parent’s mental illness, and that when a parent was hospitalized the stay was too short, resulting in the children taking on greater caring responsibilities (Mowbray et al., 2006). Experiences as children also included worry, increased responsibility, negative emotions and changed parent-child relations (Knutsson-Medin et al., 2007; Cree, 2003). One

of the main strengths of these studies is the descriptive data, which shows participants' experiences to be reflective of other children of mentally ill parents.

Adult offspring of parents with bipolar and depression

Mowbray and Mowbray (2006) conducted a study of adult offspring of mothers diagnosed with depression and mothers diagnosed with bipolar disorder. The aim of the study was to describe the status of adult offspring on a range of psychosocial outcomes. The participants in this study ranged in age from 20 to 29 years old. 62% were male and 33% were female; 59% were African American; 28% were Caucasian; 7% were Latino and the balance stated they were of mixed race origins. Approximately one third had some high school education; one third had a GED or went to trade school and one third had a college education or higher. In this study, the majority of the participants reported having in their family either serious injury or trouble with the law, or experiencing neglect before the age of 18 years (p. 134). They also reported physical illness in their families; experiencing childhood abuse, or that they thought one parent was addicted to alcohol or drugs. Furthermore, 40% of the parents had separated and 33% reported growing up in a single parent family. Social support was found to be an important factor for functioning. Adult offspring described growing up in families who had strengths and reported having social supports as children. Best friends were reported to provide the most amount of social support, followed by support from grandparents, mothers, siblings and fathers. Social support was found to positively correlate with working and current social economic status and negatively to criminal history.

Overall, the adult offspring had few problems with alcohol use or behavioural health problems, but did show a high incarceration rate and high use of mental health services. When compared to national statistics of incarceration the sample in this study was nearly

triple the national rate of the population in the same age group, 3.3% compared to 9.8%; for males whose mothers had a bipolar diagnosis the incarceration rate was 12.5%. Educational achievement varied widely with as many adult offspring not completing high school as did complete post secondary education. All of the adult offspring came from similar backgrounds including living in lone parent families; living in poverty and having a minority status. Mowbray and Mowbray (2006) argue that the findings of this study are evidence that “conclusions about across-the-board negative outcomes for children of parents with serious mental illnesses are clearly inappropriate” (p. 139). They go on to stress the need for researchers to focus on identifying specific mechanisms that may contribute to positive or negative outcomes. The authors had speculated that self-reported childhood risk factors would be predictive of adult outcomes; this prediction was not proven (Mowbray & Mowbray, 2006).

Adult offspring of parents with bipolar or schizophrenia

Although children of parents with schizophrenia are at higher risk of developing a mental illness, most do not (Duncan & Browning, 2009). There is limited research that focuses on the experiences of children of parents with schizophrenia or bipolar. One qualitative study, conducted by Dunn (1993), found that participants who were raised with mothers with schizophrenia or bipolar recalled childhood abuse, neglect and isolation. The participants in this study ranged in age from 24 to 61 years of age. Most study participants lived with both parents, at least as young children, and had mothers with either schizophrenia or bipolar. These adult children also reported experiencing a lack of effective communication with their mother, which they felt often lead to isolation. Participants in this study also stated they had at least one supportive person who helped them in childhood and all but one participant had undergone therapy as an adult (Dunn, 1993). As with most maternal mental illnesses, the impact on

parenting may lead to the inability of a mother to respond effectively to a child has been reported in studies of maternal schizophrenia (Duncan & Browning, 2009). Some children in this study recalled a “kind of absence” (p. 81), which was often due to hospitalization. Other children described the family as a whole as not providing protection. For the child this meant they had to be very self-sufficient and deal on their own with the unpredictable behaviour of their parent (Duncan & Browning, 2009). In this study of adult attachment of offspring of parents with schizophrenia, Duncan and Browning (2009) found that some adult offspring experience mistrust of people as adults. Other participants reported difficulty with forming lasting relationships, while one participant felt that her childhood experiences with her mother did not adversely affected her adult life.

Some adult offspring described their relationship with their mentally ill mother as being closer from adolescence onward (Duncan & Browning, 2009). In contrast, one adult child felt that her instinct was to distance herself from her mother for self-preservation. Another study participant felt that her choice in a partner reflected her childhood experience growing up with a mother with schizophrenia. She found herself attracted to a man who was funny and a “bit on the crazy side” (p. 82) because the relationship felt familiar (Duncan & Browning, 2009). Another participant in this study described the confusion and chaos she felt as a child living with her father. She described still feeling the same as an adult. A mother-daughter relationship was described by another participant as “knowing that it was something I was always on the outside of” (Duncan & Browning, 2009, p.82). Finally, another study participant described wanting guidance as a teen because she did not know “what it was like to love somebody” (p. 82). Overall, study participants spoke of difficulty trusting in relationships and that they were sometimes frightened of feelings. The authors of this study suggest that the detachment or unpredictability experienced in childhood living with a parent with schizophrenia were

generalized and moved forward into adulthood as the child grew older (Duncan & Browning, 2009).

Making meaning of experiences as an adult

Grief and loss

“Grief without end” (Wasow, 2000, p. 127) is sometimes how the grief and loss of children of parents with mental illness is described by adult offspring of a mentally ill parent. Wasow (2000) conducted a series of informal interviews for her book entitled, *Skipping Stone: Ripple effects of mental illness on the family*. Adult offspring spoke of the grief they experienced over serious parental mental illness as being different from grief that is felt by the loss of a loved one. Lay literature such as Wasow’s (2000) discusses families who frequently experiencing a dual loss: loss of the person that was and the person who will never be. Children of parents with mental illness (COPMI) may also mourn the loss of their own hopes and dreams and for what could have been. Sometimes learning more about mental illness can help families, but overtime, less chaos and desperation within the family may occur and help to ease emotions (Wasow, 2000). The stigma and silence associated with mental illness can contribute to ineffective expression of feelings. Some COPMI are able to explore their feelings, while others distance themselves. According to Mueser and Gingerich (2006), adult children of a parent with schizophrenia have reported having intense feelings of grief and loss, empathic pain for their parent, and guilt that they had somehow caused the illness. These adult offspring expressed a belief that their own needs had not been met and some had feelings of helplessness, hopelessness and regret for their unfulfilled potential.

Marsh and Dickens (1997) incorporated the heart-felt narratives of experiences of families living with mental illness in their book, *Troubled journey: Coming to terms with the mental*

illness of a sibling or parent. The authors conducted informal interviews with adult offspring and adult siblings of individuals living with mental illness. Adult offspring of parents with mental illness described the grieving process as being at the core of the family experience of mental illness. These offspring described experiences that may suggest they continue to experience unresolved grief (Marsh & Dickens, 1997). Interviewees described their grief as an “emotional roller coaster” and as “empathic pain” (p. 24-25), both experienced as ongoing and persistent across time. One adult reported feeling as if his mother’s pain was his own.

Grief and loss felt by children of parents with mental illness may be exacerbated because of the periods of wellness and acute illness experienced by their parent (McElroy, 1987). Literature refers to this type of loss as psychic loss whereby a parent lives on, but changes profoundly, altering the parent-child relationship (McElroy, 1987). This type of loss likely changes overtime and is likely different for young people when compared to adult children. In fact, Mordoch and Hall (2002) caution that further research is necessary to support these claims and that more research is need to gain a better understanding of “how those feelings operate in children’s lives” (pg. 214).

Maunu and Stein (2010) explored religious faith and spirituality of young people in relation to personal loss due to parental mental illness. The study participants were between the age of 18 and 22 years. In this study personal loss was grouped into loss of social roles, loss of former relationship, loss of sense of self, loss of normal routine and loss of a sense of the future (p. 649-650). Participants who reported feeling a greater amount of loss felt they were spiritually “adrift” (p. 650) and somewhat spiritually confused. Those who experienced less overall loss due to parental mental illness expressed contentment with what they referred to as their spiritual journey.

Childhood maltreatment

Child maltreatment includes neglect, emotional, physical and sexual abuse (Thomas & Hall, 2008). Children who experience one form of abuse are more likely to experience other forms of abuse. This abuse is likely to occur in families who experience multiple stressors including family conflict, substance problems, non-nuclear family structures and parental mental illness (Menard, Bandeen-Roche & Chilcoat, 2004). Children often felt the message conveyed by abuse was that they were unsafe (Menard et al., 2004). Studies have found that neglected and sexually abused children tended to have poor emotional regulation skills, while children who experienced physical abuse may show deficits in emotional understanding (Jungmeen & Cicchetti, 2010). In contrast, children who experienced emotional maltreatment did not show significant differences in emotion regulation when compared to non-maltreated children (Jungmeen & Cicchetti, 2010). Jungmeen and Cicchetti (2010) also suggest that children who experience family environments that are unpredictable and frightening regularly have caregivers who lacked impulse control and overreact to life stressors. Living in this type of environment where distress and conflict is the norm, physically and sexually abused children almost constantly experience high levels of arousal and vigilance. These high levels of sustained exposures to stress may eventually reduce a child's capacity to effectively regulate their emotions (Jungmeen & Cicchetti, 2010).

There is evidence of a greater psychological trauma in children who experience abuse at the hands of their fathers (Phares & Compas, 1992). Other studies found greater impacts on psychosocial adjustment associated with sexual abuse by fathers (Sirles, Smith & Kusama, 1989). In general, abuse by a parent was related to poorer adjustment (Sirles, Smith & Kusama, 1989) and families at risk for abuse were often found to be more enmeshed and chaotic (Garbarino, Seves, & Schedlennbach, 1984). Amrunga, Fisher, Harris, Macedo, and Rogeness (1986) found higher rates of mental illness in parents, especially fathers, of physically abused

and neglected children. Mothers of neglected children had higher rates of mental illness, while fathers of abused or neglected children had higher rates of psychiatric disorders and antisocial personality than fathers of non-abused or neglected children (Phares & Compas, 1992).

Felt obligation

Connections with family are important to many children, and children of parent with mental illness are no exception. A study conducted by Abraham and Stein (2010) is one of the first studies to explore young adults' feelings of obligation towards parents and the associations between obligations and psychosocial adjustments. Stein (1992) describes felt obligation as a construct that contains both separateness and connectedness characteristics of the young adult-parent relationship; "the glue that connects generations" (Stein, 1992, p.525). While felt obligation is similar to the construct of affection between adult children and their parents in that they are both a way to maintain intergenerational relationship, they differ. Felt obligation is defined as "a set of actions or behaviours adult children feel bound to perform" (Abraham & Stein, 2010, pg. 126). In comparison, affection is defined as "general fondness adults feel towards their parents" (p. 126). Felt obligation is also described as different from "filial obligation" (p. 126), which is defined as the attitudes that adult children hold towards their responsibilities to their parents. Abraham and Stein (2010) explain felt obligation as being "negotiated commitments" (p. 126), which are felt by adult children and are "applied within a family context, and are relevant across the life course, not only when a parent is elderly" (Abraham & Stein, 2010, pg. 126).

This current study compared young adult children's self report of psychological symptoms, psychological well-being, interpersonal loneliness, and felt obligation across families affected by maternal mental illness; families affected by paternal mental illness and families without mental illness (Abraham & Stein, 2010). Participants in this study were young adults, with a mean age

of 19 years old, who attended a medium sized, Midwestern American university. Young adults in the study were primarily female (69%) and Caucasian (88%). Participants reported that 33 had mothers with mental illness; 20 had fathers with mental illness and 41 reported that neither parent had a mental illness. The majority of parents with mental illness were diagnosed with major depression, while others included bipolar disorder and schizophrenia. Participants whose parents did not have a mental illness reported that approximately 80% were married. Conversely, marriage rates in families of participants with parents who had a mental illness ranged from approximately 64% to 75%. Findings in this study suggest that connectedness to both mother and father in all types of families may influence emotional and social well-being of adult children.

Abraham and Stein (2010) found that reports of felt obligation by young adults who lived with a mentally ill parent to be relatively comparable to young adults who did not experience parental mental illness. Furthermore, there was no significant difference in felt obligation between sons and daughters towards their parents. Findings of this study suggest that adult children, regardless of gender, felt a greater obligation to mothers than towards fathers. Young adults with a mother who lived with a serious mental illness reported more symptoms of mental health, loneliness, and less overall psychological well-being. Surprisingly, young adults with a father with a serious mental illness reported mental health, loneliness and overall psychological well-being that was similar to young adults who did not have a mentally ill parent. The authors of this study suggest that these findings may point to “something uniquely challenging about having a mother, rather than a parent, with a serious mental illness” (Abraham & Stein, 2010, p. 131). Given that young people generally feel more connected to their mother, having a mother with a serious mental illness may be “a particularly challenging life course disruption” (p. 131). Abraham and Stein (2010) also suggest that more connectedness and a higher obligation to maintain parent-young adult relationships may promote greater psychological well-being in adult

offspring of parents with mental illness. When fathers had a serious mental illness, felt obligation was found to be in the form of assistance and personal sharing with both mothers and fathers, which was associated with better psychological adjustment in adult children. This may indicate that tangible and emotional connections to both parents are important to young adults' psychological well-being (Abraham & Stein, 2010). In previous studies childhood relationships with both parents was found to be important to psychological well-being of offspring of mothers with serious mental illness (Mordoch & Hall, 2008; Mowbray & Mowbray, 2006).

Adult offspring caring for parents with a mental illness

Changes in the availability of drugs to treat mental illness together with de-institutionalization and a focus on integrating individuals into their community have all been positive changes for families who experience parental mental illness. Unfortunately, support services are not always available for families, especially when a parent is released from hospital too early creating stress for themselves and often their adult offspring. The lack of available housing and family-centered programs can exacerbate the challenges. Research on the outcomes and experiences of young people, generally under the age of 18, who care for parents with a mental illness, can be readily found in young carer literature (Aldridge, 2006; Aldridge & Becker, 1999; Cree, 2003). However, as young adults leave home to pursue education and job opportunities they are often caught between the need to live their own lives and the need to leave their parent and possibly other family members to care for themselves. There is a gap in the existing literature in adult offspring caring for parents with mental illness, especially young adults. Little, other than anecdotal accounts of caring is known about this group of caregivers. Young adult caregivers may be assisting an ill parent with finances, acting as a liaison between a parent and the health care or criminal justice system, or assisting with care planning and providing practical day-to-day support. This caring often occurs because of a lack of available formal services during acute

episodes of illness and because adult children continue to feel responsible for their mentally ill parent.

Parental mental illness can cause delays in life course events of individuals with an illness as well as in their families (Cook, Cohler, Pickett, & Beeler, 1997). Many parents successfully live in the community and only require additional assistance during acute episodes of illness. If these episodes are prolonged, or occur frequently, a young adult child's life course may be disrupted. For example, they may delay or postpone post secondary education as they attempt and perhaps even initially fail to stay connected with their mentally ill parent and move on with their own adult life. There is minimal knowledge about the experiences of young adults who continue to care for their middle aged or elderly mentally ill parent.

Transition to adulthood and life course events

Marsh and Dickens (1997) conducted informal interviews with adult children of parents with mental illness to explore their experiences. Fifty one percent of participants reported difficulties with separating from their families as young adults. The authors suggest that adult children whose needs were not met as children and adolescents due to their family being overwhelmed as a result of parental mental illness may not have developed the resources necessary to cope effectively in an adult world. Although difficulties with transitions into adulthood have been found in other studies (Kinsella, Anderson & Anderson, 1996) specific details are not regularly reported. One study that may provide a starting point for considering possible difficulties in transitions is a study conducted by Yahav, Vosburgh, and Miller (2007) that examined the separation-individuation process of adolescents of parents with multiple sclerosis (MS). Separation is characterized by the need to separate from one's parent in order to build one's own identity (Yahav et al., 2007, p. 88). The findings of this study suggest that children of parents with MS behaved more maturely and felt more responsible for the well-being of their parent. The authors of this study hypothesized that

these children may give up their own needs in order not to burden their parents and this may result in a disruption in the separation-individuation process. Children of parents with MS display a significantly higher degree of separation anxiety than adolescents of healthy parents. They also report more symptoms of depression and anxiety. Connectedness that develops during a child's early years is considered a stable feature of the parent-child relationship (Buhl, 2008). Separation-individualization occurs when a balance between the need for independence and the need for support is achieved (Yahav et al., 2007, p. 88). Significant events that are often associated with individuation include leaving the parental home; marriage; and entry into the workforce. More research is required about how transitioning into adulthood may be influenced by the experiences of living with a parent with a chronic physical and/or mental illness.

The self help movement of the 1980s and 1990s began to touch on the experiences of children of parents with mental illness with a number of books for "adult survivors" (Brown, 1989; Marsh & Dickens, 1997; Wasow, 2000). Lay literature based on autobiographical accounts of adult offspring of parents with mental illness may illuminate some of the experiences of transitioning from adolescence into adulthood. In these accounts adult offspring talk about feelings of "survivor guilt" (Brown, 1989, p.16), which often reached a crisis point around the issue of leaving home. Brown (1989) suggests that in well-adjusted families an adolescent has been given the tools to move smoothly into adulthood, but for children who grow up in families who experience parental mental illness the story is often quite different. Brown (1989) writes of accounts of children who arrive in adulthood without the skills or support. Furthermore, these adult children talked about transitioning from late adolescence to adulthood as a period of time that is confusing and painful. She describes accounts of young adult child who struggle to leave their ill parent and their long term family role and the grief and guilt that follows them as they also leave their well parent. The accounts frequently end with adult children experiencing

periods of depression as a result of their inability to cope (p. 17). While some children choose to remain separate, but close to their family home, others consciously choose to make their own lives, moving far away. The later choice frequently includes a complete break from family. For some adult children the choice to leave family comes at a high price and their constant guilt manifests itself in unconscious ways (Brown, 1989). One adult child stated “because I abandoned my family in their pain, I don’t deserve to have a successful and enjoyable life” (Brown, 1989, p. 19). Another strategy of self sabotage revealed by adult children included making sure “you never get really good at what you are doing, so that you never get to enjoy the praise of others” (p. 20). Others stated that they took on the role of perpetual “fixer” (p. 20). Finally, these transitions as described by adult offspring of parents with mental illness rarely occur in a lineal fashion. Hitlin and Elder (2007) suggest that the timing and order of transitions are highly variable, depending on the individual.

Making meaning of childhood experiences

Physical and psychological well-being has been linked to individuals who are able to create meaning in their lives (Frankl, 1963). The meaning of “meaning” has been defined in many different ways. Baumeister (1991) argued that the experience of meaning in life is dependent on meeting four psychological needs: purpose, value, efficacy, and self-worth. Individuals often feel that their life has meaning when it matters in some larger sense (King, Hicks, Krull & Del Gaiso, 2006). There is a long history in coping research of exploring the making of meaning in traumatic life events as positively influencing overall well-being in individuals (Kray, George, Liljenquist, Galinsky, Tetlock, & Roese, 2010). Constructing meaning in life is done by employing various strategies. According to McAdams, Reynolds, Lewis, Patten and Bowman (2001), one strategy used to construct life stories, which in turn can create meaning, is the use of redemption sequences. McAdam et al., (2001) investigated how individuals made narrative sense

of life altering personal experiences. In constructing a redemption sequence in life storytelling the storyteller tells of a transformation from bad to good. The bad is redeemed, salvaged or mitigated (McAdams et al., 2001, p. 474) as it transforms to good. This process of identity-making through life story construction continues throughout most of the adult life course and is profoundly shaped by the cultural rules and traditions concerning good lives and good stories to which individuals are exposed (p. 475). It may be possible that as adult offspring of parents with mental illness construct their life story the cultural norms and beliefs they experience about mental illness may play a significant role in how they make meaning of their experiences living with parental mental illness across their life course. This process of making meaning may also be influenced by significant events in an offspring's life including leaving home, struggles with their own mental health, marriage and parenthood.

Risk, protective factors and resilience

Studies suggest that any influences of parental mental illness on children needs should be considered through a number of different lenses including the age of the child, chronicity of parent's illness, factors associated with resilience, psychosocial context of the family and available social supports (Bifulco et al, 2002; Mordoch & Hall, 2002; Peisah et al., 2005; Rutter, 1985). Much of the existing research that focuses on positive outcomes and negative consequences for children of parents with mental illness is framed around the notion of risk and protective factors. This concept suggests that protective factors can mitigate risks leading to higher levels of overall wellness for children who grow up with a mentally ill parent.

The term risk is defined as individual or environmental factors that increase a child's vulnerability to experience negative developmental outcomes (Rutter, 2007). Examples of risk factors reported in literature include timing of parental mental illness in terms of children's growth and development; parental psychiatric diagnosis; and socioeconomic status (Mordoch &

Hall, 2002). In comparison, protective factors are seen as those that positively mediate the effects of risk, decreasing the chance of negative outcomes (Bandura, 2006; Foster, O'Brien & McAllister, 2005). Protective factors are reported to include factors such as a belief in one's own effectiveness, being optimistic, using effective communications and problem solving skills; involvement in activities outside of the family home and a low level of marital discord (Foster, O'Brien & McAllister, 2005). Rutter (1985) suggests that protective factors also include: a mentally healthy spouse and maintenance of a good relationship with at least one parent. However, it is not possible to predict success for children and ultimately grown-up children of parents with mental illness simply by weighing the number of protective against the number of risk factors. Many experiences can lead to risk or protection for children depending on how they are experienced (Rutter, 1985). For example, how are individual factors, family factors, parental functioning and parenting, social and environmental aspects of life experienced independently and how do they interact together (Foster, O'Brien & McAllister, 2005; Rutter, 1985).

The lack of consistency in studies of the effects of parental mental illness on children's health has contributed to a shift in focus from negative aspects of living with a mentally ill parent to a shift in focus to children who appear to thrive despite their life circumstances (Mordoch & Hall, 2002). Definitions of resilience are controversial (Mordoch & Hall, 2002). Knutsson-Medin et al., (2007) define resilience as "a dynamic process whereby high risk individuals, such as children of parents with mental illness, bounce back from adversity and adjust well to life" (p.744). Rutter (2007) suggests that resilience implies relative resistance to environmental risk experiences, or the overcoming of stress or adversity. Meaning is also important as a person's appraisal of a situation may define whether or not it is seen as positive or threatening (Rutter, 1985). Finally, Rutter (2007) suggests that "the mediating mechanisms

giving rise to resilience might be in personal agency, or coping strategies, that is, what individuals do in order to deal with the challenges they face” (p.205).

Resilience and coping literature focuses on the phenomenon that some individuals have relatively good outcomes despite suffering high risk experiences (Rutter, 1985; 2007). One concept of resilience is grounded in the literature on stress and coping (Fraser, 2002). This type of resilience refers to “sustained competence under stress” (Fraser, 2002, p. 14) where children and adolescents living in families where conflict is high display an ability to cope with chronic environment and interpersonal stress. This perspective considers a child’s ability to both interpret and act on a situation allowing for the restoration or maintenance of their internal or external equilibrium. This is not to suggest that children live without pain or anxiety (Fraser, 2002). Generally, resiliency is thought to be resulting from the interaction between risk and protective factors. However, these factors must be understood within the context that they occur. From an ecological perspective the effects occur at multiple systems levels including psychosocial and biological characteristics of individual children, contextual factors in the family, school, neighborhood or larger settings (Fraser, 2002).

RE-CONCEPTUALIZING: BEYOND RISK AND RESILIENCE

During the 1960s and 1970s research focused on the kinds of pathology children inherited from their parents (Anthony, 1968; Mednick, Schulsinger & Schulsinger, 1973). This perspective considered the negative consequences, or risks, to children living with a parent experiencing mental illness. Numerous research studies suggest that many children of parents with mental illness (COPMI) will experience adverse consequences that often persist into adulthood. Over the past few decades researchers have also emphasized positive outcomes in children of parents with mental illness (Foster, O’Brien & McAllister, 2005). This prevailing discourse seeks to understand childhood risk and protective factors in an attempt to predict

adult outcomes. This current discussion often portrays children of parents with mental illness as victims who are unable to contribute to shaping their own lives. Children of parents with mental illness (COPMI) do experience adversity as well as benefits from positive experiences. These young people and their families do require support, and in some cases children do require protection. With the current focus on positive outcomes in some children there has been an increase in characterizing some COPMI as exceedingly competent; sometimes labeling them as “invulnerable” or “resilient” (Anthony, 1987; Cohler, 1987; Rutter, 1985). For the most part, offspring of parents with mental illness tend to struggle at some point in their lives, but these struggles do not necessarily indicate that they will have poor outcomes as adults. Using the formula of childhood risk, less protective factors, equals positive or negative adult outcomes does not tell the whole story of growing up in a family that experiences parental mental illness. It does not suggest how these experiences may influence outcomes in adulthood. Gaining knowledge from individuals may provide some clues. To date, few studies have explored the subjective experiences of grown-up children of mentally ill parents (Mowbray et al., 2006; Mowbray & Mowbray, 2006; Knutsson-Medin et al., 2007).

Most research about children who lived with a mentally ill parent primarily view the children as being at risk of developing mental illness themselves and that those who do not are considered to be resilient (Gladstone, Boydell & McKeever, 2006). Seifer and Sameroff (1997) argue that the problem with most risk models is that they are based on a single factor that defines child vulnerability, such as parental mental illness. For example, Seifer and Sameroff (1997) studied the risk factors for children of living with a mother with a mental illness. They found that severity and chronicity of maternal mental illness was a better predictor of poor outcomes than a diagnosis. This example shows that a factor, maternal mental illness, which is often treated as a simple index of risk, has its own complexities that

must be considered (Seifer & Smeroff, 1997, p. 65). This finding strengthens the argument that only considering risk and protective factors, while neglecting how risk and protective factors are experienced and in what context does not tell the real story of who is at risk and who is not. Moreover, Gladstone, Boydell and McKeever (2006) argue that this prevailing discourse on risk and resilience limits the way the children are conceptualized. This view casts children as “passive, developing, and unfinished persons” (p. 2541) instead of casting them as “competent contributors to social life despite their vulnerabilities” (p. 2541). Despite the extensive literature that emphasizes the risks parental mental illness poses to children, many studies support the notion that children of parents with mental illness are also found to be socially accomplished, even though they experienced difficult childhoods (Knutsson-Medin et al., 2007; Mowbray et al., 2006).

Limiting the conceptualization of children of parents with mental illness to a focus on risk and resilience does not allow for expression of children’s experiences, which could reveal the potential range of positive and negative consequences of growing up with a mentally ill parent. What does it mean to children and adolescents to “respond healthily to parental mental illness” (Gladstone, Boydell & McKeever, 2007, p. 2543)? Often research fails to consider the unique meaning, including the experiences, perceptions and understanding for each young person who lives with a mentally ill parent. These children are often invisible within the social processes that shape their lives (Gladstone, Boydell & McKeever, 2007). Children’s social competencies should be viewed as suggested by Gladstone, Boydell & McKeever (2007) as “socially constructed and negotiated” (p. 2545). From this perspective, children are considered to be engaged and actively contributing to the world. This does not mean that children are not vulnerable. Children’s competencies vary with context and co-exist with their biological vulnerabilities such as their genetic vulnerability to mental illness (Gladstone, Boydell &

McKeever, 2007). Children may also have a relative lack of experience that may lead to unrealistic expectations about levels of competency place on them by themselves or others.

Mordoch and Hall (2002) suggest that it would be helpful in clarifying, redeveloping and extending the concept of resilience to understand children's perceptions about what assists them to define themselves as successful in a family that lives with parental mental illness. Rutter (2000) adds that understanding of the meaning of resilience and the nature of the protective processes that operate in children's lives in a number of contexts, including class and cultural, would be useful in helping define the concept of resilience. This meaning is constructed through interaction between the child and their parent and groups within society (Mordoch & Hall, 2002).

RATIONALE FOR STUDY

Only a small number of studies have focused on adult offspring of mentally ill parents (Mowbray & Mowbray, 2006) and even fewer studies have explored subjective experiences (Kinsella, Anderson & Anderson, 1996, Knutsson-Medin et al., 2007; Mordoch & Hall, 2002). This exploratory retrospective study focuses on the experiences of adults, who as children, grew up with a mentally ill mother and/or father. In addition, it aims to gain a better understanding how adult offspring of parents with mental illness make meaning of their experiences. While prospective studies have focused on outcomes and experiences of children and adolescents living in families who experience mental illness, retrospective studies have the ability to consider childhood experiences in the context of significant life events in adulthood. Transitions into adulthood have been reported as difficult (Kinsella, Anderson & Anderson, 1996), but descriptions of how they were experienced are missing in the literature. Young to middle adulthood is also traditionally a time when significant life events such as moving out of the family home or away from home to attend post secondary education, marriage and

parenthood are experienced. This study will explore the childhood experiences of adult offspring of parents with mental illness as well as how they make meaning of these experiences as they moved through various life experiences in adulthood. The findings of this study may provide a glimpse into the lived experiences of children of parents with mental illness and contribute to a better understanding of the influences, if any, childhood experiences of parental mental illness have on adult offspring's lives. In turn, findings may contribute to improving current social work practice with child and families who experience parental mental illness. The context in which these children grow up plus the way that they experience the various aspects of their lives varies significantly from individual to individual (Rutter, 1985). It is for these reasons that gaining a better understanding of the subjective experiences of grown-up children who lived with a mentally ill parent is of importance.

RESEARCH QUESTIONS

What are some of your experiences growing up with a mother and/or father who experienced mental illness? How do you make sense of the experiences you had as a child as you experience significant events in your own life?

METHOD

Byrne (2003) suggests that the inclusion of the information seeking process of inductive inquiry can assist in understanding a phenomenon from a participant's point of view, focusing on subjectivity or the meaning that individuals attribute to aspect of their lives. Qualitative research can help with understanding the experiences of adult offspring, who as children, lived with a mentally ill mother and/or father. In addition, seeking to understand these experiences shifts the focus from seeing children of parents with mental illness as victims who have little control over life outcomes to a view that assumes that individuals are active participants in life (Byrne, 2003). When considered from this perspective, the paths that these offspring take in their lives are created by the interaction between personal factors and diverse influences in the environment in which they live their lives (Byrne, 2003). Life events, which vary and occur over time, also play a role in shaping the course of an individual's personal development (Bandura, 2006). Understanding the lived experiences of children who grow up with parental mental illness can help to inform how they construct meaning of their experiences. This knowledge could in turn assist in further understanding the processes that occur and the influences of negative and positive experiences (Byrne, 2003). Furthermore, understanding these experiences can aid in the development of policy and inform practices that support children of parents with mental illness and their families.

Research design

An exploratory qualitative study is the best approach for examining the experiences of individuals (Charmaz, 2006). This study is informed by a social constructivist view of the world that reality is constructed through human activity. Specifically, a social constructivist view assumes that reality is socially and culturally constructed leading to the experience of one

individual being different from another's experience (Charmaz, 2006). Moreover, many factors contribute to how one views his or her experience. For example, different families will have different definitions of mental illness including to what degree a parent is seen as mentally ill. Psychosocial factors such as socio-economic class; support networks; experiences with health and/or mental health care, the criminal justice system and/or child welfare systems; cultural backgrounds; lone parent or two parent families; marital discord, and open versus closed communication within and outside a family will all contribute to individual experiences. One assumption of constructionist grounded theory is that people are active, creative beings who attempt to solve problems in their lives and worlds. From this perspective subjective meanings emerge from experience and they change as experience changes (Charmaz, 2008, p. 521).

This qualitative exploratory study is informed by Grounded Theory. In Grounded Theory preconceived ideas and theories are not forced upon the data rather themes emerge and the data is analyzed (Charmaz, 2006). From the beginning of the research the Grounded Theory method is used to learn what is happening. Themes and ideas are chosen and pursued during the interview process. During studying of the data further ideas may emerge, which are pursued by the researcher. According to Weiner (2007) the fundamentals of grounded theory include: concurrent data collection, analysis and theory construction, beginning coding with the first interview, memo writing, constant comparison, theoretical sampling, theoretical saturation, and identifying a basic social process. A major strength of grounded theory methods is that they provide the tools for analyzing processes and hold much potential for studying social justice issues (Charmaz, 2008, p. 508). This study is informed by Grounded Theory, but does not seek to create a mid-level theory related to the experiences of children of parents with mental illness. However, this study does aim to inform policy and practice for children who experience parental mental illness and their families.

Selection and recruitment

Sampling design

This study took a purposive approach to sampling. The goal was to recruit participants who are uniquely able to be informative because they are adults, who as children, lived with a mentally ill mother and/or father. This type of sampling is most suited for an exploratory qualitative study that seeks to gain a better understanding of unique experiences of individuals (Padgett, 2008).

Method of recruitment

Study participants were recruited through the University of British Columbia, School of Social Work. A recruitment poster (see Appendix A) was designed to educate potential study participants including undergraduate and graduate students, staff and faculty, about the study and to clearly articulate the criteria for participation. Posters were displayed at various locations throughout the School of Social Work including the student lounge, the reading room and the hallways. Hardcopies of posters were placed in each faculty member's mailbox in the main office. In addition, the recruitment poster was distributed to current students, faculty and staff electronically using the School of Social Work's email list.

Prospective study participants were asked to contact the researcher either by email or telephone for further information. If an individual met the criteria for participation a consent form (See Appendix B) was emailed to them for review. The researcher contacted the participant within 48 hours of receipt of the consent form to setup a mutually agreed upon interview time. This time lag between receiving the consent form and setting up an interview gave the prospective participant time to review the details of the study as outlined in the consent and provided time to reconsider their participation. The prospective participant signed the

consent form prior to the interview taking place. A copy was provided to the participant and the signed copy was kept in a locked file cabinet.

The goal was to recruit between six and eight study participants. Six individuals participated in the study. Four responded from the School of Social Work and two additional participants from outside of the School responded as a result of being forwarded the research flyer. Five of the six study participants are trained social workers with a minimum of an undergraduate degree in social work. Four are practicing social workers. One study participant completed three years of a four year undergraduate degree in general studies.

A second phase of recruitment was undertaken. An amendment to the initial ethics application was submitted and approved by UBC's Behavioural Research Ethics Board (BREB) allowing the researcher to recruit study participants from the general public. Recruitment posters were placed in various community centers and coffee shops. Copies of recruitment posters were also emailed to local Neighbourhood Houses for posting on their community bulletin boards. There were no responses from the second phase of recruitment for this study. Due to the nature, limited timeframe and resources of this study no further recruitment activity was pursued.

Criteria for participation in this study

The following was the criteria for this study: 19 years of age or older; speak English; have lived in a family where at least one parent had a mental illness, diagnosed or self-reported; willing to share their experiences; and sign a consent form. I acknowledge that these criteria may have excluded certain individuals and been a barrier for participation. However, the use of an interpreter was not within the scope of this study.

I interviewed six study participants ranging in age from 27 to 63 years old. Two parents with a mental illness were mothers, while four were fathers. Three of study participants grew up with parents who were diagnosed with bipolar disorder; two fathers and one mother. The other three

study participants were unaware of their parents' diagnosis, but recalled reoccurring periods of mania and depression during their childhood. Three of the four fathers in the study were described as heavy drinkers. Two study participants continue to have frequent contact with their ill parent. Four of the study participants reported that their parent has passed away.

Table 1 **Participant demographics**

	Age of adult offspring at time of interview	Parent with a mental illness	Diagnosis of parent's illness	Number of siblings	Status of Parent
1	33	Bipolar disorder/drinks	Father	1	Living with Bipolar disorder
2	44	Unknown diagnosis	Mother	2	Deceased
3	27	Bipolar disorder	Mother	1	Living with Bipolar disorder
4	63	Bipolar disorder/drinks	Number of siblings	8	Deceased
5	57	Unknown/heavy drinker	Father	1	Deceased
6	54	Unknown/drinks	Father	4	Deceased

Data collection and analysis

Interviews

According to Pletson (2007), a qualitative study using interviews can provide a richer, more in-depth understanding of individual experiences. Charmaz (2006) suggests that the use of an interview guide is helpful for novice researchers to help keep the interviewing process on-track and to avoid asking leading questions. Questions asked during in-depth interviews

should be general enough to cover a wide range of experiences and narrow enough to draw out and elaborate on a participant's specific experience. Furthermore, the interviewing process is a "flexible" and "emergent" technique and as ideas and issues emerge the interviewer can immediately pursue these leads (Charmaz, 2006, p29). Grounded Theory interviewing differs from other methods of in-depth interviewing because throughout the ongoing process of interviewing the researcher narrows the range of interview topics to gather specific data for developing theoretical frameworks (Charmaz, 2006). In this study I conducted, one, approximately 90 minute, semi-structured interview per participant. An interview guide (see Appendix C) was used to ensure each interview covered the same basic set of questions. However, generally I began with the first question in the Interview Guide and then followed the issues and ideas that emerged during conversation. An open-ended, semi-structured interview allows for in-depth exploration of an aspect of life that the interviewee has substantial experience, often combined with considerable insight (Charmaz, 2006, p. 29). The interviews in this study were all conversational in style. When appropriate, notes were compiled after the interview documenting any observations, personal and/or theoretical reflections from the interview. These notes were integrated into the data analysis as appropriate. Participants agreed to a second interview if required to clarify information obtained during the first interview, but no second interviews were conducted.

The interviews were conducted either at the School of Social Work, at the participant's home or office with the exception of one study participant who by her choice was interviewed in a coffee shop. Although a semi-public location such as a coffee shop is not an ideal location for an interview due to possible confidentiality concerns I wanted the study participants to decide where they felt most comfortable. I briefed the study participants on ethical issues including confidentiality. Interviews were audio-taped using a digital recorder. All interviews were

transcribed either by myself or a third party transcriber. The audio recordings were kept on a computer that was password protected. Transcripts were kept in a locked cabinet. Transcripts and audio records were transferred to the Principal Investigator for safekeeping when this project was complete. Notebooks that contain memos about observations and reflections were also kept in a locked cabinet with the transcripts and forwarded to the Principle Investigator upon completion of the study.

Coding in data analysis

Data analysis for this study was informed by Grounded Theory. Grounded theory is a comparative method where the researcher compares data with data, data with categories and categories with categories (Charmaz, 2005). According to Charmaz (2006) while engaged in initial coding the researcher mines the early data for analytic ideas to pursue in further data collection and analysis. Codes emerge as the researcher analyzes the data and defines the meanings within it. In Grounded Theory it is important to ask questions of the data. This openness in the initial coding is meant to “spark thinking and allow new ideas to emerge” (Charmaz, 2006, 48). Charmaz (2006) suggests that the key to initial coding is to remain open, stay close to the data, keep codes simple and precise, construct short codes, preserve action, compare data with data and move quickly through the data. The “logic of discovery becomes evident as you begin to code the data” (p. 51).

A researcher must be cognizant of the specific language that we use that reflects our own values and views. We construct our codes because we are actively naming data. Nonetheless, the process is interactive. We interact with study participants initially during an interview and subsequently with them through studying their statements and observed actions. We work towards understanding the participant’s view and actions from their perspective. As researchers, we must dig into the data to interpret participants’ implied meanings (Charmaz, 2006, 47).

A constant comparison of data was used. An interview was concluded and transcribed and initial line by line analysis was complete. This process was used after each subsequent interview. Moreover, the emerging findings in the data were used in subsequent interviews. This process of constant comparison of data continued until the final interview was complete. As soon as the interviews were transcribed the transcription was read through fully to search for ideas and issues (Padgett, 2008, pg. 152). The transcripts were hand coded line by line, making notes in the margins and highlighting any applicable passages. After initial hand coding of the transcripts was complete the documents were imported into the qualitative data analysis software, NVivo8, a tool that is useful for handling large amounts of data (Bazeley, 2007). I again read through the transcripts, for the most part on a line by line basis, and coded any emerging ideas into free nodes. A node is a storage area in InVivo for accessing coded text (Bazeley, 2007). It is used to organize data starting with open coding, which is considered the most appropriate method for initially coding data (Charmaz, 2006). If applicable, in vivo code labels that came directly from a participant's words were identified. In vivo codes serve as "symbolic markers of participants' speech and meanings" (p. 55). However, like any other code in Grounded Theory in vivo codes do not stand alone, but rather need to be integrated into the overall analysis (Charmaz, 2006).

Focused coding is the second major phase of coding in Grounded Theory. This second level of coding is used to pinpoint and develop salient categories in large chunks of data (Charmaz, 2006). This process includes using the most frequent and/or major codes to continue to narrow down the large amount of data. Moving from initial coding to focused coding is "not an entirely linear process" (Charmaz, 2006, 56). The more a researcher works with the data the more it will begin to make sense. For example, a researcher may experience seeing some of the respondents' statement in a different way when beginning the focused coding phase of data analysis. This may

prompt the researcher to go back and explore the data for a different topic. Charmaz (2006) sees this process of following the leads in data like “a camera with many lenses, first you view a broad sweep of the landscape. Subsequently, you change your lens several times to bring scenes closer and closer into view” (p. 14). I continued to work with the categories that I created in InVivo8, combining similar ones into a single free node. Related categories were then combined into tree nodes, which are hierarchical categories. Related nodes are combined and create new tree nodes that in turn make up a larger category. For example, families perceived strengths, belief in staying together, and family values were each initial free nodes that we combined into a tree node. This tree node, labelled *family values growing up*, was one of a number that when combined made up the theme called *family life growing up*.

I used both field notes and memos in my research. After each interview I wrote a brief field note. These notes included any new ideas that came out of the interview, any specific information that was relevant about the interview and any obvious comparisons with earlier interviews. As I worked with the data I also wrote memos including theoretical memos that noted emerging ideas related to previous research and/or identified gaps in literature. These notes and memos were also used to discuss emerging ideas and issues with my thesis advisor.

Credibility and usefulness of inquiry

Credibility

Focusing on ways to enhance credibility of the research process and study findings was important to me. One strategy I used was paying attention to the fundamentals of Grounded Theory data collection and analysis including: concurrent data collection and analysis, beginning coding with the first interview, memo writing, and constant comparison. The use of constant comparison of data enhances the quality of the study (Milliken & Schreiber, 2001).

According to Beck (1993) credibility in qualitative research is demonstrated when ‘informants, and also readers who have had the human experience...recognize the researcher’s described experiences as their own’ (p. 264). Throughout the findings of this study I aimed to highlight emerging themes using the words of the study participants. Several study participants as well as other individuals who had lived with a mentally ill parent reviewed the study findings and provided feedback. Each individual reported that the findings in this study resonated with their personal experiences. Two study participants read the final draft of my thesis document and reported that the interpretation of their experiences were accurate. Also, they both commented that it was interesting to them that other study participants had very similar experiences. Carpenter Rinaldi (1995) suggests that credibility relates to the trustworthiness of the findings. Some of the findings related to transition from adolescence to young adulthood and making meaning of experiences were unique to this study. Charmaz (2008) suggests that a strong combination of originality and credibility increases resonance, usefulness, and the subsequent value of the contribution of the research.

Saturation

Saturation is the point at which data replicates and no new information emerges from the interviews (Morse, Barrett, Mayan, Olsen & Spiers, 2002). Saturation is not seeing the same pattern over and over again, but rather relates to saturation of categories established during data analysis. According to Charmaz (2006) categories are saturated when “gathering fresh data no longer sparks new theoretical insights” (p. 113). Theoretical sampling is the strategy used to gather data focused on a category to elaborate and refine categories. After six in-depth interviews no little new theoretical insights emerged.

Ethical issues

There were no direct benefits to the study participants. Participation was voluntary and no remuneration was provided. There were several potential risks to participants including the possibility that interview questions may evoke unpleasant or traumatic memories. If a participant had a diagnosed or self-reported mental illness there was a limited risk that participating in the study may potentially lead to an increase in symptoms or the possibility of triggering an acute episode of their illness. No known adverse effects were reported by study participants as a result of participating in this study.

Establishing validity

I understand that my position as a student researcher influenced how students, staff and faculty members who participated in this study answered interview questions. There are some procedures that I used to reduce negative consequences such as using an Interview Guide to reduce the possibilities of asking leading questions. Ultimately, it was very difficult to minimize my influence, so I focused on memoing and incorporating my understanding of how I may have influenced responses throughout the study. There were two interviews that were declined as a result of either the prospective participant or the researcher believing that a conflict of interest may exist. In both cases the potential participant and the researcher had a pre-existing personal or professional relationship.

Whenever possible and appropriate member checking occurred by providing a copy of the transcript of the interview to study participants if requested or if clarification was required.

FINDINGS

This study aimed to learn more about two aspects of the experiences of offspring who grew up in a family with parental mental illness. First was to gain a better understanding of the childhood experiences of adults, who grew up with a mentally ill mother and/or father. Secondly, was to learn more about how adult children made meaning of their experiences as they became older and lived through their own significant life events such as leaving home, choosing an occupation, getting married, having children and in some cases the death of their parent. Six women who ranged in age from 27 to 63 years old were interviewed. While each study participant had unique family environments including whether their mother and/or father had a mental illness; the specific diagnosis; varying socioeconomic status; number of siblings; and cultural and religious backgrounds there were some common themes across their experiences.

Themes in this study that supported previous studies of adult offspring of parents with mental illness (Kinsella, Anderson & Anderson, 1996; Knutsson-Medin et al., 2007; Mowbray et al., 2006; Mowbray & Mowbray, 2006) include:

- the use of positive and negative coping skills that assisted in managing and adapting to adverse circumstances
- constructive escape used to physically or mentally escape the family environment in order to gain some relief from their situation
- the use of spirituality or faith for comfort and support
- having additional family responsibilities such as household chores, caring for siblings and providing practical and emotional support to parents.

Participants in this study also reported their roles in the family being fixer, scapegoat and caregiver. Experiences of abuse and/or neglect, having negative emotions as a child and living in

families characterized by chaos and unpredictability were common themes. Being involved in activities outside of the family, having support from an adult, and perceived strengths as a child was also frequently reported. Despite these findings, study participants also expressed that they often suffered in silence because they were seen as being outwardly competent. A unique finding in this study was the theme of “not knowing” as both a child and a young adult. All study participants described experiences such as not knowing that other families did not live like their family. In addition, they reported not feeling prepared for young adulthood. This finding was in contrast to reports by many of the study participants that they were very capable academically, they frequently assumed household responsibilities such as cooking, cleaning and caring for siblings, and were actively involved in activities outside the family home.

The six women who participated in this study eloquently described growing up with a mentally ill parent and their perceptions about how their life experiences have shaped who they are as adults. They identified perceived negative experiences and coping strategies as children. Several study participants reported that these coping strategies endure in their adult life. They described how they learned to put together the pieces in order to make meaning out of their experiences living with a mentally ill parent. All the study participants believe they have strengths and through their life experiences have been able to make meaning of their experiences growing up with a mentally ill parent. Putting together the pieces and making meaning has allowed them to continue to shape their own lives and subsequent personal growth. The following highlights some of the findings of this study.

Theme one: Growing up with a mentally ill parent

Parental mental illness

All six study participants interviewed grew up in two parent families. Two of the women lived with a mother who had a mental illness, while the other four lived with a mentally ill father. Four of the parents with mental illness have passed away, but two of the women are still in frequent contact with their parent. Bipolar disorder was the most common diagnosis of the parents in this study. One study participant has a mother diagnosed with bipolar and two women, fathers. The other three study participants reported their parent having a mental illness, but were unsure of a formal diagnosis as mental illness was not discussed in their family. Several of the study participants were aware of their parent either having been hospitalized or seeing a mental health professional at some point during their life. Of the three study participants who were uncertain of their parent's diagnosis all described living with a parent who exhibited multiple episodes of depression and manic like behaviours over an extended period of time. Additionally, three of the four study participants whose fathers had a mental illness also described their parent as having abused alcohol for much of their lives. A history of parental trauma, ranging from spending two years in a concentration camp to childhood physical and sexual abuse, was reported across the majority of the interviews. All six study participants knew of a family history of mental illness including schizophrenia, bipolar, and depression and/or alcoholism or substance abuse.

Living in a family with parental mental illness

Study participants described many incidences of parental behaviour similar to those reported in other studies (Mordoch & Hall, 2008; Riebschleger, 2004). All study participants described

intense rages that seemed to come from nowhere, which were often out of context given the situation.

...I was about thirteen or so and I remember that morning...she's [mother] screaming at me it was six am or so, I was in my pyjamas "I told you to vacuum the floor, get down here and vacuum the floor" and dragging me out of bed I came downstairs and I've got tears in my eyes because I know what's coming and I finally said "Mom you're sick, you need help".

Another study participant had a similar childhood experience, which illustrates how unpredictable her father's behaviour could be.

...he [father] got us up, ten o'clock at night to take us down...to the inlet, you know to the water through the bush, no flashlight, nothing. He was half drunk and was raving, raving, raving in the night with his two kids.

Many of the study participants describe their parent as being extremely intelligent and creative. Four of the mentally ill parents of the study participants were reported as being well read; they valued and appreciated the arts and literature, which the adult child respected. One study participant describes the admiration she had for her father.

...my father was passionate and he loved life and he loved music and he loved literature and he loved learning... he was for me, even with the illness ...a compelling figure.

Another study participant described her father who was a gifted painter.

...he would just paint and paint and paint and paint into the wee hours of the morning and get very little sleep and he would do this and then all of a sudden it would seem like something was happening and he would get really really depressed and be lying in his bed for weeks.

Acute periods of illness and times of wellness

Although the participants in this study more commonly recalled periods of acute parental mental illness several women described fairly long periods of wellness. Both of these study participants are still in frequent contact with their parents. In general, their parent functions fairly well, despite having lost many family supports over the years. One study participant spoke about her father.

Sometimes he's fairly even keeled...he's a little bit manic, but he's not totally depressed, but sometimes he gets a nice stretch when he seems normal, like a normal person, a normal dad.

Other study participants were not able to recall periods when they considered their parent as well. They reported sensing that there may have been times that were okay, but could not provide an example.

Denial of parental mental illness

Mental illness was not a topic of discussion, except in one study participant's family. It was more commonly reported that a parent's mental illness was denied by the ill parent and sometimes by the well parent. Even for one father, who was a physician, denial was the norm.

My father knew he was bipolar, my father hated mental illness
...paradoxically [he] didn't believe in it.

Another study participant spoke of her experience.

I don't even know now if he was sitting in the room today, if he would
fess up to having bipolar. He seems to do it when it's convenient.

It was not only mentally ill parents who denied their illness. One study participant explained.

...he actually didn't know, but I think that was a little on purpose...I just think he couldn't bear to think about his marriage and so he basically compartmentalized that...

Paternal mental illness

Four of the six study participants interviewed lived in a family who experienced paternal mental illness. There is little research on the experiences of children of fathers with mental illness. Fathers of participants in this study were often described as being controlling, authoritarian and harsh disciplinarians. Interestingly, two of the study participants described their fathers as “Dr. Jekyll and Mr. Hyde”, referring to experiencing their fathers as both “good” and “evil”. Fathers in this study were described as having both a mental illness and alcoholism. All of the fathers were either diagnosed with bipolar disorder or study participants believe their father had bipolar disorder. Study participants also described their fathers as being highly intelligent and creative. However, on one hand they described their father as brilliant, creative and able to create magical moments. On the other hand they frequently described being fearful as children and reported chronic physical, emotional and in one case, sexual abuse.

Theme two: Family life

All six study participants grew up in two parent families. Two sets of parents divorced when their children were in their late teens and early adulthood. One study participant's mother and her mentally ill father both died when she was in her mid teens. Furthermore, of the six study participants only two of their ill parents are still alive. One mother with bipolar is in her late forties and a father with bipolar is in his sixties. Two of the families were reported by study participants as being poor, two were middle class, one was described as upper middle class and

one was a prominent family who lived in a rural community. Parents' occupations ranged from unemployed to professionals. One mentally ill father was a physician and one parent held a PhD.

Family values

Two of the study participants described growing up in traditional patriarchal families. In both cases the father of these families had a mental illness. Harsh discipline including physical abuse was described as being the norm. Typically the mothers in these families played a supportive role to their husband. Study participants remember a hierarchy in the family where their father was considered the head of the household, with mother second and the children third. In spite of the closed, and as two study participants described their families, enmeshed dynamic in the family the study participants described having strong family values instilled in them from a young age. Two of the study participants reported that reading to the children when they were young was a part of their family life. One study participant describes her mentally ill father's belief in the importance of education.

I think my dad saw education as the way out of poverty. The way out of poverty was college. Prestige. Having a position in the community, being respected, getting a good job and not being poor. That was important to my dad.

Education was described as being highly valued by all study participants. All six of the study participants attended university with three study participants completing a graduate degree.

Siblings

All of the study participants reported having siblings ranging in number from one to eight. Five of the six study participants were the eldest child in the family. Study participants all described having a different relationship with their ill parent and different lived experiences in

comparison to their siblings. One study participant, who was the youngest of seven children, described her sister as her surrogate mother. She describes their relationship.

...she was often given the responsibility to watch over me. She doted on me and she was good to me and she was often a buffer between me and my dad.

Five of the six participants in this study stated that they are still in frequent contact with their siblings. While some siblings were estranged from their parent others were considered enmeshed. One study participant reported that her adult sibling cared for her mentally ill mother as a child, and as an adult child she moved herself and her family into her mother's home. One sibling of a study participant is diagnosed with bipolar. Many of the siblings of women in this study were reported to have depression and/or anxiety as adults. Another study participant described her sister, five years young than herself, as having a very difficult childhood and adolescence. She also indicated that her niece, now in her twenties, has a serious drug addiction. Typically, siblings were reported as fairing poorer than the participants in the study. One study participant spoke of her brother and sister; all three children had been adopted, as having quite a different experience growing up with a mentally ill mother than she had.

My sister was sexually active since the age of 12...my brother was a substance abuser from a very young age...[he had] ADHD...they never found a kind of home in school, or sports, or music...they ended up finding it with friends who also didn't have a home anywhere.

Well parent

Descriptions of "well parents" varied. The father of one study participant is described as being in denial of his wife's mental illness. The study participant believes that he was unable to

accept his wife's illness and only considered separation from her when it was clear she had become extremely ill. Another study participant echoed a similar belief about her mother. She states that her mother "didn't have a good sense of who she was and she didn't have it in her to leave him". This same study participant expressed a great deal of anger towards her mother who she felt put her own needs before hers or her sister's.

She carved out her own life by going out and getting women friends and becoming involved in activities outside of the home and leaving me and my sister there when my father was dead drunk every night.

Another study participant expressed how she felt her mother did the best that she could under the circumstances. She has fond memories of the pride her mother took in her family and how she used all of her resources to provide for them.

She was a very kind person and very sweet...even though we were very poor and our house was really nothing our garden was really beautiful...I regarded my mom as being the nice one. She kept things going, because he [father] would periodically just be bedridden, and then she would make sure the kids were fed and everything was done that needed to be done and try to eke out an existence from next to nothing.

Talking about mental illness

Silence, as commonly found in literature about the experiences of children of parents with mental illness, was a theme across all six interviews. Study participants spoke about an unwritten rule in their family that they did not speak of their parent's mental illness, or anything else that was happening in their family. One study participant reported that the children in her family were threatened by their ill parent not to tell. As children, the study participants were frequently

worried about what the consequences may be if they told about their situation. This study participant recalls the constant threats from her father.

...we kept secrets and were told that he'd kill us, he was always going to kill us if we told...he would corner you in the kitchen...and get down to your level and bare his teeth and say "I'll kill you if you ever talk about anything in this house".

The sibling of this same study participant told social services about the abuse by her mentally ill father, despite the fact that her father had threatened to harm her if she told.

My mother cut her off for eight years; well it's a family betrayal, right.

Stigma was also evident in the lives of these children. Several study participants spoke about how extended family members called their parents names. One describes her experience.

...there's more communication and maybe the family are starting to understand what's happening rather than cousins who would say "Oh crazy auntie", which sets off my feelings.

In contrast, one study participant reported always being open about discussing her father's mental illness. She felt that being able to talk to others was, in general, helpful for her.

Although the participants in this study reported having friends, being connected at school and through community activities, they rarely talked to anyone about mental illness or what was happening at home. As adults, a few of the study participants reported talking retrospectively to friends who they have maintained long term friendships with, but the friends expressed having no idea about their situation during childhood. One study participant reflected on how it would have been helpful to her as a child if her father could have talk about her mother's mental illness.

I think that if we had talked about it when I was a kid, if my Dad had taken me aside after one of these incidents and said, "Wow, I bet you're

embarrassed, this must be really hard. I know your Mom doesn't act like the other moms"...any of those things, it would have been really profound...but the modus operandus of our house was a lot of secrets.

Other study participant, who continues to be in close contact with her parents, expressed a similar sentiment. She did receive some education about mental illness as a child, but it was not until she was in university and learned about mental illnesses in a psychology class that she was able to integrate her experiences and knowledge.

I would definitely say that I think because of the education I've had in the more recent years it's allowed a better understanding in what to say and who to communicate with, when I was a kid I, I couldn't even put into words what was happening it was just, mom is not mom and dad is not dad.

Most of the study participants stated that they learned about mental illness during psychology courses they attended in university. Several of the study participants also indicated that when they first attended university they planned to become a psychologist. Five of the six participants in this study have at least a bachelor degree in Social Work.

Family support system

Family support appeared to come and go throughout the children's lives. For several study participants their aunts and grandmothers provided some emotional and practical support, which the children appreciated. The support often made them feel special and created a sense of some normalcy in their lives. One study participant spoke about being sent to school in clothing that made her look awkward and stood out. She also reported being bullied for a time in elementary school. She fondly recalls an aunt who supported her during middle childhood.

My Aunt, you know was cool, so she'd do things like buy me Eagles albums and macramé wedge shoes...So I started to dress a little better, you know more normal, finally when my aunt was around. And that was good and that was kind of the end of my Mother dressing me too.

Another study participant recalled how she received some respite from her mentally ill father when she visited with her aunts.

I stayed with my aunts...when things got too hard they would bring me to live with them for a weekend or for a time... So I'd go there and that was wonderful that was really a relief and my aunts and my grandmother were wonderful.

Uncertainty, unpredictability and chaos

One of the most common themes about growing up with a mentally ill parent was the experience of uncertainty and the inability to predict what was going to happen next. This often left the children with a deep sense of powerlessness and lack of control in their day-to-day lives. One study participant describes her experience living with her father.

He had violent rages all through my life and my sister's life I don't remember him ever being someone you could trust... because living with that kind of atmosphere ...you were always, I was always afraid you never knew when it was going to erupt.

The lack of control was also described by several study participants as creating an ongoing sense of fear. One study participant, the eldest of eight children, describes her experience.

...when he was hypo manic he thought he was invincible and he would scare the hell out of us and he would laugh and he would be completely unpredictable.

While most study participants described uncertainty as fear of their parent, one study participant, who continues to have an ongoing relationship with her father, had a slightly different perspective about uncertainty.

...[the] dad I had as a young child is different from the dad I had as a teenager, is different from the dad I have now, so sometimes we feel like saying will the real you please stand up, like I don't know really who the real him is anymore and I don't know what it's going to look like in ten years or twenty years and I find that really unsettling, just not knowing.

Marital discord and family violence

Stress and conflict were reported as common in the households of these women growing up, which for two sets of parents ultimately caused the breakdown of their marriage. Physical abuse of spouses was not as common as emotional abuse, which was described as fighting, arguing and denigration of their marital partner. Physical abuse of the children was reported in four of the six families. These four families lived with a father with a mental illness. The study participants also reported that their parents did not attempt to shield the children from the chronic fighting. One study participant reflects on the situation in her family.

...there was a lot of fighting and arguing between my parents and they never really went to any effort to shield that from us intentionally. My dad would say...he doesn't believe in closed doors or privacy or he thinks everything should just be out in the open, which as a parent now I disagree with.

Another study participant also reflects on the family violence that she, her mother and her sister suffered at the hands of their father.

I don't think it was bad enough physically...he did push her [mother] around, but certainly didn't beat her and the emotional abuse she just

tolerated it and presumably it didn't have the same impact that it had on my sister and myself.

Rituals and special memories

Childhood family rituals and special memories experienced by study participants ranged from enjoying special occasions such as Christmas to memories of fun times with their mentally ill parent. One study participant described remembering how much fun she had with her father as a child and how he was well liked by her and her brother's friends. Although she still fondly remembers the fun she also recalls how as she grew older the behaviour went from being experienced as fun to being embarrassing.

My brother and I were the most popular kids in school because our dad was fun, like he was doing wheelies in the parking lot with his four-by-four...he'd come on field trips and just do outrageous things, which the teachers were mortified [but] the kids were "Oh your dad's so cool and he's got this Corvette and wow"...sometimes it was fun but it was also embarrassing...having people feel sorry for you.

Another study participant describes how her father, who struggled with mental illness for as long as she can remember, was a gifted storyteller who transformed the family's special occasion into magical events.

...special occasions whether it was Christmas or any kind of event...the showman in him, he knew how to make things magical and that's....actual I have fond memories as well because of his ability to make events really special. I have very fond memories of Christmas.

This finding is consistent with Leon and Jacobitz (2003) who suggest that family rituals may contribute shared memories and foster ties. Specifically, they found that fathers tended to be

more involved in rituals associated with leisure time in which they enjoyed a more relaxed time with family.

Theme three: Childhood experiences growing up with a mentally ill parent

The participants in this study reported that they knew about their parent's mental illness as young as aged seven, even though mental illness was not talked about openly. All six study participants believed that their parent had always had a mental illness and several participants have been told as adults that their parent was either diagnosed or had symptoms as young adults, prior to marrying and having children. While the childhood experiences of each study participant are unique some similarities were found. Childhood abuse was common for four of the six study participants as was fear of their ill parent. All six study participants spoke about the chronic unpredictability and chaos in their households as child. They expressed how they were able to monitor their parent's behaviour and adjust their own behaviour accordingly. The study participants also spoke of providing care for their mentally ill parent and siblings. A common finding was the appearance of outward competence as children, which often led to adult interpretation of them being invulnerability or resilience. The study participants also reflected on how some of the maladaptive coping strategies they used in childhood continue to endure in their adulthood. They spoke about being blamed by their parent for their mental illness. In the face of negative experiences the study participants found some respite in activities outside of the home, at school, and through the support of others. The participants in this study also reported doing well academically and gave examples that suggest high levels of intelligence.

Abuse

Physical and emotional abuse was common in the childhoods of four of the six study participants. While the majority of the abuse towards children was at the hands of the fathers

who experienced mental illness sometimes the family dynamics were such that the “well” parent was also abusive. One study participant was forced by her mother into emotionally caring for her mentally ill father, who in turn sexually abused her and her sister. She was also physically abused by her mother.

I was maybe four years old and I had a little table and chair set and I was doing a tea party with my dolls and she [mother] couldn't stand ...[study participant reports mother telling her as an adult] ...”I went over and I slapped you as hard as I could across the face”.

Another study participant also reflected on her experience of living with a mentally ill, physically abusive father, in a large family who she described as low income. She shared feeling in need of protection, but invisible to the outside world.

I'm quite certain if the MCFD had been involved at the time I would have been removed, not that that necessarily would have been a better thing...but, maybe I would have understood it was not me.

The theme of not feeling protected as a child was expressed by study participants. One study participant felt that because her family was middle class child protection services did not get involved. She reported that family and friends knew their situation, but no one got involved. She expressed that in some cases child protection services needs to get involved. One of the study participants reported that her younger sibling was removed from the family home when she was a teenager. This study participant reported that she is five years older than her sibling.

I wish that they had taken me from my family and I had never seen them again and that is the truth and I'm saying that would have been better for me and my sister.

Alternate caring arrangements as a child

Although most of the children lived at home with their mentally ill and well parent for much of their lives study participants reported living outside of their immediate family at some point in their childhood. One study participant was sent with her sibling to live in a convent from the age of ten to the age of twenty. Another study participant recalls her younger sister, who was five years her junior, being removed by child protection services and placed in a group home when she was a teenager. One study participant reported that as a teenager she moved in with her older brother after her mother died of cancer and her mentally ill father passed away.

Emotions felt as a child

Study participants expressed feeling many different emotions as children. Some reported feeling blamed for their parent's illness, guilty and angry about their situation and feeling alone. In addition, they also reported feeling hopeful, respected by extended family members who stepped in to support them, and proud of academic and other accomplishments. In this study two of the study participants reported regularly being blamed for their parent's behaviour or for making their parent mentally ill. One study participant reported how she internalized feelings of blame after being told constantly that her father's mental illness was her fault.

We were always blamed for anything that went wrong...if he was depressed it was our fault if he was angry it was our fault, if things weren't going wellwhen my mother had a nervous breakdown it was because I wasn't speaking [our native language] at home. She had a breakdown when I was about 10...I don't know why...my father said it was because I wasn't speaking in [our language]. I know that wasn't the case. I don't know.

One study participant reported internalized feelings of guilt because she felt responsible for her father's failings. Some of the mentally ill parents were reported as sharing suicidal ideations with their children. One study participant spoke of her experience.

She would just sort of say things like "I want to kill myself, you children make me want to kill myself" we're like nine years old or something, you know, it's like – who talks that way? A very disturbed person talks that way.

The nature of parental mental illness frequently impacts the parent-child relationship. One study participant described the difficulty she had with receiving affection from her mother as a child.

I knew that when my Mom was hugging me, and I would let her cuddle me...it was about making her feel good about being a parent, it wasn't about my feelings, it never felt like it was about my feelings...and that's pretty terrible when I think about it. I was probably eight or nine when I started to feel that way.

School was cited more than once as contributing to eliciting positive feelings during childhood. One study participant expressed how her school studies provided her with some comfort.

It gave me hope...I've always had kind of a little hope, but I remember when I was ten, I knew that my salvation would be through studies.

This same study participant experienced being treated fairly and respected by her extended family, which was not common in her immediate family. She felt that having these experiences help her understand that the dynamics within her immediate family were not the norm.

...but in my family you would never be believed so I think adults who were very nice to me...just being fair and ...respecting me I think that was very, very useful.

Appearances of outward competent

All of the study participants described being perceived by adults as being very competent in many facets of their lives. Many of the study participants reported excelling academically, participating in activities outside of the family home, and having friends growing up. However, what was often misinterpreted by adults was the motivation behind their actions. One study participant described excelling academically partly in response to her father's expectation that the children would do well in school. What was not known about this child's academic experience was that she often suffered severe anxiety as a result of the pressure to succeed and explained that for many years her self-esteem had been dependent on her doing well academically. She felt there was a "strong correlation between my performance and my self-esteem and how I felt about myself and my level of happiness".

Having friends was another aspect of childhood that was often misinterpreted as protecting by adults. Several study participants reported having friends as young people, which was frequently viewed by others as a sign that they were functioning well. One study participant described her experience of not feeling connected or trusting of friendships.

...I didn't have a lot of confidence with my friends...making friends was never an issue for me...but around people I didn't know or felt uncomfortable with or thought they might be better than me...I would do the whole withdrawing thing.

Another study participant described a similar experience of childhood friendships. She has re-kindled several childhood friendships and has learned that her childhood friends had truly valued her friendship.

I felt like I didn't have friends that people didn't really like me...I just wasn't sure...I went through a long period of time where I expected to be rejected all the time. I spent a lot of time kind of pre-empting rejection by just not being involved with stuff and I see a pattern of me kind of rejecting friendship, it's not that people left me they actually liked me.

An additional aspect to outward competence was being seen by others, especially adults, as being very capable as a children. While others saw this competence as a strength the study participants often viewed it as being out of necessity. They believed they had no one else to rely upon except themselves. One study participant described her experience.

I didn't know how to ask for help...I just got use to doing every single thing for myself all the time and assuming that there was going to be nobody there for me, which is awful...it's made me very capable.

Several study participants expressed that being seen as competent was on one hand positive as they took pride in being successful and managing by themselves. On the other hand they believed that being viewed as capable was negative because they were not considered in need of support; both practical and/or emotional. One study participant described her experience.

...sometimes kids who are functioning well are almost at a disadvantage because they won't be spotted...she must be doing okay because she's getting her work done and grades are decent and she's showing up and she's doing

okay...[my advice is] not to use such superficial barometers as measurements for how kids are doing.

Monitoring parents behaviour and coping strategies

Children's monitoring of a mentally ill parent's behaviour and adjusting their own behaviour as a way of coping and ensuring safety has been reported in previous studies (Mordoch & Hall, 2008). Participants in this study spoke of similar experiences. One study participant explained how she managed her mentally ill father's behaviour as a child.

I learned to be very vigilant and I became very good at reading his facial expressions and his tone of voice, so I became very good at reading people and today I still am very good, which is a strength...but as a child it was just a survival mechanism. If there was no way of escaping I would just go into paralysis...make myself as quiet and as still as possible. Not to say the wrong thing or make the wrong move.

Another study participant described how she managed with her mentally ill mother.

You figure out what it is you need to do to get through day to day and you just do it.

All study participants provided examples of monitoring parent's behaviour and acting to reduce stress suggesting they were able to find a way of staying connected to their family, while protecting themselves physically and emotionally.

Young caring and parentification

All of the participants in this study described having increased family responsibilities during childhood. Frequently children of parents with mental illness demonstrate considerable skill in assisting their families, but regularly their contributions are devalued or go unrecognized

(Harstone, Bergen & Sweetgrass, 2010). As with other studies (Aldridge, 2006; Knutsson-Medin et al., 2007) these study participants described having roles that included practical as well as emotional responsibilities. One study participant recalled her caring role.

...it is more that you become like this pseudo adult, you don't have any rights of adulthood, like getting to say what you want...but you have all the burdens, at least you feel like you do...for a twelve year old it was a lot. I felt some pride about being able to do stuff. I think it allowed things to continue though.

Another study participant recalls her mother, who is diagnosed with bipolar disorder, leaving the family home during a manic episode. When she returned she was in need of mental health services, which was left to her eldest child to arrange. At the time, she was in her early teens.

I remember when she finally did come home I was the one who had to get her help and that, that's probably one of the worst things.

One study participant also recalled how she was put in charge of caring for her five brothers and sisters.

I took care of my brothers and sisters, and then I was a terrible...because I didn't know how to do that so I did a very bad job, I beat them, that was the model I had and I humiliated them that was another model.

Emotional parentification is different from the role of a young carer. When parentification occurs a parent has abdicated their responsibility (Charles, Stainton & Marshall, 2009), which is then left to a child to fulfill. Parentification is typically characterized as role reversal between a child and a parent. One study participant reported that her mother forced her to become her father's emotional caregiver.

...because on one level my mother forced me to be my father's companion...she pushed me because I was my father's favourite, lucky me, on to my father and I realised after I became a social worker that I was his emotional spouse.

Support and coping strategies as a child

The study participants reported coping in a variety of ways including escaping their family situation by participating in activities outside of the home, spending time with friends, and finding success at school. They also described talking with siblings, withdrawing and finding solace in journal writing and prayer. Four of the six study participants were involved in activities outside of the family home including participating in sports, the arts and community organizations. One study participant explains her experience.

...it felt like my meaningful life was lived away from my family, then it was very much with my friends in drama, and my friends that I worked with at Girl Scout camp.

Another participant in the study found comfort in prayer.

...and that is what helped me through it even as a teenager when I was right in the throes of it all I can remember praying, because I believed in prayer, god help me make some kind of use or help me make meaning out of this so this isn't just a wasted experience.

One study participant explained the influence that her best friend's family had on her growing up. She considered them supportive and indicated that they helped ease some of the chaos she experienced living with parental mental illness. She describes her experience.

...my best friend's parents are very conservative and so as much as my parents raised me I was in my best friend's parents house a lot too and

I learned from her parents...there was more of a properness in that environment so perhaps that was part...rubbed off on me.

Perceived strengths as a child

Adult children described their perceived childhood strengths, which ranged from being optimistic to having “spunk”. One study participant felt that her attributes and personal skills, including being intelligent and well liked as a child, made her appealing to adults. Several of the study participants also believe that having compassion and empathy as a child was a strength. One study participant described having a sense of optimism and belief in change. In some ways, the ability to normalize experiences was considered a strength. Many of the study participants described not knowing that other families did not live the way that their family did. One study participant described her experience.

Our living room flooded once and mushrooms were growing out of the carpet...you know that's just bizarre, but that was our normal. You know we didn't know anything else.

Another study participant recalls her mother making her accompany her father; believing he would be more careful if his child was with him. She remembers that she was “about five years old when she learned how to drive the car” as she became the eyes and ears for her mentally ill father who was not only considered a terrible driver, but also regularly drank and drove his car.

Two of the study participants talked about how having a sense of self preservation during adolescence helped them make good decisions as they moved through their teenage years. This study participant described her “childhood as hard, but her teenage years as hell”. She explains her sense of self preservation.

I had enough foresight to know that if I had found a drug that would eliminate so much pain I would never have gotten out. So I refused drugs

for that reason. Because I knew if anyone was going to get addicted it would be me. So I didn't do it.

Childhood mental illness

Reports of childhood mental illness were reported by participants in this study. They reported having troubles with mental health as young as seven years old. Pre-adolescence, specifically between the ages of ten to twelve, seemed to be the time when troubles began to occur, at least for two of the women. Both described having suicidal ideations. One study participant reported having an eating disorder and struggling with episodes of depression. Both study participants reported having anxiety as a child. One study participant describes her experience.

There was a period of my life in which I was so socially anxious that even going across the street to the store...I'd come back and I would have forced myself so much I'd be in tears...I was eleven...but I also had anxiety, difficulty breathing.

This same study participant recalled having periods of working hard at achieving in her life as a way of managing control, followed by periods of depression.

Powerlessness and lack of control over life seemed to be a backdrop for mental health troubles felt as a child. One study participant described living in fear of her bipolar father's behaviour.

...maybe it was when I was ten; it was the year...with the knife under the mattress and ...the only thing that I could do to not being alive would be to kill myself...well if I kill myself at least I will chose what, how it's [going to] happen.

Another study participant spoke of how, as a pre-adolescent, she suffered trying to achieve a sense of control in her life.

I experienced my first depression when I was 11...I didn't want to eat I didn't feel good a lot of the time. I was very very anxious and yeah I had a lot of performance anxiety. So that happened at 11 and then happened again when I was 13.

This same study participant also described having an eating disorder in her early adolescence.

...in puberty I decided that I could be thin, and I went down to 88 pounds. I was skinny. It was my way of control. I could control my weight and it made me feel that I could manage some area of my life.

Both of these study participants expressed feeling lonely and very unhappy during their childhood. Another study participant also felt that they were not supported and frequently experienced their pain and suffering alone. None of the participants in this study reported attended any counselling or had formal support as a child, except for one study participant who recalls briefly being involved with a school counsellor because her sister had contacted her school.

Theme four: Transitions into adulthood

Transitioning from adolescence into young adulthood was cited by all study participants as being a struggle. A common theme was “not knowing”. Not knowing as a child that their family lifestyle was different from other families; how to ask for help, and how to be as an adolescent and young adult. Although the study participants were frequently seen as competent they felt unprepared for adulthood. They discussed not having the skills.

Creating boundaries

Creating boundaries between themselves and their mentally ill parent was described as a necessary part of being able to begin having their own life. However, as one study participant described it was not always an easy process.

...it's the whole thing of conditioning again you have a certain relationship with somebody and you want to change the perimeters that person doesn't like you to change the perimeters of the relationship.

Delayed adolescence

One study participant, who grew up with a mentally mother, identified having a “delayed adolescence”. She describes her experience.

I really don't know how much was like being a goofy adolescent, but I didn't really have a sense of being in my body and myself for many many years, until I was in my 30s really...I wasn't always observing from the outside what was going on and I don't know if that's just me or if that's related to what happened in my household. [I] suspect the latter.

A similar experience of missing pieces during adolescence and young adulthood was echoed by a study participant who grew up with a father with a mental illness. She moved far away from her family in order to live her life.

...I felt like I was an infant, but I was also forty. I had the experience of being an adult and doing things for others but I didn't have the in-between and that's what I was going to do with my life, to be the in-between...I have to get born and I have to do all of that work...I have

to live and I have to live in a place where I can discover who I am, who I want to be with and everything.

Not having the skills or experience

For some of the study participants transitioning into adulthood was made more difficult because of the isolation they experienced as a child. One study participant, who lived with a mentally ill father, describes her experience.

I didn't leave home...until I was about twenty, but I couldn't make it on my own I had to come back...[they] never ever allowed me to make any money on my own...I had very few friends...because the kids that were friends when I was growing up either moved away or the girls got boyfriends, I didn't date until after I left home, I never had a boyfriend until I was about nineteen. [I had] a real anxiety and panic in me around how I was going to do that when I was so alone not having ever worked, not having had a normal social experience...I was amazed when I did get older and got more out in the world that men could be like not mean, not violent, not, not so macho.

Leaving the family home

Two study participants, who also had challenges leaving the family home, expressed their need to move as far away from their family as possible. One study participant explained how she had to move away from her bipolar father as he was constantly harassing her at school and at work. Another study participant moved far away from her family to attend college. Ironically, both describe how they were able to remove themselves physically, but psychologically were still very much connected. They report often monitoring their parent's behaviour from a far;

talking to their family on the phone and asking how their parent was doing. When a crisis occurred they easily stepped into their role, which frequently led to returning home to assist.

Continued caregiving

Another study participant reported that from her early teen years until her mid twenties she felt responsible for caring for her bipolar mother. As she transitioned from an adolescent to a young adult she began to realize that she was not living her life and the importance to her of making change.

...it was just too dramatic and that was when I put rules down in place. I can't be your therapist, I need to live my life, I need to do for me for a change because I'm in my twenties, I have no social life, I don't date, I don't go out I don't do anything. I'm in this rush, failing classes because of the psychological stuff that's going on, my work...I had no fulfilment in any part of my life at that point, and yeah, so I made the choice to leave.

This study participant reported experiences, which suggest that she has successfully started her own life and remains connected to her parent. Another study participant, who cared for her bipolar father, had a similar experience. She felt that after her parents divorced in her late adolescence it was her responsibility to care for her father.

Most of the study participants who left home kept in contact with their families. One study participant described going home from university for a visit with her mother who lived with bipolar, her father who struggled with alcohol abuse, and her adolescent sister.

...throwing parties where hundreds of kids were coming over and I was just freaking out, I went from the white picket fence and the perfect family and going to university and coming back one weekend, finding everyone smoking a joint on the couch.

Interruption in education

Interruption in education was a common theme in this study and has been found in other studies (Mowbray et al., 2006). One study participant described dropping out of post secondary school for an extended period of time.

I went to university...I was eighteen, I was really pretty depressed and I just went off a lot of time sleeping...I was kind of a messed up person in my twenties...I do regret all those years that I wasn't doing my schooling back then...but you know there was stuff I was doing during those years that I needed to do.

Subsequently, this study participant went on to complete two degrees and is continuing her graduate education.

Theme five: Experiences of adults and parental mental illness

The theme of not knowing continues into adulthood for many of the study participants. One study participant describes having her first child and not knowing how to ask for help. She reports doing everything herself because “it did not even occur” to her to ask for help even though she had relatives that lived nearby who would have been more than willing to help. Study participants spoke about their experiences of being an adult child who grew up with a mentally ill parent. Two of the study participants report that they continue to be connected with their mentally ill parent. Four of the study participant's ill parents have passed away. Several continue to have contact with their well parent. Experiences include not knowing how to be as adults, feelings of grief and loss, worries about their own mental health, coping strategies and coping behaviours as an adult, managing their mentally ill parents' behaviours and creating boundaries, and experiencing their own significant life events.

Grief and loss

Grief and loss was a common theme across all of the interviews. One study participant, whose mentally ill father has passed away, experiences grief and loss for what could have been, she explains:

...the fact that I haven't had children, the fact that I don't have a happy extended family. I will never be the person that I could have been, I will never be an optimistic person, and I know that I am, my core is kind of a happy helpful person, I can feel that because I enjoy things...I try to be very present...do a check of my feelings quite a bit...is very important, because I was not taught ever...to look after myself...we were dispensable.

Grief and loss was also expressed as feelings of not having had a mother or a father during childhood. One study participant reflects on her experiences living with a mentally ill mother.

...what I think about is what I didn't have was a mom...somebody who could guide me through all of that in a normal healthy way...because of her illness she just wasn't able to be a Mom really, she could just barely be human to be honest.

The effect of mental illness on parent's ability to participate in important events in a child's life was also felt as a loss. One study participant whose father lives with bipolar disorders tells of her experience.

...I think I missed out just not having him present at a lot of important events in life...when I graduated, when I got my degree...I mean he didn't help me with any of my projects, he didn't help pay...he just wasn't a part of that...but it still would have been nice to have him there and recognise that day with me.

The same study participant spoke of the loss she felt of not having a typical parental relationship.

...I feel like I've missed out just picking up the phone and wanting to ask his advice about something...or just having ease of relationship where I can just kind of come over whenever I like or pop in to see him without it being some big anxiety ridden...

Mental health troubles as an adult child

Knutsson-Medin et al., (2007) reported that approximately 20% of the adult COPMI participants in their study had been in contact with adult mental health services, in comparison to the expected rate of 6-7% in the general population. Five of the six participants in this study described struggles with their own mental health as young adults. One study participant describes her experience as a young adult.

I was twenty-five I had a personal crisis that resulted in a suicide attempt...I really turned the corner after that although it was a long, wide corner, took awhile... had been on and off anti-depressants for many years.

I did have counselling and medication and that made a big difference.

Study participants described various mental health issues during their adulthood ranging from depression and anxiety to suicidal ideations and suicide attempts. They reported being involved with adult mental health including participating in counselling. In addition, they reported taking medication, which they indicated was helpful.

Adult child caregiving

The findings of this study suggest that children of parents with mental illness continue to care for their mentally ill parent well into adulthood. However, the difference between caring as a child and caring as an adult may be choice. Although an adult child is likely better able to choose

whether they continue to be involved with caring for their mentally ill parent the decisions that they have to make are not always easy. One study participant describes contacting adult protective services to intervene in the care of her mentally ill mother.

...my Mom was bad, but we were kind of used to it...she always kind of smelled bad, it was always horrible...she wouldn't go and see a Doctor, she wouldn't do anything. On the advice of my Dad's attorney...I called in protective services...then my Dad told my sister that I had done that, and my sister of course then told my mother...so she disowned me...she was calling me [terrible names] you know... things, you don't want to hear from your Mom.

Shortly after contacting adult protective services her mother passed away in hospital. Her mother was fifty four years old and her adult daughter was twenty six. Despite the geographical distance this study participant reported never fully being removed from caring for her mother.

Participants in this study indicated that they spent a fair amount of personal energy figuring out how to create boundaries that allowed them to stay connected to their parent, but also have a successful life on their own. In this study, as with children of parents with mental illness adult children also monitor their parent's behaviour and adjust their own behaviour accordingly. However, as adults they have the experience and generally the knowledge to better interpret the various situations. One study participant who has stayed connected and has cared for her father most of her life described her experience.

...it's not the end of the world if I go a few months without seeing him...and when he's healthy I'm happy to have him in my life if he can be a positive influence and supportive to me and my daughter...but I'm beyond taking his crap –so listening to him scream and yell, when he's on

the phone, or be embarrassed in public...I just don't deal with that anymore...

This study participant chuckles when she discloses one of her father's favourite sayings, "Life has no stop signs". She responds, "It's the Dad contingent...that's always at the back of my mind". Referring to the ongoing push and pull of staying connected while maintaining the necessary boundaries between her father and her and her daughter.

Study participants also worry about looking after their mentally ill parent in old age. This same study participant considers the ongoing nature of her caring role;

"I do worry a lot about getting stuck caring for my dad at an old age because no one else is going to do it, that's a pretty scary proposition, but I'll cross that bridge when we come to it."

Caring for a mentally ill parent as an adult child is described by one study participant as being a part of her relationship with her parents. She describes her experience.

It's like you have to have the same set up ahead of time when the person is well, so that when they collapse somebody's there to catch you...80% of the year they do great...and there's no problem...they are uplifting and they build me up, it's just when they get unwell.

This study participant describes experiences that suggest she has successfully recruited and educated friends and family to assist in helping her family when a crisis arises. Her mother is diagnosed with bipolar disorder and her father has a long history of alcoholism.

Disruption of work and the personal life of adult offspring were also reported. One study participant explains her experience.

...anyways she [mother] left and my sister and I ended up having to walk out of her jobs and drive up to [parent's home] because at this point it

was just dad. We tracked her down...we showed up about midnight and she was standing there as if nothing was wrong thrilled we came to visit and that we were there to move her to Vancouver.

Perceived strengths as an adult

As found in previous studies (Kinsella, Anderson & Anderson, 1996; Knutsson-Medin et al., 2007) all of participants in this study described having developed strengths from their experiences. One study participant expressed how her perceived strengths have influenced her personal growth.

I had strengths growing up...and now I have compassion and empathy...through being a parent myself I have developed a lot of compassion for my mom.

Becoming a parent

Four of the six study participants are parents. A common theme amongst study participants was a reluctance or fear of becoming a parent. One study participant described that despite being adopted, so presumably not having a genetic predisposition to mental illness, she was still afraid of parenting like her mother. Other study participants also indicated that they were afraid that they would not be a good mother to a child. One study participant explained that having children “was more like a leap of faith”. She feels that her children have “certain blessings” that she did not have as a child. They have “two parents that are alive and well”. Participants in this study also described instilling in their children certain values that they learned as a child. One study participant recalls:

My parents always read to me as a child that's one of the things they really did right. So I did the same thing with her [daughter] and she's a good student.

Influences on choice of occupation

Several study participants indicated that as adolescents and young adults they wanted to be a psychologist. All of the study participants explained how taking psychology courses in university helped them integrate their experiences with a better understanding of mental illness. One study participant describes her experience of choosing an occupation.

I wanted to make meaning of it for one thing and I guess I knew what it was like to suffer emotionally and I wanted to work with people I guess to help them develop a better understanding of what was happening with them or to give them comfort and support. [It] was a pretty strong drive for me.

Four of the study participants are practicing social workers. They all expressed that their childhood experiences resulted in a high level of compassion and empathy for people, which they believed enhanced their overall social work practice. Several explained how their experiences growing up with parental mental illness have influenced their practice. One study participant described her experience.

...you know people say that adversity and coming from a bad background...it gives you a gift too...and it's made me, I think a really much better social worker because I do understand things and a lot of things that people say I totally get.

Another study participant describes how it was sometimes difficult for her working in child welfare with families who experienced parental mental illness.

...even though it makes it harder to do your work...to see it in that nuanced way, because, ...I think there is an additional ethical burden when you start to see that...to be able to see the grey.

Family involvement with criminal justice and mental health systems

Two study participants reported having parents who are currently living with bipolar disorder. These two study participants reported being involved with both the criminal justice and mental health systems more frequently than the other adult offspring in this study. One study participant recalls her father first being involved with the criminal justice system when she was a teenager.

...the older we got the less fun it became also because his illness has gotten progressively worse...he's just started to get a lot more uglier and violent and bitter and resentful and...involved with the police and the prison system... criminally involved [but] not sophisticated...he would be drunk, get in to altercations and so he was incarcerated for a time...

Interestingly, this father was formal diagnosed with bipolar when he was in prison. The study participant explains:

...it was actually in prison that he was diagnosed and they put him into a separate section I think, for people with mental illness, so that kind of precipitated him being followed by the family Doctor, and then a psychiatrist, and then he's been in and out of hospital.

She goes on to explain his journey.

...he gets scared when he gets manic, because he knows "Oh I'm going to end up in jail, I'm going to lose all my money, someone is going to beat me up – bad things have happened to me" so I think on some level...he is connecting his behaviours to his consequences, but then the medication they have put him on would just completely knocked him out or give him horrible side effects, so that wasn't the right thing to do either.

By age 17, she visited her father in prison and in the psychiatric ward of the hospital. She describes her experience.

...it's been pretty emotional and yeah I hope I don't ever have to go visit him in the psyche ward ever again...not a fun place to be at Christmas.

Other study participants had experiences with police involvement in their families, but did not talk about visiting their parent in the hospital. Police involvement was reported to generally involve one of the study participant's fathers who had been brought home by police for being drunk in public. Another study participant describes several incidents involving domestic disputes between her bipolar mother and alcoholic father. This same study participant describes challenges working with the mental health system when attempting to get medical attention for her mother during several manic episodes. She describes her experience of having to advocate for her mother in order to get support services both in hospital and after discharge in the community.

Theme six: Making meaning of experiences growing up with a mentally ill parent

Two of the participants in this study are in frequent contact and for the most part enjoy a good relationship with their mentally ill parent. The mentally ill parent of four of the study participants has passed away. The parents passed away in their early fifties to early sixties. The study participants ranged in age from fifteen to their thirties at the time of their parent's death. Making meaning of their childhood experiences living with parental mental illness was described differently for children whose parents have died in comparison to adult children who are still involved with their parent.

Acceptance of parent's mental illness

Acceptance of a parent's mental illness was described by the two study participants who are still involved with their parents. One study participant tells about her philosophy of being an adult child of a parent with a mental illness.

It's like this big elephant in the room all the time and my brother gets annoyed with that, he's like "how can you just talk to Dad and go visit him like nothing's ever happened?" and I say "well because today is today like what's the point of hashing out what happened or all that ugliness like that happened then and when he gets like that again then I don't have anything to do with him" and he is going to hopefully figure that out.

She goes on to explain.

I'm going to have my own relationship with my dad, and I'm going to be in charge... [It's] not like any of us has a crystal ball...so I just kind of learned to quit stressing out about it. There's nothing I can do, just take it day by day week by week. It's a good place for me...that might change...but I can live with that for now.

The sentiment is similar, but different for one study participant whose mentally ill mother has passed away.

...I don't think she deliberately wanted to be mean I think she was just so wrapped up in her own pain and need that she just couldn't see past the end of her nose he know.

Finding balance

Another study participant whose mother is diagnosed with bipolar disorder describes coming to terms with being an adult child of a mentally ill parent.

I'm happy with my life...now I have the satisfaction, but I guess I'm also realistic in the back of my mind thinking, just make sure I have the pieces together now because I almost lost it this last time, I got pulled in pretty deep.

Dreams

Several study participants spoke of reoccurring dreams that lasted well into their adulthood. One study participant dreamed of having a child and not caring for the baby. She describes her dreams in terms of some fear about being a good parent herself.

...for many many years that I had dreams that I would've had a baby and then just left it at home and forgot that I have a baby for two weeks...[and then in one dream]...I remember that I given the baby to my dad and then I knew it was safe...

Another study participant described how her childhood experiences as the eldest child, who was often put in charge, manifested in a reoccurring nightmare.

...it's just in the last few years that I don't have this nightmare where the whole family goes on a car trip just for the fun of it, but that my father is incapacitated.

Both of these study participants describe being in a good place in their lives right now. Both are married and have children and report being wellness in their personal and professional lives.

Death of a parent

Part of making meaning for some of the study participants was putting the death of their mentally ill parent into perspective. This also included the study participant coming to terms with how they felt about their parent's death. One study participant felt a sense of relief.

It's good that he did die because I don't know what would have become of me if he hadn't...I'm not a weak person.

Another study participant and child of a mother with mental illness expressed feeling the same sense of relief when her mother died. She also reflected on her mother's struggles in life.

...she was only fifty-four, a really terrible, terrible life [mother's]...I was grateful, because I just couldn't take it anymore. Yeah, that relationship, I couldn't get away from it, but I couldn't really take it.

Other study participants also spoke about the death of their parent. A sense of relief for themselves and their parent was a common theme across the four interviews.

Becoming a parent

One study participant described coming to terms with the grief and loss that she felt and how becoming a mother has helped her make meaning of her experiences living with a mother with mental illness.

...what I think about is that I didn't have a mom, somebody who could guide me through all of that in a normal healthy way. Healing for me has been by being a parent myself...I think I'm a good parent and that's very healing...I was very afraid of being that [like my mother] kind of parent.

Four of the six study participants interviewed were parents. They shared similar views and experiences of becoming a parent. Successfully parenting in a style that was not like their

mentally ill parent was indicated as being healing. One study participant marvels at her daughter's life, which is in sharp contrast to her own childhood. She reports happily parenting a child who is successfully progressing through her childhood.

Among the ways that adult children in this study made sense of their experiences was incorporating all of their life experiences from childhood and adulthood and retelling their story more from an adult perspective. This study participant was able to consider other aspects of her childhood when she became a parent herself.

You know my mom did her best but it just wasn't very good...at the end of the day.

Self reflection and healing

Participants in this study describe coming to terms with their experiences through self-reflection and in some cases through therapy. As social workers, many of the study participants have spent a great deal of time reflecting on their experiences as a way of coming to terms with adult challenges they believe are a result of living with a mental with mental illness. One study participant describes her experience.

It's a huge long journey now, it's like grief. Someone I heard on CBC radio, an aboriginal woman I think, saying that grief is a forest you walk through and I just love that image because I think there's a lot of grief in my past and loss and you do you walk through that. And you learn too, I wouldn't be the person, I wouldn't have the insights today if I had had this wonderful childhood, but...it's a burden to live with.

The majority of the participants in this study have been involved in either group of individual therapy. Many of the women have also been trained in counselling. One of the study participants

describes her unexpected experience of participating in an art therapy class, which was part of her professional training.

...[the task was to] draw your family. I didn't even stop to think, I drew a volcano with three little stick figures representing my mom, myself and my sister and I thought well that's pretty powerful...I looked at it [my drawing] and I really wasn't moved by it... Then, what really upset me was I looked at everybody else's drawings and none of them were that bad to be honest, that was powerful.

This same study participant goes on to explain her ongoing processes with making meaning as a part of healing from her experiences growing up with a mentally ill father.

I've processed so much throughout my life...I've been in a lot of counselling, I've done tons and tons of reading, I have a good intellectual understanding of what happened [in my childhood]...emotionally that's much harder...I still have trouble with intimacy and relationships.

Another study participant who grew up with a mentally ill father described her process of making meaning out of her childhood experiences.

...those skills I learned in childhood and adolescence, I wouldn't wish it on anyone, but it certainly taught me compassion, insight, understanding, many many many things...I wouldn't want to repeat it.....the repercussions of all of that stuff followed me well into my adulthood and influence the kinds of choices that I made...I think I would have done things differently...but I think that's an important part of the healing is making meaning of the experiences because it's so easy to go into the victimization. She goes on to reflect on how her experiences have shaped her life philosophy.

All of it has made me a more well-rounded person. You learn skills from all of that stuff and the life experiences that I have the philosophy that I develop.

Things could have been worse

One study participant who grew up with a mentally ill mother describes how she puts her experiences into perspective.

...yes I have been fortunate, really fortunate actually, and I think that what happened in our childhoods, in my household, was actually pretty tragic, had a really terrible impact on my brother whose life has been ruined by the way he went off the rails. He just is never going to catch up, you know, my sister is doing ok, but...I feel like I've landed on my feet, I've been really really lucky and that I have some depth that I wouldn't have had probably.

This perspective was common across many of the interviews. Themes of “feeling lucky” that adult life was good and that “things could have been worse” were expressed by many of the women in this study. The study participants compared their current life with those of siblings and other adults that they either worked with or knew and came to accept that they had, for the most part, successfully journeyed through the adversity in their lives. Philosophies of some of the study participants were summed up in their sayings such as “you make lemonade out of lemons” and “if life hand you shit you make manure”.

Spirituality

Two of the study participants talked about have a sense of spirituality, which helped them make meaning of their experiences. For one study participant, spirituality meant believing in

something that was bigger than herself. The other study participant grew up in a large religious community and linked her spirituality to her belief in God. She explains.

...I have a spiritual side as well and I think that God doesn't give you these things as meant to break you it's meant to teach you and show you what to do, so that you can do the rest of what you're supposed to do in life.

Reconnecting with extended family and friends

Four of the six study participants have reconnected with extended family and/or friends as adults. A common theme associated with reconnecting with friends was how differently they experienced friendship in childhood in comparison to their friends. One study participant explains:

I'm in contact with some of the friends in the convent that I haven't seen for fifty years and it's interesting their view of me then and my view of myself how it's not the same thing.

Being an adult child of a mentally ill parent can be challenging. One study participant explained how she actively sought reconnecting herself and her parents with friends and family to build a support network. Some family members are more willing and able to help than others. She explains.

...my auntie is probably my closer one I trust her to help when needs to happen, my uncles mean well but they don't understand mental health very well.

Reconnecting with extended family members as adults was a common theme related to healing and making meaning of experiences. One study participant had a unique experience resulting from her adoption at age ten months old. She describes reconnecting with her biological family

and the positive influence that reunion had on strengthening adoptive family relationship. This experience occurred after her mentally ill mother had passed away.

...I had this great experience, especially with my grandmother and aunt of this unconditional love and acceptance, and I was twenty-six...and I realized that after experiencing it from them, when I didn't expect it, that I had always had that from my father, but I just hadn't known it...that really healed my relationship with my dad...after all those years of thinking, cause my mother said so, that he was like some scary guy.

Humour

The participants in this study eloquently described their lives growing up with a mentally ill parent. They shared their stories of strength and of sorrow. Many expressed feelings of loss during their interview. At times they expressed being surprised by what they were feeling as they told their stories. Each interview had moments that were difficult and some that were light-hearted. Two study participants used humour to sum up the 10,000 foot view of their lives. One study participant noted, with an optimistic tone, "If it wasn't my own life I'd probably think it was a lot funnier." After describing her childhood, one study participant reflected, "So, I think it's a great childhood for a southern gothic novel." This light-heartedness was seen a way for these study participants to put their lives in some kind of perspective.

Theme seven: Wishes for children growing up with parental mental illness

Five of the six study participants are trained social workers. Four of them are practicing. Their experiences growing up with a mentally ill parent have provided them with firsthand knowledge about potential consequences for children who live with parental mental illness. As adult children they have share many similar experiences transitioning from adolescence into

adulthood. As adults they have experienced their own significant life events such as graduating from university, getting their first job, first relationships, getting married and having children. They describe the process of integrating knowledge of parental mental illness with their experiences. For these study participants, their journeys have often been long and rarely without pain. However, the participants in this study have also described coming to terms with parental mental illness and making meaning of their experiences, which have allowed them to move on with their own lives. The following is a summary of the wishes that these study participants have for children of parents with mental illness (COPMI). It also includes what they wanted people to know about COPMI.

Working with children and families who experience parental mental illness

One study participant has social work experience with families who live with parental mental illness. She particularly wanted individuals to “stop making them [children] feel selfish for having needs.” She also believes in giving children the language to talk about mental illness, so that they can have a conversation. Let know it’s not about them, “it’s not about their mom not liking them, it’s about illness”. She also felt that educating children of parents with mental illness about the risks of recreational drug use was critical. Educating families and professionals about safety and contingency plans for families was also considered to be extremely important for when the inevitable decompensation occurs. This study participant stressed the importance of having a plan and having someone to talk to, preferably a family member. Some support should be provided to the well parent in order to help them keep working and supporting their families financially, practically and emotionally. She explains.

...if you have a parent with a mental illness the other parent is having to take care of them and at a pretty intense level sometimes and the consequences of not doing it can feel really serious, it can be suicide.

Another wish for children was that they are told that just because their parent has a mental illness does not mean “just because your Mom’s sick, your Dad’s sick, doesn’t mean that you are going to be sick.” They need the education. One study participant explained.

...for kids, it’s I think about knowing that they have the capacity to deal with it [parental mental illness], but they just need the support and they need people, to talk about it.

In one study participant’s professional and personal experience she does not believe that children of parents with mental illness should have to be resilient. Although supporting the children and their parents to remain together was considered important by the majority of the study participants they also recognized the importance of somebody being prepared to draw the line and protect the children. In this study it was commonly reported that friends and extended family were aware of the families’ situation, but no one was prepared to step in. Another study participant wishes for more early intervention for children who are growing up with parental mental illness. She also believed that she would have suffered less as a child if she had access to more “emotional support...that would've really helped a lot”. She felt that by the time she could afford to pay for a psychologist, so much damage had already occurred. She describes her experience.

My hope is they will be more just so that the earlier the intervention the better the results. Don't wait until they are adults and chronically depressed and chronically anxious and chronically, you know, all that stuff. When it becomes chronic in becomes so... you're neural transmitters are not working.

Using superficial measures when assessing children of parents with mental illness

A common theme across the interviews included feelings of loneliness and unhappiness, despite appearing outwardly competent. One study participant hoped that professionals would make more effort to understand the lived experiences of children who are growing up in a family with parental mental illness and “not use such superficial barometers as measurements [to assess] how kids are doing. Finally, several study participants wanted individuals to know that growing up with a mentally ill parent was not all bad. They believe that when they tell people their stories everyone tends to focus on the bad.

DISCUSSION

Parental mental illness touches the lives of families without discrimination. Some families have financial resources, while others are marginalized and live at the edges of society. Mothers and fathers both experience mental illness; parents live as couples or single parents; have varying psychiatric diagnoses, and differ in ethnicity, culture and religions. Some children of parents with mental illness manage to ride the wave, while others struggle to keep their heads above water. Positive strides have been made for individuals and their families living with parental mental illness. People who live with mental illness are no longer placed in institutions or generally have long stays in hospital, but rather are supported to live in their community. In addition, the availability of improved medications has enhanced the quality of life for many individuals. Finally, there has been a positive shift away from a deficit-based medical model that blames the parent for their illness towards a family focused model that is inclusive of family, support networks and the broader community. Despite this movement towards a recovery model in mental health many families continue to struggle.

The participants in this study reported experiences as children similar to findings seen in previous studies (Mordoch & Hall, 2008; Mordoch, 2010; Riebschleger, 2004). Findings in this study included reports of abuse, coping, offspring mental illness, perceived strengths, family involvement with child protection services, and caring. There were several aspects of this study that were somewhat surprising. First, of the six study participants four lived with a father with mental illness. Literature that looks at children's experiences living with mentally ill fathers is sparse. Secondly, all of the study participants reported growing up in a two parent family. A number of existing studies focus on lone parent families, but few studies have focused on the experiences of children of parents with mental illness who live in two parent families. They also reported a wide variation in their socio-economic status, cultures and religious backgrounds.

Finally, three of the six parents were diagnosed and three were suspected of having bipolar disorder. The recruitment criteria for this study included being the child of a mother and/or father who had a mental illness. The diagnosis of the illness did not have to be known by the study participants. It is unclear if the fact that all six study participants had a parent who was either diagnosed or suspected of having bipolar disorder was coincidental. Alternatively, it may be that these study participants, who lived with a parent with bipolar disorder, were compelled for some reason to share their experiences. A number of the study participants reported wanted to share their experiences in order to inform policy and practice to improve the situations of families who live with parental mental illness.

Most of the study participants described experiencing periods of parental wellness as children, which made them feel like other kids. However, most study participants also described living with a constant sense of not knowing what was going to happen next as their parent's illness often left a trail of unpredictable behaviour in its wake. This sense of unpredictability may have been influential in the way the personal growth of these children was shaped. According to Pretis and Dimova (2008) living with a parent with mental illness changes children's coping and "absorbs energy" from children's global functioning (p. 154). At least half of the study participants described experiences where their lives were so chaotic that they often functioned day-to-day in order to cope, or as some described "survive". This may suggest that some children of parents with mental illness are delayed in their biopsychosocial development because they are expending their limited energy to manage their daily lives. For example, the adult children in this study describe making themselves invisible as children in order not to provoke their parent; they worked hard at school and achieved high marks, and they adopted family roles such as "the good child". While these strategies helped them as children they were not transferrable into adolescence or young adulthood when they were challenged with living more independently in

the outside world. Children in these circumstances usually show non-specific symptoms of stress, which is comparable to children whose parents have chronic illness (Pretis & Dimova, 2008). As an adolescent or young person subsequent personal growth became more difficult in the context of family demands and frequently limited resources. It was no longer as simple as getting out of the way of a parent. In order to succeed the maturing offspring needed both a solid foundation and life skills to move forward.

As the study participants matured overtime they reported experiencing a great deal of distress not “knowing how to be”. Several study participants reported being surprised when they realized that their family was not like other families. Two of them reported that as young adults they experienced a process of personal growth that they reported felt like “being born” or living through a “delayed adolescence”. One study participant described being 40 years old and still feeling like an infant; the other reported being in her 30s before she felt comfortable in her own body. This may imply that while typically personal growth occurs during adolescence for some children of parents with mental illness the energy expended coping with family life may result in a delay in their personal growth. As the study participants matured they became more skilled at understanding parental mental illness as well as at using strategies that were more functional and less maladaptive. Armed with experience and increased life skills children of parents with mental illness had the wherewithal to focus on their own psychosocial development and personal growth.

The participants in this study all reported having difficulties transitioning from adolescence to young adulthood. A transition is described as the psychological process people go through to come to terms with a new situation (Bridges, 1994). A common thread throughout most of the interviews included “not knowing”. This finding was similar to the findings in a prospective study conducted by Mordoch and Hall (2008) who described children trying to make sense of

living with a parent with mental illness while only have some pieces of the puzzle. It is interesting to note that for most of the study participants that same sense of missing pieces or not knowing continued to influence their personal growth well into adulthood. One study participant described being so isolated by her family that she was unable to manage on her own when she left home. Among the life skills that she reported lacking including not ever having searched for or having a job and not knowing how to enter into or maintain a relationship, despite being an accomplished student. Another study participant described significant difficulties with depression; a personal crisis and subsequently a suicide attempt when she left home to attend university. She reports being a gifted student who, as a child, participated in many community activities. For most of the study participants the challenges of engaging in a kind of “catch-up” in their personal development together with the challenges of transitioning into their own independent life was felt well into adulthood. Two of the study participants in particular described taking time during early adulthood to learn about themselves, gain the life skills they needed and to make meaning of their experiences. This process was described as part of “what they had to do” during their early to mid adulthood. Attending to the process of making meaning of their experiences growing up with a mentally ill parent as they went through their own significant life events was described by study participants as healing and necessary in order for them to move on with their own lives.

The participants in this study ranged in age from 27 to 63 years of age. In general, they described having come to terms with their own experiences growing up with parental mental illness, at least to some degree. Some study participants expressed that their experiences have given them strengths and they see themselves as empathetic, compassionate, and capable. This finding is consistent with other studies of the experiences of adult children of parents with mental illness (Mowbray et al., 2006). In general, the study participants have experienced many

significant life events of their own. Five of the six study participants have at least a bachelor's degree, the majority of them are married or have been married in the past, four of the study participants are mothers. They described having a sense of pride in what they have accomplished as adults. Four of the six study participants have children of their own and describe themselves as skillful parents whose children are doing well. For them making meaning of their life experiences was often described in the context of becoming a parent. One study participant eloquently described how the absence that resulted from her mother's mental illness was keenly felt as a loss of not having a mother to guide her. She spoke of how having her own child has helped her understand her mother's illness and she believes has led her to have more compassion for her mother. Making meaning for her was, in part, a process through which she was able to come to terms with the fact that her mother did the best she could given her illness. Although the feelings of loss have not completely gone away they may be less intense because she has now been able to wrap them in a sense of understanding that has allowed her to move on with her life. This ability to make meaning in life has been linked to better physical and emotional well-being (Frankl, 1963).

Making meaning of their experiences growing up with parental mental illness differed for each study participant, although there were some similarities. According to Byrne (2003) meaning never stands still. Brandtstader (2004) posits that in family systems negotiating meaning can be seen as a basic strategy for establishing agreement between family members who have to co-ordinate their actions and developmental goals. For example, two study participants who are still connected to their mentally ill parent have gone to great lengths to establish boundaries between themselves and their parent. This allows them to remain connected while at the same time living their own lives. This process of children of parents with mental illness separating themselves from their parent's illness in order to maintain some form of connection

was also seen in the prospective study conducted by Mordoch and Hall (2008). Interestingly, the two study participants who described “being in a good place” in their lives had quite different experiences growing up with a mentally ill parent. One lived with a mentally ill mother who is thought to have had bipolar disorder. Her mother was quite physically and mentally ill when she died. At the time of her death the study participant was in her mid twenties. She describes a challenging childhood and major difficulties transitioning into adulthood. Prior to her mother’s death she describes having to make extremely difficult decisions regarding her mother’s care. She reports having reconnected with family and friends since her mother’s death. As an adult she has made meaning out of her experiences and describes being in a good place in life. She describes herself as an accomplished and well adjusted adult, wife and parent to a young daughter. In comparison, another study participant whose father is diagnosed with bipolar describes having challenging and also fun times as a child. She recalls periods of wellness and unusual, but fun times with her father as a child. On-going caregiving and support has been a significant part of her adolescent and adult life. Her father has had periods of wellness in which she describes him being “like dad”. He has also had many episodes of acute illness that have resulted in police, criminal justice and mental health system involvement. This study participant also described experiences that suggest she is an accomplished and well adjusted adult earning a bachelor’s degree, becoming a skillful practitioner, and a mother. While her journey has been different from other adult offspring in this study she too feels that she is in a good place in her life. She has accepted her father’s illness and has been able to create boundaries so that she can remain connected to him, but at the same time she is able to live her own life. Establishing a relationship with her father that is on her terms is one way she has been able to move on with her own life. She describes having a child as being a catalyst for change. Even though these two study participants had quite different experiences they have both been able to make meaning of

their experiences growing up with a mentally ill parent. Significant life events such as leaving home, important relationships, post secondary education, choice of occupation and parenthood seemed to be influential in meaning making and personal growth. While the experiences of growing up with a mentally ill parent may have set the trajectory of some negative experiences in the lives of these offspring they did not appear to doom these children to a life of mental illness and maladjustment, which is often how children of parents with mental illness are portrayed in early literature; in fact, quite the contrary.

Traditionally, children of parents with mental illness are seen as at risk of developing their own mental illness and those who grow up relatively healthy are determined to be resilient. Being classified as at risk is a powerful label that is often unavoidable by families who experience parental mental illness. This label of risk frequently follows children of parents with mental illness (COPMI) into their adulthood. For some families the label of risk reaches far and wide affecting the offspring's children (Gladstone, Boydell & McKeever, 2006). This contemporary discourse is viewed as part of the larger discussion of risk and childhood and specifically about a developmental stage in life when children are at greater risk physically and psychologically (Gladstone, Boydell & McKeever, 2006). More recent literature does not see children as blank slates who become victims of their parent's illness, but rather sees children as active participants in life (Gladstone, Boydell & McKeever, 2006). One challenge that has been noted in previous studies is the "lack of voice" in research of children of parents with mental illness (Gladstone, Boydell & McKeever, 2006; Mordoch & Hall, 2008). Gladstone, Boydell and McKeever (2006) suggest that recasting children as having competencies and vulnerabilities linked to their developmental stages would lead to a different line of inquiry (p. 2541). Currently, assessment of how a child living with a mentally ill parent is doing is determined by considering the adult's capacity to parent, which is judged according to the child's accomplishment of

developmental tasks. In addition, resiliency is measured by the child's social abilities, evaluated in terms of his or her attachment to the parent (Gladstone, Boydell & McKeever, 2006).

Broadening the scope of research to include children's accounts of their experiences may provide for better answers to the question "how do we know what children's needs are?" (Gladstone, Boydell & McKeever, 2006). I agree with this supposition and reiterate the need for qualitative research that allows for the exploration of individual experiences of children who grew up with families who experience parental mental illness. Not only is it important to understand the subjective experiences of children, but also how COPMI make meaning of their experiences. In addition, I challenge researchers to look closer at various aspects of risk and resilience. For example, several women in this study stress that despite being seen as outwardly competent as children they experienced considerable psychological distress. In some cases excelling academically was a strategy used by children to reduce stress in their family in hopes that their mentally ill parent would have reduced symptoms. One study participant described how she took on the role of "good child", which is consistent with the findings of other studies of children of parents with mental illness (Kinsella, Anderson & Anderson, 1996).

The findings of this and other quantitative and qualitative studies have found a number of similarities of the childhood experiences in children who experience parental mental illness. Considered through conventional child development lenses it is easy to see that these children do have vulnerabilities. For example, parental absence, both physical and psychological and childhood abuse and psychological distress appear to be common threads. Clearly some children may be at physical and psychological risk, particularly young children. These children and their families need to have support and if necessary interventions to protect children may need to be implemented. Participants in this study wondered why as children someone did not come forward to protect them from abuse at the hands of their mentally ill parent. Assessment of

children's vulnerabilities and strengths during childhood is critical to providing families with support and to designing prevention programs. Study participants described coping strategies as young children that would suggest that inexperience played an important role in their choice of actions. For example, one study participant describes in detail how she would monitor her father's behaviour and decide whether she was able to retreat or "become invisible" in order to protect herself, both physically and psychologically. She describes this coping strategy as being her survival mechanism during childhood. This response became so ingrained that she reports continuing to use the same coping strategies as an adult; not in response to abuse, but rather in response to situations where she feels uncomfortable.

Gladstone, Boydell and McKeever (2006) suggest that the concept of competence be used in studies of children living with parental mental illness. They posit that research that assumes children are competent as well as at risk may "illuminate the range of possibilities for participation and the positive and negative effects on children" (p. 2545). By not pathologizing the family living with parental mental illness as a necessarily 'deficient family structure', and seeing children other than as victims, the ways agency is accomplished and vulnerabilities and challenges are dealt with, may be revealed (Alanen, 1998, p. 39). While I agree that measures of strengths need to be a part of research studying the experiences of children of parents with mental illness I caution that the appearance of outward competence in COPMI can be misleading. One study participant stressed from her own personal experience that practitioners should be careful to "not use such superficial barometers [such as academic achievement] as measurements [to assess] how kids are doing". Furthermore, I propose that as researchers we strive to look beyond the traditional child development lens and consider psychosocial development and personal growth across the lifespan, particularly for older adolescents and young adults.

Implications for Social Work Practice Participants in this study described feeling isolated as children despite many of them appearing competent and participating in community and school activities. Silence and stigma continue to be significant reasons why families remain invisible to helping professionals. The literature associated with social work practice and children of parents with mental illness stresses best practice as being family-centered and family-inclusive (Beardslee, Versage & Gladstone, 1998; Lees, 2004). Regardless of the existing research child welfare systems and adult and child and youth mental health systems still remain focused on treating the individual with the assumption that children's needs will be met. Mental health and child welfare systems are disconnected, have separate funding and are mandated to work with treating the individual rather than the family. Furthermore, social work, health care, education and other helping professionals rarely receive training about parental mental illness. Those professions that do offering training in mental health usually omit parental mental illness. Training regarding collaboration among professionals is sometimes offered. However, it is often optional rather than part of core training in programs.

Parental mental illness and the child welfare system

It has been reported that as many as 70 percent of parents with serious mental illness have lost custody of their children (Marsh, 2009). Some children live in foster care, while others are placed for adoption within or outside of their extended family. In many cases custody decisions are made with minimal communication between the parent's treatment team and child protection services (Marsh, 2009). Ackerson (2003) suggests that some parents with serious mental illness are victimized twice, once by a devastating mental illness and secondly by the loss of custody of their children because they are viewed as permanently incapable of fulfilling their parenting role. Incompetent parenting as a result of mental illness is one of the most common reasons why courts terminate parental rights. These parents are often caught in the middle between children

welfare services, and adult and child and youth mental health care systems. Assessment of families who experience parental mental illness are often complex and require not only a high level of collaboration among professionals, but the use of both diagnostic and functional assessments (Marsh, 2009) in order to determine risk and effective family plans. Functional assessment should focus on resources needed and emphasize strengths and skills rather than deficiencies and symptoms. Parenting assessments can be problematic as standardized assessments that avoid assumptions of parental incompetence are not readily available for this population (Marsh, 2009).

The challenge with working with families who experience parental mental illness include a lack of knowledge about mental illness among some professionals and a need to make timely decisions regarding the safety of children. Confidentiality can also be a barrier to collaborating with other professionals if the parent is unable or unwilling to give consent to sharing information. Interprofessional collaboration between child welfare workers, adult and child and youth mental health systems is considered best practice for supporting families who live with parental mental illness. In addition, professionals should provide support to children and family members including education about parental mental illness and counseling for children and family members. Collaborative practices in child welfare such as those used in the B.C. Ministry of Children and Family Development can be a supportive and empowering intervention for working with families that experience parental mental illness. Strength-based forms of investigation that are less intrusive are considered best practice in working with families who experience parental mental illness. Family case planning conferences can be used for emergency, short-term interventions where alternative care arrangements are required for families. The key to using these interventions is to ensure that they are truly collaborative. Social workers should enter into the process with an open mind to possibilities rather than considering these

interventions as a means to gather evidence for their assessments. A respectful, meaningful family-centered process is considered best practice. Furthermore, as parents tend to experience periods of wellness and periods of acute illness planning for crisis should be an integral part of a family's safety plan (Reupert, Green & Maybery, 2008). Family case planning conferences and family group conferences can also accommodate age-appropriate participation of children. Identifying and supporting the coming together of nature as well as professional support networks is an important part of social work interventions for families involved with the child welfare system. Working with families, in particular those where children's safety is in question can be an extremely complex process. Engaging professionals early on in the process can assist with ensuring families are treated fairly and with respect as professionals go about their work of ensuring safety for the children.

Parental mental illness and mental health systems

Children of parents with mental illness are regularly invisible to the mental health professionals who treat their parents. A review of adult psychiatric inpatient charts found that 44% had no mention of children even though 20% of the patients reported having children (DeChillo, Matorin & Hallahan, 1987). Research in B.C. also indicates that a significant portion of adults who use mental health or concurrent mental health/addiction services have children who live with them full or part time. Yet mental health services for adults and children and youth remain separate (Gladstone, Boydell & Kinsella, 2006; Lees, 2004) and individuals are regularly not asked about family members. The mandate of separate mental health services also remains a barrier for families. Adult mental health services focus on individual functioning, monitoring of medications, general health and recovery. Child and youth mental health focuses on therapy and counseling for children who met the criteria for various mental illnesses including anxiety disorders, depression and severe mental illnesses. Even if the clinician has the time and

inclination to consider family functioning they often do not have adequate knowledge of parental mental illness. In addition, they are frequently constrained by the requirements for measuring individual treatment of children rather than family counseling. Identifying children and youth who live with mentally ill parents is a worthwhile first step. Educating children about mental illness is critical. Many children of parents with mental illness believe that they are to blame for their parent's illness. Parents who are experiencing illness often tell children that they are to blame. In some cases children get caught up in their parent's behaviour not having the experience or knowledge to know any different. Young people frequently worry about "getting" mental illness themselves. Erroneous information about parental mental illness exists within the general population as well as in the minds of some professionals. A lack of information available to children can cause significant worry and anxiety. Children who are shunned from care planning and excluded from discussions about parental mental illness frequently "fill in the blanks" with incorrect or incomplete information about parental mental illness. This is not to suggest that children be involved in all discussions regarding their parent's illness, but rather that service providers and family members recognize that even the youngest of children understand that mommy or daddy is sick. Age appropriate communication about parental mental illness can help ease anxiety and provide information about parental mental illness that is helpful to children.

Best practices

B.C.'s provincial working group supporting families with parental mental illness

In 1997 a small group of professionals from the Ministry of Children and Family Development and community agencies started the B.C. Provincial working group for supporting families with parental mental illness. The mandate of the group is to increase awareness of the

needs of families with parental mental illness and to advance policy, practices, programs and protocols related to this population (Lees, 2004, p. 5). Over the years the provincial working group has held a number of community forums that included participation from mental health consumers, adult mental health workers, child/youth mental health workers, child protection workers, educators, family services organizations and advocacy groups. Several training tools for community education and workshop development came out of this process. These tools include a process for community development, information on advanced planning in the form of Ulysses Agreements.

Family centered practice and focused interventions

Best practices for social workers and other professionals supporting families with parental mental illness include listening to families about their concerns and asking for clarification or elaboration with compassion, empathy and respect. The use of family centered practice is associated with more positive and less negative parent, family and child behaviour and functioning (Dunst, Trivette & Hamby, 2007). Glynn, Cohen, Dixon and Nix (2006) found that family intervention was effective in improving medication compliance and reducing substance abuse in parents who live with schizophrenia. It also assisted in fewer relapse and fewer symptoms in parents with bipolar disorder (Miklowitz, George, Richards, Simoneau & Suddath (2003). Maybery and Reupert (2008) suggest family and child focused interventions lead to sustained improvements in the well being of families including improvements in functioning, child reported better understanding of parental mental illness and a reduction in internalizing symptoms for young children. Family centered practice is the context in which child or parent-child focused interventions are implemented. According to Dunst, Trivette and Hamby (2007), interventions are what are done and family centered practice is how the interventions are implemented.

What the findings of this study suggest

Study participants were both implicit and explicit about the support and services they felt would have been helpful. It seems to me that these families and study participants could have benefited from the following:

- Early identification and intervention by the professionals who were in contact with the study participants as children including family doctors, school teachers and counselors, adult and child and youth mental health professionals, physicians and nurses, community program leaders and social workers.
- Opportunities to learn about mental illness through education and a supportive adult or group of peers for ongoing support
- An informal and formal network of adults or young people who are able to answer questions about mental illness, listen to concerns and provide long term practical and social emotional support as the children aged
- An informal or formal network of adults who are able to provide the family with respite as required
- Practical and social emotional support for the 'well-parent' and other family members
- Preplanning for families such as education and assistance with the creation of a Ulysses agreement
- Age appropriate inclusion of children, adolescents and young adults in discussions and decisions regarding parental mental illness
- Counseling and/or health promotion for children and family members

- Young adults could benefit from practical and social emotional support with transitioning into post-secondary education, the job market, significant relationships, and independent living
- Adult children who grew up with parental mental illness can benefit from a support group and/or some form of connection with each other
- Adult children who are still caring for their aging parent who has a mental illness could benefit from practical and social emotional support and respite

Change can occur beginning with new social work professionals. Social workers who plan to work with children and families should be required to prove competence in strength-based, family-centered practice. At a minimum basic training in mental health should be required and should include topics related to parental mental illness and child and youth mental health. The strengths and benefits of collaborative practice should be an integral part of all helping professions training. Social work educators can also benefit from training about parental mental illness. Study participants reported having significant difficulty as students during their first year of university. University counselors should be aware of the potential consequences of growing up with a mentally ill parent in order to provide appropriate supports. Social workers and social work educators should play a leadership role in the education of professions such as teachers, counselors, health professionals such as doctors and nurses. Finally, all social workers should be able to use their professional values of integrity and respect to probe a little deeper when working with families who are suspected of living with parental mental illness.

STUDY LIMITATIONS AND IMPLICATION FOR FUTURE RESEARCH

There are a number of limitations to this study. First, the sample size was relatively small due to the nature of this exploratory qualitative study as part of course work for my Master of Social Work thesis. Although purposive selection was used the recruitment of study participants was somewhat limited to the School of Social Work and the larger University of British Columbia campus. Recruitment did result in three study participants who were outside of the University. However, the method of recruitment may have limited participation by individuals with lower levels of education, low income, and certain ethnic, cultural and/or sexual orientations. Furthermore, as in the social work discipline in general the School of Social Work typically has a high ratio of females to males, which may have skewed the gender of study participants.

Further research focused on children of fathers with parental mental illness may add important knowledge to the limited body of literature, particularly in light of fathers taking a more active role in parenting. Research that focuses on two parent families where one parent has a mental illness may provide some insight into their unique experiences and needs. This study supported findings of existing research that suggests that some adolescents and young adults of parents with mental illness experience considerable challenges transitioning into independent living. Additional research that explores this population could inform policy and practice working with older adolescents and young adults. This population is at risk of falling through the cracks as they age out of child/youth services and transition into adult services. Caregiving was also found to be a significant challenge for some of the adult offspring in this study. Even though they are adults, who have lived with parental mental illness often for many years, they are frequently excluded from planning for their aging parent. Research that provides demographics about children of parents with mental illness would be helpful in setting priorities for policy and

funding for services for this population. Finally, evidence for best practices supporting families with parental mental illness may be necessary and should be pursued in order to inform future policy and practice.

CONCLUSION

One in five individuals in the general population will experience mental illness at some point in their lifetime. Individuals who experience mental illness are known to have children at the same rate as the general population. While some studies suggest that as many as 12% of Canadian children live with a parent who experience mental illness and/or addiction the statistic is likely much higher due to the tendency of families in this population to isolate themselves. Children have been found to experience both negative and positive consequences as a result of living with parental mental illness. Numerous studies have identified specific risk and protective factors. Several qualitative studies have added children's voices to the literature and some retrospective studies have explored outcomes in adult offspring of parents with mental illness. Despite strides in deinstitutionalization, community inclusion and new medications that have helped individuals living with mental illness have better quality of life families continue to struggle, often in silence.

Understanding the subjective experiences of adult offspring of parents with mental illness across their lifespan can offer a unique perspective on their childhood experiences. Furthermore, it can provide insight into how these children make meaning of their experiences and the actions they take as they experience significant events in their own lives such as moving away from home, attending post secondary education, getting married and having children. This exploratory qualitative study explored some of these experiences and has resulted in several unique findings that could benefit from further exploration. For example, the experiences of living with fathers with parental mental illness and challenges transition from late adolescence to adulthood are not well understood and literature on these topics is sparse. Best practices for supporting families with parental mental illness have been outlined by organizations such as the BC Provincial working group for supporting families with parental mental illness. Further education of

professionals about best practice and working collaboratively across systems that service these families would be beneficial. Finally, policy, funding and research to support evidenced based practice would ensure that the needs of families who live with parental mental illness are met on a long-term basis. In the words of one study participant “why should children have to be resilience” and feel guilty for having needs. A lot of good work is being done to support families in B.C. The hope of this researcher is that this study may contribute in some way to the literature and subsequently to policy and practice related to supporting families with parental mental illness. It is my hope that those who read this paper hear the voices of the women, who shared their experiences so children and their families do not feel alone, but rather feel hopeful and supported as they continue their life journey.

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APPENDICES

Appendix A: Recruitment poster

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work
2080 West Mall
Vancouver, B.C. Canada V6T 1Z2
www.swfs.ubc.ca

An Invitation to Participate in a Study of:

The experiences of adults, who as children, lived with a mother and/or father with a mental illness

What is the Purpose of the study?

The purpose of this study is to explore the experiences of adult children who lived with a mother and/or father who has a mental illness. Understanding these experiences may contribute to knowledge about the experiences of adult children of parents with mental illness. Findings may also inform future programs or services for families who experience mental illness.

What is involved?

- Participation in one to two 60 to 90 minute interviews, which will be audio taped and transcribed
- A copy of the transcription of your interview will be made available to you
- Topics to be discussed will include: your role and responsibilities in your family; your support network growing up; unique experiences of your family; and supports and services you found helpful and/or changes needed in services for children of mothers and/or fathers who experience mental illness

Who is invited to participate?

- Anyone over the age of 19 years old; who as a child and/or adolescent lived with a mother and/or father with a mental illness; who speaks English; is willing to share his/her experiences, and is willing to sign a consent form

What about confidentiality?

- Your identity will be kept confidential
- Documents such as transcriptions will be identified by only a code and kept in a locked file cabinet. Computer data will be password protected
- You will not be identified by name in reports or presentations about the study

Your participation in this study is strictly voluntary. You can refuse to participate, refuse to answer some questions during the interview or withdraw at any time.

If you are interested in more information or would like to participate in this study please contact Co-Investigator, Andrea Harstone, MSW Student, School of Social Work, University of British or Grant Charles, Principal Investigator. This research is part of a Master of Social Work degree. Study findings may be used in a thesis or scholarly presentation or article.

Appendix B: Consent form

THE UNIVERSITY OF BRITISH COLUMBIA



School of Social Work
2080 West Mall
Vancouver, B.C. Canada V6T 1Z2
www.swfs.ubc.ca

Consent Form

Title: Experiences of adults who as a child lived with a mother and/or father with a mental illness.

Principal Investigator: Dr. Grant Charles
Associate Professor
School of Social Work
University of British Columbia
Telephone: 604-822-3804
Email: gcharles@interchange.ubc.ca

Co-investigator: Andrea Harstone
Graduate Student, Masters of Social Work
School of Social Work
University of British Columbia

Purpose:

The purpose of this study is to explore the subjective experiences of adults who as a child or adolescent lived with a mother and/or father with a mental illness. This research is for a Masters of Social Work degree and may be used in a thesis or scholarly presentations or publications.

Who is eligible to participate?

- you are 19 years of age or older
- you speak English
- you lived in a family where at least one of your parents experienced mental illness
- you are willing to share your experiences
- you are willing and able to sign this consent form

How long will it take?

Each interview will take approximately 60 to 90 minutes. Each study participant will take part in one to two interviews.

Where will the interviews take place?

Interviews will take place at the UBC School of Social Work or at a mutually agreed upon semi-public location in the community.

What procedures will be used for this study?

The interviews will be recorded and the initial interview will be transcribed into a document that will be identified only by code or a pseudonym. Results of this study may be used in a thesis and/or future scholarly presentations or publications. If the results of this study are presented in a meeting, or published, nobody will be able to tell that you were in the study. Please note that although you will not be identified as the speaker, your words may be used to highlight a specific point. Audiotapes and transcriptions will be kept for five years in a secure locked file cabinet in an office at the University of British Columbia. Only the researchers will have access to them.

What are the risks associated with participating in this study?

We do not think there are any risks associated with the study. However, you may find that talking about your experience might be upsetting. You do not have to answer any questions that make you feel uncomfortable or that you find upsetting.

What are the benefits of participating in this study?

There is no direct benefit to you. However, findings from this study may contribute to a better understand about the experiences and needs of children and adolescents living with a mother and/or father with mental illness, which could help enhance programs and services in the future.

How do I get more information?

If you have any questions or desire further information with respect to this study, you may contact the Co-investigator, Andrea Harstone or the Principal Investigator Dr. Grant Charles 604-822-3804 or gcharles@interchange.ubc.ca.

Contact for concerns about the right of research subjects:

If you have any questions or concerns about your treatment or rights as a research participant, you may contact the Research Subject Information Line in the UBC Office of Research Studies at 604-822-8598.

Consent:

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without consequence. Your signature below indicates that you have received a copy of this consent form for your own records. Your signature indicates that **you consent to participate in this study**.

I understand that participation in this study is voluntary and that I may refuse to participate or withdraw from the study without consent at any time. I have read and understand the description of the study, and I have received a copy of this consent for my own records. By signing the below, I consent to participate in this study and give the researcher permission to contact me to set-up an interview.

Print Name

Date

Signature

email address

Phone number

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

Please keep a copy of the consent form for your records.

Appendix C: Interview guide

Prior to beginning the interview the consent form will be reviewed with the study participant and any questions will be answered. A copy of the form will be provided to the participant for their file.

Questions:

1. Can you tell me about the make-up of your family when you were growing up? Did you live with one or two parents, brothers and/or sisters, extended family, others?
2. What was it like for you growing up in a family with a parent who experienced mental illness?
 - a. Can you tell a story that would help someone understand what it was like for you growing up in a family where your parent experienced mental illness?
 - b. How do you describe your role and main responsibilities in your family?
 - c. How would you describe anyone who you felt was supportive to you growing up?
 - d. Were you close to extended family members, friends, church or community groups?
3. Were there any other unique circumstances about your family that you would like to share?
4. Do you recall at what age you understood that your mom/dad had a mental illness? Explain.
5. Does your parent have a diagnosed mental illness?
6. What were your experiences transitioning from your teenage years to young adulthood?
7. How do you make meaning out of your childhood experiences as you experience your own significant life events?
 - a. Moving away from home
 - b. Getting married
 - c. parenthood
8. Can you think of services or supports that were helpful to you? Services that would have helped, but were not available?
9. Did you want to add any other comments?
10. Can you tell me your current age, gender, ethnic/cultural background, occupation? What is your current marital status?

The interviewer/researcher will debrief with the participant after the interview is complete and will offer a list of support resources.

Appendix D: Resources

UBC Counselling Services

1040 Brock Hall-1874 East Mall
Vancouver, BC V6T 1Z1
Tel: (604) 822-3811
Fax: (604) 822-4957

Canadian Mental Health Association

<http://www.cmha.bc.ca>

Canadian Mental Health Association Delta

Century Square, 14-1835 56th St.
Delta, BC, V4L 2L8
Phone: 604-943-1878
Fax: 604-948-1479
E-mail: cmha.delta@dccnet.com
Web Site: www.delta.cmha.bc.ca

Canadian Mental Health Association North and West Vancouver

211- 260 West Esplanade
North Vancouver, BC, V7M 3G7
Phone: 604-987-6959
Fax: 604-980-0336
Web Site:
www.northwestvancouver.cmha.bc.ca

Canadian Mental Health Association Richmond

7351 Elmbridge Way
Richmond, BC, V6X 1B8
Phone: 604-276-8834
Fax: 604-276-0342
E-mail: info.richmond@cmha.bc.ca
Web Site: www.richmond.cmha.bc.ca

Canadian Mental Health Association Simon Fraser

101 - 403 6th Street
New Westminster, BC, V3L 3B1
Phone: 604-516-8080
Fax: 604-524-2870
E-mail: cmhasf@cmha.bc.ca

Canadian Mental Health Association South Fraser

208-8334 128 Street
Surrey, BC, V3W 4G2
Phone: 604-543-1357
Fax: 604-543-1369

Canadian Mental Health Association

Vancouver-Burnaby

175 West Broadway
Vancouver, BC, V5Y 1P4
Phone: 604-872-4902
Fax: 604-872-5934
E-mail: info.vb@cmha.bc.ca
Web Site: www.vancouver-burnaby.cmha.bc.ca

Vancouver Coastal Health, 24-hour Mental Health Service

24 hour mental health crisis line:
604-874-7307
http://www.vch.ca/find_us/find_health_services/

Appendix E: BREB certificate of approval



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

CERTIFICATE OF APPROVAL - FULL BOARD

PRINCIPAL INVESTIGATOR: Grant Charles	INSTITUTION / DEPARTMENT: UBC/Arts/Social Work	UBC BREB NUMBER: H09-02992
INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:		
Institution		Site
N/A		N/A
Other locations where the research will be conducted: University of British Columbia Vancouver campus; semi-public locations in the community.		
CO-INVESTIGATOR(S): Andrea Harstone Tim Stainton Brian O'Neill Sheila Marshall		
SPONSORING AGENCIES: N/A		
PROJECT TITLE: Experiences of adults who as a child or adolescents lived with a mother and/or father with a mental illness.		
REB MEETING DATE: December 15, 2009	CERTIFICATE EXPIRY DATE: December 15, 2010	
DOCUMENTS INCLUDED IN THIS APPROVAL:		DATE APPROVED: January 12, 2010
Document Name	Version	Date
Protocol:		
9.1.A. Protocol	Version 1	November 16, 2009
Consent Forms:		
Consent Form	Version 2	January 8, 2010
Advertisements:		
Recruitment Flyer	Version 1	November 16, 2009
Questionnaire, Questionnaire Cover Letter, Tests:		
Interview Guide	Version 1	November 16, 2009
Other Documents:		
Resource List	Version 1	November 16, 2009
Listserver approval	Version 1	November 21, 2009
The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.		
<p>Approval is issued on behalf of the Behavioural Research Ethics Board and signed electronically by one of the following:</p> <p>Dr. M. Judith Lynam, Chair Dr. Ken Craig, Chair Dr. Jim Rupert, Associate Chair Dr. Laurie Ford, Associate Chair Dr. Anita Ho, Associate Chair</p>		