STORIES OF LOSS AND CHANGE: SIX MOTHERS’ EXPERIENCES OF PARENTING AN ADULT CHILD WITH A MENTAL ILLNESS

by

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ABSTRACT

A qualitative narrative research method was used to explore and describe the experiences of personal growth and change of six mothers of adult children with schizophrenia or schizoaffective disorder who volunteered to participate in this study. A total of twenty-eight semi-structured interviews (average four per participant), were conducted over a period of two years. The research question was: How do parents of adult children with schizophrenia or schizoaffective disorder experience personal growth and change as they live with the challenges and uncertainties associated with their child's mental illness?

Individual, co-constructed first person narratives of each participant's mothering experiences were written following an in-depth, holistic-content analysis of the interview data. A cross-narrative analysis was also conducted which resulted in four common themes (Enduring sadness and loss, Distress and struggle, Commitment to helping/action, Personal and relational change); four significant threads (What will happen when I am no longer able to care for my child?, Impact on siblings who are well, Fluctuations in hope, Regret/Guilt); and four broader dimensions (New normal mothering, Changes in mothering over time, Involvement in the mental health system, Adaptation and engagement with life in new and meaningful ways). These findings were found to be best understood through the conceptual lens of nonfinite loss – reflecting the ongoing challenges and lifetime implications of this mothering experience. Implications for theory, research and counselling psychology practice are addressed, based on these findings.
PREFACE

This original unpublished dissertation was written and conducted by the author, Sandra Wiens, under the supervision of Dr. Judith Daniluk. The research involved human subjects and as such, was reviewed and approved by the UBC Behavioural Research Ethics Board prior to the start of the research. The number of the original certificate pertaining to the research in this dissertation is: H09-03270.
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Thank you to the six mothers who gave so generous of their time to meet with me to share their experience and entrusted me with their stories. I have learned a great deal from them and have been inspired by their courage, strength, determination, patience, love, and mothering expertise.

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Throughout this research project I have often been mindful of my father and am grateful for how he taught me to think carefully – never to be “in a hurry.” I have felt his support all along the way, although he did not live to see or even hear about this study. I am also grateful for the ongoing encouragement of my friend Alexia, who never ceased to have confidence that this project would get done and well done. Although she did not live to see its completion, she so often reminded me: “Sandra, we are going to do this. We can and we will!”

I am also grateful for the encouragement and support of many friends and colleagues – Lara, Emily, Ashley, Marianna, Yaari, Dianne, Janet, and Cathy – to name but a few. To my sister, Sylvia: Thank you! Your ongoing support, encouragement, and assistance has meant so much!
CHAPTER ONE: INTRODUCTION TO THE STUDY

My interest in mental illness and the family emerges from my personal experience as the mother of an adult child with schizophrenia. Since the onset of my son’s illness, my story as a mother has been punctuated with periods of confusion, anxiety, and at times a sense of helplessness and desperation. Personal growth and change have also been a significant part of my parenting experience. I am not the same person I was fifteen years ago before my son was diagnosed with schizophrenia, nor is my family the same. My experiences have shaped who I have become as a mother, as a woman, as a counsellor, and as a researcher. My story is not over. It is an ongoing story because my son’s struggles with this mental illness may well be life-long. Consequently, it is a story of who I am becoming. Through contacts with other parents of adult children with schizophrenia or schizoaffective disorder, both informally and professionally as a researcher and counsellor, I have heard stories like my own. I have heard parents speak of the personal growth, change and learning they have experienced through their experience of parenting an adult child with schizophrenia or schizoaffective disorder (hereafter referred to as this parenting experience). Interestingly, personal growth and learning emerged as an important theme for the six fathers of adult children with schizophrenia who shared their stories with me as part of my Master’s research (Wiens & Daniluk, 2009).

Contrary to the more traditional focus in the psychological literature on the costs and challenges of coping with highly stressful life events and situations, more recently the field of health psychology has begun to acknowledge and focus on resiliency through adversity and stress-related growth (Calhoun & Tedeschi, 2006; Linley & Joseph, 2004). Such a focus on growth and change seems particularly suited to an examination of how parents of adult children with schizophrenia or schizoaffective disorder experience personal growth and change as they
live the ongoing and ever-changing reality of coping with, and responding to, their child’s mental illness. The purpose of the current study was to add to the literature by giving voice to mothers and fathers of adult children with schizophrenia or schizoaffective disorder who believe that they have experienced personal growth and change as they have lived with the challenges and uncertainties associated with their child’s mental illness and to learn from their experiences.

In order to provide a context within which to understand these stories, this introductory chapter begins with a brief overview of the nature of schizophrenia and schizoaffective disorder and the resultant impact of these illnesses on parents and their families. Attention is then drawn to the research that has informed the current understanding of this parenting experience, followed by a brief introduction to the current theoretical understanding of stress-related growth that informed the focus of this study and the research question. Unanswered questions that emerge from the research literature are pointed out. The purpose of the study and the overarching research question that guided the study are then presented. Narrative inquiry is introduced as an appropriate methodology to address this research question. I then briefly suggest possible ways that I, on entering the research process, anticipated that the findings of the study might be helpful to parents, their families, and communities, as well as research and practice in counselling psychology and related mental health fields. I end this chapter with part one of my own story. It is my story of personal growth and change through living with the challenges and uncertainties associated with my son's mental illness, written at the beginning of this research project and before meeting any of the participants. The second part of my story is found at the end of chapter five. It is the story of my personal experience of change throughout the research process.
The Nature of Schizophrenia and Schizoaffective Disorder and the Impact of these Illnesses on Parents and Families

Schizophrenia and schizoaffective disorder are mental illnesses that present very similarly and, as pointed out in the *Diagnostic and Statistical Manual of Mental Disorders, DSM-IV-TR* (American Psychiatric Association, 2000), it is often difficult to differentiate between these diagnostic categories (Kantrowitz & Citrome, 2011; Walker, Kestler, Bollini & Hochman, 2004). Schizophrenia is considered one of the most common of the major mental illnesses and is characterized by disordered thinking and a distorted sense of reality usually involving hallucinations and delusions, impaired emotional responses, and interpersonal difficulties (Birchwood & Jackson, 2001). These symptoms also figure largely in the presentation of schizoaffective disorder – both diagnostic descriptions in the DSM-IV-TR require that the full active phase symptoms of schizophrenia be significantly present for at least one month. The diagnosis of schizoaffective disorder additionally requires an uninterrupted period of illness during which the full criteria of a mood disorder are met simultaneously with the active-phase criteria of schizophrenia (American Psychiatric Association, 2000; Kantrowitz & Citrome, 2011). To meet the diagnostic criteria for schizoaffective disorder the mood disorder symptoms must also be present over a large portion of the total duration of the illness. For a detailed description of the specific criteria for schizophrenia, mood disorders, and schizoaffective disorder, the reader is referred to the DSM-IV-TR, 2000. The differentiation between these diagnoses is further complicated given that mood symptoms are also common in schizophrenia, however in schizophrenia these mood symptoms either do not meet the full criteria for a mood disorder, or are less prominent over the course of the illness (American Psychiatric Association, 2000).

It is therefore not surprising that it is common for a diagnosis to change between these
disorders over time (American Psychiatric Association, 2000). Notably, Kantrowitz and Citrome (2011) point out that there continues to be considerable difference of opinion amongst researchers and clinicians as to whether schizoaffective disorder should be classified as a distinct diagnosis. They also point out that relatively few studies specifically focus on schizoaffective disorder and their review of studies comparing schizoaffective disorder with schizophrenia suggests that differentiating between these diagnoses may not be “clinically useful” (p. 319). In the literature focused on the experience of families living with schizophrenia it is not unusual to include family members living with schizoaffective disorder (e.g. Tuck, du Mont, Evan, & Shupe, 1997). In my review of the literature I did not find any studies specifically focused on the experience of parenting an adult child with schizoaffective disorder. The discussion of the impact of schizophrenia and schizoaffective disorder on parents and families in this chapter is therefore based on the literature that has focused on the experiences of parents and families living with a family member who has been diagnosed with schizophrenia.

Schizophrenia has been described in the literature as “a destructive force that interrupts and radically transforms the normative family trajectory” (Tuck, du Mont, Evan, & Shupe, 1997, p. 118) – an illness that has an enormous impact on the experience of parents, families, and society as a whole (Knock, Kline, Schiffman, Maynard & Reeves, 2011). The onset of schizophrenia is typically in late adolescence or early adulthood for males and somewhat later (mid to later twenties) for females (Pennington, 2005). The onset of schizoaffective disorder is also typically in adolescence or early adulthood (American Psychiatric Association, 2000). The incidence of schizophrenia is frequently reported to be equal for males and females, although a number of well designed studies have reported a higher incidence among males (Birchwood & Jackson, 2001). The incidence of schizoaffective disorder, however, is reported to be slightly
higher for women given the higher incidence of depression amongst women (American Psychiatric Association, 2000). Individuals diagnosed with schizophrenia often experience long term chronic illness irrespective of their age at the onset of the illness (Perkins, Miller-Andersen, & Lieberman, 2006). Similarly the course of schizoaffective disorder often extends over many years although schizoaffective disorder is thought to be associated with a “somewhat better” prognosis than schizophrenia (American Psychiatric Association, 2000; Walker et al., 2004).

Crisis situations associated with schizophrenia and schizoaffective disorder are not uncommon. Approximately 10 percent of individuals diagnosed with schizophrenia end their lives by suicide (Birchwood & Jackson, 2001). Between 40 and 60 percent attempt suicide (Public Health Agency of Canada, 2002), often more than once.

One percent of individuals develop schizophrenia in their lifetime (Pennington, 2005, Walker et al., 2004). Schizophrenia is reported to be twice as prevalent as Alzheimer’s disease, six times as prevalent as insulin-dependent diabetes and sixty times as prevalent as muscular dystrophy (British Columbia Schizophrenia Association, 2008). It is clear that the economic and social costs of schizophrenia are high. One out of every twelve Canadian hospital beds is occupied by an individual with schizophrenia (Schizophrenia Society of Ontario, 2007). In an assessment of the “global burden of disease” (p. 247) published by the Harvard School of Public Health on behalf of the World Health Organization and the World Bank, schizophrenia was ranked as one of the top ten causes of disability in the developed countries of the world (Murray & Lopez, 1996). The majority of individuals with schizophrenia are not able to live independently and it is estimated that at least 10 percent of the homeless population suffer from schizophrenia (Muesser & Gingerich, 2006). The high economic cost to society associated with this illness has been clearly acknowledged in the research literature (Georee, Goering,
Blackhouse, Agro, & Rhodes-Watson, 1999; Pennington, 2005). Less is known about the short- and long-term psychosocial and emotional costs and consequences of schizophrenia for individuals and families faced with coping with this illness over time.

Early signs of schizophrenia can be difficult to recognize (Walker et al., 2004). The onset of schizophrenia can be sudden and severe, or the symptoms may develop slowly over time (McKenna, 2007; Walker et al., 2004). Early signs of the illness often occur when the child is still living with his/her parents. These early symptoms can sometimes be difficult to distinguish from the normal responses to the psychological and emotional adjustments that are typical of adolescent development (Tuck et al., 1997; Walker et al., 2004). The early stage of the illness is often characterized by the insidious and prolonged development of symptoms such as social withdrawal, impairment of attention, lack of energy, poverty of speech, or a blunting of drive or emotions – referred to in the mental health literature as negative symptoms, i.e. symptoms that reflect the loss of normal abilities that are part of negotiating the activities of daily living (Pennington, 2005). When these symptoms are pronounced they can eclipse the more obvious indicators of the illness and the need for intervention such as hallucinations, delusions, bizarre behaviours, and marked disorders of thinking – referred to in the mental health literature as positive symptoms, i.e. symptoms that reflect additions to the normal repertoire of human experiences (Pennington, 2005). For a more in-depth discussion of negative and positive symptoms of schizophrenia the reader is referred to Andreason, Roy, and Flaum, (1995).

In retrospect, when reflecting on their child’s illness, many parents describe early signs of unusual behaviour as having been very confusing and recall their struggles “to frame events as normal” (Tuck et al., 1997, p. 120). Parents, and often mental health professionals, try to place the adolescent or young adult’s unusual behaviours within a normal developmental context. As
one father in my previous research put it: “He just didn’t seem to know where he was going and or what he wanted to be and I can remember feeling that way when I was his age myself” (Wiens, 2005, p. 74). Another parent recalled wondering: “OK, I think he’s a lot like me. I can work with him. I can see exactly where he’s coming from, but … it became more than that” (Wiens, p. 74).

Establishing a diagnosis of schizophrenia is often further confounded when the illness is co-morbid with other common adolescent disorders such as depression and substance abuse (Birchwood & Jackson, 2001). Substance use may in fact reflect an attempt on the part of the adolescent or young adult to self-medicate in order to cope with his or her developing symptoms. Consequently, families may live with the illness for several years before a diagnosis is sought or confirmed. Given the research evidence that links early intervention and treatment of schizophrenia with more positive outcomes (Birchwood & Jackson, 2001; Walker et al., 2004), a great responsibility for recognition of early symptoms falls on parents and failure to do so can be a source of lingering guilt as it was for some of the fathers in my Master’s research (Wiens & Daniluk, 2009). These fathers talked about how they “should have realized it sooner,” how they “thought [their child] was being lazy – just needed a good boot to get going – which wasn’t in retrospect right at all” (Wiens, 2005, p. 75), and how, even “… if [their child] needed to be tied down physically [they] should have done something like that to get… some professional help a little sooner” (p.77).

Although the etiology of schizophrenia is not yet understood, researchers agree that schizophrenia is a complex brain disorder (Torrey, 2006; Walker et al., 2004). Changes in neurotransmitter systems and structural abnormalities of the brain (e.g. ventricular enlargement, smaller overall brain size, smaller cerebellum, smaller structures in the temporal lobes, and a
smaller thalamus) have been reported in individuals with schizophrenia (Pennington, 2005; Walker et al., 2004). Functional neuro-imaging studies suggest that negative symptoms may be linked to under-activity in the prefrontal cortex, while positive symptoms may be associated with over-activity in the temporal-limbic system (Pennington, 2005). Adding further to parental burden is the fact that genetic factors also appear to play a role in the development of the illness (Pennington, 2005; Walker et al., 2004). Not surprisingly, parents whose genetic familial history includes mental illness have reported feelings of self blame when their child is diagnosed with schizophrenia (e.g. Wiens & Daniluk, 2009).

Prior to the 1970’s parents were often viewed as responsible for their child’s illness. Misunderstanding and mistaken assumptions based on early theories attributed the primary etiology of schizophrenia to dysfunctional family interactions (Bateson, Jackson, Haley, & Weakland, 1956; Bowen, 1961; Fromm-Reichmann, 1948; Hadju-Gimes, 1940; Lidz, Cornelison, Fleck, & Terry 1957; Wynne & Singer, 1963). In the 1970’s research attention shifted to a focus on “family attitudes and behavior as [an] exacerbating factor[s] of a preexisting disorder” (Kanter, Lamb, & Loeper, 1987, p. 374). As Kanter et al. pointed out, this research (e.g. Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976) which reported a positive correlation between expressed emotion (criticism, hostility, and emotional over-involvement) and the frequency of relapse in the family member with schizophrenia, led to a mistaken assumption that families of individuals with schizophrenia were characterized by criticism, hostility, and an unhealthy degree of emotional over-involvement and that parents were in some way responsible if not for the etiology, then for the course of their child’s mental illness. Although it is now widely accepted that the etiology of schizophrenia is based on complex genetic and neurological factors, parental reports of being blamed by mental health and medical professionals for their
child’s illness can still be found in some of the more recent literature (e.g. Jones, 1997; Nystrom & Svensson, 2004). Psychosocial influences are no longer considered etiological agents, however, research based on the vulnerability-stress model of schizophrenia (Zubin & Spring, 1977; Walker et al., 2004) which posits that that psychosocial stresses can influence underlying vulnerability factors resulting in the exacerbation of psychotic symptoms, suggests that psychosocial factors such as stress, degree of coping skills, social support can influence the course and outcome of the illness (Pennington, 2005; Mueser & Gingerich, 2006; Walker et al., 2004).

The course of the illness over time has been described by McKenna (2007) as “erratic” with a range of possible outcomes “from complete recovery to profound disability” (p. 72). Recent studies have shown that, contrary to the suggestions of early investigators, the illness is no longer assumed to follow a deteriorating course over an individual’s lifetime (Hopper, Harrison, Janca, Sartorius, & Wiersma, 2007; McKenna, 2007). Approximately 20 to 25 percent of individuals diagnosed with schizophrenia experience a single acute psychotic episode and subsequently recover almost completely; two-thirds “will make a substantial recovery” (Birchwood & Jackson, 2001, p. 34). Recent outcome studies report as high as 50 percent full or social recovery from schizophrenia. McKenna (2007), however, cautions that it is important to keep in mind when considering these optimistic reports, that these findings are based on objective rating scales and include individuals who, according to family members, have actually declined in their level of functioning in areas not addressed by these scales. Due to the uncertain course of schizophrenia, parents frequently report living with changing levels of hope and despair especially when the course of their child’s illness has involved repeated acute episodes over time (Tuck et al., 1997; Wiens, 2005). As noted in the literature on developmental
transitions in adult life, coping with an illness that has an uncertain cause and uncertain prognosis has been associated with more intense and prolonged stress than coping with an illness with a known prognosis, course, and duration (Schlossberg, Waters & Goodman, 1995). In his review of the literature on stress and coping, Gottlieb (1997) pointed out that much less is known about the experience of coping with long term chronic stress than is known about coping with acute stressful events. Facing the reality of living with a long term unpredictable illness was described by one father in my Master’s research study in the following way:

We were really hoping that – We were really looking for a quick fix. I think most families are. We were looking for – Give him the right diagnosis, give him the right medication – things will be all right. Get us right back on track and life will go on. It was a real eye-opener when we started to realize that this was going to be - [a long painful journey]. We really didn’t know how we could cope with it. Stress – it was very stressful – very, very stressful… (Wiens, 2005, p. 83).

Clearly, the nature of schizophrenia and schizoaffective disorder, in terms of the symptoms of these illnesses, the significant risks of self-harm during critical episodes, and the uncertain course of the illnesses, present enormous challenges to parents in their attempts to support and care for their child. This study sought to provide insight into how parents of a child with schizophrenia and schizoaffective disorder are able to experience personal growth and change through the process of coping with the ongoing challenges and uncertainties of their child’s mental illness.

**Current Understanding of the Experience of Parenting an Adult Child with Schizophrenia**

Current understanding of the experience of parenting a child with schizophrenia is based largely on studies focused on: (a) the concept of *family burden* (e.g. Greenberg, Greenley,
McKee, Brown, & Griffin-Francell, 1993; Hoenig & Hamilton, 1966; Jones, 1997; Jungbauer & Angermeyer, 2002; Knock, Kline, Schiffman, Maynard & Reeves, 2011), a term used to identify the effects of mental illness on the family; (b) research focused on grief and loss in this population (e.g. Atkinson, 1994; Eakes, 1995; Miller, Dworkin, Ward, & Barone, 1990; Richardson, Cobham, Murray & McDermott, 2011) as well as (c) studies using in-depth interviews with mothers and fathers to explore their parenting experience (e.g. Howard, 1994, 1998; Milliken, 2001; Nystrom & Svensson, 2004; Ryan, 1993; Tuck et al., 1997; Wiens & Daniluk, 2009).

Family burdens that have repeatedly been associated with caring for a family member with schizophrenia include: financial challenges; the physical and psychological demands associated with care-giving and advocacy; disruption of household routines; restriction of social activities; impaired relationships with others outside of the family; emotional distress associated with difficult and at times bizarre behaviours; as well as secondary distress associated with the reactions of others both within and outside of the family (Hatfield & Lefley, 1993; Jones, 1997; Jungbauer & Angermeyer, 2002; Knock et al., 2011). Another frequently reported parental burden is concern related to their child’s future needs. Given the uncertain prognosis associated with the illness, parents worry about how their child’s needs will be met when they are gone and/or are no longer able to provide for and take care of their child (e.g. Jones, 1997; Wiens & Daniluk, 2009).

The experience of grief in the face of multiple losses has also been a frequently reported theme in the literature for both mothers and fathers of children with schizophrenia (e.g. Eakes, 1995; MacGregor, 1994; Milliken, 2001; Richardson et al., 2011; Wiens & Daniluk, 2009). It has been suggested by several researchers (e.g. Eakes, 1995; Howard, 1998) that the nature of grief
experienced by these parents is consistent with the description of chronic sorrow, a concept originally introduced by Olshansky (1962) to describe a pervasive, long-lasting, recurrent form of grief experienced by parents of mentally disabled children.

Studies using in-depth interviews with mothers and fathers have increased our understanding of the experience of parenting a child with schizophrenia. This body of research has been focused primarily on the experiences of mothers (e.g. Crisanti, 2000; Howard, 1994; Milliken, 2001; Pauch, 1996; Ryan, 1993; Thorpe, 1994; Vatri-Boydell, 1996) and has drawn attention to the complex and at times contradictory nature of caring for a child with schizophrenia (Vatri-Boydell, 1996). Mothers in these studies have spoken about the “interminable” nature of mothering - living with uncertainty, isolation, and a lack of understanding (Thorpe, 1994). They have emphasized the need for psychosocial and structural support in caring for their child’s needs and ensuring their child’s safety and well-being (Milliken, 2001; Pauch, 1996; Thorpe, 1994). In a study conducted by Vatri-Boydell (1996) entitled Mothering adult children with schizophrenia: The hidden realities of caring, mothers reported being told by health care professionals that they had the skills to care for their child, yet subsequently were blamed by these professionals when something went wrong in their child’s life. In a grounded theory study of the parenting experience which included primarily mothers but also some fathers of children with schizophrenia, Milliken (2001) described parenting over the course of a child’s illness as a process of “redefining parental identity” (p. 149). Interviews with fathers have drawn attention to themes of devastation and vulnerability (Howard, 1998; Nystrom & Svensson, 2004; Wiens & Daniluk, 2009), the stressful nature of care-giving (Howard, 1998; Nystrom & Svensson, 2004; Wiens & Daniluk, 2009), the difficulty of living with the stigma of mental illness (Howard, 1998), and frustration with the mental health system
A notable difference between the findings of Wiens and Daniluk (2009) and previous studies of the parenting experience (e.g. Crisanti, 2000; Howard, 1998; Milliken, 2001; Pauch, 1996; Nystrom & Svensson, 2004; Ryan, 1993; Thorpe, 1994; Vatri-Boydell, 1996) was the emergence of the two themes: “admiration for their child” and “personal growth and learning.” Similar positives have been reported by individual participants in previous studies on this topic (e.g. Howard, 1998; Marsh, Lefley, Evans-Rhodes, Ansell, & Doerzbacher, 1996; Tuck et al., 1997), although not to the same extent and not as themes central to the parenting experience. Few references have been made to positive personal changes in the reports of mothers of children with schizophrenia (e.g. Crisanti, 2000; Milliken, 2001; Pauch, 1996; Ryan, 1993; Thorpe, 1994; Vatri-Boydell, 1996) possibly due to differences in the questions asked by the researchers or perhaps gender differences in the parenting experience. What is clear, however, is that both mothers and fathers of children with schizophrenia report multiple “family burdens,” experiences of being blamed for their child’s illness, struggle with the “interminable” nature of care-giving, multiple losses, the need for psychosocial and structural support, the experience of stigma related to their child’s mental illness, a sense of devastation and vulnerability, and frustration with the mental health system. In light of these considerable challenges it is important to know how both men and women are able to experience personal growth and change as a consequence of their parenting experiences. I am interested in learning how mothers and fathers of children with schizophrenia or schizoaffective disorder experience personal growth and change and the nature of this growth and change.

Theoretical Understanding of Stress-Related Growth

As previously noted, personal growth and change through the struggle with highly
stressful life situations has been a growing focus of research attention in health psychology over the past 20 years. Positive psychology has provided further impetus for this perspective, being a “science of positive subjective experience” (p. 5) that focuses on the process of “constructing” (building competencies and strengths) as opposed to the process of “repairing” that is central to the medical model (Seligman & Csikszentmihali, 2000). Seligman and Csikszentmihali suggest that competencies and strengths play an important role in the process of improving health and well-being. Indeed, one of the “defining features of positive mental health” (p. 213) according to Ryff and Singer (1998), is “having a purpose in life and a sense of personal growth” (p. 213).

Consistent with the perspective of positive psychology, a number of theoretical conceptualizations of personal growth and change through stressful life situations have been developed within the field of health psychology. The most empirically supported of these theoretical frameworks and the models most relevant to a study of growth and change through this parenting experience are the Model of Life Crises and Personal Growth (Schaefer & Moos, 1992), the Revised Model of the Coping Process (Folkman, 1997), and the Comprehensive Model of Posttraumatic Growth (Calhoun & Tedeschi, 2006).

The Model of Life Crisis and Personal Growth (Schaefer & Moos, 1992) on which Park, Cohen, and Murch’s (1996) concept of stress-related growth is based, draws attention to the influence of environmental and personal characteristics, coping resources, and social support on how life crises are experienced. The Revised Model of the Coping Process (Folkman, 1997), an extension of Lazarus and Folkman’s (1984) theory of stress and coping, draws attention to the key role of meaning-based coping in the development of positive outcomes associated with stressful experiences. In their review of 35 years of coping research in the Annual Review of Psychology, Folkman and Moskowitz (2004) point out that this model reflects the new and
growing awareness of the presence of positive emotions in the stress and coping literature.

The current most comprehensive theoretical framework of stress-related growth and the primary model that informed the conceptual basis of my understanding of stress-related growth was Calhoun and Tedeschi’s (2006) Model of Posttraumatic Growth. These researchers use the term *posttraumatic growth*, defined broadly as “positive psychological changes as a result of the struggle with highly challenging life circumstances” (Tedeschi & Calhoun, 2004, p. 1). It is important to note that there is a lack of agreement in the literature regarding the use of this term. For example, Park (2004) suggests that the term “stress-related growth” is a more accurate reflection of this growth phenomenon than “posttraumatic growth” and points out that Tedeschi and Calhoun use the term “posttraumatic growth” loosely to include “a broader range of stressful events” (p. 69) and not just growth related to “trauma” as this term is used in the psychological literature. Park also suggests that out of respect for “those individuals who have truly suffered traumatic experiences” (p. 69), the term “trauma” should be used “only to describe situations that truly are” (p. 69), i.e. “severe events or conditions involving perceived threat to life or bodily integrity” (p. 69). I agree with Park’s suggestion and for the purpose of this research, have chosen to use the term stress-related growth to represent growth and change through the challenges of this parenting experience.

Calhoun and Tedeschi’s 2006 model has significantly contributed to the theoretical understanding of stress-related growth in a number of ways. It incorporates and expands on the process of meaning-making in addition to the influence of environmental factors, personality characteristics, and social support, factors that have been identified in previous theoretical models. The model also includes additional components that may play an important role in the development of stress-related growth such as: management of the emotional distress, rumination
understood as cognitive engagement, self-disclosure, distal and proximal socio-cultural influences, the development of life wisdom, ongoing distress, and the individual’s life-narrative. These components may be particularly relevant to understanding growth and change through the parenting experience that is the focus of this study.

Although Calhoun and Tedeschi’s (2006) theoretical model has significantly contributed to the understanding of growth through highly stressful life experiences, as Park (2004) and Calhoun and Tedeschi (2006) point out, the conceptualization of stress-related growth is as yet incomplete and more research is needed. According to Park (2004) there is a need for more descriptive work and Park and Lechner (2006) suggest that there may be dimensions of stress-related growth associated with specific life experiences that are as yet unidentified. Although numerous studies (see Linley & Joseph, 2004 for a review) have addressed stress-related growth associated with a variety of different stressful life situations (e.g. cancer, HIV/AIDS, assault, bereavement, addiction), the experience of parenting an adult child with schizophrenia or schizoaffective disorder has not yet been a focus of research in the stress-related growth literature. Consistent with Park and Lechner’s suggestion, there may be dimensions of stress-related growth associated with this experience that differ from those associated with other stressful life experiences, particularly given that the focus is on living with a child’s mental illness rather than on the personal experience of illness.

**Purpose of the Study**

The purpose of this study was to expand on the theme of personal growth and change that emerged in my previous research on the experience of fathers of adult children with schizophrenia. The research question that guided this research is: **How do parents of adult children with schizophrenia or schizoaffective disorder experience personal growth and**
change as they live with the challenges and ongoing uncertainties associated with their child’s mental illness?

A narrative approach was used to learn about personal growth and change through the stories of six self-selected mothers who believe that they have experienced personal growth and change through their parenting experience. As Lieblich, Tuval-Mashiach, and Zilber (1998) point out, the stories people tell about their experience are “one of the clearest channels for learning about the inner world” (p. 7). Stories “open up new possibilities for understanding” (Leggo, 2008, p. 9) – provide/create an openness that is vital to the understanding of personal growth through challenging life experiences. Narrative approaches also help us understand what happens during stressful experiences when lived stories break, when life narratives “decompose” (Polkinghorne, 1991, p. 135). Narrative inquiry can illumine how new stories start, how these stories are constructed, how they help individuals make meaning of their experience, and how they shape a narrator’s identity. Importantly, narrative inquiry is open to whatever aspects of the experience the narrator deems most important. Also important in the current study, narrative inquiry is open to multiple forms of data (e.g. one on one semi-structured interviews, art, poetry). Indeed, some researchers (e.g. Neimeyer, 2004; 2006; Pals & McAdams, 2004) have suggested that narrative inquiry may be an ideal approach to the study of stress-related growth. According to Robert Neimeyer (2004): “Of the many literatures relevant to the phenomenon of posttraumatic growth, literature concerned with the construction, deconstruction, and reconstruction of narratives may be among the richest, but also least utilized” (p. 53).

Through narrative inquiry with a focus on personal growth and change through living with the challenges and uncertainties associated with a child’s mental illness, an important and neglected area in the research literature, I anticipated that the findings of this study might provide
a greater understanding of this parenting experience which could benefit mental health professionals and parents in a number of ways. The findings could enhance the ability of counselling psychologists and other mental health professionals to support and work with parents. The findings could perhaps contribute to a greater understanding of the possible dimensions and pathways of growth, the meanings parents associate with personal growth, and the implications of this growth in the lives of parents and their adult children. I also anticipated that the findings might provide mental health professionals with a greater awareness of the important role that a parental perspective can have in treatment planning and the monitoring of treatment effectiveness. Although there is currently an increased interest within the mental health system in involving family members (e.g. family advisory committees) on an individual case basis, it has been my experience that all too frequently health professionals do not appear to understand the value of the parental experience or recognize the strengths parents can bring to understanding and managing their child’s mental illness. Additionally, I anticipated that the stories of this parenting experience could contribute to the evolving understanding of the nature and process of stress-related growth in the health psychology literature, possibly through suggesting dimensions of growth not yet considered or expanding on the understanding of factors that facilitate or hinder the development of stress-related growth associated with this population. Finally, and very importantly, I entered this research with the hope that the co-constructed stories in this study would serve to honour and validate the experiences and efforts of parents of the mentally ill.

I also entered this research by reflecting on my own parenting journey and understanding of personal growth and change. Part one of the researcher’s story below is a summary of my personal growth and change through living with the challenges and uncertainties associated with
my son’s mental illness. This first part of the researcher's story was written at the beginning of the research process – before writing the proposal and meeting the participants. Part two of the researcher’s story, found at the end of chapter five, reflects my experience as the researcher and how I have been shaped throughout the research process. It is informed by the entries in my research journal and my interaction with the participants as I engaged with their stories and the analytic process.

The Researcher’s Story of Change

Part One: Personal Growth and Change through Living with the Challenges and Uncertainties Associated with my Son’s Mental Illness

Personal growth and change has been, and continues to be, an ongoing process for me. In the early, chaotic, and troublesome years of my son’s developing illness, I was unaware of and unable to recognize any growth and change in my life. It felt like I was living in a cloud of fear, confusion, and uncertainty. I had only enough strength to keep going. At times I felt robotic and focused only on doing, not feeling. There were always lots of things to do. I had four other sons. I was a busy mother. Later I recognized that I had been confronted with experiences that did not fit my understanding of how life should be: A mother should not be afraid of her own son. Mental health professionals understand, know what to do, and can be trusted. It will get better. There is a fairness to life. If I live well, do my part conscientiously, life will make sense. Life is good. Looking back on the early experiences I can see that I was growing in courage and determination in those early years – developing inner strengths that I now consider valued parts of who I have become.

My expectations of life have changed. I no longer believe that life is fair. I no longer have positive expectations of, and a naïve trust in, mental health professionals. I accept that life is full
of uncertainty and always will be. I am comfortable with many more questions than answers. I accept that there are many aspects of life that I will never be able to make sense of. I can live well with that. I can live more with that and when I think of living more, I think of how the words “invitation” and “surprise” have taken on new meaning for me. I often think about life as an “invitation” – an invitation full of surprises. Some of these surprises are welcome, others are not, but I can enjoy living with the sense of anticipation that “invitation” brings. I am curious about what is coming around the corner. I do not need to know what it is. I can sit with, and ponder the questions that come up and I can let these questions shape who I am becoming.

Through living with my son’s mental illness I have become able to see, hear, and feel in ways that I could not prior to the onset of my son’s illness. These changes reflect growth to me. I now see beauty in everyday life that frequently stops me and I welcome the interruption — a spider’s web, the ever-changing beauty of the garden that I visit on my morning walks, beauty in the faces of the people that I meet throughout the day, beauty in the way that little children walk and talk, and so much more. I have grown in my ability to hear. The sounds of wind, water, laughter, and crying draw my attention in new ways. I can hear a depth of emotion that I could not hear before. I have also grown in my ability to feel. I can be more present and feel with others who are experiencing grief, hopelessness, confusion, or uncertainty. I have a greater freedom to experience and express my own feelings – to laugh and cry with others and to experience a greater sense of intimacy. I have a greater awareness of my physical body – a greater sensitivity to signs of building stress and the need for sleep. I more easily recognize when I need help and am more ready to receive it.

I have also gained a greater understanding of self and choice, and a greater sense of direction and purpose in life. I know better who I am and what I have to offer. I have a clearer
sense of my values and choices and how to respond to situations that come my way. Although I may not always have the choices I would like, I know that I always have some choice and I will be empowered as I make decisions and take responsibility for the decisions I make. Being empowered through decisions reminds me of the growth and change I experienced several years ago through the decisions I made at a meeting arranged by the mental health professionals who were looking after my son at a large in-patient psychiatric institution. It was not the first meeting with these professionals, but it was the first time that I decided to make sure that my role as a parent was understood and valued. At previous meetings I had sensed that I was viewed as merely a token representative of the family and a receiver of information, rather than an important contributor to the treatment planning process. On this particular day I found a voice I did not know I had. I asked for, and was given an opportunity to clarify my role, explain why my role was important and what I had to offer. I made it clear that what I had to say was not only relevant – it was crucially important given the decisions at hand. I pointed out that I had a perspective that no one else in the room could provide. I was heard. What I said made a difference to the decisions made about my son’s treatment, and in the process of saying what I did, I discovered a new part of who I was becoming – a new strength and a way to use that strength effectively. The process of self-discovery has continued.

Personal growth and change for me also includes changed values and a greater appreciation of artistic forms of expression. For example, I value my increased sensitivity and vulnerability, and have begun to express these changes through poetry. Poetry has been a way for me to express the ever-present “ache” of the unresolved grief that is part of my experience of being a parent of an adult child with schizophrenia. At times this “ache” swells unexpectedly and demands expression, but for the most part it just sits quietly in the background of my experience.
As for other forms of artistic expression, the quilt that hangs on the wall of my study is to me a visual reminder of how my experience has shaped and formed me. It is full of multi-coloured fragments, unevenly cut, with lines that don’t meet. Some are more “off” than others. To me it represents how life is. When I stand back and look at the quilt I see stories – vibrant stories, each story a collage of colours and patterns. Each story “speaks” meaning to me, often ambivalent meaning, but meaning just the same – understood this way for now. The stories are beautifully framed in a background of black and blue and around the edge of the quilt there are tiny multi-coloured polka dots that seem to celebrate life. To me they represent the surprises and the possibilities that surround the stories that make up my world. For me the quilt is about growth and change. It seems to be alive and in motion – dancing, shouting, singing, crying. The quilt also seems to hold for me many unanswered questions about growth and about formation – questions that I expressed through poetry as I contemplated what this research might be about:
Formation Questions and Reflections

Why does closing one chapter and opening another have to hurt so much?
Is losing part of moving forward?

Flesh and bone transitions: Are there others?

Struggle
Longing for relief
Knotted up inside

Is this the process of formation … to know what living is?
Anticipation… Expectation…
Invitation… Confirmation…
Ambiguities… Confusion… Questions…
Terror… Risks…
Regrets…
Searching…
Learning…

… and then?

What happens when the stories break?
Is there a witness?

What does the breaking sound like?
Who hears the sound?

How do the pieces fall?
Where do they go?
Who finds them?

How do new stories start?
How do they grow?
Who shapes and keeps them?

Could I be a witness,
hear the breaking sounds,
watch where pieces fall and find them,
join in creation?
be a part of stress-related growth?
Personal growth for me also includes a new perspective on mental illness. I now view mental illness as part of normal life – not a welcomed part, but a part of life that must be integrated within what ‘normal’ is. I am in an ongoing process of learning how to carefully, flexibly, and responsibly respond to the reality of mental illness in my world. The current study is part of this process.
CHAPTER TWO: REVIEW OF THE LITERATURE

In this chapter I review the literature that informed my thinking at the onset of this study. It is relevant to the purpose of the study as stated in chapter one as well as the research question that guided the study: **How do parents of adult children with schizophrenia or schizoaffective disorder experience personal growth and change as they live with the challenges and ongoing uncertainties associated with their child’s mental illness?** The chapter begins with a discussion of the conceptual understanding of stress-related growth in order to provide a context for considering how the findings in the literature on this parenting experience might fit within this construct. Within the section on stress-related growth attention is drawn to the core tenets of Positive Psychology that inform the study of growth and change. Three current theoretical models of stress-related growth are then presented, as well as a brief summary of the research that informs these models. Next, I review the research literature that informs the current understanding of this parenting experience. Specifically, I address the research focused on the concept of family burden, the nature of grief and loss experienced by parents of adult children with a mental illness, as well as the research that has given voice to parents as they have told the stories of their experiences, paying particular attention to reports of personal growth as a consequence of this parenting experience. I then review two studies that have specifically focused on positive aspects of this parenting experience (Bulger et al., 1993; Marsh et al., 1996).

**Stress-Related Growth: Conceptual Understanding and Supporting Research**

This section begins with an overview of Positive Psychology, the “science of positive subjective experience” (p. 5) that provides an overall perspective on growth and change through a focus on the development of competencies and strengths in the face of life challenges and adversity (Seligman & Csikszentmihalyi, 2000). Attention is then drawn to the rapidly growing
body of literature within Health Psychology that has focused on stress-related growth. The major theoretical conceptualizations of stress-related growth are presented and relevant studies that inform these theoretical models are reviewed. Attention is drawn to areas of particular relevance to the study of growth and change through this parenting experience.

**Positive Psychology**

Positive psychology is “the study of the conditions and processes that contribute to the flourishing or optimal functioning of people, groups, and institutions” (Gable & Haidt, 2005, p. 103). Seligman and Csikszentmihalyi (2000) describe positive psychology as being about “valued subjective experiences” and “what makes life worth living” (p. 5). The positive psychology movement has rapidly expanded since the turn of the 21st century (Gable & Haidt, 2005; Csikzentmihalyi, 2009) in response to a perceived need for balance in the academic psychological literature which has traditionally been based on the medical model with a focus on the process of *repairing* disease as opposed to the process of *constructing* satisfying lives (Seligman & Csikzentmihalyi, 2000; Sheldon & King, 2001). The positive psychology focus on constructing meaningful and satisfying lives is consistent with Counselling Psychology’s focus on facilitating growth and development across the lifespan. It is also relevant to the focus of the current study – a study of personal growth and change through living with the challenges and uncertainties associated with a child’s mental illness. As I began this study I anticipated that the “growth” stories told by parents of adult children with schizophrenia or schizoaffective disorder (hereafter referred to as “these parents”) would highlight valued subjective experiences that would reflect the construction of strengths and competencies in the face of the challenges that these parents have faced and continue to face. I anticipated that the positive psychology perspective would provide a more complete and perhaps a more balanced understanding of this
parenting experience. My review of the research literature in this chapter demonstrates that a considerable amount of research has highlighted the burdens and multiple losses associated with this parenting experience and little is known about if, when, and how these parents experience personal growth and change through their parenting experience.

That said, it is important to note, as Gable and Haidt (2005) point out, that positive psychology does not ignore or deny “the distressing, unpleasant, or negative aspects” (p. 105) of challenging life experiences such as the burdens and multiple losses faced by these parents. Indeed, a study focused on growth and change through this parenting experience must acknowledge the context of distress that is inherent in living and coping with the uncertainties and challenges that are a part of the course of this mental illness over the adult child’s lifetime. This point is emphasized in Marsh et al.’s (1996) study of resilience, reviewed later in this chapter, in which a significant number of family members objected to being asked only about positive outcomes of their experience. A positive psychology focus on personal growth and change thus adds to what is already known about this parenting experience. Notably, and relevant to the discussion that follows, positive psychology also provides an over-arching perspective on the growing body of research in Health Psychology on stress-related growth.

**Theoretical Conceptualizations of Stress-Related Growth**

I begin this section with an overview of the major contributors to the current understanding of stress-related growth in psychology and the terms used in the psychological literature to represent this phenomenon. Attention is then drawn to the major conceptual models that inform the theoretical understanding of stress-related growth. This is followed by a review of the research on stress-related growth that informs these models and is relevant to a study of personal growth and change through this parenting experience.
"Growth from the struggle with suffering and crisis" (p. 3) has been a theme throughout literature and philosophy from ancient times and is an integral component of major religions worldwide (Calhoun & Tedeschi, 2006). The underlying foundation for the focus on stress-related growth in psychology was laid by “major pioneers who addressed the possibility of growth from the encounter with loss in the 20th century” (Calhoun & Tedeschi, 2006, p. 4), namely Caplan (1964), Dohrenwend (1978), Frankl (1963), Maslow (1954), and Yalom (1980). The systematic study of stress-related growth in psychology is still relatively new, but has rapidly expanded over the past 15 to 20 years (Calhoun & Tedeschi, 2006; Helgeson, Reynolds, & Tomich, 2006; Park & Helgeson, 2006). Within this time period the major contributors to the literature on stress-related growth have been Schaefer and Moos (1992), O’Leary and Ickovics (1995), Park et al. (1996), and Tedeschi and Calhoun (1995; 1996).

Multiple terms have been used in the research literature to describe this growth phenomenon including: positive psychological changes (Yalom & Lieberman, 1991), perceived benefits or construing benefits (Tedeschi & Calhoun, 1991; Tennen, Affleck, Urrows, Higgins, & Mendola, 1992), flourishing (Ryff & Singer, 1998), positive by-products (McMillen, Howard, Neville, & Chung, 2001), discovery of meaning (Bower, Kemeny, Taylor, & Fahey, 1998), positive emotions (Folkman & Moskowitz, 2000), thriving (O’Leary & Ickovics, 1995), stress-related growth (Park et al., 1996), and posttraumatic growth (Tedeschi & Calhoun, 1995; 1996). Stress-related growth and post-traumatic growth are the two most commonly used terms in the recent theoretical and research literature to refer to positive psychological change that develops through coping with, and adjusting to, stressful life experiences.

The term, stress-related growth is widely used in this literature, although as Park et al. (1996) point out, there is a lack of agreement on what is meant by stress-related growth and a
lack of consensus on the dimensions of this growth. Park and Fenster (2004) define stress-related growth as “positive changes in the aftermath of stressful life experiences” (p. 195). Park et al. (1996) initially used this term in the development of their measure of these positive changes, the Stress-Related Growth Scale. Based on factor analysis in the development of this scale, Park et al. proposed that stress-related growth is a unidimensional construct. Their conceptualization of stress-related growth was informed by Schaefer and Moos’ (1992) Model of Life Crises and Personal Growth (discussed below), a model based on clinical experience and research within the large body of literature on stress and coping. This stress and coping literature is largely informed by the work of Lazarus and Folkman (1984). For a summary of the research evidence for the Model of Life Crises and Personal Growth the reader is referred to Schaefer and Moos (1992).

Posttraumatic growth (PTG), the term used by Tedeschi and Calhoun (1996, 2004) is defined somewhat differently. According to Tedeschi and Calhoun (2004), PTG is “the experience of positive change that occurs as a result of the struggle with highly challenging life crises” (p. 1). Based on factor analyses in the development of their measure of positive changes, The Posttraumatic Growth Inventory, Tedeschi and Calhoun (1996) identified five dimensions of PTG. These include: relating to others, new possibilities, personal strength, spiritual change, and appreciation of life. Unlike the term stress-related growth, PTG is informed by, and situated within, the trauma literature largely influenced by the work of Janoff-Bulman (1992). Although stress-related growth and posttraumatic growth are similar and appear broad in scope, Tedeschi and Calhoun (2004) distinguish PTG from the term stress-related growth by stating that PTG “focus[es] more distinctly on the conditions of major crises rather than lower level stress” and involves “transformative life changes” (p. 4). Tedeschi and Calhoun also state that PTG, unlike stress-related growth, does not reflect a coping process, but rather an outcome or ongoing
process. This statement has been challenged by a number of researchers including Aldwin and Levenson (2004), Janoff-Bulman (2004), and Park (2004).

As stated in chapter one, in this study I have chosen to use the term stress-related growth rather than PTG for the following reasons. I am interested in how parents experience personal growth and change due to a wide range of stressful situations, given, as demonstrated in the literature reviewed later in this chapter, that both acute and more chronic ongoing stressors reportedly have a significant impact on this parenting experience. The term stress-related growth takes into account a wide range of stressors and is thus more appropriate. Also, as previously noted, Park (2004) points out that there is a difference between how the term “trauma” is understood in the psychological literature and the way in which Tedeschi and Calhoun use the word “trauma” in their conceptualization of PTG. In the psychological literature the term “trauma” refers to an experience that involves a perceived threat to life or bodily integrity, whereas Tedeschi and Calhoun use the term “trauma” with reference to a broader range of stressful events. Stress-related growth thus seems to be a more accurate term. Additionally, I share Park’s concern that the term PTG could be perceived as offensive or at least disrespectful to those who have experienced severe personal trauma as it is understood in the psychological literature and should therefore be avoided. That said, the model of PTG is relevant to the purpose of the current study as it includes components that may have particular relevance to a study of growth through this parenting experience. The PTG model will therefore be discussed in the following section along with the two models of growth that are based on the stress and coping literature.

As pointed out in chapter one, a number of models of growth have been proposed (see O’Leary, Alday & Ickovics 1998 for a review of these models). Of these models there are three
models of growth following challenging life events that appear to be particularly relevant to the current study and for which there is research evidence. These include Schaefer and Moos’ 1992 Model of Life Crises and Personal Growth, Folkman’s 1997 Revised Model of the Coping Process, and Calhoun and Tedeschi’s 2006 Comprehensive Model of Posttraumatic Growth (PTG model).

**Model of Life Crises and Personal Growth (Schaefer & Moos, 1992).** The Model of Life Crises and Personal Growth (Schaefer & Moos, 1992) is the model that informed the initial conceptualization of stress-related growth. It provides a broad general framework applicable to both acute, highly stressful and more chronic stressful experiences and clearly links the development of stress-related growth to the stress and coping process by highlighting the role of cognitive appraisals and coping strategies. According to this model the individual’s environmental system and personal system both “affect the likelihood and characteristics of a life crisis or transition” (p. 151). The environmental system refers to the individual’s financial, home, and community situations as well as relationships with others. The personal system refers to the individual’s socio-demographic characteristics and personal resources such as: cognitive abilities, health status, motivation, and self-efficacy. The life crisis then shapes the individual’s cognitive appraisal and coping resources which then affects the likelihood of positive outcomes. Several possible positive outcomes have been identified by Schaefer and Moos including: closer relationships with family and friends, an expanded support network, empathy, altruism, maturity, changed values and priorities, self-reliance, self-understanding, enhanced cognitive and intellectual skills, and new coping skills.

This model proposed by Schaefer and Moos, however, does not address some of the influences in the development of stress-related growth that are addressed in other models and
may be important when seeking to understand the experience of personal growth and change through this parenting experience. For example, the model does not address the role and management of ongoing distress, pathways leading to negative and positive outcomes, or the role of meaning-making coping strategies, the struggle with existential questions, and the reconstruction of an individual’s life narrative.

**Revised Model of the Coping Process (Folkman, 1997).** Folkman’s 1997 Revised Model of the Coping Process is a revision of Lazarus and Folkman’s original 1984 Model of the Coping Process (for a schematic representation of these models the reader is referred to Folkman, 1997). The Revised Model of the Coping Process is similar to Schaefer and Moos’ (1992) Model of Life Crises and Personal Growth in that it highlights the role of cognitive appraisals and coping strategies in response to stressful life events. In addition, based on Folkman’s 1997 longitudinal study of the caregiving partners of men with AIDS, Folkman’s Revised Model of the Coping Process takes into account three components that may be particularly important for understanding the coping process throughout “enduring and profoundly stressful circumstances” (p. 1207) such as the circumstances associated with the parenting experience that is the focus of the current study. These three components are: the co-occurrence of negative and positive psychological states, the meaning-making coping process associated with positive psychological states, and the role of positive psychological states in the ongoing coping process. Possibly particularly relevant, Folkman’s revised model draws attention to the meaning-making coping processes that can result when outcomes of stressful events are unfavourable and/or associated with distress. Four meaning-making coping processes are identified in this model that may be relevant to the parenting experience of the current study: (a) positive reappraisals, (b) revision of goals, (c) activation of spiritual beliefs, and (d) infusing
ordinary events with positive meaning. Folkman’s model also proposes that positive psychological states play an important role in sustaining problem-focused and emotion-focused coping processes in situations of chronic stress. Given the significant impact of the chronic stresses reported by parents in the studies reviewed later in the current chapter, these components may play an important role in the development of growth and change in this population.

Folkman’s model, however, does not address some of the factors that are addressed in Calhoun and Tedeschi’s PTG model and that may be important to the understanding of personal growth and change in this parenting experience. These factors include self-disclosure and socio-cultural influences as well as the process of reconstructing a life narrative.

The Comprehensive Model of Posttraumatic Growth (Calhoun & Tedeschi, 2006). Calhoun and Tedeschi’s 2006 Model of Posttraumatic growth (PTG Model) is based on clinical practice and research. For an extensive review of this research and a schematic representation of the various associations between the components within this model the reader is referred to Calhoun and Tedeschi’s 2006 Handbook of Posttraumatic Growth: Research and Practice. In this chapter I briefly discuss the components of the PTG model that I anticipated could be relevant to this parenting experience. I also draw attention to areas of the model that could potentially be expanded by the findings of this study. As previously pointed out, the PTG model includes components not addressed by the models reviewed above that could be relevant to the understanding of growth associated with this parenting experience. I anticipated that the following components of the PTG model could be relevant: the person pretrauma; the seismic event; challenges produced by the seismic event; the process of rumination; self-disclosure and the socio-cultural context; and distress. I also anticipated the relevancy of the proposed coexistence of (a) ongoing distress, (b) PTG, and (c) the reconstruction of a life-narrative, as well
as the proposed mutually informing relationships between these components.

**Person pretrauma.** Like the “personal system” component of Schaefer and Moos’ Model of Life Crises and Personal Growth (1992), Calhoun and Tedeschi’s PTG Model (2006) acknowledges the influence of pretrauma personal characteristics on how individuals respond to challenging life situations. However, much is yet to be learned regarding the influence of these personal characteristics. Some evidence (e.g. Tedeschi & Calhoun, 1996) suggests that the personality characteristics of extraversion and openness to experience as measured by the NEO Personality Inventory (Costa & McCrae, 1992), and optimism as measure by the Life Orientation Test (Scheier & Carver, 1985) may be associated with an enhanced ability to engage in the schema rebuilding process that Calhoun and Tedeschi propose leads to PTG. Also relevant to the understanding of this “personal system” component, in my master’s research (Wiens & Daniluk, 2009 reviewed later in this chapter) in which “personal growth and learning” emerged as a major theme, the participants reported that the process of reflecting back on their early parenting prior to the onset of their child’s illness helped them to make-meaning of how they parented after the onset of their child’s illness. Several fathers experienced an affirmation of their strengths as fathers through this reflective process. These fathers drew on the strengths they had prior to the onset of their child’s illness to help them cope with the challenges associated with their child’s developing illness. For some fathers this process of reflection led to an intentional decision to parent differently and ultimately to personal growth and change. In the current study I was curious about and asked the participants, if they had not spontaneously addressed this question: How has “who you were as a parent prior to your child’s illness” (e.g. traits, strengths, weaknesses, coping styles) influenced who you have become?

**Seismic event.** It is important to remember, as Park (2004) has pointed out, that the
“seismic event” in the PTG model refers to a broader range of stressful events than is understood by the term “trauma” in the psychological literature. Calhoun and Tedeschi (2006) state that they “use the terms trauma, crisis, major stressor, and related terms as essentially synonymous expressions to refer to “circumstances that significantly challenge or invalidate important components of the individual’s assumptive world” (p. 3). They also point out that individuals who have experienced events of this magnitude tell their stories in terms of before and after the event. This observation is relevant to the current study as the stories of many of the participants in the studies reviewed later in this chapter (e.g. Tuck et al., 1997; Wiens & Daniluk, 2009) were told in terms of before and after the onset of their child’s illness. It is also notable that in Tuck et al.’s study, the participants described the diagnosis of schizophrenia as a “destructive force,” not unlike Tedeschi and Calhoun’s (2004) description of a “seismic event.” To aid the reader’s understanding of a seismic event, Tedeschi and Calhoun use the metaphor of an earthquake – an event that shakes or severely threatens “schematic structures that have guided understanding, decision-making, and meaningfulness” (p. 5).

As previously pointed out, the PTG model accounts for the possibility of growth only through stressors of this magnitude and does not address the possibility of stress-related growth through the long-term chronic stressors that are reportedly also a significant part of the realities of this parenting experience. Notably, other researchers such as Aldwin and Levenson (2004) question this limitation and suggest that stressors of lesser magnitude such as those associated with normative developmental events also contribute to growth that may not be qualitatively different from the PTG in this model. Insight into growth through acute and chronic stresses may be provided through the findings of the current study through questions such as: How do you feel the stresses associated with your parenting experience have contributed to your personal
growth/growth as a parent? The following components address the theoretical understanding of the responses to the seismic event and the process of reconstruction that follows such a life-altering event.

**Challenges produced by the seismic event.** Calhoun and Tedschi (2006) propose that the seismic event challenges: the individuals’ ability to manage emotional distress, the individual’s beliefs and goals, and the coherence of the individual’s life narrative. Calhoun and Tedeschi (2006) suggest that the distress associated with these challenges can initially be overwhelming and over time needs to be managed in order for the cognitive processing necessary for growth to occur. However, the model does not fully address the process by which individuals may manage their initial levels of distress. Similar to the two previously discussed models, the PTG Model focuses largely on cognitive processes, referred to elsewhere in the trauma literature as “top-down” processes (Ogden, Minton, & Pain, 2006). These are in contrast to “bottom-up” processes that address the sensorimotor and emotional components of highly stressful experiences.

Recent developments in the trauma literature (e.g. Ogden et al. 2006; Siegel, 2006; van der Kolk, 2006), suggest that the management of distress associated with highly stressful life events requires an integration of both “bottom-up” and “top-down” processes. According to Siegel and van der Kolk, a key component of self-regulation and management of distress involves increasing conscious self-awareness of bodily sensations and emotional experiencing (Siegel, 2006; van der Kolk, 2006). Greenberg and Watson (2006) similarly maintain that emotional regulation involves “the ability of the cognitive system to gain information from the emotion system” (p. 79). Siegel (2006) suggests that “an overemphasis on logical, linguistic, linear, and literal thinking may tilt the balance of our minds away from the important sensorimotor, holistic, autobiographical, stress-reducing, image-based self-regulatory functions
of our non-verbal neural modes of processing” (p. xiv). In the current study I was curious about the possible role of sensorimotor, holistic, autobiographical, image-based self-regulatory functions in managing the distress associated with this parenting experience.

**Rumination.** The component of rumination is at the heart of Calhoun and Tedeschi’s (2006) explanation for the development of PTG. It is important to note that the term “rumination,” like the term “trauma,” is understood somewhat differently in the PTG model than the way “rumination” is more commonly used in the psychological literature being the repeated negative thinking frequently associated with depression. According to the PTG model rumination is best understood as cognitive engagement – “repeated thinking that is not necessarily intrusive and that includes reminiscing, problem solving, trying to make sense…and perhaps searching for how the struggle has changed one in positive ways” (p. 9). Notably, this process appears to be similar to the grieving process described later in this chapter in the section on chronic sorrow. In the current study, to expand the understanding of this rumination process I strove to be attentive to participants’ descriptions of cognitive processes and curious about what, if any, thoughts or questions the participants may have struggled with and how these thoughts and questions might be associated with their growth experience.

The process of rumination in the PTG model is described in terms of three sequential levels. Early rumination is described as primarily automatic and intrusive, and associated with attempts to gain a sense of comprehensibility about what has happened. Later rumination is associated with management or ways to “cope with the changed circumstances” (Calhoun & Tedeschi, 2006, p. 10), which is noticeably similar to the coping responses that are central to both Schaefer and Moos’ (1992) and Folkman’s (1997) models. The final level of rumination is thought to lead directly to PTG and is a deliberate form of cognitive processing that is associated
with meaning-making, the rebuilding of cognitive schemas, and the reconstruction of the individual’s life narrative. Relevant to the experience of parenting a child with schizophrenia or schizoaffective disorder, this meaning-making reconstruction process may in part reflect a response to the existential loss that MacGregor (1994) (reviewed later in the current chapter) suggests may be an important component of the grief experience of parents of a child who has a serious mental illness. As Calhoun and Tedeschi point out, the psychological rebuilding process involves reconstructing assumptions about oneself and one’s world – something that might be necessary for parents whose hopes and dreams for their child’s future have been dashed or radically altered.

All three levels of cognitive engagement are thought to occur over varying amounts of time. However, how much time is required for growth is as yet unknown and may depend on the severity of the stressful event as well as multiple contextual factors such as characteristics of the person and amount of social support. Notably, parents who reported personal growth in the studies to be reviewed later in the current chapter had been coping with their child’s illness for a number of years – a minimum of four years in Wiens and Daniluk (2009) and an average of twelve years in Bulger et al. (1993). Unfortunately, a time frame is not provided in Marsh et al.’s (1996) study in which participants also reported personal growth.

**Self-disclosure and socio-cultural context.** In the PTG model the components of self-disclosure and socio-cultural context are viewed as influences on the process of cognitive engagement. The self-disclosure component of the PTG model refers to the various ways in which persons may communicate their experience such as interpersonal conversations, poetry, music, photography or other art forms. The socio-cultural context refers to the influence of others in the person’s immediate social context or in the larger social context and includes cultural and
religious influences.

These components of ‘self-disclosure’ and the “socio-cultural context” as described above, in addition to influencing the process of cognitive engagement, may also play a role in the multilevel (bottom-up and top-down) integrative processes proposed by Ogden et al. (2006), Siegel (2006), and van der Kolk (2006), although these processes are not addressed in this model. With reference to the importance of multilevel integrative processes, Siegel (2006) points out that we need mutual, contingent, meaningful communication with others in order to thrive and not just survive. For a discussion of these integrative processes and the neurobiological research that supports them the reader is referred to Siegel (2006).

In order to gain an understanding of the influences of self-disclosure and the socio-cultural context on the development of growth in this study, I noted participants’ responses to questions such as: In what ways, if any, have you communicated your experience to others? How has this communication influenced your growth and change? How, if at all, have any projects, activities, or hobbies influenced your growth? How have relationships with others, for example professionals, family members, or friends influenced your growth experience? How, if at all, do you feel that your growth and change has been influenced by your culture? Importantly, the participants in the current study were invited to include as data any forms of communicating their story (e.g. poetry, art forms) that they thought would contribute to a fuller understanding of their experience.

**Distress, PTG, and narrative reconstruction.** According to the PTG model, individuals who experience PTG may also experience ongoing distress. The experience of PTG is also associated with ongoing narrative reconstruction. According to Calhoun and Tedeschi (2006) the process of narrative reconstruction, at least in part, involves the development of wisdom. The
Wisdom that is associated with narrative reconstruction and the experience of PTG has been described as “the ability to balance reflection and action, weigh the known and the unknowns of life, be better able to accept some of the paradoxes of life, and to more openly and satisfactorily address the fundamental questions of human existence” (Calhoun & Tedeschi, 1999, p. 21). This perspective on wisdom is consistent with the Berlin wisdom paradigm that defines wisdom as “an expert knowledge system concerning the fundamental pragmatics of life” (Baltes & Staudinger, 2000, p. 122). Importantly, Tedeschi and Calhoun (2004) also suggest that the three components of distress, PTG, and narrative reconstruction may “mutually inform” one another. However, how these components may mutually inform one another is yet to be understood.

The association in the PTG model between ongoing distress, the experience of growth, and the process of narrative reconstruction may be particularly relevant to understanding the experience of parents of adult children with schizophrenia or schizoaffective disorder who feel that they have grown and changed through coping with the challenges associated with their child’s mental illness. Notably, each of these three components have been reported by participants in the studies of the parenting experience reviewed later in this chapter. For example, the family burden literature has drawn attention to the reported ongoing multiple subjective burdens faced by parents (e.g. Jones, 1997; Jungbauer & Angermeyer, 2002). The literature focused on the parental grief experience also suggests that parents may experience ongoing distress due to an unresolved form of grief similar to the concept of chronic sorrow (e.g. Atkinson, 1994; Eakes, 1995; Miller et al., 1990). Other studies (e.g. Milliken, 2001; Tuck et al., 1997) have reported a process of redefining and reformulating parental identity that is suggestive of an ongoing process of narrative reconstruction. Notably, in Tuck et al. this reformulation process was associated with wisdom. Parents have also reported personal growth in several
studies (Bulger et al., 1993; Marsh et al., 1996; Wiens & Daniluk, 2009). However, how these components may be related and how they may be mutually informing for parents who report that they have experienced growth and change is as yet unknown. The stories of parents in the current study who believe they have grown through their parenting experience may be able to provide some insight into the relationships between these components – insight which could potentially enable counselling psychologists and other mental health practitioners to normalize, validate and value these aspects of the parental experience and ultimately help to facilitate the process of personal growth.

Notably, relationships between distress, growth, narrative construction, and wisdom have also been suggested by others. For example, the coexistence of growth with distress has been reported by Yalom and Lieberman (1991) in their study of bereavement. Grams (1996) suggests that the process of grieving is intimately tied to the telling of stories and ultimately to the development of wisdom. According to Grams, story-telling is the language of grief and the re-storying of experience, at least in part, involves gleaning the wisdom that develops through change.

In summary, the three theoretical models of growth each highlight components that may be relevant to the understanding of growth and change through the parenting experience that is the focus of the current study. Both Schaefer and Moos’ 1992 model and Folkman’s 1997 model take into account stressors of varying magnitude and highlight the role of cognitive appraisals and coping strategies. Schaefer and Moos’ model points out the importance of environmental and personal influences on the responses to stressful events. Folkman’s 1997 model draws particular attention to meaning-making coping processes and the role of positive psychological states in sustaining the coping process. The PTG model highlights a number of additional components
that may also be relevant to an understanding of personal growth and change through life-altering events such as the ongoing challenges experienced by parents of children with schizophrenia or schizoaffective disorder. These components include self-disclosure, socio-cultural influences as well as a mutually informing relationship between the components of growth, ongoing distress, and the reconstruction of a life-narrative. However, as Calhoun and Tedeschi (2006) acknowledge, our understanding of what contributes to growth, for whom, and under what circumstances is still incomplete. Processes other than cognitive engagement may play an important and as yet unacknowledged part in the development of stress-related growth, particularly in the management of distress and through self-disclosure and socio-cultural influences. More research is needed to refine and extend the current conceptualization of this growth phenomenon. In the following section I review some studies that have informed the current conceptualization of stress-related growth and also have some relevance to the current study.

**Research on Stress-Related Growth**

Most studies of stress-related growth have been cross-sectional and have focused on determining the presence of stress-related growth, the correlates of stress-related growth, and the predictors of stress-related growth associated with various stressful situations. Brief overviews are provided in this section of four studies that focus on stress-related growth associated with stressful situations that have some, albeit limited, similarity to the experience of parenting an adult child with schizophrenia or schizoaffective disorder. The first study (Hogan, Morse & Tason, 1996) focuses on stress-related growth through the experience of the loss of a loved family member. The following two studies (Best, Streisand, Catanian & Kazak, 2001; King, Scollon, Ramsey & Williams, 2000) focus on stressful parenting experiences. The fourth study
(Linley & Joseph, 2004) is a review of 39 studies of stress-related growth.

The study by Hogan et al. (1996) is included in this review as it identifies personal growth as an important part of the grieving process for the participants, the majority of whom were parents. Using a grounded theory approach to study the experience of the death of a loved family member, Hogan et al. examined stress-related growth associated with grief and loss for 34 adults (8 male, 26 female) who had experienced the death of a child (22), parent (9), or sibling (3). These participants were recruited through social networks as well as organizations such as Parents of Murdered Children, Survivors of Suicide, and an AIDS survivor support group. Unstructured telephone interviews guided by a single open-ended question – “Tell me what happened” – were conducted with these participants. Consistent with a grounded theory approach, the data analysis proceeded concurrently with data collection and involved a process of coding to identify categories and subcategories, and a constant comparative method to identify relationships between categories and patterns in the data. The data collection continued to the point of saturation.

Importantly, these researchers reported that personal growth was “a vital component of the grieving process” (p. 43) for these participants. On the basis of their findings, they proposed a seven phase Experiential Theory of Bereavement to describe the process of surviving the death of a loved one. Relevant to the focus of the current study, the seventh phase in this theory was entitled *Experiencing personal growth.* Personal growth was reportedly experienced “to some degree across all phases of the bereavement process but was most evident as the survivor is emerging from the acute pain of grief” (p. 58). Relevant to the current study, this observation underscores that time may be required before personal growth is perceived following a loss. Certainly this was the case for the fathers in my master’s research and also my personal
experience. I anticipate that in parenting an adult child with schizophrenia or schizoaffective disorder the amount of time required to realize growth may vary considerably across participants given the overall uncertainty of the course of the illness with periods of stability often followed by periods of instability.

Hogan et al. (1996) also reported that personal growth for their participants involved a search for meaning and purpose, becoming less judgmental and more caring, tolerant, and compassionate, and reassigning priorities. The participants also reported that they developed a greater sense of closeness with family members and found ways to mentor others. These descriptions of growth are consistent with the meaning-making process that the PTG model associates with the rebuilding of schemas and the reconstruction of the individual’s life-narrative. These descriptions are also similar to the descriptions of personal growth in the parenting research reviewed in the following section (e.g. Marsh et al., 1996; Wiens & Daniluk, 2009). That said, the experience of parenting an adult child with a mental illness differs considerably from the loss due to death of a family member that is the focus of Hogan et al.’s study – the most obvious differences being the finality of loss due to death, the absence of stigma in bereavement loss, and the expectation that the intensity of grief over time will diminish.

The following two studies focus on the experience of parents who have a child with paediatric leukemia (Best, Streisand, Catanian & Kazak, 2001) and parents of a child with Down Syndrome (King, Scollon, Ramsey & Williams, 2000). In the first of these two studies, a longitudinal follow-up study, Best et al (2001) investigated the relationship between parental anxiety during treatment of their child’s paediatric leukemia and the presence of parental posttraumatic stress symptoms approximately four years after treatment for a sample of 113 parents (66 mothers, 47 fathers). Two sources of data were included in this study. The first data
source consisted of self-report questionnaires assessing parental anxiety during a child’s treatment which had been completed in a previous prospective randomized clinical intervention trial (Langner’s 1962 Symptom Checklist and Kazak, Penati, Waibel, & Blackall’s 1996 Perception of Procedures Questionnaire used in Kazak, Penati, Boyer, et al., 1996 and Kazak, Penati, et al., 1998, cited in Best et al.). The second data source consisted of measures assessing anxiety, social network, PTSD symptoms, stress-related growth, and parental perceptions of self-efficacy that were completed four years posttreatment (Speilberger’s 1983 State-Trait Anxiety Inventory; Kazak’s 1987 Social Network Reciprocity and Dimensionality Assessment Tool; Weiss & Marmar’s 1997 Impact of Event Scale-Revised; Tedeschi & Calhoun’s 1996 Posttraumatic Growth Inventory; The Pediatric Anxiety and Avoidance Scale developed for this study; and the Children’s Hospital of Philadelphia Self-Efficacy Scale also developed for this study).

The results of a hierarchical multiple regression analyses indicated that anxiety during treatment was a significant predictor of posttraumatic stress symptoms for mothers but not fathers four years after treatment. This finding may be expected given that mothers reportedly more often accompanied their child to procedures than fathers, and thus had more direct exposure to the stressful events of treatment. Relevant to stress-related growth, Best et al. also reported that higher growth scores on the PTGI predicted anxiety and avoidance for both mothers and fathers. This finding suggests that although these mothers and fathers believed they had grown through their experience, they continued to experience distress. Consistent with Taylor’s 1983 Cognitive Adaptation Theory, Best et al. speculated that this finding may reflect the need for parents to manage their distress by constructing stories of positive outcomes.

From the perspective of the PTG model this finding provides some evidence for the
coexistence and perhaps mutually informing relationship between distress and growth associated with a stressful parenting experience. However, given the significant differences between the experience of parenting a child with leukemia and parenting an adult child with schizophrenia or schizoaffective disorder, one can only speculate that the growth experience of parents in the current study may coexist with, and be informed by ongoing distress.

Additional understanding of stress-related growth in a stressful parenting experience is provided by King et al. (2000) in their multi-method longitudinal study investigating how subjective well-being, ego development, and “consciously struggling with a major life transition” (p. 510) may relate to personal growth and personality development for 87 parents of children with Down Syndrome. The data for this study were collected at two time periods. At time one, 87 parents wrote narratives about their experience of discovering that their child had Down Syndrome. They also completed self-report measures of subjective well-being (Diener, Emmons, Larsen, & Griffen’s 1985 Satisfaction with Life Scale; Antonovsky’s 1988/1993 Sense of Coherence Scale; Scheier & Carver’s 1985 Life Orientation Test; and Rosenberg’s 1979 Self-Esteem Scale), stress-related growth (Park et al.’s 1996 Stress-related Growth Scale), and ego development (Loevinger & Wessler, 1970 and Hy & Loevinger’s 1996 Sentence Completion Test). Two years later, 42 parents from the original group completed the same self-report measures. Narratives were not written at the second data collection point. The narrative transition stories from the first data collection were content analyzed and coded for the presence of foreshadowing, happy beginnings and endings, degree of closure and accommodative change. Responses to the self-report measures were analyzed using multiple correlation and hierarchical regression techniques.

The researchers reported that stress-related growth was not related to ego development at
either time period, suggesting that stress-related growth and ego development are independent of each other, although both refer to a type of growth. Stress-related growth was also unrelated to concurrently measured subjective well-being at both time one and two, however, positive subjective well being at time one was related to lower levels of stress-related growth at time two. King et al. point out that this finding is consistent with the understanding that “some amount of discontent is required for personal growth” (p. 530). Thus, the individuals who felt relatively satisfied at time one were less likely to engage in a struggle with life challenges. This explanation is consistent with the PTG model which emphasizes the important role of the struggle with life challenges in the development of growth. Also consistent with the PTG model, a positive relationship was found between accommodative change, “an essential change in their orientation to the world” (p. 513), and stress-related growth at both time periods. This finding, as King et al. point out, suggests that “telling a story that conveys one’s struggle with a life problem… is associated with the subjective sense that one has grown” (p. 530).

The parenting experiences addressed in the above two studies appear to share similarities with the experiences of parenting a child with schizophrenia or schizoaffective disorder — similarities such as challenges to one’s assumptive world, losses related to dreams and expectations, stigma, living with chronic disability, and perhaps a foreshortened future. However, as the review of the literature in the following section and my personal experiences suggest, there are also significant differences. Specifically, parents of adult children with schizophrenia or schizoaffective disorder will likely have experienced parenting their child through a normal childhood with the onset of symptoms typically not occurring until late adolescence (Pennington, 2005). Also, the early distressing symptoms of the illness are often confused with adolescent adjustment difficulties and it can take considerable time and assessment before a diagnosis is
made (Tuck et al., 1997; Wiens & Daniluk, 2009). Reminders of losses contribute to recurrent episodes of unresolved grief (MacGregor, 1994). Additionally, the loss of dreams and expectations for their child based on the early years of parenting and the ever present concern for their child’s future when parents will no longer be able to meet their needs also contribute to parental distress (Jones, 1997; Wiens & Daniluk, 2009). Parents of adult children with schizophrenia or schizoaffective disorder also live with the stress related to the uncertain course of the illness, and during acute episodes need to cope with bizarre behaviours and suicide risks (Wiens & Daniluk, 2009). The stigma associated with mental illness also adds to the complexity of their experience (Howard, 1998; MacGregor, 1994). What, if any, influences these aspects of the parenting experience have on stress-related growth remains to be determined.

The final article to be addressed in this section is Linley and Joseph’s (2004) review of 39 peer-reviewed studies of adversarial growth defined as “positive change following trauma and adversity” (p. 11). Linley and Joseph suggest that adversarial growth is an appropriate inclusive term that incorporates PTG, stress-related growth, perceived benefits, and thriving. The research in their review included studies of adversarial growth associated with a wide variety of stressful events such as cancer, bone marrow transplants, heart attacks, tornadoes, plane crashes, HIV/AIDS, military combat, marine disasters, shootings, rape and sexual assault, bereavement, as well as experiences related to substance abuse and living with a disabled child. Cognitive appraisal variables (threat, harm, and controllability), problem-focused coping, acceptance and positive reinterpretation coping, optimism, religion, cognitive processing, and positive affect were reportedly consistently associated with adversarial growth across these studies. However, socio-demographic variables such as gender, age, education, income, and psychological distress variables such as depression, anxiety, posttraumatic stress disorder, were not found to be
consistently associated with adversarial growth. Regarding the temporal course of adversarial growth, Linley and Joseph reported that in some studies greater growth was associated with longer periods of time following the stressful event, however, this was not the case in other studies suggesting that intervening events play an important role over time.

As Linley and Joseph point out, it is important to note that these findings only represent summaries of reported findings. Comparisons across studies cannot be made with any degree of certainty given the wide range of stressful events that cannot be compared, the diverse methods and measures that were used (only 12 of the 39 studies used previously published measures), and the “overreliance of self-report measures that [did] not allow for negative responses” (p. 18). The authors suggest the need for more methodologically rigorous studies of growth over time, in particular multivariate longitudinal studies, as well as studies focused on the relationship between growth and distress. They also suggest the need for studies focused on identifying additional dimensions to adversarial growth. A study of personal growth and change through the experience of parenting an adult child with schizophrenia or schizoaffective disorder may provide insight into the relationship between growth and distress as well as possibly identify additional dimensions of stress-related growth. Linley and Joseph conclude that “as difficult as it may be … to demonstrate adversarial growth experimentally, the expanding body of research endorses its validity” (p. 19).

Although the theoretical conceptualization of stress-related growth has been applied to the study of a number of serious developmental, health-related, and parental issues, it has yet to be the lens through which researchers examine and understand the experiences of parents of adult children with schizophrenia or schizoaffective disorder. The following section provides an overview of what is currently known about this parenting experience.
The Experience of Parenting an Adult Child with Schizophrenia

The current understanding of this parenting experience is primarily informed by three bodies of research: (a) research focused on the concept of family burden, (b) research on the nature of parental grief, and (c) research on the experience of parenting an adult child with schizophrenia.

Family Burden

This section begins with a description of family burden, followed by a review of studies that have focused on the major subjective burdens reported by parents (Jones, 1997; Jungbauer & Angermeyer, 2002). Research on family burden, “the strains of living with psychiatrically impaired persons” (Lefley, 1989, p. 556), began in the mid 1950’s. This body of research has drawn attention to the highly stressful impact of mental illness on the family. This literature is in sharp contrast to the large body of research which has focused on investigating the effects of the family environment on the development of schizophrenia (e.g. Bateson, Jackson, Haley, & Weakland, 1956; Bowen, 1961; Fromm-Reichmann, 1948; Hadju-Gimes, 1940; Lidz, Cornelison, Fleck, & Terry 1957; Wynne & Singer, 1963) and on the course of the family member’s mental illness (e.g. Brown, Birley, & Wing, 1972; Vaughn & Leff, 1976).

Early studies of family burden (e.g. Clausen & Yarrow, 1955; Mills, 1962) established that burdens were present in families of the mentally ill and that these burdens were often extensively experienced by family members (Fadden, Bebbington, & Kuipers, 1987). In 1966 Hoenig and Hamilton differentiated objective burdens from subjective burdens. Objective burdens were defined as the observable effects on the family such as financial expenses or the disruptions of everyday life as a consequence of abnormal behaviours on the part of the mentally ill family member. Subjective burdens referred to how family members feel about the effects of
the illness on the family and the extent to which these effects are considered a burden.

Significant objective and subjective burdens experienced by family members of the mentally ill are consistently reported in the research literature (Lefley, 1989; Maurin & Boyd, 1990), similar to families in which a member has a chronic developmental, mental, or physical disability. Common burdens include but are not limited to, the affected family member’s economic dependence, disruption in family functioning, and limited opportunities for social activities and relationships with others due to the demands of caregiving (Lefley, 1989). Additional burdens specific to families living with mental illness include: the mentally ill person’s inability to consistently carry out age-appropriate role functions; the time and energy invested in seeking help and negotiating the mental health system; difficulties associated with bizarre and at times abusive behaviours; crisis management which can involve emergency services, involuntary hospitalization, difficult interactions with service providers; and the effects of stigma on relationships both inside and outside the family (Lefley, 1989).

Two studies of subjective burden provide insight into the major subjective burdens experienced by families of the mentally ill (Jones, 1997; Jungbauer & Angermeyer, 2002). In a study by Jones (1997), 426 telephone interviews were conducted with family caregivers (parents, spouses, siblings & children; 50% were parents) over a three year period (sample size 148 in year one, 135 in year two, and 143 in year three) using the Caregiver Burden instrument (Tessler, 1989, cited in Jones, 1997). During the interviews open-ended questions were posed to elicit the reasons for the participants’ choices on the Lickert scale used in this instrument. Major subjective burdens reported by the parents in this study included weariness associated with the long-term commitment to providing care and frustration with being blamed for their child’s behaviours. Parents in this study also voiced a pervasive concern regarding the future when they would no
longer be able to provide for their mentally ill child’s needs. Children of a mentally ill parent reportedly experienced feelings of having been “robbed of a parent” (p. 86). Caregivers whose brother or sister were mentally ill emphasized ambivalent feelings and felt the stress of being in a “sandwich” position between their mentally ill sibling and other siblings, which resulted in “forced divided loyalties” (p. 86). In cases where a partner’s spouse experienced a mental illness, spousal subjective burden centred around the loss of the couple’s earlier relationship as well as loss of dreams for the future. Spousal caregivers also expressed an awareness of the voluntary nature of their caregiving relationship and experienced a great deal of ambivalence in their relationship with their mentally ill partner.

The findings of this study underscore the experience of caregiver burden among families in which a member has a mental illness. They also suggest that caregiver burden is experienced somewhat differently by various family members depending on their relationship to the family member with the mental illness. The strength of this study is in the large sample size. However, the findings need to be considered with caution given the demographic similarity of the participant sample. Seventy-five percent of the participants were white and female and most were described as being economically deprived. Unlike most studies on this topic, only five percent of the respondents were associated with a support group. Also, it is not clear if any of the participants were included in more than one of the three samples and the process of data analysis is not described. The findings are also limited by the depth of rapport possible through telephone interviews. With these cautions in mind, the study does add to our understanding of the burdens experienced by families when a member has a mental illness.

Additional insight into the parental experience of subjective burden was provided by Jungbauer and Angermeyer (2002) in their study of subjective burden experienced by 51 parental
(42 mothers, 9 fathers) and 52 spousal caregivers of an adult child/partner who had been diagnosed with schizophrenia for an average of 11 years. The data analysis in this study was described as thematic field analysis (Fischer-Rosenthal, 1998, cited in Jungbauer & Angermeyer) using grounded theory (Glaser & Strauss, 1998, cited in Jungbauer & Angermeyer). Through in-depth, in-person interviews including a questionnaire addressing socio-demographics, financial burdens, and health concerns; these researchers reported that the experience of subjective burden for parental and spousal caregivers was influenced by the symptomatic course of their loved one’s illness as well as family roles. Subjective burden at the onset of the illness involved shock, anxiety, and feelings of helplessness. Chronic subjective burden, although less dramatic, reportedly had a greater adverse affect on the quality and course of caregivers’ lives. For example, in the chronic phase of the illness, the constant fear of another acute episode was described as “hanging like a sword of Damocles over everyday life” (p. 115). In day-to-day interactions with their mentally ill family member both parental and spousal caregivers reported that they experienced a sense of “permanent ambivalence” (p. 115) as they struggled to determine whether or not problematic behaviours were due to their child or partner’s mental illness. Over time the burden of care took a toll on the caregivers’ own mental health with some reporting exhaustion, burnout, and at times, severe bouts of depression.

Unique to the parental experience of subjective burden in this study was the struggle parents experienced as they tried to cope with the uncertainty regarding the cause of schizophrenia and the resultant “diffuse feelings of guilt” (p. 117). Parents also reported that they tended to vacillate between hope and anxiety as they lived with an unending sense of responsibility in a climate of uncertainty. Although these reported findings based on in-person interviews have provided a rich description of the parenting experience, confidence in these
findings could have been enhanced had the interpretations been checked with the participants after the analysis was completed. Member checks are not reported in this study. However, as Jungbauer and Angermeyer point out, their study “underlines that caregivers of patients suffering from schizophrenia are also severely affected by the disorder” (p. 120).

In summary, the family burden literature has demonstrated that parenting an adult child with schizophrenia is a highly stressful life experience associated with multiple objective and subjective burdens suggestive of the degree of stress that could, according to the models discussed earlier in this chapter, result in stress-related growth. Additional insight into the stressful nature of this parenting experience is provided by the literature in the following section that addresses the nature of grief and loss in this population.

The Nature of Parental Grief

Several researchers (e.g. Eakes, 1995; Howard, 1998) have suggested that the concept of chronic sorrow may be particularly relevant to understanding the nature of grief experienced by parents of adult children with serious mental illnesses. Relevant to the conceptualization of stress-related growth discussed earlier in this chapter, the experience of this form of grief may be an important part of the ongoing distress that Calhoun and Tedeschi (2006) suggest coexists with, and may mutually inform, stress-related growth. This section begins with a discussion of chronic sorrow, including the origins of this concept (Olshansky, 1962), how chronic sorrow contrasts with bereavement grief (Teel, 1991), and the multiple losses and possible consequences of the grief experienced by parents of children who have a serious mental illness (MacGregor, 1994). This discussion is followed by a review of key studies that have informed the current understanding of the parental experience of grief and loss (Atkinson, 1994; Eakes, 1995; Davis and Schultz (1998); Miller, Dworkin, Ward & Barone, 1990; Richardson, Cobham, Murray &
Based on personal and professional experience as well as the experience of the professional staff at the Cambridge, Massachusetts Department of Public Health Children’s Developmental Clinic, Olshansky (1962) introduced the concept of chronic sorrow to describe the pervasive, often unrecognized form of grief experienced by parents of mentally disabled children. According to Olshansky chronic sorrow is a long-term form of grief that varies in intensity across situations and time. It is influenced by personality, ethnicity, religion, and social class. Importantly, the experience of chronic sorrow does not preclude the ability of parents to also experience times of joy and satisfaction in relation to their child. Olshansky emphasized that chronic sorrow is a normal, natural parental response to living with long-term multiple losses. This is in contrast to the prevailing tendency in the 1960’s to pathologize this pervasive form of grief and view it as an indicator of a parent’s failure to accept his/her child’s condition. Olshansky also emphasized that the presence of chronic sorrow has important implications for counselling, suggesting that counsellors need to normalize and validate chronic sorrow, and to acknowledge the courage and perseverance of parents living with this pervasive form of grief. Given the ongoing nature of chronic sorrow, he pointed out that the needs of parents experiencing this type of grief likely vary across the developmental and illness continuum. Therefore he suggested that it is important for counsellors to adopt an “open door” policy to address the changing needs of this population as they arise.

Based on a review of the literature on chronic sorrow and from the perspective of attachment theory, Teel (1991) extended Olshansky’s (1962) description by comparing chronic sorrow with the bereavement grief associated with the loss of an attachment relationship. Teel pointed out that, in contrast to bereavement grief in which the bereaved person has been lost but
not changed, chronic sorrow is “due to a permanent disability that renders the individual forever changed from the hoped-for child or from the known person” (p. 1316). Chronic sorrow, she suggested, is also characterized by episodic pain and sadness that recurs throughout the lifetime of the disabled person, in contrast to bereavement grief in which a return to pre-bereavement functioning is expected over time – although significant memories or milestones/markers may induce periodic feelings of sadness. Consistent with Olshansky’s description, Teel pointed out that the periods of pain and sadness characteristic of chronic sorrow are “interwoven with periods of neutrality, satisfaction, and happiness” (p. 1316). She also suggested that chronic sorrow is associated with a kind of intense sorrow or “psychic pain” (p. 1317) that can lead to withdrawal in relationships and psycho-immunological changes, eventually resulting in deterioration of physical health. According to Teel, persons experiencing chronic sorrow may, through an ongoing process of reappraising their loss, reach a point where the loss is no longer interpreted as a loss. Relevant to the research question of the current study, perhaps the experience of personal growth for parents in this study is obscured by the multiple burdens and losses faced in the early years of their child’s illness and may be perceived more clearly as a valued part of their experience over time.

A comprehensive picture of the nature of grief experienced by parents of adult children with a serious mental illness was presented by MacGregor (1994) in her article entitled, Grief: The unrecognized parental response to mental illness in a child. Based on personal experience as a parent of a seriously mentally ill child, as well as professional experience as a social worker working with families of chronically ill children, MacGregor identified a multitude of losses associated with parenting a child with a mental illness. She suggested that the grief experienced by these parents is comparable to the grief experienced by parents who have lost a child to death.
According to MacGregor the multitude of losses experienced by parents of a mentally ill child include the loss of a child’s: personality; role in the family and in society; joy and pleasure in life; potential, talents, and competence; gratifying relationship of reciprocity within the family and with others; and hoped-for future. In some cases parents also experience the actual loss of a child who wanders off to disappear among the homeless population or dies by suicide.

Psychosocial losses for the parent can include loss of: self-esteem and a sense of competence as a parent; dreams; control; pleasure in a child’s success; hope; security and certainty, both about the illness and the future; religious faith; and a positive sense of the past life of the family.

Depending on the severity of their child’s mental illness parents might also have to cope with the loss of a normal and predictable family atmosphere, privacy, sense of spontaneity, social network, faith in mental health professionals and the health care system, financial resources and the ability to purchase treatment, freedom in their own lives as caregivers, normal interactions with other family members, and the loss of the family’s normal direction toward independence.

In addition to these multiple losses MacGregor also noted a possible existential loss in terms of the “loss of a previous worldview [in order] to find meaning in the child’s illness” (p. 163).

Importantly and relevant to a consideration of stress-related growth, this existential loss may reflect key components of the PTG model that Calhoun and Tedeschi (2006) propose are necessary for growth, namely the challenge to one’s assumptive world and the resultant meaning-making process of schema rebuilding and narrative reconstruction.

Like the grief experienced by parents who have lost a child to death, MacGregor (1994) suggested that the grief experienced by parents who have lost a child to serious mental illness is severe and long-lasting and involves a “loss of a piece of oneself” (p. 161). Consistent with the description of chronic sorrow, she pointed out that grief for parents of chronically ill children is
experienced in recurring cycles – cycles that can be precipitated by stressor events, medical crises, and missed developmental steps. She suggested that these cycles can surface each time at the same intensity as at diagnosis and that the grief experienced by these parents can be complicated by feelings of guilt, given an illness that is associated with multiple uncertainties in terms of etiology and the course of the illness over time. MacGregor also pointed out that the parental grief experience can be complicated by anger related to the meaninglessness and unfairness of the loss as well as oversensitivity to the reactions of others, in parents’ sometimes desperate search for help. She stated that ultimately “parents must deal with their grief alone, and often their partner’s style of grieving does not match their own” (p. 162). A number of barriers to a healthy grieving process for parents of a child with a mental illness were identified by MacGregor. These included the lack of societal recognition and validation of their losses, the lack of opportunity to mourn and to reinvest energy into other relationships, and the tendency of mental health professionals to misunderstand or misconstrue the parental grief experience. Relevant to stress-related growth in this population, these multiple losses and possible barriers to a healthy grieving process further underscore the stressful nature of this parenting experience. Perhaps this pervasive ongoing form of grief is relevant to understanding the ongoing distress that Folkman’s 1997 Revised Model of the Coping Process suggests may play an important role in the development of positive outcomes and the maintenance of the coping process, or the ongoing distress that Calhoun and Tedeschi in their PTG model suggest coexists with and informs PTG.

The following studies provide evidence for, and additional insight into, grief as it is experienced by parents of adult children with schizophrenia. Studies by Miller et al. (1990), Atkinson (1994), and Eakes (1995) provide evidence for the ongoing pattern of grief in this
population that is consistent with the concept of chronic sorrow. A study by Davis and Schultz (1998) extends the understanding of parental grief further by also including a focus on possible gender differences with respect to grief and loss in this population. Most recently, Richardson, Cobham, Murray and McDermott (2011) provided additional insight into the nature of parental grief in their review of twelve studies that have addressed parental grief in the context of an adult child with mental illness.

In 1990 Miller, Dworkin, Ward and Barone undertook a study for the purpose of determining the presence of grief in a sample of 58 parents and siblings of individuals with a serious mental illness (33 with schizophrenia, 25 with bi-polar illness). These researchers were interested in comparing the level of grieving between family members of patients with schizophrenia and family members with bi-polar illness, and in identifying factors associated with the grief experienced by these family members. The participants were all members of support groups, thereby limiting the generalizability of the findings. Miller et al. reported that the median range of illness of the participants’ mentally ill child or sibling was two to five years, suggesting that many of these family members were still in the early years of coping with the effects of the illness. Grief was measured using a self-report measure developed for this study, the Mental Illness Version of the Texas Inventory of Grief (MIV-TIG). This instrument measures both the level of grief at the onset of the illness and the respondent’s current level of grief. Correlation analyses were used to determine the relationships between patient and family variables and current levels of grief. Analysis of variance techniques were used to compare levels of grief across groups. The findings revealed a presence of grief in both groups at a level that Miller et al. suggest is comparable to the levels of grief experienced by family members grieving loss due to the death of a family member. No significant differences were found between the
responses of family members of patients with schizophrenia and family members of patients with bi-polar disorder, or between subgroups of parents versus siblings. However, this finding must be considered with caution given that the number of parents and siblings was not provided.

Regarding predictive factors, no relationship was found between patient or family demographic factors and MIV-TIG scores, and only weak correlations were reported between chronicity and severity of illness variables and MIV-TIG scores.

However, a striking pattern of grief emerged in this study with overall scores of current levels of grief being considerably higher than overall scores assessing initial levels of grief. Miller et al. (1990) speculated that the pattern of grief in this population may reflect family members’ difficulty in identifying, acknowledging and mourning the losses associated with living with a family member with a mental illness. They also suggested that these findings may reflect a delayed grief reaction, the effect of increasing losses concurrent with the progression of the patient’s mental illness, or possibly the time required before the impact of mental illness on the family is realized. Relevant to the purpose of the current study, this pattern of grief appears to be consistent with the concept of chronic sorrow, although as pointed out above, many of the participants in Miller et al.’s study were still in the early years of coping with the affects of the illness and thus the experience of grief in this population over a longer period of time remains to be determined.

A similar ongoing pattern of grief consistent with the concept of chronic sorrow, was reported in a study by Atkinson (1994) in which the MIV-TIG was used to compare levels of grief across three groups of parents: 25 parents of adult children with schizophrenia; 25 parents who had lost an adult child to death; and 25 parents who had lost an adult child due to a head injury that resulted in a diagnosable organic personality disorder. In the group of parents of adult
children with schizophrenia, the range of years since their child was diagnosed was between one and five years. Statistical analyses of the data using analysis of variance revealed a significantly different pattern of grief in the group of parents of adult children with schizophrenia compared to the pattern of grief in the other two groups. Consistent with the concept of chronic sorrow and the findings of Miller et al. (1990), an ongoing pattern of grief, with a higher level of current grieving compared to the initial level of grieving, characterized the grief experience of parents of adult children with schizophrenia. In the remaining two groups the levels of current grief were significantly lower than the initial levels of grief, suggesting that the level of grief decreases over time for these parent populations.

When considering these findings, it is important to note that the group of parents of children with schizophrenia, similar to many of the parents in the study by Miller et al. (1990), had been coping with the effects of the illness for five years or less. Thus it is possible that the pattern of grief experienced by these parents may be different over a longer period of time. The patterns of grieving between the three comparison groups may also reflect a number of differences in these parenting experiences. For example, in contrast to the parental experience of absolute loss due to death and the loss due to a traumatic head injury, the often erratic nature of schizophrenia and the uncertain course of the illness may result in a complex pattern of grief for parents of adult children with schizophrenia over time. Also, unlike the parents in the other two groups, the grief experience of these parents may be exacerbated by possible feelings of guilt associated with the evidence of a genetic link in the etiology of schizophrenia or guilt associated with the inability to access appropriate treatment for their child early in the development of the illness given that early treatment is linked to a more optimistic prognosis. Also, as Miller et al. in the previously reviewed study suggest, parents of adult children with schizophrenia may become
aware of increasing losses over time and/or require a longer period of time for the impact of their losses to be fully realized. Given the intensity of grief and the likely increasing awareness of losses over time, perhaps parents coping with their child’s illness within the early years may not be able to perceive personal growth and change or reflect on these aspects of their experience.

Additional insight into the incidence and nature of chronic sorrow experienced by parents of adult children with mental illness was provided by Eakes (1995). In this study, interviews guided by open-ended questions on the Burke/Nursing Consortium for Research on Chronic Sorrow (NCRCS) Chronic Sorrow Questionnaire (Caregiver Guide) were conducted with 10 parents (two mothers and four couples) of adult children diagnosed with either schizophrenia (four children) or bi-polar disorder (four children). This was a convenience sample recruited from a mental health centre. The length in years since their child had been diagnosed ranged from four to twenty years, a notably greater range than in Miller et al. (1990) and Atkinson (1994), therefore extending the applicability of the findings. The data analysis involved a coding process and the identification of common themes. Chronic sorrow was reported by the eight Caucasian participants, but not by the two African American parents in this study (a couple – step mother and genetic father). Eakes suggested that this finding raises questions about possible cultural influences or perhaps family structure on chronic sorrow.

Chronic sorrow for the parents in this study was evidenced through statements such as “It has been about five years, so grief is an emotion that abates but it does not die… The grief has abated somewhat, but it certainly doesn’t leave” (p. 79). The intensity of recurrent grief reported by these parents varied. In contrast to the findings of Miller et al. (1990) and Atkinson (1994), five of the eight parents reported that they experienced less intense grief than at the onset of their child’s illness. As Eakes suggests, this may be a reflection of the length of time that these parents
had lived with their child’s illness (average of 12 years compared to a median range of two to five years in Miller et al., 1990 and between one and five years in Atkinson, 1994). Recurrent grief was triggered most often by the unending sense of caregiving responsibility reported by these parents. Interestingly, this sense of responsibility was reportedly similar whether their child was living at home or away from home, suggesting that parenting a mentally ill adult child differs significantly from other parenting experiences in which adult children assume responsibility for their own care. The unending sense of responsibility reported by parents in this study may also be a reflection of their lack of confidence in the mental health system, given that they reportedly viewed their relationships with mental health professionals largely in a negative light. Additional triggers of chronic sorrow for the parents in this study included their child’s inability to achieve developmental milestones, crises situations, and the “recognition of the disparity between their situations and social norms” (p. 81). The experience of chronic sorrow was reportedly similar for parents of adult children with schizophrenia and parents of adult children with bi-polar disorder, which may be a reflection of the ongoing uncertainties concerning the course of these mental illnesses.

Eakes (1995) also notes that feelings of anger reportedly related to caregiving responsibilities as well as difficulties with the health care system “permeated the experience of chronic sorrow” (p. 82) for many of the parents in her study. She suggests that anger may be a “manifestation of the never-ending grief” (p. 83) these parents face. Perhaps this anger was a reflection of the difficulties these parents experienced with health care professionals who reportedly failed to provide adequate information about or involve parents in their child’s treatment. This anger may also have been a reflection of the perceived unfairness of their situation. One parent is quoted as saying: “Do we deserve to have this?” (p. 81). As MacGregor
(1994) pointed out, parental grief can be complicated by anger related to the meaninglessness and unfairness of their loss. Relevant to the theoretical conceptualization of stress-related growth discussed earlier, perhaps for some parents such as those in Eakes study, anger may be part of the distress component of Folkman’s (1997) Revised Model of the Coping Process and Calhoun and Tedeschi’s (2006) PTG model. Also relevant to the development of stress-related growth, Eakes pointed out that the parents in her study relied on cognitive coping strategies to manage their grief experience. They reportedly tried wherever possible to take control of their situation and to focus on positive aspects of their experience. Consistent with the findings of Miller et al. (1990) and Atkinson (1994), the results of this study underscore the pervasive and chronic nature of parental grief in relation to their child’s mental illness and the parental sense of responsibility for their child’s care.

The above studies suggest that grief and loss may be a prominent and ongoing part of the parental experience of mothers and fathers. The following study, Davis and Schultz (1998) adds to the understanding of the parental grief experience and includes a focus on possible gender-related differences. Gender-related differences in grieving have been associated with other loss experiences as pointed out by Doka & Martin (1998). The reader is referred to Doka and Martin (1998) for a discussion of these gender-related differences.

Davis and Schultz (1998) undertook to determine the presence of grief, possible gender-related differences, and how the number of parent-child contact hours might influence parental grief in a sample of 16 mother-father dyads who were parents of adult children with schizophrenia (43% diagnosed for 10 years). Davis and Schultz operationalized grief in terms of intrusive thinking, avoidant behaviours, and distress related to reminders of the diagnosis. Their measures included the Impact of Event Scale (Horowitz, Wilner, & Alvarez, 1979), the
Experience of Stress Scale (Horowitz, Krupnick, Kaltreider, Wilner, Leong, & Marmar, 1981), and Holmes & Rahe’s 1967 Schedule of Recent Events. They proposed that these measures “tapped into the male experience of grief” (p. 376) and thus provided unbiased measures of grief in contrast to measures like the MIV-TIG that measure grief as emotional expression. Parent-child number of weekly contact hours were categorized as either high or low. Mothers with nine or less weekly contact hours were considered to have a low level of contact whereas mothers with more than nine weekly contact hours were considered to have a high level of contact. For fathers seven hours determined “high” or “low” contact. Mailed questionnaires were used to collect the data.

Analysis of variance confirmed the presence of grief in both mothers and fathers with no significant gender-related differences being found. On the basis of these findings Davis and Schultz (1998) suggested that both mothers and fathers of children diagnosed with schizophrenia struggle with existential issues and are engaged in “efforts to create meaning in an unpredictable and difficult reality” (p. 376). Parent-child contact hours reportedly only minimally influenced mothers’ and fathers’ grief experience and only with regard to intrusive thinking. Mothers in the category of high contact hours reported a greater intensity of intrusive thinking than mothers in the low category. For fathers the pattern was reversed. The relationship between contact hours and intrusive thoughts for mothers might be expected, as Davis and Schultz suggest, however the reverse relationship between these variables for fathers was less easily explained. Davis and Schultz speculated that the greater intensity of intrusive thoughts reported by fathers in the category of low contact hours may indicate that these fathers had not yet processed their grief, therefore even “minimal exposure to reminders of loss [were] extremely painful” (p. 376). Consistent with this explanation, they speculated that fathers in the category of high contact
hours may have processed their losses more completely. However, as these researchers point out, it is also possible that the differences in intrusive thinking may not be adequately explained by variables such as gender and contact hours. Other factors such as personality characteristics may play an important role. It is also possible that standard research instruments may not be equally able to capture the grief experience for men and women. A narrative approach may provide additional insight into differences in the grief experience of mothers and fathers. As pointed out by the researchers, the results also need to be interpreted with caution give that the sample was small, self-selected, and all of the participants were members of a Schizophrenia Fellowship and thus likely not representative of this population.

Additional insight into the nature of parental grief and loss in response to an adult child’s mental illness was provided by Richardson, Cobham, Murray and McDermott in their recent (2011) review of 12 studies that drew attention to grief associated with this parenting experience. Five of these studies were limited to parents of adult children with schizophrenia. In the other seven studies the participants were mostly parents but also included some other family members. Most of the adult children in these seven studies had been diagnosed with schizophrenia, although some were diagnosed with other serious mental illnesses such as schizoaffective disorder, bipolar disorder, or major affective disorder. However, the vast majority of participants over all of the 12 studies were aging parents of a child with schizophrenia and most were mothers. The duration of the adult child’s illness across the 12 studies ranged from twelve months to more than twenty years. Four of the studies (Atkinson, 1994; Davis & Schutz, 1998; Eakes, 1995; Miller et al., 1090) have already been discussed in this section. Two of the studies (Tuck et al., 1997; Wiens & Daniluk, 2009) are discussed in the following section. Relevant to the understanding of parental grief, Richardson et al. reported that all of the studies in their
review provided evidence that parental and family grief is significant and complex and that these parents experience prolonged grief. With respect to possible trajectories of grief or variables hypothesized as predictive of this grief experience, Richardson et al. (2011) reported that the findings across the five studies that used a quantitative approach were not consistent. In all of the seven qualitative studies grief was a common theme and associated with a “myriad of losses” (p. 33) that had a great impact on the parenting experience.

Richardson et al.’s 2011 review provides further evidence of the protracted nature of grief and loss associated with this parenting experience. However, the findings may not be representative of this population as a whole given that the participants across these 12 studies were, with few exceptions, ethnically homogenous and drawn from parents associated with support organizations and the sample sizes were small. The studies were also all cross-sectional. Questions about the experience of parental grief over the course of the illness therefore remain unanswered. Richardson et al. (2011) also caution against comparing the findings of the studies that used a quantitative approach given that grief is operationalized differently across these studies and different instruments are used to measure grief, often instruments developed for the specific study. Importantly, Richardson et al. point to the need for further research on the experience of grief and loss in this population, particularly research on this topic that is “oriented within a theoretical framework” (p. 38) that could inform grief interventions with this population.

In summary, the studies reviewed in this section provide evidence that grief and loss is a common and possibly a prominent component of the distress experienced by parents of adult children with schizophrenia or schizoaffective disorder. These studies also suggest that multiple losses, complex contextual factors, and the uncertain course of the disease may complicate the
experience of parental grief and that, similar to the description of chronic sorrow, the nature of grief in this parenting population appears to be pervasive and long-lasting, with cycles of sadness recurring at varying intensities over time often in response to reminders of “what once was” or “what might have been.” More research is needed to gain a greater understanding of how mothers and fathers experience and process their grief. Qualitative methods using in-depth interviews are appropriate at this stage, given the reported difficulty of adequately capturing the grief experiences of both mothers and fathers with the currently available standardized measures.

Grief and loss also continues to be a central theme in the research on the parenting experience reviewed in the following section. This research provides additional in-depth understanding of the parenting experience by giving voice to parents of adult children with schizophrenia as they communicate their experience in their own words.

**Research on the Parenting Experience**

Taken together, the following studies summarize the research findings regarding the experience of parenting an adult child with schizophrenia. The first two studies in this section (Howard, 1994; Ryan, 1993) summarize the experience of mothers. The experiences of father are addressed in the studies by Howard (1998) and by Nystrom and Svensson (2004). Two studies are then reviewed (Milliken, 2001; Tuck et al., 1997) that include both mothers and fathers and also draw attention to the changing nature of the parental experience over time. The final study reviewed in this section (Wiens & Daniluk, 2009), is based on my master’s research on the experience of fathers of children with schizophrenia in which *personal growth and learning* emerged as a dominant theme for the fathers in the study.

In 1993 Ryan conducted an ethnographic study to explore the caregiving experiences of five mothers of adult children with schizophrenia. These mothers were all recruited through a
community support group. The length of time since their child had been diagnosed ranged from six to twenty years. Ryan reported that the mothering experience for these women was very similar although the course of their respective child’s illness varied considerably. Mothering was reported to be not only all-encompassing, but also “particularly complex, characterized by ambivalence and dilemmas in care-giving” (p. 24). The subthemes of disruption and loss, emerged as part of the overarching theme of “a lifetime of mothering” (p. 24). Disruption was reflected in the mother-child relationship as well as in the participants’ own lives. In their relationships with their adult child these mothers reported that they had to flexibly manage difficult illness behaviours, at times returning to patterns of mothering they had used when their child was much younger. In their own lives disruption was described in terms of “constancy,” “centrality,” and “uncertainty” (p. 25). Constancy referred to the energy-draining ever-present and unremitting nature of their situation. Centrality reflected their sense of responsibility to protect and advocate for their child in a societal climate characterized by a lack of understanding and stigma. Uncertainty was related to the disruption in these mothers’ lives due to the ambiguous nature and unpredictability of their child’s illness. As one mother put it: “It’s like living on top of a volcano… You never know when it’s going to erupt” (p. 26). Loss was primarily reflected as loss of the child’s potential to live a normal life and loss of freedom in these mothers’ lives due to the demands of mothering over a lifetime.

Relevant to the current study, the findings emphasize the unending, complex and stressful nature of caregiving a child with schizophrenia over a lifetime, and provide further evidence for the centrality of grief and loss in this experience. Although personal growth was not identified as a theme in this study, according to Ryan (1993) these mothers reportedly maintained a sense of hope for the future in the midst of the stressful context of their lives. Perhaps personal growth did
not come up as a theme in this study because the researcher did not anticipate this possibility and therefore not look for it or ask questions about it. As noted by Bulger et al. (1993) reviewed later in this chapter, the participants in their study were reportedly surprised to be asked about personal growth. Only after being asked about growth and reflecting on this question, did they consider this aspect of their experience. Given the wide range of time since the time of diagnosis in Ryan’s study, it is also possible that it may have been too early for some of these mothers to gain a perspective on personal growth. Importantly, Ryan provides a detailed account of her data collection and analysis procedures enhancing confidence in her reported findings. However, only three of the five women reportedly completed second interviews to validate the findings suggesting that the findings need to be interpreted with caution. Cautious interpretation is also in order given the small sample of five women all of whom were recruited from a support group. Their experience may not reflect the experience of other mothers in this population.

Similar descriptions of the mothering experience were reported by Howard (1994) in her grounded theory study of the caregiving experience of 10 mothers of adult children with schizophrenia. Like the mothers in Ryan’s (1993) study, the mothers in Howard’s study were also likely not representative of the population of mothers as a whole given that they were all members of a state Alliance for the Mentally Ill, Caucasian, and from either middle-income or affluent neighbourhoods. The mean number of caregiving years for the mothers in this study was 16.5 years (five of these mothers had been caregivers for over twenty years). Howard described the overall maternal caregiving experience of these women as a process of “watching,” “working,” and “waiting” (p. 110). Watching involved a constant state of vigilance – being alert to and watching for signs of problems. Working referred to the physical and mental tasks of caregiving – tasks described by the mothers in the study as intense and long term. Waiting
involved thinking about the future and, for some mothers, was associated with a sense of helplessness and dread.

Through the analytic process of thematic identification, classification, and constant comparison Howard (1994) developed a theoretical model of learning to live with a child who has schizophrenia. This model is comprised of the following four stages: (a) perceiving a problem; (b) searching for solutions; (c) enduring the situation; and (d) surviving the experience. A potential time frame was not associated with these stages. Descriptors associated with the first stage included: “scared out of my wits,” “shocked,” “devastated,” “terrified,” and “our world fell in” (p. 111). Similarly intense descriptors such as “frantic,” “panic,” “sick with worry,” “a nightmare,” and “living in fear of the next catastrophe” (p. 112) were associated with the second stage. The third stage involved an intense period of learning about the illness, finding support, and becoming persistent and perseverant in care-giving. Words such as “distressful, “frustrating,” “turmoil,” and “ordeal” (p. 112) were used in the participants’ descriptions of this stage of responding to their child’s mental illness. The final stage, surviving the experience, involved a sense of acceptance, hope, and determination.

Relevant to the conceptualization of stress-related growth, Howard (1994) stated that the stressful nature of the experience of maternal caregiving reported by these women was of an intensity that raises questions about the possibility of posttraumatic stress syndrome in this population. This statement suggests that the mothering experience for these women during the first three stages may have been of an intensity similar to that of the seismic event in Calhoun and Tedeschi’s (2006) PTG model discussed earlier in this chapter. Importantly, the description of the final stage suggests the possibility of positive changes. It is also important to note that it is only in the final stage of the mothering experience that these changes are reported. Given that a
timeline is not associated with the stages we do not know how many years it took for these mothers to experience these positive changes. However, it is significant that these mothers had been caring for their child for an average of 16.5 years. Importantly, Howard reported that sorrow was pervasive and present throughout the lifelong caregiving process, a finding that is consistent with the findings of the studies reviewed in the previous section on the nature of parental grief and also possibly relevant to an understanding of the ongoing distress that is thought to be coexistent with growth in the PTG model.

Following from her study of mothers, Howard (1998) turned her attention to the caregiving experiences of 12 fathers of adult children diagnosed with schizophrenia. These fathers may also not be representative of the population of fathers as a whole given that they were referred by the women who participated in Howard’s (1994) study. Howard (1998) reports that they had been caring for their mentally ill child for average number of 15.67 years. Using a constant comparative method to analyze these interview data, three themes emerged: “involvement in care” (p. 406), “unresolved issues” (p. 407), and “severity of the event” (p. 408). Regarding involvement in care, all of the fathers in this study reported that they were personally involved in caring for their mentally ill child, although they felt that the mothers of their children “carried the major load” (p. 406). Three of these fathers assumed the role of primary caregiver when their spouses were unable to do so. The second theme, unresolved issues, highlighted the fathers’ concerns about the quality of time spent with their other children in the family who were well, their worry about the future care of their mentally ill child, disruptions in the life of the family, and financial concerns. The third theme, severity of the event, reflected the extremely stressful nature of the parenting experiences of the fathers in this study. The experience of caring for a child with schizophrenia was described by all of the participants as the most difficult
experience of their lives. One father described his child’s mental illness as “a life crushing event” (p. 409). On a note suggestive of personal growth Howard quoted one father in the study as saying: “My wife’s devotedness has increased my love for her. I am more concerned for my other children. Knowledge and working with mental illness helps put things in proper perspective…” (p. 409). Relevant to the current study these findings suggest that similar to the experiences of mothers, fathers also find parenting a child with schizophrenia to be extremely stressful and challenging. Their level of stress may also be of the magnitude of the “seismic event” in the PTG model. Importantly the one father’s statement that is suggestive of growth, appears to reflect a domain of posttraumatic growth that Tedeschi and Calhoun (1996) identified through factor analysis, namely, enhanced relationships with others. This father’s comment also leads to speculation that perhaps other fathers may have identified aspects of growth had they been asked about personal growth through their fathering experience.

Further insight into the fathering experience was provided by Nystrom and Svensson (2004). These researchers used a life-world hermeneutic approach to explore the lived experiences of seven fathers of adult children with schizophrenia. Participants were recruited through branches of the Swedish National Fellowship for Schizophrenia. The fathers in this study reportedly had been coping with the effects of the illness for more than two decades. An overarching theme of “the struggle to regain control” (p. 363) was used by the authors to describe the fathering experience for these men. Similar to the findings of Howard (1998), the fathers in this study reportedly experienced severe distress particularly in the early years of their child’s illness. In reflecting on the early years of his child’s schizophrenia one father in the study referred to himself as “a broken man” (p. 368). Grief and loss characterized these fathers’ experiences as they became increasingly aware of the long-term consequences of living with
their mentally ill child. They reported an ever-present sense of worry as they faced a future of uncertainties. Nystrom and Svensson suggested that grief played an important and perhaps a necessary role for these fathers in the process of regaining control and adapting to their situation.

Despite the severity of their experiences, the fathers in this study also cited several positive outcomes of their parenting experiences that are suggestive of personal growth. For example, several fathers reported that their own personality changed for the better. They felt that they gained insight into the experience of living with mental illness, had more sympathy with the difficulties of life, and had a greater ability to cope with other personal crises. Nystrom and Svensson (2004) concluded that, for the fathers in their study, the process of grieving may have been “the beginning of a way back to a meaningful life.” (p. 375). This link between grief and personal changes suggests the possibility of a relationship between ongoing distress and growth as proposed by the PTG model discussed earlier in the current chapter. Consistent with the findings of Ryan (1993), Howard (1994) and Howard (1998), the findings of this study also underscore the severely stressful nature of, as well as the centrality of grief in the experience of parenting a child with a mental illness the course of which is unpredictable. Also importantly, given that it may take time for stress-related growth to be recognized and experienced, most of the fathers in this study had been caring for their mentally ill child for over 20 years. One of the strengths of this study and the previously reviewed three studies is the participants’ length of experience (an average of 12 or more years) as a parent of a mentally ill child. Regarding limitations, as in the previously reviewed studies, the participants in this study were also recruited through a support organization and therefore may not be representative of this parenting population as a whole – in that they may have a better support and referral network in responding to the needs of their mentally ill child. Also, Nystrom and Svensson do not report meeting with
the participants for the purpose of a member check which would have enhanced confidence in the reported findings.

Two additional studies expand on the previously reviewed studies by drawing attention to the changing nature of the parental caregiving experience over time and include both mothers and fathers (Milliken, 2001; Tuck et al., 1997). In the earlier of these studies, Tuck et al. employed a phenomenological approach to highlight the impact of the diagnosis of schizophrenia on the lives of nine primary caregiving parents (seven mothers, two fathers) whose mentally ill child had been diagnosed within the past ten years. When the diagnosis was finally received by these parents after what they described as a desperate and frustrating search for help, it was experienced and described as a destructive force that interrupted and radically transformed their family life. Consistent with the reports of parents in previous studies (e.g. Jones, 1997; Jungbauer & Angermeyer, 2002; Ryan, 1993), caregiving after the diagnosis was reportedly characterized by endless caring and learning to live with constantly changing levels of hope and despair. In the midst of ongoing stress and with feelings of deep sadness these parents struggled to make sense of their experiences and to maintain a separate sense of identity from that of their child, a process that involved “reformulating what it means to be a parent under these conditions” (p. 118).

Suggestive of stress-related growth, Tuck et al. (1997) also noted that the tragic events experienced by the participants in their study “assume[d] redemptive qualities and … shap[ed] the parent into a better, wiser, more spiritual and discerning person” (p. 124). Particularly noteworthy is the reported identity-forming and reformulating process that the participants in this study linked to wisdom. These findings are suggestive of the narrative reconstruction process that the PTG model suggests follows stressors of a magnitude that challenge an individual’s
assumptions about life. The PTG model also links wisdom to narrative reconstruction. The parental reports of enhanced wisdom, increased spirituality and discernment in this study also suggest that these parents may have engaged in a struggle with existential questions about life, perhaps as a response to the existential loss noted by MacGregor (1994). Notably, the struggle with challenges to goals and beliefs is another important component of the PTG model. One of the strengths of Tuck et al.’s (1997) study is the detailed and comprehensive articulation of the data analysis procedure and the inclusion of a multidisciplinary qualitative research team for the purpose of reviewing and verifying the transcripts, the analytic procedures, and ultimately the findings. Confidence in the findings, however, would have been further enhanced if member checks had been conducted with the participants.

Further insight into the changing nature of the parental experience across time was provided by Milliken’s (2001) grounded theory study of the caregiving experiences of 29 parents of adult children with schizophrenia (16 mothers, 13 fathers). Caregiving over the course of their adult child’s illness for these parents involved a process of redefining their parental identity. Milliken identified the stages in this redefinition process as: a) parent of a teen/young adult, b) becoming marginalized, c) disenfranchised parent, d) embracing the collective of other parents, e) parental suffrage, f) evaluating my life, and g) emancipated parent. In the first stage parents viewed their child’s difficult behaviour in terms of typical teenage rebellion that they expected to change over time. The descriptions of the parental experience in the following two stages echo the descriptions of distress reported by parents in previous studies (e.g. Howard, 1994, 1998; Nystrom & Svensson, 2004; Ryan, 1993; Tuck et al., 1997). Milliken drew attention to the grief experience of parents at these stages and reported that the parents in her study often grieved alone, having lost close connections to friends in part related to the stigma of mental illness.
Importantly and relevant to the consideration of stress-related growth, the stages of embracing the collective and parental suffrage highlight the experience of relationships with others, which may play an important role in development of stress-related growth. Relationships with others for the parents in this study led to participation in volunteer work focused on improving services for the mentally ill and increasing public awareness of mental illness. These activities may also reflect aspects of personal growth for these parents, such as new competencies or strengths. Regarding the final two stages, evaluating my life and emancipated parent, these stages involved acknowledging realities and focusing on the parent's own needs. Importantly, life evaluation suggests the possibility of an existential focus and perhaps also reflects the reconstruction of these parents’ life narratives – important components in the theoretical conceptualization of stress-related growth. Unfortunately, like Ryan (1993) in her description of mothering stages, Milliken did not identify a time frame related to these parenting stages. It is also not clear how long the participants in this study had been coping with the effects of the illness. Importantly, Milliken pointed out that the process of redefining parental identity for the participants in her study was not a linear process.

In a subsequent publication, based on the study of Milliken 2001, Milliken and Northcott (2003) further discussed the stages of redefining parental identity. Importantly, they renamed the stage of “parental suffrage” to “the re-enfranchised parent,” thereby drawing attention to an important aspect of this stage which could perhaps be reflective of personal growth and change. In the “reenfranchised parent” stage, these parents reportedly identified with other parents within an established and respected organization (British Columbia Schizophrenia Society) and redefined their child as part of the whole community of persons with schizophrenia. By identifying with this organization and working within it, their scope of parenting was expanded
with the realization that by helping others they were helping their child. Perhaps identification with the BCSS also validated the importance of their role as a parent. Milliken and Northcott also pointed out another change that could be related to stress-related growth at the stage of “evaluating my life.” At this stage these parents had reportedly become tired and their “hopes” had changed and become more limited. Importantly Milliken and Northcott also pointed out that the final stage, “emancipated parent,” reflected a “mutual independence” rather than full emancipation which according to the parents in this study, would never be attainable given the uncertainties associated with the course of the illness and the very real possibly of multiple relapses.

Particularly relevant to the current study, personal growth and learning, emerged as one of six themes in my phenomenological study of the experiences of six Caucasian fathers of adult children with schizophrenia (Wiens, 2005; Wiens & Daniluk, 2009). Three of these fathers were interviewed four years after their child’s diagnosis. Three were interviewed eight years after their child’s diagnosis. Three themes that emerged in this study – a sense of devastation and vulnerability, a sense of sadness and loss, and a sense of frustration with the mental health system – also parallel many aspects of the parenting experience described in the studies reviewed above (e.g. Howard, 1994, 1998; Milliken, 2001; Nystrom & Svensson, 2004; Ryan, 1993; Tuck et al., 1997). A sense of devastation and vulnerability was epitomized in comments such as: “It was like falling into a black hole” (Wiens, 2005, p. 82), and “It’s probably the most devastating thing you can have in your life” (p. 89). Multiple losses were identified by these fathers including: loss of who their child once was, loss of their child’s potential to be productive, loss of dreams for their child’s future, losses experienced in the present lives of these fathers, as well as the loss of hopes and dreams for their own future. All the fathers in this study reported a sense of
frustration with the mental health system involving having to make sense of multiple inconsistent opinions from a variety of mental health professionals, a lack of resources and problems accessing needed resources especially in crisis situations, and difficulties in the decision-making process particularly related to hospital discharge planning and care facility arrangements. These three themes clearly reflect the stressful nature of this parenting experience. However, these findings need to be considered with caution given that all of these fathers were Caucasian and middle class. The experiences of parents of children diagnosed with schizophrenia from other ethnic and socioeconomic groups may be different.

The remaining three themes in this study include reflection on roles and responsibilities, admiration for their child, and personal growth and learning (Wiens & Daniluk, 2009). These themes underscore the possibility for personal growth and change as a consequence of this parenting experience. For example, reflection on their roles and responsibilities prior to their child’s illness ultimately led these fathers to develop a greater commitment to relationships both with their mentally ill child and with the other members of their family. As one father poignantly said: “You know, in a positive way it has made me develop a father-son relationship that I should have developed a long time ago” (p. 345). In reflecting on their admiration for their child, the five fathers in the study whose children were relatively stable and taking steps towards independence were “united in their pride and appreciation for the many ways their children faced and coped with their illness” (p. 346). Their admiration was reflected in words like “courage” and “hero.” The final theme, personal growth and learning, explicitly reflected ways in which these fathers felt they had grown and changed through their parenting experience. All of the fathers reported having gained a greater understanding of themselves as fathers, which they felt helped them to make meaning of their fathering experiences and ultimately led to personal and
life-style changes. As one father put it: “I think it’s a real eye opener to me to see how I can change” (p. 345). Another father felt his fathering experience “became a portal and a gateway to be able to accept some of the things that happened in [his] life...” (p. 345). These fathers also felt that through their experience of parenting their mentally ill child they discovered the depths of the love they had for their child. Personal growth was also reflected in a greater sense of gratitude for aspects of life they felt they had previously taken for granted, as well as in the development of a greater sensitivity toward, and understanding of, mental illness – resulting in a desire to help others. It is important to note, however, that these positive outcomes were not part of the initial and early experiences of these men but developed over time as they learned more about the illness, felt more capable of understanding and responding to the uncertainties associated with the illness, and reflected on the impact of the illness on their lives. It remains to be seen if prolonged experience with the effects of the illness is necessary for parents to experience personal growth and change as a result of living with the challenges and uncertainties of their child’s mental illness.

In the current study I sought to expand on this theme of personal growth and to provide a greater understanding of how both mothers and fathers, within the context of the challenges they face, experience personal growth and change, a topic that has yet to become the focus of a research study. As demonstrated throughout this literature review, positive aspects of parenting a mentally ill family member are rarely a specific focus in the research literature. The following two studies are exceptions. The first study draws attention to “gratifications” as well as burdens experienced by parental caregivers (Bulger et al., 1993). The second study provides evidence for resilience in parents as well as other family members of the mentally ill (Marsh et al., 1996).
Research on Positive Aspects of the Parenting Experience

One of the first studies to draw any attention to positive aspects of parenting a child with schizophrenia was Bulger et al.’s (1993) mixed-methods study entitled *Burdens and Gratifications of Caregiving*. These researchers used quantitative measures as well as open-ended questions, including questions about personal growth, in structured interviews with a sample of 60 parents of adults with schizophrenia. Eighty-five percent of the participants were mothers, 43% were black, and a significant proportion of the participants were described as poor with 40% of the households represented having an income of less than $10,000. Notably this is a more diverse sample than in most other studies. The adult children of these parents had been ill for an average of 15 years. The objectives of the study were to determine: (a) whether gratifications as well as burdens were part of the caregiving experience for these parents; and (b) whether the caregiver-adult child relationship had an important role in parents’ perceptions of caregiving as rewarding or frustrating. The researchers examined the relationships between the variables of burden (caregiver subjective burden and objective burden), gratifications, intimacy (as a measure of parent-adult child relationship), and conflict. Correlational and hierarchical regression analyses as well as the responses to open-ended questions confirmed that gratifications as well as burdens were an important part of these parents’ caregiving experiences. The results also suggested that the caregiver-adult child relationship played an important role in the parental experience. Intimacy and gratification were highly correlated ($r = .78, p < .05$) as were caregiver burden and conflict ($r = .69, p < .05$) and the relationship variables of intimacy and conflict were more important predictors of gratifications and burdens respectively than severity of illness symptoms. Interestingly, white caregivers reported greater burden and less gratification than black caregivers, which raises questions regarding the influence of culture on
Overall the participants in this study reported a “great degree of gratification from caregiving” (p. 263) and a relatively low level of caregiver burden. Those who reported greater gratification in their caregiving role were also the parents who were more disadvantaged in terms of income, education, formal support, and racial-minority status. Bulger et al. (1993) suggest three possible reasons for this finding: (a) Parenting may be perceived more positively when the mentally ill child is the primary source of income for the family. This may have been the case for the majority of these parents, whose children were reportedly receiving Social Security payments. (b) The low level of reported caregiver burden may have been a reflection of a parental need to minimize their sense of caregiver burden so as not to be perceived as being complainers. (c) These parents may also have redefined what is considered a burden over the lengthy period of time that they had been caring for their mentally ill child.

Particularly relevant to the proposed study is the parental response to the open-ended question regarding personal growth in Bulger et al.’s (1993) study. The participants reportedly were surprised to be asked this question and had not consciously associated personal growth with their caregiving experience. This may help explain why the findings differ from those discussed earlier in this chapter. On reflection, the majority of parents in this study stated that as a result of their parenting experiences they were stronger, more patient, and more assertive with mental health professionals. Some parents also reported that they were more caring and less judgmental as a consequence of having to deal with their child’s mental illness. Other positive responses included a greater acceptance of their circumstances, learning to attend to their own needs, and a better understanding of family interactions. Importantly, and relevant to the current study, these changes reflect dimensions of growth identified by Tedeschi and Calhoun (1996), namely,
personal strengths and relationships with others. This study also suggests that some parents may not spontaneously associate personal growth with their parenting experiences given the more obvious burdens that they face. Therefore, in order to gain insight into this aspect of the parenting experience, a direct question about personal growth and change, such as the question guiding the current research, may be needed.

The second study to focus on positive aspects of the parent experience was Marsh et al.’s (1996) study of resilience among family members of the seriously mentally ill. In this study resilience was defined as “the ability to rebound from adversity and prevail over the circumstances of our lives” (p. 3). The purpose of this study was to provide a more balanced understanding of the family experience of mental illness given that “[the concept of family burden] is so robust that it has come to define the family experience of mental illness” (p. 3). The data for this study included the responses of 131 family members (53.4% mothers and 17.6% fathers, 29% other family members) to a national survey distributed through the National Alliance for the Mentally Ill. Fifty-three percent of the mentally ill family members had a diagnosis of schizophrenia, 13.7% were diagnosed with schizoaffective disorder, and 32.9% had other diagnoses including mood and personality disorders. The participants reportedly reflected the typical membership of NAMI, in that they were older, Caucasian, highly educated parents and thus are likely not representative of the population of family members of the mentally ill as a whole. The results therefore need to be interpreted with caution.

The survey questions for this study were framed in order to elicit positive responses regarding family members’ experiences. For example, family members were asked to identify and describe “any family, personal, or consumer [the mental ill family member] strengths that had developed as a result of the mental illness” (p. 3). Interestingly, a number of unsolicited and
powerful negative comments regarding the survey were received from 39.7% of the respondents. These comments reflected anger or disbelief that one could even consider positive outcomes associated with the experience of mental illness in the family. This reaction on the part of many of the study participants underscores the fact that questions regarding possible benefits or gains need to be asked in a sensitive manner, given the considerable challenges these family face. As Marsh et al. point out, resilience does not occur in isolation, but is “universally accompanied by a powerful family burden” (p. 4). Importantly, the current study acknowledges the challenging context within which personal growth and change may develop as is demonstrated in the primary research question, and the tentative interview questions in Appendix D. Interviews were only conducted with parents who: believed that they had grown and changed through their experience, volunteered to participate, and were interested in telling their stories of growth and change. As a researcher with personal experience as a parent of a mentally ill child, I was committed to being sensitive and open to both positive and negative aspects of these participants’ stories.

The data analysis in Marsh et al.’s (1996) study involved a coding procedure that produced composite scores on the following three variables: family resilience, consumer resilience, and personal resilience. Scores on these variables were compared across parent, spousal, sibling, and offspring groups using analysis of variance techniques. No statistically significant differences were found between these groups of family members. Of particular relevance to the current study were the reported indicators of personal resilience which included: “personal contributions, improved personal qualities, personal growth and development, enhanced coping effectiveness, personal gratifications, and better perspectives and priorities” (p. 9). Personal growth was described in terms of “new competencies,” “new insights,” and “new
direction in their lives” (p. 9) which precipitate questions such as: What is the nature of the competencies, insights, and new directions that emerge through the parental experience, how do these develop and for whom, and what meaning might they have for the participants who experience them?

**Conclusion**

Much has been learned about the experience of parenting an adult child with schizophrenia since the 1950’s and 1960’s when researchers first began to consider the effects of mental illness on the family. The family burden literature has demonstrated that parents face a multitude of objective and subjective burdens that profoundly affect their everyday experiences and quality of life (Fadden et al., 1987; Hoenig & Hamilton, 1966; Jones, 1997; Jungbauer & Angermeyer, 2002; Maurin & Boyd, 1990; Lefley, 1989). Major subjective burdens typically experienced at the onset of the illness include shock, devastation, and a sense of helplessness (Jungbauer & Angermeyer, 2002). More chronic subjective burdens are associated with the ongoing demands of caregiving and anxiety related to the uncertain course of this illness (Jones, 1997; Jungbauer & Angermeyer, 2002). Depending on the course of the illness, parents’ feelings reportedly vacillate between hope and despair (Jungbauer & Angermeyer, 2002). Regarding the future, many parents report fear of another acute psychotic episode and concern for their child’s future when they may not be able to provide for their needs (Jones, 1997; Jungbauer & Angermeyer, 2002).

In addition to the stressors identified in the family burden research, grief associated with a multitude of losses is reportedly an ongoing reality for many parents (Atkinson, 1994; Davis & Schultz, 1998; Eakes, 1995; MacGregor, 1994; Miller et al., 1990; Richards et al., 2011). Unlike bereavement grief, the form of grief experienced by these parents has been described as an
ongoing, unresolved, pervasive sadness that can be re-experienced at varying levels of intensity in response to reminders of the multiple losses in parents’ lives (Eakes, 1995; Howard, 1998; Milliken, 2001). This description is consistent with the concept of chronic sorrow (Olshansky, 1962; Teel, 1991). The research focused specifically on the experience of parenting (e.g. Howard 1994, 1998; Milliken 2001; Milliken & Northcott 2003; Nystrom & Svensson, 2001; Ryan, 1993; Tuck et al., 1997; Wiens & Daniluk, 2009) has further underscored the devastating impact of the diagnosis of schizophrenia and the stressful nature of the parenting experience. Mothers in particular have drawn attention to the unending demands of caregiving, the need for support, and the challenges associated with negotiating the mental health system and advocating for their child in a societal climate of misunderstanding and stigma (e.g. Howard, 1994; Ryan, 1993). The stories of fathers (Howard 1998; Nystrom & Svensson, 2001, Wiens & Daniluk, 2009) echo the concerns of mothers. It is clear that fathers are also profoundly affected by their parenting experience. Over time parents reportedly experience a process of renegotiating parental identity (Milliken, 2001; Milliken & Northcott, 2003).

Within the context of the multiple burdens, losses, and uncertainties that these parents face there have also been reports suggestive of personal growth and change, particularly in the studies of the fathering experience (e.g. Nystrom & Svensson, 2004; Wiens & Daniluk, 2009). Although studies that have included both mothers and fathers have also included reports suggestive of growth (Milliken, 2001; Tuck et al., 1997), little to date is known about the growth experience of mothers. Also, little is known about how and when mothers and fathers experience growth and in what ways they believe that they have grown and changed. We do not know how parental growth is influenced by the severity and course of their child’s illness and relationships within the family. We do not know how parental growth may be influenced by whether their
mentally ill child is living at home or in a professional care setting. We do not know how the help-seeking process, negotiating the mental health system, and incidents such as crisis situations are related to parental growth. We do not know how ongoing distress, changing parental roles, the struggle with existential questions, stigma, culture, or specific events/activities are related to growth; what hinders growth; and how growth influences these parents’ life narratives. More research is needed to gain greater insight into this aspect of the parenting experience.

The concept of stress-related growth which has become a rapidly growing focus of research in Health Psychology over the past twenty years (Calhoun & Tedeschi, 2006) may be relevant to a study of growth and change through the experience of parenting an adult with schizophrenia or schizoaffective disorder. Schaefer and Moos (1992), Folkman (1997), and Calhoun and Tedeschi (2006) have been key figures in developing a conceptual understanding of this phenomenon. Their theoretical models of stress-related growth include components that may be important in the development of growth and change in this population. Potentially important roles of environmental and personal influences, as well as cognitive appraisals and coping strategies in the development of personal growth are highlighted in Schaefer and Moos’ (1992) model. Folkman’s model includes additional potentially important components such as the co-occurrence of negative and positive psychological states, meaning-making processes, and the role of positive psychological states in sustaining the ongoing coping process. Calhoun and Tedeschi’s model draws attention to components such as challenges to the individual’s goals, beliefs, and existing life narrative; the role of self-disclosure and socio-cultural influences; as well as the cognitive engagement that is central to the reconstruction of the individual’s life-narrative. Perhaps also important to the understanding of growth and change in this parenting experience, the PTG model suggests that ongoing distress and ongoing reconstruction of the
individual’s life narrative coexist with, and may inform growth.

However these models are, as yet incomplete. They do not take into account the integration of “bottom-up” and “top-down” approaches that recent developments in the trauma literature (Ogden et al., 2006; Siegel, 2006; van der Kolk, 2006) suggest may be important in the management of distress and perhaps ultimately in the development of growth. While Schaefer and Moos’ 1992 model and Folkman’s 1997 model take into account stressors of varying magnitude, Calhoun and Tedeschi’s 2006 model differentiates PTG from coping processes and addresses only highly stressful events of the magnitude that challenge an individual’s assumptive world, thus not accounting for growth through ongoing chronic stressors of lesser magnitude. Both high level acute stressors and lower level on-going chronic stressors reportedly significantly influence the experience of parenting an adult child with schizophrenia (Jungbauer & Angermeyer, 2002) and may also play an important role in the development of growth in this population. As Linsay and Joseph (2004) in their review of the literature point out, more research is needed to expand the current understanding of stress-related growth. As demonstrated in the literature of this chapter, the theoretical conceptualization of stress-related growth has been applied to the study of a number of serious developmental, health-related, and parental issues, however stress-related growth has yet to be the lens through which researchers examine and understand the experiences of parents of adult children with schizophrenia or schizoaffective disorder. The stories of participants in the current study who believe they have grown through their parenting experience may help to expand the understanding of this phenomenon.

In summary, the experience of parenting an adult child with schizophrenia or schizoaffective disorder is clearly a highly stressful one. Within this challenging and stressful experience the research suggests that some parents may experience personal growth and change
growth and change that may be an important part of their parenting experience. However, little
to date is known about personal growth and change in this population. Personal growth and
change through the experience of parenting an adult child with schizophrenia or schizoaffective
disorder has yet to become the primary focus of a research study. The stories of parents who
believe they have grown through their experience may provide insight into this potentially
important part of the parenting experience – insight that may be helpful to parents and their
families, and to counselling psychologists and other mental health professionals who work with
families of the mentally ill.
CHAPTER THREE: METHODOLOGY

As the literature review of chapter two demonstrates, research to date on the experience of parenting an adult child with schizophrenia or schizoaffective disorder has focused primarily on the difficult and at times devastating challenges associated with this parenting experience. There have also been some reports of positive outcomes and personal growth (Bulger et al., 1993; Marsh et al., 1996; Tuck et al., 1997; Wiens & Daniluk, 2009), however, a study focused specifically on personal growth and change through this parenting experience has yet to be undertaken. The purpose of the current study is thus to expand on the as-yet limited reports of personal growth and change through an in-depth narrative examination of the stories of mothers and fathers who believe that they have personally grown and changed through this parenting experience. This chapter begins by drawing attention to the appropriateness of an inductive qualitative approach to researching this topic. This is followed by a rationale for the use of narrative inquiry as opposed to other possible qualitative approaches. Attention is then drawn to the epistemological assumptions that are foundational to narrative inquiry and the assumptions and presuppositions that I, as the researcher, bring to the work. A step by step description of the procedure that was followed in this study is then presented. These procedural steps include: the criteria for inclusion, recruitment of participants, data collection, the process of analysis and the process of validation. The chapter concludes with a discussion of the criteria that were used to address trustworthiness and rigour. The methodological decisions were made in response to the research question that guided this study: How do parents of adult children with schizophrenia or schizoaffective disorder experience personal growth and change as they live with the challenges and the ongoing uncertainties associated with their child’s mental illness?
Appropriateness of a Qualitative Narrative Approach

Inductive qualitative approaches are appropriate when the purpose of the research is to gain a greater understanding of a little or partially known phenomenon (Palys, 1997; Stebbins, 2001). Qualitative approaches are also appropriate to address the research question of the current study because they are flexible and open to new possibilities (Stebbins). They have the potential to provide a rich description of experience. Very importantly, they draw attention to the particular aspects of experience that participants identify as relevant and meaningful (Park & Lechner, 2006). Various qualitative approaches could have been used to research personal growth and change through the challenges of this parenting experience. These approaches include: ethnography, case study methods, grounded theory, phenomenology, or narrative inquiry. All of these methodologies focus on understanding life experience and use “personal descriptions of experience” as a primary data source (Osborne, 1994, p. 179). They differ in terms of purpose and degree of emphasis (Osborne). Ethnography presents “a socio-cultural interpretation” (Merriam, 2002, p.9) of group experiences and seeks to understand “predictable patterns of thought and behaviour” (Osborne, p. 178) within a group. Case study methods aim to provide a comprehensive description and analysis of an individual case or social unit (Merriam; Osborne). Grounded theory uses a constant comparative method to develop “theoretical explanations of the relationships among categories of data” (Osborne, p. 181) throughout the research with an ultimate focus on the development of theory (Richards & Morse, 2007). Phenomenology systematically “attempt[s] to uncover and describe the structures, the internal meaning structures of lived experience” (Van Manen, 1992, p.10). Narrative inquiry “begin[s] with experience as lived and told in stories” (Clandinin & Connelly, 2000, p. 128) and interprets these stories of experience to learn “how individuals perceive, organize, give meaning to, and express their
understanding of themselves, their experiences, and their worlds” (Mishler, 1991, p. ix). This is the purpose of the current study, that is, to learn through the stories of parents how they “perceive, organize, give meaning to, and express” their experience of personal growth and change through the challenges and uncertainties associated with their child’s mental illness.

Narrative inquiry is an appropriate approach to the study this life experience given the mimesis between life and narrative (Bruner, 1987). As Bruner in his article "Life as narrative" puts it: "[It is] a two-way affair – narrative imitates life, life imitates narrative" (Bruner 2006b, p. 130). Bruner points out that it is through narratives that we learn about life events, the reactions of humans to these events, and the working out of "human intentions in a real or possible world" (Bruner, 2006a, p. 121). The stories of the participants in this study are stories about real world experiences, how the participants have responded to their experiences, and importantly, how they have worked out their intentions in the world they now live in. These stories help us to understand human life more fully as they draw attention to a part of human life that I suspect is unknown to many and all too often kept in the shadows of what is known. As pointed out in part one of my personal story (in chapter one), I have come to view the experience of living with the challenges and uncertainties associated with mental illness as an important part of normal human life. Although often unacknowledged and at times misunderstood, this part of human life is a part of normal life that directly or indirectly affects us all. The stories in this study consequently provide a greater and broader understanding of normal human life.

Narrative inquiry is also a relevant approach as narrative thinking is central to the experience of being human (Kohler Riessman, 1993, 2008; Leiblich, Tuval-Mashiach, & Zilber, 1998; Murray, 2003; Polkinghorne, 1988). As Gottschall (2012) put it: Humans are "storytelling animals" – "soaked to the bone in story" (p. 18), "bound up in stories" (p.1). Story, he says
"dominates human life" (p. 8) and is how we human beings think. It is "the mind's default state" (Gottschall, p. 11). Bruner (2006a) also points out that narrative thinking is our "natural mode of thinking (p. 120) – a way of thinking that develops early in childhood and continues throughout our daily lives. A narrative approach to addressing the research question of this study thus invites participants to think about and reflect on their experience of growth and change in a naturally intuitive and spontaneous way.

A narrative approach is also appropriate when seeking to understand an ongoing and changing experience over time, such as the experience of personal growth and change that is the focus of this study, for storytelling is a dynamic changing process. As Leggo (in press) put it: “story-making is … always changing… exuberantly organic” (p.8). Bruner (1987) points out that narrative may be the best way to describe "lived time" (p. 129). The stories in this study reflect change over time and are based on multiple interviews conducted over a period of two years.

Narrative inquiry is also a way to draw attention to experience by engaging the imagination and using language in a compelling way (Bruner 2006). Kohler Riessman (1993) points out the importance of writing narratives in a way that moves those to whom the story is told. I strove to write the stories of the participants in this study in a compelling way that would have an impact on the reader. This was accomplished in part by including direct quotations that I thought were compelling and particularly meaningful. I also invited the participants to share additional forms of storying that were personally meaningful for them, such as poetry and other art forms.

A narrative approach is also appropriate given that narrative is an important way that culture alerts its members to experiences that are troublesome and out of the ordinary (Bruner, 2006c). Narratives help us make meaning of these troublesome experiences (Bruner, 1990;...
Kohler Riessman, 1993). The parenting experience that is the focus of this study is one of the troublesome and out of the ordinary experiences of life that challenge the ability to make meaning. Bruner (2006c) points out that one of the key functions of narrative is to illustrate what happens when "trouble" unexpectedly strikes and how those who encounter trouble respond to it and come to some kind of resolution. As he put it: "[Stories] achieve their meanings by explicating deviations from the ordinary in a comprehensible form" (Bruner, 1990, p. 47). Stories thus help us make meaning by helping us "resolve the inevitable clash between what is conventionally expected and the seemingly unexpected" (Bruner, 2006c, p. 230). Kohler Riessman (1993) similarly emphasizes that through our stories we organize experiences in a meaningful way that makes sense to us – through our stories we construct a sense of cohesion and unity in what would otherwise appear to be isolated fragments of experience (Polkinghorne, 1988). These fragments or "disorderly experiences" (Riessman, 1993, p. 26) become meaningful through the stories we tell. Bruner (2006c) tells us that telling our stories is an important way that we help each other learn how to live with challenging aspects of our lives.

These meaning-making aspects of storying were important to me as I thought about possible approaches for the current study. I reflected on how I have personally made meaning of my experience through "casting it in narrative form" (Kohler Riessman, 1993, p. 4) - how through the writing of my story I have made meaning of some of the disorderly events in my own parenting journey. I was interested in, and curious to learn, how the participants in this study made meaning of the challenges they faced. I also wanted to be part of their meaning-making process through listening and attending to, and co-constructing their stories.

I also considered narrative inquiry an appropriate approach for this study given the formative function of story-telling. As Bruner (2006c) points out, our minds are shaped "through
the stories we tell and listen to" (p. 230). Story-telling "build[s] the very events of a life ... In the end we become the autobiographical narratives by which we tell about our lives" (Bruner, 2006b, p. 131). Certainly story-telling has been a "becoming" and empowering process for me as reflected in the researcher's story (part one in chapter one and part two in the epilogue of chapter five). I have personally been shaped by the stories that I have listened to, the narrative analytic process described later in this chapter, and the writing of the co-constructed participant stories. At the beginning of the study I looked forward to being part of, and now consider it a privilege to have been part of, that "becoming" and empowering process in the lives of the participants in this study.

A narrative approach is also appropriate for this study given that it acknowledges the importance of and constructs "two landscapes simultaneously" (Bruner, 2006a, p. 117), i.e. the landscape of action or "what happened" and the landscape of consciousness or "what those involved in what happened know, think, or feel" (p. 117). Both of these landscapes are important when seeking to understand this parenting experience. Also importantly, narrative inquiry situates individual stories within "a community of life stories" (Bruner, 2006b, p. 134). A holistic understanding of this parenting experience requires an understanding that these individual stories are immersed in a complex “a sea of stories” (Murray, 2003, p. 98). This sea of stories includes cultural tales about mental illness (current and historical), stories of family burden, as well as the unique family stories of each of the participants.

Also relevant to the current study, narratives are open to contradictions and ambiguity (Bruner, 2006a). This parenting experience is rife with contradictions and ambiguities. Importantly, stories are also about agency. I was curious about, and wanted to learn about, what the participants did with the contradictions and ambiguities in their lives, what impact these
contradictions and ambiguities have had and continue to have on their parenting experience — how these contradictions and ambiguities have shaped who the participants have become.

I was also drawn to the "up close and personal" (Josselson, Leiblish & McAdams, 2003, p.4) nature of narrative inquiry. Being up close and personal is important when seeking to learn about an emotionally sensitive and personal subjective experience such as personal growth and change. According to Lieblich et al. (1998), narratives provide a window into the inner world of subjective experience and facilitate the construction of stories that are personal. “We know or discover ourselves, and reveal ourselves to others, by the stories we tell.” (Lieblich et al., p.7). I wanted to join the participant in this close "knowing," "discovering ourselves" process. I anticipated that "the story of a life as told to a particular person is in some deep sense a joint product of the teller and the told" (Bruner, 1990, p. 124). As stated in my researcher's story of change through the research process at the end of chapter five, I wanted to be sensitively thin-skinned as I joined "the chorus of voices" (Kohler Riessman, 1993, p.16) that are embedded in the research process. Through this study the participants' stories became part of my story and my story became part of theirs.

I also chose to use a narrative approach given that stories are not only about what happened to and in the participants, they are also "tailored to meet the condition of ‘So what?’" (Bruner, 1990, p. 86). As a counsellor and as a researcher the “So what?” question is important to me for it leads to implications for theory, for counselling practice and further research. These implications are discussed in chapter five.

I also chose to use a narrative approach given the varied ways (e.g. thematic approaches, structural approaches) of working with narrative data. I invited the participants to include any forms of data (e.g. poetry and other art forms) that they felt were relevant to understanding their
experience. The specific narrative approach used in this study evolved throughout the research process and is therefore somewhat unique to this particular study. The methodological decision-making process that I followed in this study is presented and discussed later in this chapter.

In summary, narrative inquiry is an appropriate way to learn about the parenting experience that is the focus of this study as narrative imitates life, and for humans the natural mode of thinking is narrative thinking. Narrative inquiry is an appropriate way to learn about an ongoing changing process for storying itself is a dynamic process. Storying engages the imagination and is open to the use of language that can move the reader. Very importantly, narratives help us make-meaning of troublesome experience and shape who we are and who we are becoming. Narratives construct the landscapes of action and consciousness simultaneously and situate stories within a “sea of stories.” Narratives are open to contradictions and ambiguities. Narratives are also up close and personal and provide a window into the inner world of subjective experience. Through narratives the "so what?" question emerges that invites us to consider the implications of storied experience. Narrative approaches are also flexible and can be developed throughout the research process. Story-making has also personally shaped me and helped me make-meaning of my parenting experience. It is appealing to me and a privilege for me to be a part of this formative and meaning-making experience with others.

Epistemological Foundations of Narrative Inquiry

In contrast to the positivist stance of objectivism that is foundational to much of the research in the natural sciences, narrative research methods are interpretative and positioned within an epistemology of social constructionism (Crotty, 1998). Whereas objectivism views knowledge and meaning as something to be discovered by means of verification through observation and experimentation, social constructionism views knowledge and meaning as
“constructed in and out of interaction between human beings and their world, and developed and transmitted within a social context” (Crotty, 1998, p. 42). Meaning, according to social constructionism, “comes into existence only through the engagement of knowers within the world” and is not independent – not “out there awaiting discovery” (Schwandt, 2007, p. 257).

Thus, in the current study, I, as an interpretive narrative researcher, have co-constructed together with my participants a description and interpretation of their experiences rather than the one “true” interpretation of these experiences. As Lieblich et al. (1998) have pointed out, narratives are not “complete and accurate representations of reality” (p. 8), although they do reflect the “personal truths” of those involved in the construction of the story (Hirakata, 2007). The storyteller, myself as the researcher, and the reader of the story each bring our individual “cultural, social, economic, political, and spiritual views and experiences” to the understanding of these stories (Leggo, 2008, p. 8). The stories can therefore be interpreted in multiple ways and all of these interpretations remain tentative. The individual narratives that have been co-constructed in this study are “possibilities” offered through a process of careful analysis (Leggo).

As the researcher my voice is one of multiple voices in the research. How I have heard and interpreted the stories told by the participants has inevitably been filtered through my personal beliefs and assumptions about the experience of growth and change as well as my own experiences as a parent, and my review of the relevant literature presented in chapter two. In the following section I have chosen to identify my personal assumptions and presuppositions.

**Researcher Assumptions and Presuppositions**

The following description of my assumptions and presuppositions was written prior to meeting the participants in this study and included in the research proposal:

*Given that the early stages of schizophrenia and schizoaffective disorder can be dif*
and frequently punctuated with crises, I expect that my participants will report that they were unable to recognize the ways in which they were growing and changing prior to and in the first few years after their child’s illness was diagnosed. That said, I expect to hear that as these parents reflect back on their experience during the early stages of the illness, they will recognize ways in which they were growing and changing. I also expect that the ways in which these parents have coped with the challenges associated with their child’s illness will be different and associated with different dimensions of growth. Across the participants’ stories I expect to hear themes that reflect the dimensions of posttraumatic growth identified by Tedeschi and Calhoun (1996), i.e. new possibilities, relating to others, personal strengths, appreciation of life, and spiritual change. I also anticipate that contextual factors such as support networks will significantly influence how the various dimensions of personal growth and change are experienced. Based on my review of the literature related to stress-related growth, I also assume that my participants’ stories will reflect a struggle with fundamental beliefs about how life should be. The outcome of this struggle will likely reflect changed expectations and values, increased self-awareness, and possibly a changed sense of life purpose and meaning. I also anticipate that there may be cultural differences in how personal growth and change is viewed and experienced.

Although many of the changes reported by the participants may differ from my personal experience of growth and change, I expect to find a common experience that I can best describe as an underlying ever-present “ache” that for me co-exists with growth. This “ache” may be described by some parents in ways that are consistent with the concept of chronic sorrow as presented in chapter two. I expect that some stories may reflect a change in the experience of this ache/sorrow over time that involves an affirmation of “continued life in spite of sorrow” (Westwood & Wilensky, 2005, p. 156). I also anticipate that some participants may associate this
“ache” with the development of a heightened sensitivity to the difficult life challenges of others, particularly a greater sense of compassion for persons affected by mental illness. I also expect that some participants will report a greater commitment to family relationships and changed life priorities. These changed priorities may reflect newly discovered strengths and competencies or perhaps new interests and avenues for creativity.

I expect to find that personal growth for the participants may include an acceptance of uncertainty and an increased level of comfort with ambiguity. I anticipate that there may be some gender-related differences in how personal growth is experienced and described. Based on the findings of my previous research on fathers of adult children with schizophrenia, I anticipate that personal growth and change for fathers may reflect a greater commitment to family relationships. Given the literature that suggests that mothers often take on the key care-giving roles for their mentally ill child (Ascher-Svanum & Sobel, 1989; Milliken, 2001), a role that has been described as all-consuming (Milliken, 2001; Pauch, 1996; Ryan, 1993; Thorpe, 1994; Vatri-Boydell, 1996), I expect that personal growth in mothers may be reflected in an increased priority on self-care, possibly in creative artistic ways. I also anticipate that both mothers and fathers will report that they have experienced personal growth through their role as advocates for their child.

As described in the researcher story of change throughout the research process at the end of chapter five, these assumptions and presuppositions continued to be shaped throughout the research process. The researcher story (in chapters one and five) identifies for the reader the biases that could interfere with my ability to be a “naïve” listener to the stories of the participants, as Lieblich et al. suggest.

**Procedure**

As previously stated, the specific methodological steps undertaken in this study evolved
throughout the research process – a process of co-constructing a “creative non-fiction” (Dr. Carl Leggo, personal communication April 22, 2013). This co-construction process involved multiple voices – most obviously the voices of my participants and my own voice, but also the voices that have contributed to the formation of who the participants and I have become. I was committed to honouring these voices. It was therefore important that I reflect carefully on the procedural decisions I made. These decisions/procedural steps are outlined below and resulted in the six stories of mothers who reported that they had experienced personal growth and change through living with the challenges and uncertainties associated with their child’s mental illness. A seventh story was also written and then later removed when the participant decided to withdraw from the study. This participant reported that the story I had written did not reflect her experiences and that she was not comfortable with having her story written in the first person. The decision to withdraw from the study was made in a mutually respectful way and after meeting with the participant to hear her responses and concerns. Ideally I would have liked to include fathers as well as mothers in the study, however, no fathers responded to the recruitment notice.

**Criteria for the Selection of Participants**

All of the participants met the following criteria:

1) The participant was a genetic parent of an adult child who has been diagnosed as having schizophrenia or schizoaffective disorder.

2) The participant affirmed that she had experienced personal growth and change through living with the challenges and uncertainties associated with her child’s mental illness.

3) The participant was actively engaged in her parenting role.

4) The participant was interested in telling her story and willing to commit to a minimum of two audio-taped interviews over the period of one year for the purpose of hearing her story.
She was also willing to participate in an additional interview after the story was written. The purpose of this interview was to check in with each participant to see if the story reflected and resonated with her experience and to provide an opportunity for the participant to suggest any changes or additions to the story.

5) The participant was able to reflect on her experience and meaningfully articulate her experience (Kvale, 1996; Rubin & Rubin, 2005). The potential participant’s motivation and ability to communicate her experience was assessed at the time of the initial telephone conversation during the discussion of the study inclusion criteria. In my conversation with the potential participant I was mindful, as Kvale (1996) pointed out, that the ideal interview subject – one who has a high level of motivation, eloquence, and knowledge does not exist and that it was largely my task, as the researcher and primary research instrument, to motivate and facilitate a rich description of the participant’s experience.

**Recruitment of Participants**

Participants were recruited through a notice (see Appendix A) distributed through an email list associated with the Schizophrenia Society of parents of children who had been diagnosed with a mental illness and as well as through snowball sampling. The recruitment notice included a brief description of the study and the criteria for participation. Potential participants who were interested in participating were invited to contact the researcher by telephone or email.

As potential participants responded they were briefly interviewed by telephone to determine whether or not they met the criteria for participating in the study. During this initial contact I strove to establish a comfortable rapport with the potential participants by being sensitive, respectful, and using the active listening skills that I have developed through my
training in Counselling Psychology. The first seven respondents that met the inclusion criteria and were interested in participating in the study were accepted to participate in the study. At the time of the screening interview I reviewed with each of the respondents the purpose of the study, the required time commitment, issues of confidentiality, and the right of participants to withdraw from the study at any time. The participants were also given the opportunity to ask questions about the study. I then scheduled an initial one-on-one interview with each of these participants at a mutually agreed upon time and location that was private, convenient, and comfortable for the participants (their home, office, or a private centrally located apartment that was made available specifically for the purpose of these research interviews).

**Data Collection**

The primary data sources for the study were the multiple in-depth one-on-one semi-structured audio-taped interviews conducted with each participant over the period of two years. There were 28 interviews in total. The interviews varied in length and ranged from one hour to two and a half hours. As emphasized in the interview approaches of Rubin and Rubin (2005) and Kvale (1996), throughout all of the interviews I strove to build and maintain a strong, trusting relationship with each of the participants and to be a respectful, sensitive, and attentive listener. I demonstrated an interest in both the content and the emotions associated with the content of each participant’s story. Knowing that my emotions and behaviour had an effect on the interview process, as Rubin and Rubin point out, I arranged my schedule so that I could be relaxed and alert during the interviews. At all times I strove to maintain a safe, non-judgmental accepting environment with an atmosphere of equity between myself and the participant.

Before beginning the initial data collection interview I reviewed the purpose of the study and issues of confidentiality with the participant. I also reminded the participant of the voluntary
nature of her participation and her freedom to withdraw from the study at any time. Opportunity was also given to choose a pseudonym to be used throughout the study to protect the participant’s anonymity. The participant was then given the opportunity to read through the consent form approved by the UBC ethics review board (Appendix B) and to ask any further questions about her involvement in the study. The participant was then asked to sign two copies of the consent form to indicate her willingness to participate in the study, one of which was retained by the participant. The audio-taped interview began after the consent forms were signed.

The interviews were largely unstructured and guided by an orienting statement (Appendix C) that was read to each participant at the beginning of the first interview. Throughout each interview I strove to be as non-directive as possible and allowed the participant to tell her story in her own way. As Lieblich et al. recommended, I attempted to be a “naïve listener,” respecting the subjectivity of my interviewee” (p. 76). By maintaining an attitude of curiosity and empathy, and using active listening skills I strove to facilitate rich detailed descriptions of the experiences that the participant considered relevant to her story. Several open-ended questions (Appendix D) were used on an "as needed" basis to facilitate more in-depth exploration of the participant’s experience. I strove to be comfortable with ambiguity and attentive to the nuances and tensions communicated by the participant as she told her story. I also tried to be open to, accepting of, and curious about aspects of the participant’s experience that differed from my own as well as aspects of the participant’s experience that I had not yet considered. I invited each participant to include other forms of narrative data that could possibly add to the understanding of her experience.

Laura chose to share some of her poems, one of which is included in her story.

I encouraged each participant to keep a record of any additional thoughts, feelings, or insights that might arise after each interview which would then be included in the following
interview. Immediately following each interview I recorded my personal reactions to, reflections on, and observations of, the interview in my research journal. These journal entries were taken into consideration in the process of data interpretation and analysis and also informed the researcher story of change that is included in chapter five.

**Data Interpretation and Analysis**

As previously stated, the process of interpretation and analysis for the current study was ongoing throughout the research process. It began at the idea stage and continued through the review of the relevant literature, the development of the proposal, the interview process, the research journal entries, as well as the step by step process of analysis, and ultimately resulted in the six individual narratives and the findings of the cross narrative analysis. The six individual narratives represent the primary findings of this study. Each story was written around central themes that were identified and interpreted in the light of the story as a whole – an overall process guided by Lieblich et al.’s (1998) holistic – content approach. The identification of major themes and subthemes for each of the participant's story also involved a detailed analytic coding process similar to Lieblich et al.'s (1998) categorical - content approach. Given the emphasis on content in the analysis and the analytical coding process used to identify and organize themes and subthemes, the resultant individual narratives are more “episodic” (Kohler Riessman, 1993, p. 17) than sequential. They are “stitched together by theme rather than time” (p. 17). After the six narratives were written and presented to the individual participant for the purpose of a member check, in consultation with my research supervisor I decided to also include a cross-narrative analysis. The identification and description of common themes identified through a cross-narrative analysis served to provide a greater understanding of the more prominent findings and to further inform the implications for theory and counselling practice. Through the cross-
narrative analysis I identified major themes that were common to each participant’s story and also significant threads that were prominent in the stories of most, but not necessarily all of the participants. At this point in the analysis, Dr. Mathison (an experienced qualitative researcher and member of my research committee) suggested that further understanding of this parenting experience might be gained by taking a "step back" and reflecting on the findings as a whole to see if there might also be broader dimensions suggested by the data. Dr. Mathison also encouraged me to consider how I might represent the relationships between common themes, significant threads and any broader dimensions – possibly in a diagrammatic format. The procedure of data analysis and interpretation included the following steps:

1) Consistent with the holistic - content approach of Lieblich et al. (1998), the audio-taped interviews were transcribed verbatim and read multiple times from beginning to end. I also read the entries in my research journal that were associated with the interviews. Throughout these readings I strove to maintain an empathic stance toward the narrator’s experience while listening carefully, anticipating that the story “will speak” (Lieblich et al., p. 62). I was listening for a unifying thread that could provide an understanding of the participant’s experience as a whole.

2) As Lieblich et al. (1998) suggest, I then wrote an initial “global impression” (p. 62) of the participant’s story and identified a single overall unifying thread that provided coherence to the story as a whole. I kept this unifying thread in mind as I proceeded with the detailed analytic process that followed. The unifying thread helped to inform my understanding of the major themes and subthemes – their significance and place in the overall story. This unifying thread later became the title of the individual story.

3) I then entered the transcripts of each of the participants into the Atlas ti qualitative
software and coded the transcripts for each participant line by line, a "categorical -
content analysis" (Lieblich et al., 1998, p. 112) that resulted in the identification of
multiple codes/small descriptive meaning units. This process allowed me to work closely
with the data and gain a comprehensive understanding of what the participant was
explicitly and implicitly saying. I wanted to be sure that I didn’t miss anything important
or aspects of the story that I might be blind to given my personal biases or way of making
sense (Bruner, 1990). While immersed in the detailed coding process, the unifying thread
(identified in step two) provided a sense of balance – an overall perspective that
prevented me from getting “lost” in the data.

4) Having identified multiple meaning codes for each participant, I then used the Atlas ti
software to “play” with these codes, paying attention to similarities and differences
between codes, and reflecting on how they might inform larger themes or patterns in the
story – fundamental aspects of the story whose “significance depends on the entire story
and its content” (Lieblich et al., p. 62). Throughout the analysis I was mindful of Lieblich
et al.’s suggestion that significant themes can be recognized by the amount of space they
occupy in the text or the richness with which they are described.

5) I then drew my attention to the context in which each theme was situated. The Atlas ti
software provided me with the ability to access the contexts associated with each code
quickly and in doing so I noted, as Lieblich et al. suggested, where a theme begins and
ends as well as how one theme transitions to another. Steps four and five resulted in a
significant reduction in the total number of codes and the identification of major themes
and subthemes.

6) I then wrote an interpretive description of each major theme using the subthemes that
informed that major theme. I incorporated relevant quotations from the interview transcripts within this description. As Lieblich et al. suggested, in the interpretation of each theme I paid special attention to unusual comments made by the participant and/or comments that were associated with a marked level of emotional intensity, recognizing that these comments may be indicators of how themes are evaluated by the narrator (Lieblich et al.). I also considered thematic interpretations in light of the content of my reflexive journal.

7) I then wrote an individual narrative of each participant’s experience that reflected the themes and subthemes that were identified through the process of interpretation and analysis described above while keeping in mind the overall unifying thread that provided coherence across the story as a whole. These narratives were written in the first person. I chose to write in the first person given that writing in the first person, as Ely (2007) suggested, places the participant’s voice at the centre of the story, is respectful, and makes the story “more powerful in the reading” (p. 573). Writing in first person also helped me to write in a manner that seemed consistent with the style of the storyteller. For me it was like sitting in the presence of the participant and hearing the story from the teller once again. That said, I can appreciate that the experience of the reader may be different given that the reader did not hear the story first hand as I did. Writing in the first person also allowed me to include many direct quotations without interrupting the flow of the story. This was particularly important given that the narratives were already necessarily somewhat “interrupted” by the story structure, i.e. written around the major themes rather than sequential actions/events.

Writing in first person also confirmed that my voice as the researcher is present
the story. It is a "created" first person story – a co-constructed story – as the researcher I am not “removed, impersonal or neutral” (Ely, 2007, p. 575). Writing in the first person also represented for me the close relationship between my voice, the voice of the participant and the many voices that have shaped both of our experiences. It felt like writing from the inside and brought me closer to the story and to the participant. As I suggested in the researcher’s story at the end of chapter five, I experienced joining the participants’ stories. Their stories became part of my story and my story became a part of theirs. Together we co-constructed a story that is part of the larger story of what it means to be the mother of an adult child with a mental illness. Perhaps we also held hope together. As Boss (1999) put it: “We together find meaning in the chaos” (p. 130).

Writing in the first person also caused me to be mindful of the responsibility of writing in “another’s” voice and the risks associated with writing in the first person as described in the researcher’s story in chapter five. I was also mindful that these narratives provide a “possible” rather than a “true” presentation of the participant’s experience. As Kohler-Riessman (1993) emphasized: “All forms of representation of experience are limited portraits… …Although the goal may be to tell the whole truth, our narratives about other’s narratives are our worldly creations… … All we have is talk and texts that represent reality partially, selectively, and imperfectly.” (p. 15).

8) After each individual story was written it was sent to the participant by mail. I allowed two weeks for the participant to read and evaluate the story before scheduling a meeting to receive her feedback and to check for “correspondence” (Kohler-Reissman, 1993, p. 67) between the interpreted findings and the participant’s experience. All but one of these member check meetings were audio-recorded and portions of my conversations with each
of the participants at this meeting were transcribed. During the member check meeting I asked the participant: Is this story an adequate reflection of your experience? Does the story resonate with your experience? I also invited the participant to share any additional thoughts, feelings, or insights regarding her experience that she might wish to have included in her story. I then asked the participant about her experience of participating in the study. All but one of the participants (the participant who withdrew) stated that the stories adequately reflected and resonated with their experience. Several participants suggested minor changes and/or additional material that they wished to have included in the story. These additions/changes were incorporated into the story and did not change the themes and subthemes of the stories. All of the six participants whose stories are included in this study expressed gratitude for the opportunity to participate in the study. Several participants reported that participating in the study had been helpful for them. It was clear that the stories “moved” the participants. As previously said, it was my hope that these stories would move readers as well.

9) As pointed out in the introduction to this section, in order to provide a greater understanding of the more prominent findings and to further inform the discussion of implications for theory and counselling practice, in consultation with my research supervisor I decided to include a cross-narrative analysis after the six stories were revised and in their final form. This cross-narrative analysis identified themes common to all of the narratives. My attention was also drawn to significant threads that stood out in the stories of some, but not necessarily all of the participants. I then wrote a brief description of the common themes and significant threads and included these descriptions in the presentation of the findings in chapter four.
10) As previously pointed out, I was then encouraged by Dr. Mathison to take a step back and revisit all of the findings to see if there might be broader dimensions suggested by the data. Four broader dimensions were identified. I wrote a brief description of these broader dimensions and included these descriptions in the presentation of the cross-narrative findings in chapter four.

11) I then worked with the common themes, significant threads and broader dimensions, considered the relationships between them, and looked for a way to communicate these relationships in a simple but meaningful way. This process resulted in a diagram (Figure 1). My research committee suggested that the diagram is in itself a story. This story was then briefly described.

**Trustworthiness and Rigour**

As the researcher I was aware of the ethical responsibility that I have to be “trustworthy” in all aspects of the research process. I addressed this responsibility in several ways. First, I established competence as a researcher through a number of graduate level courses in qualitative research methodology. I also gained qualitative research experience through the phenomenological study I conducted for my Master’s thesis. In the current study I worked closely with my research supervisor and consulted the members of my research committee, all of whom have expertise in qualitative research methods. Through my experience as a counsellor I developed proficiency in active listening skills. These skills, together with my personal interest in the focus of the current study and my personal experience as the mother of an adult child with schizophrenia, I believe assisted my ability to build rapport and maintain a close working relationship with the research participants. I was mindful throughout the research process that I have inevitably brought my voice and experience to the interpretation of the participants’ stories.
and explicitly stated my assumptions and presuppositions prior to my contact with the research participants. I also reviewed the relevant research literature prior to meeting with the participants. Throughout the research process I maintained a reflexive research journal of my personal process. Through a member check meeting with each participant I established the criteria of “resonance.” I also strove to meet the following four criteria that Lieblich et al. suggest are important for evaluating the quality of narrative studies: comprehensiveness, coherence, insightfulness, and parsimony.

**Comprehensiveness**

I strove to meet the criterion of comprehensiveness by providing a rich description of the participants’ experience and supported my interpretations with quotations from the interview transcripts. I also invited the participants to include other forms of narrative data such as artwork or poetry that might be helpful in understanding their experience. One participant chose to include some of her poems. As noted above, I also kept a reflexive journal throughout the research process and communicated highlights of my personal process through the researcher story that is included at the end of chapter five.

**Coherence**

I strove to meet the criterion of coherence by communicating the participants’ experiences through the stories in a clear way that is easy to follow, makes sense and is persuasive. I took heed of Kohler-Reissman’s (1993) statement about the importance of persuasive interpretations, i.e. that the interpretations should be “reasonable and convincing” (p. 65). Consistent with part of Schwandt’s 2007 definition of verisimilitude I tried to write the story in a way that would reflect “the appearance of truth or reality” (p. 313). Coherence was also addressed through confirming with the participants that the narratives resonated with and
adequately reflected their experience. I also worked closely with my research supervisor to address this criterion.

**Insightfulness**

To meet the criterion of insightfulness I strove to represent the findings in a way that would have an impact on the reader’s life, a criterion closely tied to the second part of Schwandt’s definition of verisimilitude, “the evocative power or sense of authenticity of a textual portrayal” (p. 313). According to Schwandt this criterion is met through a style of writing “that draws readers into the experiences of respondents in such a way that those experiences can be felt” (p. 313).

**Parsimony**

Lieblich et al. suggested that good narrative studies are “based on a small number of concepts” and presented with “elegance and aesthetic appeal” (p. 173). I addressed this criterion through careful and thoughtful work with the multiple codes/meaning units in each story, contemplating how these codes informed/influenced larger aspects of each participant’s experience and then writing the stories around these major themes. In the cross-narrative analysis I strove to present the findings in a concise and appealing way through the diagram representing the relationships between the major common themes, significant threads and broader dimensions. By striving to be concise and appealing in the representations of the findings, I hoped to enhance the potential usefulness of the study, i.e. facilitating the awareness of possible implications for counselling practice as well as for theory development and future research.

In summary, narrative inquiry is an appropriate method to address the research question that has guided this study. The narrative method used in this study is understood from the perspective of social constructionism. The individual narratives at the heart of this study are
therefore co-constructed stories and my voice as the researcher is inevitably part of these stories. As the researcher I bring assumptions and presuppositions to the research which I have shared with the reader. I also bring my personal experience to the research as reflected in the researcher's story in chapter one and at the end of chapter five. In this chapter I have provided a detailed description of the procedure that was followed in this study as well as a description of the criteria used to ensure trustworthiness and rigour. The method used in this study emerged through the research process. Other methods of representation, such as poetry or drama could have been used and may have been more powerful and captivating in their impact. Third person sequential stories would likely have resulted in more story “flow” and perhaps also have resulted in a greater impact. That said, the stories in this study and the cross narrative analysis do communicate important findings. These findings are presented in the following chapter.
CHAPTER FOUR: PRESENTATION OF THE RESEARCH FINDINGS

This chapter presents the findings of the study and is written in two sections. The first section presents the six first person narratives that are at the heart of this study and begins with a table of demographic information about the study participants. Section two presents the results of the cross-narrative analysis which includes four major common themes, four significant “threads,” and four broader dimensions, as well as a diagram (Figure 1) illustrating the relationships between these themes, significant threads, and broader dimensions.

The Six Individual Narratives

As noted above, this section begins with a table of demographic information about the participants in this study and is followed by the six individual narratives of growth and change through living with the challenges and uncertainties associated with this parenting experience. Each individual narrative is preceded by a brief summary of the main findings in the story and followed by a table outlining the story's common themes and subthemes. As described in the previous chapter, the detailed process of data analysis followed in this study focused on gaining a comprehensive understanding of the content of the individual participant's experience and resulted in “theme-centred” individual narratives, i.e. “topic-centred narratives (snapshots of past events that are linked thematically)” (Kohler Riessman, 1993, p. 18). Although the flow of these stories is somewhat compromised by this thematic framework, I strove to insure that the narrator’s voice is clearly heard and that the stories have an impact. This was accomplished in part through using the first person and also by incorporating numerous direct quotations from the interviews. ¹ The order in which the stories are presented is not a reflection of their importance, but rather the order in which the interviews were completed. The title of each story represents the

¹ To facilitate the flow of the story all quotations, regardless of length, are included in quotation marks in the text.
overall unifying thread that emerged through the narrative analysis of the interview data for that participant. As noted above, each story is narrated around the major themes that emerged through the data analysis. The subthemes are italicized in the text. When the stories were presented to the participants for validation, they began with a brief introductory paragraph describing the co-constructed nature of the narrative. To avoid unnecessary repetition in this chapter, this brief introductory paragraph is included only in the first story.
<table>
<thead>
<tr>
<th>Participant age</th>
<th>Laura</th>
<th>Catherine</th>
<th>Karen</th>
<th>Ellen</th>
<th>Lisa</th>
<th>Sharon</th>
</tr>
</thead>
<tbody>
<tr>
<td>Occupation</td>
<td>Social Work</td>
<td>Medical Professional</td>
<td>Retired Journalist</td>
<td>Medical professional</td>
<td>Health care professional</td>
<td>Retired business professional</td>
</tr>
<tr>
<td>SES</td>
<td>Middle</td>
<td>Upper middle</td>
<td>Upper middle</td>
<td>Upper middle</td>
<td>Upper middle</td>
<td>Upper middle</td>
</tr>
<tr>
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<td>Caucasian</td>
<td>Caucasian</td>
<td>Caucasian</td>
<td>Asian Canadian</td>
<td>Caucasian</td>
</tr>
<tr>
<td>Partner</td>
<td>Deceased</td>
<td>Divorced 6 years ago</td>
<td>Married</td>
<td>Married</td>
<td>Married</td>
<td>Married</td>
</tr>
<tr>
<td>Adult child with MI</td>
<td>Son 44</td>
<td>Son 30</td>
<td>Daughter 28</td>
<td>Daughter 40</td>
<td>Son 27</td>
<td>Son 30</td>
</tr>
<tr>
<td>Siblings</td>
<td>Older daughter 45</td>
<td>Younger daughter 27</td>
<td>Younger son 25</td>
<td>Younger son (a few years)</td>
<td>2 younger sons 24 &amp; 22</td>
<td>Daughter 27</td>
</tr>
<tr>
<td>Diagnosis of adult child with MI</td>
<td>Schizo-affective Disorder</td>
<td>Schizo-affective Disorder</td>
<td>Schizo-affective Disorder (7 years ago), originally schizophrenia</td>
<td>Schizo-affective disorder, originally schizophrenia</td>
<td>Schizophrenia</td>
<td>Schizophrenia</td>
</tr>
<tr>
<td>Onset of symptoms</td>
<td>~ 19 years</td>
<td>~ 10 years</td>
<td>~ 15 years</td>
<td>&gt; 20 years</td>
<td>~ 7 years</td>
<td>~18 years</td>
</tr>
<tr>
<td>Time since diagnosis</td>
<td>~ 17 years</td>
<td>3 years ago</td>
<td>12 years ago</td>
<td>20 years ago</td>
<td>5 years ago</td>
<td>4 years ago</td>
</tr>
<tr>
<td>Hospitalizations</td>
<td>Multiple</td>
<td>Multiple</td>
<td>Multiple</td>
<td>Multiple</td>
<td>Single</td>
<td>Two</td>
</tr>
<tr>
<td>Living situation of child with MI</td>
<td>Independent with mental health supervision</td>
<td>Interim housing; waiting for mental health housing placement</td>
<td>Currently living independently with mental health supervision: In and out of family home over the course of the illness</td>
<td>Currently living independently with mental health supervision; Has lived outside of the family home for most of her illness.</td>
<td>Currently living at home with parents and brothers. Short period of time in grandmother’s basement suite</td>
<td>Living at home with the exception of one year, several years prior to his diagnosis, while attending university.</td>
</tr>
<tr>
<td>Employment status of child with MI</td>
<td>Unable to work; Never been able to work; Requires mental health supervision</td>
<td>Unable to work; Requires mental health supervision</td>
<td>Employed at the time of the first interview. Unemployed for past 1.5 years</td>
<td>Unemployed throughout most of her illness, but able to be employed early in her illness</td>
<td>Employed several days/week computer related work; teaching computer skills to mental health consumers; Also taking one online UBC course.</td>
<td>Able to complete a college studio art program several years ago. Currently holds several part-time volunteer positions (working 4 days/week)</td>
</tr>
</tbody>
</table>
Laura’s Story: Commitment to Change

**Main findings in Laura’s story.** Laura’s story highlights her commitment to change primarily through advocacy and activism. Her metaphor of a willow tree standing strong despite being battered by the storms of life provides insight into the development of the personal and relational changes that she reported having gained through her parenting experience. The storms in this metaphor are descriptive of two of the major themes in her story: Enduring loss, and Frustration and distress. Also central to Laura’s story is her “ongoing firm resolve” – her passion to make a difference for her son, her family and for society generally by continuing to expand her advocacy and activism skills (developed previous to the onset of her son’s illness) in mental health as well as other areas of social concern. Her story also strongly reflects her desire to pass on this passion to others. Other key findings in Laura’s story include: concern about the impact of an adult child’s mental illness on siblings who are well; concern about how her son’s needs will be met in the future; as well as the important role of exercise, talking with others who understand, and humour in adapting to, and engaging with, life in meaningful ways.

**Introduction.** This is the co-constructed story of Laura’s experience of growth and change through living with the challenges and uncertainties associated with her son’s mental illness. As the researcher, my voice is inevitably part of this story, as I have heard and interpreted the conversations that I have had with Laura through the filter of my own experience. Laura is the mother of two children, a son (44) and a daughter (45). Her son, Leo, has been diagnosed with schizoaffective disorder and has been ill for approximately seventeen years. Laura is currently in her early seventies and has been the sole parent of her son throughout the course of his illness. Throughout the years of his illness she has been, and continues to be, an advocate and activist in mental health as well as other sociopolitical areas. This is Laura’s story as I have
interpreted it, written in the first person:

Laura’s Story…

Growth and change have been a “very significant part” of my overall story of parenting an adult child with schizoaffective disorder. My story could be entitled “Commitment to change” as this has been a strong personal value throughout my life. Many things have changed since the onset of my son’s illness/my son’s diagnosis. “I think the only thing that really hasn’t changed is my commitment to change.” “There is an article written about me that I have put on the wall that talked about the fact that I’ve always been somebody who worked towards positive change. And I’ve been prepared to be there. So this goes back to when I was young. I just was always very much a proactive person.”

I want to make a difference. I want to do what I can to make the world a better place. Since the onset of my son’s illness I have been committed to making a difference for him, my family, others living with mental illness, and for society as a whole. I have made a difference in my own way: “I took my own path.” The metaphor of a willow tree helps to understand the way that I have grown and changed through the experience of having an adult child with schizoaffective disorder: “The willow tree gives the impression of being fragile. You know, if you put a willow tree next to an oak tree, a willow tree doesn’t look as though it’s got the same sort of strength. The willow tree has storms that come at it on a really regular basis that are pretty brutal and a lot of the trees around it are knocked down. But because the willow tree has movement and can bend, I say that it sometimes grows and is sometimes bent to the ground. And when the storm is over the branches are broken and the leaves are tattered, but it is still standing.” It is the ability of the willow tree to be flexible and change that allows it to survive the storms and continue to grow. The “storms” – the challenges I have faced and continue to face as
the mother of an adult child with schizoaffective disorder, are a vital part of the story of how I have been shaped and formed to become the person I am and the person I am becoming. These challenges include enduring sadness and loss, as well as frustration and distress. That said, I think it is important for me to add that I “rejoice when there are moments of growth and success.”

My growth and change has also been influenced by other stressful experiences in my life – events such as the suicide death of my husband (1981) and my daughter’s past drug and alcohol addiction. How I have grown and changed has also been influenced by my experience as an advocate and political activist before the onset of my son’s mental illness, as well as my current experience as an activist in social political issues unrelated to mental illness. The following four primary themes are central to my story of growth and change through my parenting experience: (a) Enduring loss and sadness, (b) Frustration and distress, (c) Continued expansion of advocacy and activism skills, and (d) Substantive relational and personal change.

Enduring loss and sadness. I live with many losses as a mother of an adult child with schizoaffective disorder – *losses related to the pervasive effects of the illness, loss related to my son’s inability to meet developmental norms, loss of the ability to communicate with my son, loss of “what once was,” loss of relationship with my son within the family and loss of normal family life, loss of hope, loss of freedom, loss of dreams for the future - what might have been, and sadness related to changes in the mental health system*. The feelings of sadness associated with these losses are sometimes “up front and centre.” At other times the sadness sits more in the background – but it doesn’t ever go away. I will elaborate on each of these losses.

I am sad when I see *the effects of the illness on my son’s life*. “His cognition is shot. It’s really shot.” He has lost the ability to function well in the everyday things of life. “Even simple
tasks such as making a meal, choosing clothes to wear during the day. All those things are very, very difficult.” “He does his best and goes to [the mental health association] clubhouse… [He] participates because he’s bored and he’s lonely and he’s not a young man at this point who wants to sit at home and do nothing. He really wants to be out and he really wants to do things, but it’s difficult.” I’m sad when I think of his inability to do what is expected of young men his age. I am sad when I think that he doesn’t have close friendships or a strong social support network, things that are so important in a young man’s life. I am sad because “communication with him is very, very difficult.” “His brain is really atrophying.” My sense of sadness is also for all people with mental illness - sadness about the loss of “what once was.” I used to work on the downtown eastside and I have an understanding of the experience of some of the mentally ill people who sleep on the streets. A reflection of their former selves, they are often unseen, unacknowledged, and uncared for. At times I have expressed my sadness through poetry. My poem, City of Shadows, talks about the experience of the mentally ill who live on the streets.

In and out of doorways.

Blending into grey spots

Of the city.

No colour

Just a reflection of my former self.

I’m mostly seen on sunny days

If I even come out at all.

And if the sun does shine you may see me as I change shapes

And people often step on my reflection because they don’t know I am there.

My sense of sadness is also related to knowing that we are unable to have the kind of
relationship with Leo in the family that we would like to have and we can’t have a normal family life. “I’m really sad…I’m sad as much for my daughter as anything - because she doesn’t have an interactive responsive brother. And in fact she has a brother who drains her energy.” My son cannot be part of our family life the way we wish he could be. We can’t invite him to some of our family events, such as my grandson’s recent birthday party. “There are a lot of things that just aren’t doable as a family.”

My sadness is also about the loss of hope. I have lost hope for his recovery. “I don’t see it getting better as long as his brain is as non-functional as it is.” Sadness is “pretty prominent because I think his health is going to continue to go down the tube.” I am very aware that his life span may not be very long. It’s hard for me to imagine what happens to mentally ill family members “when they turn 50 and 60 because their health is so bad.” Years ago Dr. L [a respected psychiatrist] said, “Leo’s brain is solidifying or calcifying and that he really did not think working with Leo would be productive.” That was very hard to hear then because it made Leo’s situation seem so hopeless. I realize now that Dr. L. was right. I don’t think it will be long before Leo will not be able to live in his apartment. Where will he go then? “I don’t see much changing that’s going to be hopeful.”

When I see his loss of freedom I feel sad. One of those times was when Leo was on an in-patient psychiatric ward. At the time he was very angry and he would “roar” and the mental health professionals who were in charge would force him to be quiet. “Out of deep sorrow and deep anger” I wrote a poem about my experience and entitled it Born Free. “It talks about Else the lion and I said that Else was born free and then she was put in a cage and people worldwide fought for her rights and her freedoms. I said my son was also born free and he is also in a cage and he also roars. …Where are the people who should be also fighting for his freedom?”
I am sad about the loss of hopes and dreams for the future, my son’s future and my own future. One of my poems is about an imagined future - what might have been. Of all my poems it is probably the one that I like the most. In the poem I talk about what Leo was like before he became ill. I also talk about who I was and what I had done and the award I received. And then, in the imagined part of the poem I wrote: “As time has gone on the young man who had been so shy and quiet with low self esteem has also done well enough to get an award… [He says] I would like you to meet someone, my mother. …And so in my fantasy Leo gets this award and he stands up and he says: I would like to thank somebody – my mother. And then he says ‘Thank you.’” For me, this poem reflects many losses around what could have been and never will be, losses such as: the loss of my son’s ability to make a valuable contribution to others; the loss of the ability for us to work together for change; the loss of the ability to express love, admiration, and gratitude to and for each other; and maybe even the loss of his ability to understand my experience as his mother and my dream of a close mother-son relationship.

The changes that I see in the mental health system also make me sad, changes such as the closing of mental health facilities. The closing of R, a large psychiatric hospital “is being done with a great deal of despair. The morale at R is grim. And it’s just felt within the whole system and the people who leave R are going to be placed in institutions and they will be moved from one institution to another and they are going to be ‘no fixed address.’ Now, to me that is not a forward step at all…So it’s very sad. For these people who have seen R as their home [as my son has at times] and know people in the unit, it’s really going to be, I think, terrible…So for somebody like Leo, if he can’t survive in his [apartment] for any period of time, there will be no R for him to go to.”

Group homes are also being closed and the residents are being moved from “the shelter
of a small house to small independent living units.” I’m not sure that this will work out well because they will lose “a sense of community in those small houses” and that makes me feel sad. Unfortunately the system can’t afford to keep them. “So I’m not somebody who will jump up and down and say this is really a good time in our lives.” Although there are outreach workers, I doubt that they “will be able to meet the needs of the people they have been serving.” I think the mentally ill people “are going to fall between the cracks … So a lot of people, and I would be one of them, feel it’s going to continue to fall back on the family members,” and that is very sad.

Frustration and distress. As there are multiple losses associated with my experience of sadness and loss, so there are frustrations and multiple forms of distress that have influenced my growth and change. These include: fear, anxiety, and worry - some are pervasive and ongoing; distress associated with Leo’s difficult or bizarre behaviours; disruptions in the family; anger/frustration related to stigma and decisions made without consultation; a sense of powerlessness and despair; frustration with the mental health system and the ongoing struggle to manage my own anger; and the distress associated with living with multiple ongoing uncertainties. Let me tell you more.

“I remember clearly my fear when Leo was first sent to R. I was really scared because I had the feeling, and I think fairly enough, that sometimes family members who speak out about things that they don’t feel good about - their child is going to be penalized. And I saw that at R. I truly saw that.” At first I was afraid of not following orders given by mental health professionals. “They kind of put that fear in me.” Leo would run away from R and arrive at my home and the hospital would call. So “I would bundle him in the car and I would drive him back. And this would even be at two or three o’clock in the morning because I was … scared. I thought I needed to get him back as soon as I could.”
I also have a *persistent fear and worry* about housing for Leo. Housing challenges have been a major source of distress over the years. Early on in my son’s illness, when it didn’t work for him to live at home, he was placed in “a group home for young people who had a mental illness. He found it very difficult to be in that environment…They tried him in one group home after another…He ended up sleeping on the streets an awful lot and running away… Then he ended up living downtown on the eastside in one of those little single bedroom units and he continued to be in and out of the hospital…I don’t think that the group homes that he was in, I don’t think they would take him back.” He has his own apartment now, but I don’t think that he will be able to manage there for that much longer. “I would give us two more years if we can make that.” Where he will go then, I really don’t know. It is going to be very difficult to find appropriate housing for him. Sometimes I wonder “if there had been a chance of him going into one of the cottages at R, which would have been difficult but could have been doable…You know to live the rest of his life in that kind of environment I think it would have been the best thing… because it’s controlled and it’s sheltered and it’s a safe place, [but] he’s not there and I think it’s going to be very difficult to even consider that.”

Should I have pushed for that? What would have been different if I had? I don’t know. There is an *underlying sense of despair* around his future housing given that his brain functioning will not improve and housing within the mental health system is looking more and more grim. How will it be possible to meet his needs? “He was OK at [the hospital] but I don’t know if in a house people would think he is too wonderful.” I *worry* about what might happen if the only option is to live with family, my daughter’s family. “I don’t want Leo to take over their lives.”

“I also *worry* about the future given my son’s declining [physical] health. I think his
health is going to continue to go down the tube…He’s diabetic. He doesn’t eat well. His hygiene isn’t great. His teeth are beginning to decay…He probably is at risk for his kidneys going. I mean we do not have a future that one jumps up and down about.”

I have also experienced *distress related to difficult or unusual behaviours*. In the confusing early years of the developing illness when we didn’t really know what was going on, there were many distressing, unusual and bizarre behaviours. He would do some “very unusual grandiose things.” He lived in a “psychedelic environment” that was very strange. “One morning he was out on the street hanging on to a telephone pole telling everybody he was Jesus Christ.” And today, it is distressing when I see that “people just don’t understand him and are frightened by his behaviour.”

There have been many *distressing family disruptions*. Mental illness “can play havoc with a family.” All too often plans need to be changed, sometimes abruptly. I will never forget the unexpected decision a psychiatrist made to move Leo from an acute local hospital to a large psychiatric hospital just when I was about to leave on a vacation. “[I was] extremely distressed… because everything was in place… I mean I was going to go the next day. My friends all knew that Leo was in the hospital, his family physician knew that Leo was in the hospital and the understanding was that he would be followed while I was gone and that everything would be fine.” It didn’t turn out that way and I had to cancel my trip. There have also been distressing disruptions in the form of break-ins into my apartment. “He would sleep in the streets and he would kind of figure out ways to get into my apartment complex and once I came home and he had [broken in]… The neighbours knew him and they didn’t know not to buzz him in. They buzzed him in and I came home and he had broken into my apartment by pushing in a window and climbing through the window. I felt that that was unacceptable so I called the police. He was
arrested and taken to lock up and I felt that that was necessary.”

Distressing disruptions were sometimes in the form of night-time crisis calls from the hospital. “The hospital would call me and say ‘Laura, Leo isn’t on the ward. We think he’s on his way to [your place] and he was.” Review panel decisions have also been distressing and disruptive. (Review panels are held when patients, who are involuntarily committed to psychiatric care, challenge this decision.) After a review panel decision I remember saying: “I don’t feel he’s [ready to be discharged]. We don’t have anything in place and no bed. The statement was: Take him. He has won his review panel. He is no longer our responsibility … That’s your problem and so at that point again I realized that the system was not always responsive to what was fair and what was right and who I was as a mother.”

*Anger and frustration* are also ongoing, pervasive sources of distress. I get *angry in the face of unfair prejudice, when I see the stigma* associated with mental illness. I will never forget the day I went apartment-hunting for my son. The apartments I looked at were “grim, dreadful apartments.” When I said to one of the men who showed me the apartments, “This is just awful for the price that I’m paying,” he looked at me and said, “Well beggars can’t be choosers.” That is what he said to me! I could feel anger rising up in me and I said, “My son is not a beggar.” And the response I got was “You know this is the best you’re going to get.” I was extremely angry – “angry that my son was considered a second class citizen and that: Just be grateful for what we have to offer because he’s not worthy of anything else. … That’s the kind of rejection and stigma that I think a lot of families get.” There is still a lot of stigma. “You know when somebody goes up and down the aisle in a wheelchair in a grocery store, everybody works on accommodating them and when my son, when he goes up and down aisles, he looks different and he babbles and he has a loud voice and babble, babble babbles. He’ll reach out and pat people
and the security guards have been called on him more times than not.” As for the mentally ill who are on the streets, “a lot of times people make them out to be criminals.” I know there are a lot of people who do not want others to know that they have a daughter or a son with a mental illness and “kind of keep that quiet…It’s just not something that you’re going to get a lot of positive vibes from.”

Feelings of anger and frustration have been ‘front and centre’ at times when mental health professionals have made major decisions without consulting or informing me. I will never forget the day that Leo was transferred to R, a large psychiatric institution: “Nobody had told me that he was going to R. No-one had called. No-one had said anything. So Leo was taken and placed somewhere with no consultation….Nobody in Leo’s life felt that he should have been there. And nobody was consulted….Not only was I traumatized, but of course Leo was traumatized by this whole thing as well and so it was an extremely badly orchestrated situation. So I went in to this … physician and I sat down and I was like in tears and I said: How could you do such a terrible thing to us? How could you do it?”

Some decisions made at R were also extremely distressing. As I’ve said, Leo would run from R. “He ran and he ran a lot. And there’s a place on R campus called CC and it’s a hell hole. It is where horror movies are made. And the physician felt, and he was a jerk – … He felt that the only way to penalize Leo for his running was to put him in CC. And this was with totally and utterly dysfunctional people…They weren’t allowed to be in their rooms during the day… So the only place for them to be was up and down the corridors. And so it was very much like the movie One Flew Over the Cuckoo’s Nest, when you walked into this dorm of totally dysfunctional people, which Leo was not, and that’s where he was.”

At times like these, when I was not consulted, when I did not have a voice, when my
perspective as a mother was not considered and didn’t seem to matter, I was angry - but it was more than that. There was an underlying sense of powerlessness and despair deep inside, a distressing sense of powerlessness that surfaces in the face of situations where there is nothing I can do. The situations I just described happened quite a few years ago, and some things have changed, but change in the mental health system is slow and I am often very frustrated with how slowly things change. “I want to look at solution[s] and I want to continue to work on [those] solution[s]. I don’t want to just sit and talk about it. And I find that the system is not ready to do that … [It is] very frustrating. There’s studies looking at programs and resources for people who are mental health consumers, but we know all that. We don’t need to do another study on them. So we are not able to go with that information further and I find that very frustrating.”

I also find it difficult to manage my anger and frustration when I’m faced with some of Leo’s limitations, responses, and decisions. Sometimes “I’m really not nice. My frustration level becomes extreme because of his inability.” For example, the day that I fell off my bike while practicing for the mental health fundraiser. Leo just stood there and asked if I was OK, but was unable to help me. He was unable “to really be a comfort in a way that [was helpful].” “You know, he would not be the person I would want in my room if I was in an emergency. I’m unhappy with ‘the best that he can’ because at times it’s so little and I don’t know how to help him work through that. But his cognition isn’t there. Such as if I say to him, ‘Go and push the pink button and it will turn your radio on,’ because he really needs his radio, he can’t go there. I’ve got to work through [my anger] because he’s not able to go past that.” I also get angry when I see the poor food decisions he makes given his diabetes. “I don’t have a solution to my anger management with him, I truly don’t” and I feel rather powerless about that.

The many uncertainties associated with mental illness compound my distress in all its
forms. Questions that cannot be answered engender a sense of powerlessness. What course will the illness take? When will there be another relapse? What will happen then? What, if anything, can be done for Leo, given the damage the illness has already caused? Where will he go when he can no longer manage in his apartment, when the supports that he needs are no longer there? What will happen when I am no longer here?

Continued expansion of advocacy and activism skills. As I faced the challenges associated with advocating for Leo, I drew on and expanded the advocacy skills that I had already developed prior to the onset of his mental illness. Similarly, as I became aware of needed changes within the mental health system I addressed them, again drawing on and expanding the skills I had already developed as a political activist.

I learned how to be an advocate for Leo at R, a rather intimidating institution, where initially I was more of a passive observer. I remember the time when I “suddenly just realized that I needed to ask to speak to the head nurse or the psychiatrist, most of the time in situations that were very positive and that again helped me through it. But there were times that were really brutal situations. And terrible things, terrible things were done to Leo at R. And when they would happen I would go to the places that I knew would advocate for him immediately and say: “Listen this is what’s going on. What are we going to do about it?” And they would be resolved… I saw that if I hadn’t stood up for Leo’s rights as a mother that nobody else was going to….I learn[ed] how to be an advocate for Leo and not do it in a way that was ugly or aggressive…. I have worked past the point of apologizing for anything that I ask for…. My advice [to other parents is] to keep on asking for what your family member deserves…Aim high. Aim high.” Persevere and “don’t give up.” My son has “a whole lot of things in place and a lot of that had to do with my pushing.” Mothers are often the ones who get things done. “Often we are
the ones who find apartments for our family member and sometimes arrange to help them
survive in that environment...If I hadn’t been able to do it... I don’t know where Leo would have
been now.” My role as an advocate for Leo is ongoing. This morning I’ve been thinking that
“I’m going to talk to his case manager now that she’s back in town and ask for a pretty concrete
collection.”

As for my skills as an activist, I have always been active in addressing issues that
required change. For example, in the 1960s and 1970s I became involved in “ending the whole
business of segregation in the south because I was part of that whole life style and of course the
anti-Vietnam war [movement].” I also became involved at a national level with various
organizations that addressed the need for change around issues associated with learning disabled
children and the “voice of women.” “I don’t think I ever thought that I was going to be an
advocate for people who were mentally ill because that was not where I was going to go with my
life, but ... I’m one of the people who has done so and in different ways than others. I’ve done it
in my way. If I hadn’t a son who had a mental illness I’m sure it would have been something
else. ... My evolution [as an activist] has more evolved based on what the need is in my family as
much as anything or the need that is in my life...I was always up front in talking about change. I
learned how to stand up and speak publicly. I have [also] been in situations that have been rather
ugly, dealing with issues that people don’t find easy to deal with. And I wouldn’t say I’m a
natural, but I would also say that I’m not afraid to do that.”

I have learned, in mental health reform, “not to say certain things that are going to
antagonize ... [but to] wait until the timing is right.” Confronting and addressing needed change
within the mental health system is ongoing for me. “If I feel that I have something that I really
feel needs to be said or [done] ... I will do that...I’m just not one to sit back and do nothing...So
sitting on committees and making public speaking engagements and doing mental health reform… that’s a constant. I don’t feel that I have any issues that I need to keep quiet about. If somebody has done something that I feel is really wrong I will say that. Absolutely. And I have never let [the mental health professional that sent Leo to R without consultation] forget that he made a very bad decision. And he has changed.”

I am pleased to have an important role in educating and training mental health professionals. I started giving presentations in various places including UBC because “I had stories to tell.” My presentations are primarily about: “a mother’s perspective of mental illness.” One of the things that I make very clear to trainees in the mental health professions is: “If you are unable to treat us [family members] with dignity and respect and listen to us …Get out! You don’t belong here. I don’t want you working with my son.” I say this over and over again because it is so important. The people I talk to “won’t forget what I have to say.” I’ve had people come up to me and tell me what an impact my presentations have had because “they had never thought about what it’s like to be [the parent of someone with mental illness].” In my presentations I also educate trainees about the “differences between professionals and family members” and remain clear about what people who work with the mentally ill and their families need to know and understand. I always emphasize: “You’ve just got to include us in the dialogue about the treatment of our people.” I know that I have made a difference in the mental health system and in the lives of individual mental health professionals. I remember clearly the day I read my poem ‘Born Free’ to an audience that included that psychiatrist – the one who had said, ‘you know, we’ve got to stop [Leo] from roaring.’ “The look on his face was quite profound. I knew I had reached him.”

_i want to continue making a difference._ “I don’t want to sit my life out until I die doing
nothing. I think I would really much rather see if I can do things. That’s just where I am.” When *I look to the future* “I think my role is slowly becoming one of a great aunt…There are some younger people coming forward - some siblings and some mental health consumers. And I don’t know if they as yet have the knowledge and the strength, but they are the ones who are going to have to carry the baton…. For me, personal growth would be to be asked to do something new and contribute something new and if that would happen I would like that very much. I am [currently] looking at other things that I can do in the mental health movement and I see places to go.” *Advocacy and activism are a mechanism of empowerment for me.* Although I am powerless to change my son’s illness or the course of his illness, I can work for change in the system within which he and I must live with his illness.

Substantive relational and personal change. My experience as the mother of an adult child with schizoaffective disorder has changed me relationally and personally. How could it not? I have been to places that I never dreamed I would ever go to. In those places I have been shaped and formed in ways that I could not have anticipated. Words seem somewhat inadequate to describe that change. There is more than can be said. What I can say is that I have “greater empathy.” I am stronger, more courageous, and have an expanded sense of gratitude. I have a closer relationship with my daughter and now have a close relationship with my grandson.

Given the stressful nature of parenting an adult child with schizoaffective disorder, I have made self-care an important and increased, intentional focus. *My sense of humour*, which has always been an important part of who I am, has expanded and played a huge role in helping me cope, even in dire circumstances. *My determination, always strong, has been strengthened* even more as I continue to strive for change, to make a difference. Without question I have gained an in-depth understanding of mental illness and the mental health system, and have a stronger
relationship with mental health professionals that I greatly appreciate and respect.

I think “if you have come from [a place of struggle] it’s maybe easier to understand it in other people.” My experience as the mother of an adult child with schizoaffective disorder has given me “greater empathy for people who are also struggling.” Greater empathy has given me a greater ability to help others. “People will sometimes call and ask questions and sometimes they are in reasonably difficult shape and sometimes I can help them.” I am grateful to be able to do that. Being the mother of an adult child with schizoaffective disorder takes “a lot of strength.”

Like the willow tree, I have been hit by some pretty horrendous storms through my parenting experience. These storms have strengthened me. “There was a period when I was walking around really afraid of what to do and what to say.” Now “I don’t feel that I have any issues that I need to keep quiet about.” I am assertive and set firm boundaries. For example, I can and do say to mental health professionals, “you know, I am a mother and I simply am unable to do all the things that you feel I should do in the time frame that you expect me to do it.” When it comes to public speaking, “it is just a very comfortable thing [for me to do]”

Through parenting an adult child with schizoaffective disorder my sense of gratitude has expanded. I am very grateful for caregivers who care about Leo and about me and communicate that caring to me. It brings to mind the time I called the caretaker at the place on the downtown eastside where Leo was living. She asked “‘Are you his mom?’ And I said ‘Yeah.’ She said ‘He’s really nice.’ … We’re watching over him…He’s very gentle and we’re taking care of him.” That meant a lot to me. It brings tears to my eyes now. “She watched over him and if anybody seemed like they were going to be a predator they were out.” I am grateful for “people [who] made sure that I knew he was safe.” I am also grateful for those professionals who have shown concern for Leo and taken action to help him, like “the site prison psychiatrist” who saw Leo in CC and said,
“This is a young man who doesn’t belong here and let’s get him out.” I am very grateful that Leo currently has a “superb outreach worker. She is extremely family friendly and that puts us in a different situation than some case managers who believe in confidentiality and don’t talk to families.” There have also been some “really wonderful … police officers… [and] other mental health professionals who have been superb.” I am also grateful that the road we have travelled with this illness has not been worse. “I have friends whose children have lived in dumpsters and I have friends whose children have lived in the woods for years and I know those stories very clearly and we have never experienced that. I’m really grateful.” And I am grateful to be able to leave a legacy for my children, an example of what it means to stand up for what you believe in and to take action to make a difference.

As for relational changes, I have a profound sense of admiration for my son. His life is not an easy one. “He obviously knows, in his own way, that his life is not much. … and he has a family history that includes multiple suicides. I don’t see any suicidal tendencies in him now, but I think it takes a lot of courage to be able to continue in a path that doesn’t really have a lot of direction.” It touches my heart to hear him tell me on a regular basis: “‘Today has been a successful good day.’ I think he is trying to make my life good by telling me that.” He cares about me and I care about him and I am proud of his ability to carry on.

Another change is the closeness that I now have with my daughter and my grandson. “My daughter and I talk about lots of stuff. We’ve worked through some difficult times, very horrible times….I’ve been proud of her for a long time. Yeah. She has done some remarkable things in her life. I mean truly proactive.” She shares my values. She isn't going to sit around and see what happens. She is going to make a difference, make change happen, do what she can do. She is working for a better future and she is not afraid of challenges. Like me, she responds when and
where she sees that change is needed. She is now becoming much more involved in mental
health reform. For example, at a recent mental health conference she was on a panel representing
siblings of people with mental illness. “She did a superb job and was clear and concise and said
[what needs to be said] the way that it needs to be heard….So the ‘have mouth will travel’ not
only is in the mother but is in the daughter as well.” My daughter “thinks that I’m the world’s
greatest role model. And that’s where she wants to be and she is.” It is wonderful to know that I
have had a key part in how her values have been formed, in instilling a passion for, and
commitment to, change. “Her partner looks at her and I tease him because I say to him: ‘You’re a
little worried that she’s going to be like me, aren’t you?’” Over the years of parenting an adult
child with schizoaffective disorder I have found that it is very important to pay attention to my
daughter. One of the messages that I stress in my presentations is that “we’ve got to make sure
that we don’t ignore any other child [when we are so involved with our mentally ill child].” I am
also very proud of how my daughter has passed down to her son the values we share and the
influence that I have had in his formation. “I’m in there like an old shoe with books and
conversations about nonviolence, not killing whales and being peaceful and gentle….I want to
make sure that his world is as good as it can be.” Investing in the next generation is empowering
for me, and is another way that I can make a difference.

My experience of parenting an adult child with schizoaffective disorder has also
strengthened my determination. “What is changed in me, hmmm, is just an ongoing firm
resolve.” I continue to be committed to change. I continue to want to make a difference and I
“see places to go” in mental health and also in other areas. For example, “I have been asked now
to sit [on a planning committee] and maybe be a facilitator, you know, for people on ‘Death and
Dying’ and making plans for a good death and addressing what needs to be done as a result of
people my age and older recognizing the fact that they better get things in place… That interests me a lot, but still mental health … [remains] a huge issue.” I am also determined to continue working on personal change, for example, dealing with my anger, especially with Leo. “I will work on that. And I’m much better… I’m not as angry at Leo as I used to be. So that’s a skill I’m still working on.”

The stresses and challenges of my parenting experience have made it so important to be intentional about taking care of myself. I have done that in a number of ways. Exercise, always important in my life, is now even more important. “I try as much as possible to go into the pool every single day - unless I’m on my bike - for about 40 minutes and just tread water. It’s very silent and I’m a water person, but as much as I love the water, I’m not going to be there all day because I get bored. … So if I get on my bike and I’m gone for the day that’s my calm. [The person] I used to live with knew that. If I was really getting ugly, he would figure out a way to get my bike out. ‘Go’ he’d say and I would take off on my bike and by the time I came back I would be a pussycat.” I also find it helpful to talk. “I talk a lot.” Writing poetry has also been “an outlet for [me]. I started writing poetry when Leo was in hospital.” My first poem Born Free “kind of triggered an outflow of about nine poems.” It was a time in my life when I felt a need to write and so my poems “just flowed and they felt very good. And they were poems that I wanted to read to people and so I did.” “For me to hear where I’m at through poetry in those moments was very good… It was a comfortable way of expressing myself and once that was done, it was finished… It [writing poetry] has not come back. So you know, there are those moments in one’s life that you do different things.”

When I was asked to name one aspect of my story of parenting an adult child with schizoaffective disorder that has contributed the most to my growth, I knew immediately that it
was my “*sense of humour*, because I think if I didn’t have a sense of humour I’d be down the tube.” Humour has helped me cope with “some awful things that happen along the way [of this parenting journey] … times that [were] truly difficult.” Humour may have kept me from sinking into despair. My sense of humour is prominent in some of my poems. For example, in one poem “I talk about the fact that my son told me that he was going to kill me and this is all true. And so I decided I was going to call for help and three policemen came and three ambulance drivers came… Leo in the poem … he’s the narrator… said… ‘my mom said if we [knew we] were going to have so much company she would have put the coffee on.’” Ah, yes and there was the time when I went into anaphylactic shock. “I had gotten stung and had called the ambulance. And Leo was there… and I had all these ambulance drivers… There [were] six of them and I felt like handing out my daughter’s address because they were all gorgeous and young and Leo at the time was handing out his business card. So I mean here I am, of course not dying, but you know I needed somebody there. And all I could think of was, gee, I have a daughter who is single. Aren’t you guys gorgeous… And I have a son who is handing out [business cards], patting them on the head … So my sense of humour kicked in at a pretty awful time.”

I also have to laugh when I think of the bike accident I had just last week. It was the day before the bike ride for the mental health fund raiser. Leo and I were practicing. “He stopped and I slammed into him. And the people, when they came up to me as I’m lying like a giant turtle on the ground, kept saying: Are you OK: Are you OK? And I’m saying NO. I’m not. No! No! Don’t touch me. So I cracked some ribs, but I was able to ride. I was fine the day of the ride. I was fine. I had trouble sleeping, because you know… if I move in any direction. I cough and I sneeze and I laugh and it hurts.” And there was the time when a physician asked me if there was any mental illness on my side of the family and I said: “They are New York Jews. They’re all crazy…. And
you know - it’s true. Hmmm - so - humour.” Humour was a big part of my early family life and has continued to be an important part of who I am throughout my life. “My mom’s side of the family were a group of laughers. And so, you know, whenever they would get together, one thing that you would hear is laughter. You know, they had a tough life and there were times that were very difficult, but they still were laughers…If I didn’t have that??? I know a woman who has no sense of humour and I think - Oh dear god - I just would never ever want to be like her.”

Another change in me is that I now have a much greater understanding of mental illness and the mental health system. “I’ve participated in that learning process [about mental illness] enough that that feels good.” As for my understanding of the mental health system, as I said earlier, “When my son became mentally ill I was not expecting this to be part of his life and … didn’t understand the system at all.” Over the years since the onset of his illness, I have had the opportunity to see what is going on in the mental health system. I have an overall perspective. What currently stands out to me is: “The thing that has changed [in the mental health system] is maybe the families. We’ve become stronger and more organized and the services that the professionals have been able to provide have been watered down. And so the changes that I see [currently] occurring - We’re not going forwards, we’re going backwards.” I also have a stronger relationship with mental health professionals that I greatly appreciate and respect. These relationships have “changed enormously. And I suspect that my relationships with mental health professionals will continue to change. I really don’t see it as a stand still.” It brings to mind the changed relationship I have with the psychiatrist I confronted years ago about not consulting with me. Not long ago he called me and said. “Laura, I want you to know what we’re doing, and how we’re doing it and why we’re doing it. And I said ‘Good on you’.”
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Catherine’s Story: Journey to Acceptance

**Main findings in Catherine’s story.** Catherine’s story highlights her strong personal value of acceptance and describes her journey to acceptance as a process of letting go of expectations over time. Her metaphor of “having a rug pulled out from under her feet” emphasizes the impact of her son’s illness on her life as well as her perceived need, after the onset of her son’s illness, to "get her feet back on the ground" – to establish a new way of “standing” in her changed world. This new way of standing and being for Catherine required letting go of expectations and hopes that were no longer realistic or helpful. Catherine tried to make sense of the new realities she faced and struggled with questions such as: What is illness? What is personality? She also voiced sadness related to the multiple losses both in her son’s life and her own life, concern about the impact of her son’s illness on his sibling who is well, as well as the importance of self-care related to physical exercise and establishing a sense of life balance. While Catherine emphasized that the experiences of mothers faced with the uncertainties and challenges of a child’s mental illness are often misunderstood, she also drew attention to the helpfulness of having a friend who does understand. She also talked about the help she received through therapy. Notably, Catherine advised parents not to get too involved in the management of their child’s mental illness, given that this involvement can be overwhelming. She suggested that the management of mental illness is best left in the hands of mental health professionals and the mental health system.

**Introduction.** Catherine is the mother of two children, a son (30) and a daughter (27). Her son, Mark, was diagnosed with schizoaffective disorder three years ago, although he has been ill for approximately ten years. During the first four years of her son’s illness, Catherine was parenting her children together with her husband. She described taking the major role in the
everyday caretaking aspects of parenting. Then, six years ago, at a time when her son’s illness was at an acute stage, Catherine and her husband divorced. Since the divorce her son has lived with one or the other of his parents for short periods of time, but has mostly lived on his own. He has had multiple hospitalizations. Catherine is currently in her mid-fifties and a medical professional in a small town in western Canada. This is Catherine’s story as I have interpreted it, written in the first person:

*Catherine’s Story…*

Growth and change has been a “pretty big” part of my overall story of living with the challenges and uncertainties associated with my son’s mental illness. One word stands out in my mind when I think of my growth and change and that word is - acceptance. My story could be entitled: Journey to Acceptance. My goal is total acceptance, but I’m not there yet. The road I have travelled has not been easy. What I know is, I am moving forward. When I look back I see how far I’ve come and that is encouraging for me. The metaphor of “having a rug pulled out from under my feet” helps me understand what happened when my son became ill and the changes that followed: “Life is going along and … there is such a jolt. … Life wasn’t going to continue to be the way it was supposed to be - kids growing up and becoming independent and successful having families, you know. So it was a jolt… I had to grow, right? So the rug is pulled out from under your feet. Then you have to stand up and start over again. …You have to find a completely different way to sort out your life, to live your life. I guess it [my life] was going on with all these expectations and OK, I’ve got to do plan B now… That wasn’t working the way I was [expecting]… and now I have to go about life in a different way.”

How I have gone about life differently has been influenced by several stressful events in my life that were happening at the same time as my son’s developing illness. One of these events
was the breakdown of my marriage and subsequent divorce. “I was dealing with both these things at the same time, so what was causing me [to change]? It is hard to know whether it was one thing or the other.” I was also living with the challenges and uncertainties associated with my husband’s mental illness – bipolar disorder, diagnosed soon after we were married and before we had children. Unquestionably his illness has also had a profound impact on my life. With these influences in mind, I will tell the story of my journey to acceptance around the following central themes: (a) Expectations, (b) Enduring sadness and loss, (c) Frustration and distress, (d) Trying to understand, and (e) Personal and relational change.

Expectations. When my son became ill “I had to change my expectations completely and have no expectations,” at least that was, and continues to be, my goal. “This [process of letting go of expectations] doesn’t happen overnight. This happens over years. You start with “I don’t expect him to get a job. I don’t expect this. I don’t expect that. And finally, I don’t expect anything.” And I think I’m getting there. I mean I know I get caught there once in a while. You know, I get sucked in once in a while - but less.” Changing and letting go of expectations has become an intentional focus in my life. I remember well the struggle to let go of expectations in the early days of my son’s developing illness before we knew what was happening. Then, after he was diagnosed with schizoaffective disorder, there were additional expectations that needed to change: I had to change my expectations for the future and my expectations of control. Changing and letting go of my expectations required increased tolerance and a lot of hard work. I still struggle with expectations. I struggle with expectations related to my well child and, at times, I struggle in the face of my son’s unrealistic expectations. As for expectations of the mental health system, I have pretty much let go of those. Let me say more.

Before my son was diagnosed I had “expectations in the home about what you ate and
I raised my kids to appreciate the value of education and work. “You know we had that work ethic.” I expected that my kids would turn out to “be working members of society and be independent.” In the early years of Mark’s developing illness I discovered that “I couldn’t have any expectations about how he would behave.” I couldn’t expect that he would eat my meal if I cooked it. I couldn’t expect him to carry his dish over. I couldn’t expect him to be pleasant.” I also couldn’t “ask him to pick up the phone if it was sitting right there. I couldn’t expect him to help me do anything. Like if I needed him to help me lift something or any small thing that you would expect somebody else to just [do].” Although I tried not to compare my children, it became increasingly obvious to me that I couldn’t expect my son to do what his sister naturally did, even though she was three years younger. As you might imagine, this was distressing, but I’ll talk about distress later in my story.

The need to change expectations became even more obvious as Mark’s illness progressed. His first hospitalization became a turning point in terms of expectations. We had been at the wedding of one of Mark’s friends. Mark was not able to get himself ready for the wedding and needed his friends to help him. His behaviour at the wedding was not what one would expect from someone who was celebrating with his friend. He was clearly not enjoying himself. At one point he told me that he was feeling suicidal. I wasn’t sure if I should take him seriously, but I knew there was something wrong so I took him to the hospital. His illness was not diagnosed or treated at that point, but it was clear to me that my expectations of him had to change. As his illness progressed, letting go of expectations became a process of moving from expectations of what he should and will do and be to an acceptance that he will do and be whatever his illness allows him to do and be. For example, I used to try to do special things with and for him to make him happy. Several times I took him to a nice restaurant, one we used to
enjoy going to as a family. Sometimes he would seem to be OK, but then, after we were already seated, he would blurt out “No I don’t want to be here” and so we would have to leave and find a “hole in the wall” place and that would work. I began to realize that “I’m imposing my values on him, because when we were all normal – a normal family…. we would go to a nicer restaurant…and it wouldn’t be a hole in the wall. It would be a nice one. Maybe that’s where he fits in - going to little hole in the wall restaurants, in a group home, and smoking cigarettes all day and not working. That’s probably where he belongs. So it has taken me a long time because I figured you know he’d be [in a much different place in his life].” “I have had to learn… to let him find his place even though it is so contrary to what I thought” or even could have imagined. Now, when I hear about my friends’ children - one in investment banking and the other one in medical school, “it doesn’t get to me like it used to, you know. [I just tell myself] that’s where my son is and, yeah, I’ve accepted that that’s where he is. That [acceptance] is really big for me.”

Over time my expectations for the future have also changed. I have had to give up expectations for recovery. “I used to think, well, maybe he can get a little job and then he can eventually get back to normal somehow.” I would tell myself “he has to start at the beginning…. and maybe he’ll get his act together and eventually get a regular job. I had to give that up too.” Then later my expectations became “that he accept that he has a chronic mental illness and that he will take the help that is provided by our society or government or whatever.” Even those expectations had to change. Now I don’t hold expectations of the future “because I don’t know where it is going to be. I don’t know. So, I think that is a big shift for me.” That said, there are some things that I do have to think about related to his future, like having a trust fund in place for him, so that when I die there will be some funds available for his care. “That is just practical. But other than that – well, I don’t know what my future is going to be either.” So I have to let him
“find his own way” and give up “my expectations of what my family life is going to be like with adult children… Once that is given up, then everything is way easier.”

I’ve also had to change my expectations of having control. “I have to put [those expectations] in a box and say I really have no control over Mark.” “Whether he’s going to take his medicines, where he’s going to live, which hospital he’s going to go to…I have to keep telling myself I have no control over what Mark is going to do. You know, he can walk out of the hospital tomorrow. I don’t have control over it…I can only do so much. . .I have to keep working on it - changing those expectations and really understanding that I do not have control over this situation.”

Letting go of expectations is hard work and has required me to become a lot more tolerant. For example, I have had to change my expectations that Mark maintain a healthy lifestyle, something that has always been very important to me. I have to tolerate unhealthy behaviours that I find offensive, like his smoking. “He smokes. He chain smokes. I have to really let that go. I mean, I don’t like it, but I’ve come a long way in that I can actually tolerate sitting with him while he smokes. If we took the clock back and he came home and was sitting there smoking on our patio or something at home, I probably would have had a fit.” It is easier to tolerate his behaviours now that he is not living with me, but it is still not easy. “I’ve lowered [my expectations] a lot and I need to lower them more still.”

Another expectation that I continue to struggle with is my expectation of being able to communicate with and be comfortable with Mark when I am with him. Sometimes Mark talks and sometimes he doesn’t talk. Sometimes he is in a good mood and sometimes he is not. I try to accept him the way he is. I try “just to be with him when I visit him, but I have trouble with that…I’m usually busy all the time and just to sit with somebody and just be with them is hard
for me.” It is hard for me not to ask questions like: “How are you doing? Or how was your day? Who were the people you met?” or to stop myself from giving him a little advice. It helps if I’m not “rushed and just wait for him to talk.” So I work hard “at relaxing and just being with him and having no expectations.” I think it is especially hard to just sit with someone without expectations when it is someone in your family, “but that is probably what he needs the most, just somebody to be with him and let him take the lead with the conversation and if he doesn’t want to say anything [then that’s OK].” There are times when he doesn’t say anything during our visit. So “I have to have time to prepare [for my visit with him]. Maybe do something relaxing before. Maybe - walk usually. Some exercise maybe. Talk to a friend. Well yesterday I walked with my hiking friend before I went to see [Mark]. I would probably always do some exercise first. I try not to be rushed so, you know, have all my other duties done so that I’m not rushing in and looking at the clock. Saying OK I’m going to be here for this period of time and try to relax. And I just try to relax you know ahead of time and say [to myself] just try to be with him and be accepting and not have any expectations.”

I also struggle with expectations related to my child who is well. Her life and Mark’s life are extremely different. “She has a good life. She’s got a balanced life. She’s got a nice boyfriend. She doesn’t work too hard. She has fun and studies. She’s happy. And I have to think, O god, I hope I’m not putting too much pressure on her to be the perfect child.” I dare not expect her to make up for what my son cannot be or do.

There are also times when I struggle in the face of my son’s unrealistic expectations. For example, for a long time he did not accept that he had an illness and needed medication. He would say things like: “Oh, mom, I’m fine. There’s nothing wrong with me. I can get a job. I have good people skills. Well – he has terrible people skills.” He expected to become a
businessman or a stockbroker or pursue a professional career like his parents and sister. I struggled with these expectations knowing that at some point he would have to “understand that he has a long term illness and he’s not going to...be a professional and have a car, a job and a wife and kids.” When he was hospitalized again I expected that: “OK. This time he’s going to learn. He’s going to learn that if he stops his medicines he’s going to be back in the hospital.” That didn’t happen, but recently I have seen signs that his expectations are beginning to change and that is a relief to me.

Then there are expectations related to the mental health system. I have pretty much let go of those. For example, I’ve given up the expectation that I will be able to find the best doctor or the best medicine for my son. “That took me a while...not get in there or try to find the right doctor.” I know that “there is not the perfect doctor...There is not the perfect medicine.” I also know that even though I have a basic knowledge of mental illness, I don’t know “what’s really going on with [my own] kid.” So I haven’t done any research on his doctor and I have not been involved in treatment decisions. His doctors “will do the best they can. You know, I might ask the odd question, but I don’t certainly harass them about everything. [I] leave it in their [hands].” “I just can’t take the responsibility. I mean, you know, I think you have to be a little bit proactive, but I also realize that...all those experts aren’t perfect. They are going to make mistakes and if they make a mistake, then at least it is them who have made the mistake. I haven’t made the mistake.” Perhaps, because I am a medical professional, my expectations may be different from the expectations of others. I think most people think that “some doctors are so much better than other doctors and some drugs are way better...I will take whatever doctor that is going to be involved with him...I just have to let it happen, you know...I kind of accept that.” So I would advise other parents to get information about the illness but not get too involved. “I
think that that can be a negative thing in the long run.” I think that parents should “let the system, whatever that is - the doctors, the mental health workers take over, even if they are not completely competent because otherwise you just get worn out, you know, and you can’t do it. Even if you have all the knowledge in the world you still can’t do it.”

Enduring sadness and loss. When I think about the sadness in my life, I think of “huge loss.” This “huge loss” includes losses related to my son’s life as well as my own life. Losses related to my son’s life include: loss of who my son once was before the onset of his illness, loss of healthy functioning, loss of friendships and a supportive social network, loss of the ability to do the things that are expected of young men his age, loss of the ability to have fun and enjoy life, and loss of hope for recovery. Losses in my own life include: loss as a caretaker - being unable to meet my son’s needs, loss of normal family life, loss of the ability to communicate easily with my son, and loss of freedom. Sometimes the sense of sadness and loss is in the foreground of my experience. Often it is more in the background, but it doesn’t completely go away. In my journey to acceptance “I think I am coming to terms with it [sadness and loss]” I am accepting that sadness is part of my experience of parenting an adult son with schizoaffective disorder. Let me say more.

My son is no longer who he once was. He was a good student, “naturally clever, naturally athletic.” He “sailed through [school] because he was smart. He had a good memory” so he didn’t have to work hard. He “got through two years of university…without too much trouble.” When I run into “somebody that knew Mark as a kid when he was…very functional” it reminds me of the contrast between who he was and who he is now, so I will avoid talking about him if I can. These situations can be difficult “because the natural thing is to say: ‘How are your kids doing?’” and I don’t want to go there. It hurts too much.
Then there is the loss of healthy functioning. My son’s unhealthy lifestyle goes against my values. As a mother and as a medical professional, it was very important to me to pass on the value of maintaining a healthy lifestyle. “The way I raised my kids was, you know – no smoking, healthy eating, exercise. So what does he do? He smokes a lot. He only eats junk food and he never exercises….all my values were dashed.” I get teary when I think about this. It also makes me very sad when I think of how alone he is. He no longer has friendships and a supportive social network like he once did. “He has no life at all right now. No life. No friends.” And so “after a week I [feel that] should see him again…it is the only thing he has pretty much…He doesn’t seem to connect with anyone else.”

I am also sad about his inability to do many of the things that are expected of young men his age – “not going on the way they [young men] are supposed to.” The friends that Mark grew up with are now “getting married, having kids. It’s hard. It’s sad. He had three good friends…They are all married now.” Mark is nowhere near that. It saddens me that sometimes I can’t even “treat him as an adult. I have to treat him like a kid – [sometimes] like a two year old.” I saddens me to think that he may never be able to live independently. Just the other day I realized that he now worries about that himself. He said something about being “like this [dependent and in and out of hospital] forever… or …having to go to an institution. …It’s sad.”

I am incredibly sad when I see that “he has a miserable life. He has a totally miserable life.” And so “when I go to see him it is not fun…It’s hard to see your kid so miserable.” It drains me to see him the way he is. It is hard for me to even imagine him having fun. “He doesn’t know how to have any fun” and that too makes me sad. My sadness is also about the loss of hope for recovery. His “life has not worked out for him” and for the most part I’ve lost hope that it ever will. “I usually have a knot in my stomach [after I visit with him]. [I tell myself] OK, it is over
now. I have a knot in my stomach because it is sad. It is sad…I guess there is a part of me that thinks: One day I’m going to go in there and he is going to be somewhat better. I mean, and he is going to say - Yeah mom, I am going to the groups. I like this place or I’ve met a friend and I really like her or I’m going to get a job and I’m going to go to group or something [but] he won’t go to any of these things.”

There are also losses in my own life due to his illness. I have lost the ability as a caregiver to meet my son’s needs. “I’m naturally a caregiver I feel. I’m a caregiver by profession - a caregiver by nature - a mother and then I had this kid that really needed to be taken care of but I couldn’t do it. You know someone else has to do it. The government has to do it. Stepping down from that was a challenge.” I have also lost a normal family life. For example, I tried for a long time to have a normal family holiday only to find out that it made things worse for everyone. I thought: “OK let’s have a family holiday. It will be a big, you know, and his behaviour was…just terrible on the whole holiday.” I feel sad when I see my friends go on holidays with their adult children knowing that “I can’t have that.”

I am also aware of the loss of normal family life when I think of my daughter - how I am with her in contrast with how I am with Mark. When I am with her we “talk, we can have fun.” When Mark is around, things change. “We can’t laugh, we can’t have any kind of family gathering with him. It’s just stress. It’s strain.” When he comes over “I don’t ignore him but, you know, just let him be - is the word. But you know, his presence is there - so sullen…and I’m kind of conscious, conscious of that.” I’m sad when I think about how my daughter has missed out because of that. For example, “she hasn’t had the embracement and celebration of some of her accomplishments.” Every time we have celebrated an event in her life her brother seems to get worse. So “I can never imagine having a wedding for instance for her. I just think it wouldn’t be
possible because it would just be really hard, so [hard].” We also used to do family things together with some of my friends and their children. “It’s just not that way anymore.”

Then there is the loss of being able to communicate comfortably with my son. There was a time early in his developing illness when “he didn’t want to talk to anybody, although at first I thought he was targeting me because I was the closest to him.” That has changed and we talk some now. “Sometimes the conversations are what I call real conversations and other times they are not at all. It’s spotty.” It is difficult to know what to talk about. “I can’t say “How are you?” because he’s awful…So [I] can’t say that…Sometimes we just don’t talk at all.” As for being comfortable to just spend time together, “I had to give up those little fantasies that we could have a nice time together.”

I’ve also lost the freedom in my life to do some of the things I would like to do – like go on an extended holiday. “If I had a functional adult son, a functional adult daughter at this stage of my life [it would be different]. There are times when I think: “I want to live my life and I’ve got this burden.” Sometimes when I get really busy I struggle with an “uncertain sense of obligation” and feel like “I have to go see him” because I know that no-one else is visiting him. That said, over the past few years I have been intentional about carving out time for myself. I will say more about that later when I talk about personal change.

Frustration and distress. My journey to acceptance has included distress in various forms, although more so at the beginning of his illness than now. Not knowing how to respond to Mark’s difficult and confusing behaviours has been distressing. The instability of his illness over time has also been distressing and the many uncertainties associated with his illness have added to the distress. At times I have experienced worry, helplessness, and dread. Sometimes I get frustrated with my son’s unwillingness to accept his illness and co-operate with the mental health
system. At times I am frustrated when faced with his demands. I also get frustrated with myself when I get caught up with expectations. It’s also distressing when people who don’t understand mental illness try to give me advice, although that happens less now than at the beginning of his illness.

The early years of his illness were particularly distressing. As I mentioned earlier, I expected him to go out and get a job and he wouldn’t get a job. He would just sleep and “lay around, lay around, lay around, lay around.” That was distressing. My husband and I “would argue about this” and that was distressing. “Just leave him alone he’d say. He will go out and get a job.” Well, it didn’t happen. Sometimes Mark’s behaviour “was really, really bad…like agitated and just awful” and that was distressing. I couldn’t understand what was going on. That was distressing. As I mentioned earlier, his behaviour at the wedding of one of his best friends was very distressing. That was the day he said: “Oh mom, I just … I want to kill myself.”

It is also distressing to think that my son may not have received treatment for his illness as soon as he should have because my husband and I were both medical professionals and we would “present the facts to the doctor” rather objectively – in a way that didn’t convey “how sick he really was.” Emergency personal should have listened to him rather than to us. I remember the first time we called the police. “They would see - we live in a nice house and are medical professionals. [So they decided to] talk to Mark and let him stay home. Otherwise they would have taken him into the psych ward.” It took several trips to the hospital emergency before he was finally admitted and eventually his difficult behaviours required multiple hospitalizations.

With the ups and downs of his illness, I experienced the ups and downs of distress, relief, distress, relief. “Finally they realized he was really sick. I think for a while they didn’t really know what was going on. You know because he didn’t have florid psychotic symptoms and then
finally he had some florid psychosis and since then he’s had quite a few...Sometimes he was manic, sometimes he was depressed…Now he’s been to four hospitals and they’ve all said basically the same thing…and that’s a relief.”

_The instability of his illness over time has been distressing_, i.e. in and out of hospitals and, when out of hospital, living in situations that were certainly not what I would choose for him. At one point he decided to move into “a real disgusting room in a house. It was terrible and he didn’t last too long. He ended up in the hospital [again].” His last hospitalization made it clear that he is unable to function on his own, but “they didn’t have anywhere to put him and then only last week he was moved to a place called [a group home]…So they say that it is semi-long term - up to six months they would not kick him out.” Finally, now he is being “taken care of and he doesn’t seem to resist it, so that is good, but that has taken like ten years…since he got sick for the first time to where he is now.” What’s ahead? I don’t know.

The many _uncertainties exacerbate and complicate the distress_. “At first you really don’t know what’s going on. Doctors don’t know everything. I know that. [And you think] maybe he will get better.” Then when he is discharged from hospital “there’s the going home phase. Like what’s going to happen now?” There is also the uncertainty around the cause of his difficult behaviours when he is not obviously psychotic. “I don’t get annoyed when he’s really sick, but I get annoyed when he’s like this.” There is great uncertainty about the future, “I just, I don’t know where he is going to be. Whether he is going to be in a group home? Whether he is going to function better? Whether? I don’t know.”

I remember well my _worry and sense of helplessness_ when “he wasn’t coping at all. It was hard because do you let him - like just totally flounder?” His psychiatrist said “he was at really high risk for suicide so he…told me to keep an eye on him so what could I do?”
Sometimes I worry about the future and think: Is he going to kill himself and how will I handle that? I then have to be very intentional to contain these thoughts. I will say more about how I do that later in my story. I also remember the *dread* I felt when I was thinking of taking Mark with me to a destination wedding of one of his friends. “I was dreading it …because I knew Mark was supposed to go. He couldn’t handle it….How was I going to be able to have him in the car for that [long] way to the wedding. Something was probably going to happen.”

Then there is the *frustration that I experience around how to respond to Mark’s demands.* “He hassles me…he doesn’t seem to do anything immoral or illegal…but he knows how to push his limits as far as he can go.” Usually he’s asking for money. He will ask me for money and he will also ask other family members for money. That frustrates me. “If I give him an inch he’ll take a mile.” I’ve tried to handle this by asking him to come up with a plan. I say: “It’s not good for our relationship for you to always be asking me for money. I would like you to come up with a plan about how I can help you and what’s reasonable. He can’t seem to do it. He can’t seem to. Whether he doesn’t want to or he just can’t, I don’t know… I have [made] stacks of agreements with him. It doesn’t work. It doesn’t work.” I find his requests “quite wearing” and I need help with how to handle them.

*I also get frustrated with myself when I get caught up in expectations when my goal is to not have expectations.* I am especially at risk of getting caught up in expectations when Mark asks me for advice. I get “sucked in” to the expectation that he will accept his illness and “do what the doctors tell him.” I get “sucked in” to the expectation that he will follow my advice. For example, recently he asked me for money to get a bachelor of commerce degree and advice on becoming a businessman. I tried to make him think reasonably and said: “I don’t think that’s the best thing for you to do right now. You know, you haven’t had a job for nine years. You don’t
have anything on your resume. Start at the beginning. You need to get work through the [mental health system]. You know, [do] whatever the mental health people sort of gear you towards. You have to start with what they have to offer you in training. You’ve been out of the workforce for so long, a long time. And then we get into…an argument.”

*Another source of distress is the advice and lack of understanding that I get from people who think they are being helpful.* I have learned that “no-one really understands…No-one really knows what you go through…what it’s like to live with somebody that has extreme mood changes and extreme behaviour problems.” Talking about it doesn’t help a lot either because “a lot of people are not very good at listening. They want to pipe up their own advice which is usually unasked for and usually completely not very helpful.” I’ve heard all kinds of advice like: “Well, if you just be firm with Mark. If you just send him to like a boot camp or let him join the army or kick him out of the house and throw him on the street [he might get better].” I’ve also heard: How about enrolling him in a carpentry course or getting him involved in volunteer work? “It goes on and on and on” Even a medical colleague of mine suggested that if I stopped catering to Mark he might “rise to the occasion.” All I could think of at the time was: “You don’t have a clue.” We have tried everything that we could possibly think of and it hasn’t helped. Then I have a friend who wants to be encouraging and says: “It will get better. You wait and see - everything will turn out fine. I try to [explain] that it’s a chronic illness and… [I need to] understand and accept…that it is a chronic illness. It will not be cured… [I] have to accept that this kid has this illness and it’s going to be up and down for the rest of my life. And it’s way better for me to accept that than for me to pretend…or to think: Oh yeah, he’ll outgrow this. This is just a phase. It’s not a phase. It’s been nine years… [But she says] Oh no. You wait and see. He’ll be fine. I think he’ll be fine. So it’s frustrating to hear that and say: No he’s not fine.” That said, I know
that most people just don’t know any better. It is hard to understand mental illness. It really is.
There is so much that I do not understand and I am one of those people who really tries to understand what I see.

Trying to understand. I am an analytic person and a problem solver. I search for ways to understand what I see and experience. Understanding is important to me. Before Mark’s illness was diagnosed I worked hard to try to understand his behaviours. After his diagnosis I continued to try to understand why he did what he did. I struggle to understand what is illness and what is personality, and what role, if any, I have had in the development of his personality. I also try to understand his way of thinking. Sometimes I find myself trying to understand how I have come to be where I am.

In the early years of Mark’s developing illness “I just knew there was something wrong.” What I was seeing just “didn’t fit into the stuff that I knew…It didn’t fit.” I remember when I said to Mark: “Something is wrong here. Either you’re depressed, you’re lazy, or you’ve got a medical illness. One or the other.” Others didn’t agree with me and would say “boys are boys” but I couldn’t help questioning: “Is this normal for a boy or not? I just always had this sense that it wasn’t.” For a while there I wondered if I was the problem so I experimented with staying away from him for six months or maybe even a bit longer. It didn’t change his behaviour. When Mark was finally given a diagnosis it was “a relief.” My attempts to understand have continued throughout his illness. For example, I find myself questioning: Are the behaviours I see related to his illness or are they purposeful behaviours aimed at “bugging me.” Sometimes I think that “he likes to bug me about the things that he knows are really important [to me]. Like he’ll say to me…I really want to do some drugs right now. Like, where is that coming from? Like, why does he want to aggravate me? Like, I feel like he is doing that to purposely aggravate me… [He
does] all those things that I didn’t want him to do as I was raising him as a kid. So I think part of it is illness and part of it is personality. It’s all mixed together. It’s hard to know.” When Mark was young he was not sick. He was a good student and had good friendships but he was also “uncooperative, temperamental…And now he is like that except for he is not functioning.”

Because it is difficult to distinguish between what is illness and what is not, it is difficult for me to know how to respond to him. Sometimes I find myself wondering if I have done something as a mother to contribute to his behaviour/personality. “I mean I know [what I did as a mother] doesn’t cause the psychosis, but some of these other little things you know…Personality is probably in there too right?”

*I also try to understand his thinking.* For example, why he won’t go to a nice restaurant with me? Does it “bring back memories that make him sad?” And what makes him want to smoke? How did that even get started? “What makes you think I want a cigarette? …None of his friends smoked…Where did this come from?” Why did he choose to move to the city? “Maybe he separated himself from his friends who were doing well and he was …wanting to be like them and couldn’t and that made him angry and upset and now he is with these other people who are kind of like him.” I also try to understand his thinking around work. As I mentioned earlier, “he’s got this thing about not doing any manual labour.” Where did he get this from? Both his father and I are professionals, but we “always did manual things… It’s like [he is] sticking his feet in and saying I’m not doing any kind of physical work because I’m above this.” The way I see it, he is “taking away opportunities…to have some kind of life.” So I “try to figure out: What are you thinking? What are you feeling? Why are you behaving this way? Like, even if you are psychotic you have some sort of rationalization for what you are doing. You know, they still have a rationalization. It might be faulty, but they still have a reason for what they are doing. Like he
must have something in his mind explaining to him why he should be a stockbroker… [I don’t think he is] being delusional. He’s being - I don’t know what he’s being. Sometimes I think he’s bugging me. But I think he’s fantasizing - which is slightly different than being delusional.” So there is a part of me that really wants to know: “Why is it? Is it his personality? Is it - ? Has he got anxiety? What is it?” There is so much I want to understand, but can’t. “I guess I’ve got to give up understanding.”

Sometimes I find myself trying to understand how I’ve come to be where I am. I think back to how my life has changed over time. My life used to be very family oriented and my activities used to be very much centred around my neighbourhood. I found myself thinking about these things one night a few months back when I was out dancing with “a bunch of strangers.” I asked myself: “What am I doing here?” How did I get here? Sometimes I feel like I’ve lost “a sense of who I was.” I ask myself: Who am I now and who am I becoming? What is clear, is that my life looks very different than it used to and very different from any life I ever imagined.

Personal and relational change. Living with the challenges and uncertainties associated with Mark’s mental illness has “challenged…my fundamental value system, my fundamental personality,” and so it is inevitable that I would experience change both personally and in my relationships. The biggest change is that I am much more accepting. “I’m way further ahead [on my journey to acceptance] than I was five years ago.” I am more tolerant, patient, and less judgmental. My priorities have changed and along with that change I have learned a lot about myself. I am intentional about self-care. There have been changes in my mothering and my relationships with others. My understanding of mental illness has certainly increased and I am now more open to talk about mental illness. Very significantly, some of my beliefs about life have changed. My sense of hope has also changed.
Over time I have become a lot more patient, “tolerant, [and] accepting of my son” – accepting of his illness and tolerant of his behaviours, those difficult behaviours that I described earlier when I talked about changing expectations. I know that I am also more “tolerant of other people about their judging and their advice.” I recognize that “we all have our limitations.” I’m purposefully working on “forgiving, accepting and getting rid of resentments. ... I think that’s a big one for growth.” When I look back I am encouraged to see that I’ve made significant progress in all of these areas.

When my son became ill and my “values were challenged,” I came face to face with the question: “What’s important?” In answer to this question I have had to change my priorities. Two of my highest priorities have become learning how to just “be” with my son without expectations and taking care of myself. Earlier in my story I described trying to be with my son without expectations. Now I would like to expand a bit more on that, given that through putting this priority into practice, I have learned a lot about myself. I will then expand on my priority of self-care. Through the process of intentionally trying to be with my son without expectations, I became aware that I was “too rigid,” had too many rules before, in the early stages of my son’s illness. Those rules had to go. Just being with my son without expectations, means “I have to relax” which isn’t easy for me. I have learned that I am “not a totally laid back - do what you like … kind of parent.” I have also learned that I can only change so much and that change takes time, i.e. I can only “work off the rough edges” so learning to relax is an ongoing challenge for me. I have also learned that I am a person who needs to get away from home once in a while. Recently I went away for a two week holiday to a place where “nobody could reach me…That was good because, you know, I knew that if something happened it would have to be dealt with by others.” I felt very “unencumbered” while I was away and “I haven’t felt like that for a really
There are also other things about myself that I’ve learned, such as how my persevering nature can get in the way of acceptance. “I think [my perseverance] prevents me from saying OK, I’ve got to stop now. It is not working.” Another insight is that “by nature … I’m judging, I’m narrow.” I’ve done some thinking about this and can see how my narrowness and tendency to be judgmental stems, at least in part, from my protected childhood. So becoming more non-judgmental and open is also a work in progress for me.

Regarding my priority on self-care, I believe that parents of children with mental illness “need to take care of themselves” and that includes “not get[ting] too overly involved” with your child and his/her treatment. I believe that “you have to have a life and let them [the children] find their way.” In order to have a life “I really try hard to balance my life” and I think that I am doing that quite well. I have become “a very good coper. I do a lot of things [that help me cope].” One of the things I do is practice “living in the moment more [and] not thinking ahead.” I think a big part of personal growth is “being more aware of myself and what I’m doing” and how I am interacting with people. Sometimes I find it helpful to visualize “reeling in life like a fishing line. If I start to think ahead, like [when I start to worry about] whatever is going to happen to him, I [tell myself] OK, I’ve got to bring this in because I don’t know what is going to happen. Sometimes I think, oh, you know, he’s going to kill himself. I’d better be prepared for it. How am I going to deal with this? Who am I going to call?…My mind gets carried away [and] I start to go on and on and on about all the ‘what ifs’ and ‘what ifs’ and I…have to visualize [reeling in the fishing line]. OK, bring it right in. Right now he’s here. And back to the moment – the present… I think I’m doing that more than if I didn’t have this problem [mothering an adult child with schizoaffective disorder]. Definitely more!”

I also take care of myself by setting boundaries. For example, this week I told him “I’m
really busy with my mom and I don’t think I can see you right this week….I know he likes to see me but I don’t feel really guilty if I don’t make it you know.” I also know that I could not have him live with me. “It would be bad for both of us. It would encourage him to be more dependent and act like a kid and I would suddenly become a mother again [like I was when he was young] and start fussing, worrying…It wouldn’t be good.”

Another big part of self-care for me is exercise. “I do way more exercise [than I used to and] I am more fit than I was five years ago for sure.” Exercise helps depression and I was depressed. I know that some people deal with stress through meditation and prayer, but “it’s hard for me to do that kind of thing.” I started hiking and “I’ve learned to dance. I didn’t use to dance before… I enjoy it - especially the dancing. You have to listen to music. You are with a partner and you are actually doing some steps. It’s actually pretty complex compared to hiking. You don’t have a second to think about anything else. So the whole time I’m doing that I’m not thinking about anything else. So I’m having fun. Hiking is more of a reflective thing because you are walking. Often even if you are with a group you are by yourself for awhile and walking slowly and thinking and sometimes I will get a little bit wrapped up in my own misery when I do that, but I think exercise is really helpful.”

*I also find it helpful to talk.* I mostly talk to one close friend because he understands. I would never share my deep feelings with those who don’t understand. “I’ve also been in lots of psychotherapy over the years” and that has been helpful. “In a lot of ways [being in therapy] just got me through the week.” It allowed me to put stuff that came up during the week “on the back burner [knowing I had someone I could bring it to at my next appointment] and sort of carry on with life.” *I’ve also found it helpful to participate in research studies, like this one.* Participating in a research study “is a way of exploring my own feelings. You know, they’ll ask me questions
that I haven’t thought about. Makes me think about that.” Self-care for me also means doing *things with other people.* Because I’m an introvert I have to work at that. “Just a couple of weeks ago it just seemed like nobody was phoning me to do anything…So then I start phoning people…that person was not available so then I phoned someone else.” I push myself to do “whatever look[s] interesting” and I often meet new people that way.

**Another change is around my mothering.** Mothering before the onset of my son’s illness meant that I provided for my son, kept him healthy, “encouraged [him] to be independent, take care of [himself], you know, work in the world, contribute to [his] education.” I also did things that I knew would make him happy. Now that he has this illness, I know that he may not become independent, care for himself, and work in the world. I can’t make those things happen and I need to “step back.” “He is an adult and I don’t have any more responsibility for him…So, giving him up to the world, the universe, or whatever. I think it is really important for parents to let their kids find their own way even if they have an illness. I really believe in that strongly.”

Among other things, this means that I need to accept his decisions and standards. For example, when I see that his towels are threadbare and he doesn’t have a proper bed, I don’t go and replace them when he says “No, mom. I’m fine.” If I got new towels and a bed for him “I would be doing it for me, not him.” It also means, as I said earlier, that I don’t get involved in treatment decisions, although at times I have given some advice to his doctor about how to handle him. Like, not long ago when Mark refused to go to a group home, I told his doctor that Mark needs to be told what to do - that I have to “handle Mark like a two year old.” Giving him up to the world also means that I no longer try to make him happy by doing things for him that used to make him happy. That said, I still try to help him feel better when he’s down, like when I went to visit him in the hospital and he said: “Mom, you worry too much and it’s about me. I know it’s about me.”
I tried to make him feel better by saying: “Oh, Mark, if I worry about you that’s my problem. That’s not your problem. Your problem is to take care of yourself. And he kept sort of saying: No. I’m the source of your worry. And I’m causing you worry. And I said: Let’s take this as an example: Let’s say a parent worries that their kid’s not going to get the top mark in the class. That’s the parent’s worry you know. That’s the parent’s problem. That’s not the kid’s problem. The kid’s just has to do what he can do. So I try to give him some examples like that [to help him].”

*What hasn’t changed in my mothering is that I will always love him.* Not long ago he asked me: “Wouldn’t you love me more [if I didn’t have this illness]…and I said: No I wouldn’t.” Then he asked a more difficult question: “Don’t you want grandchildren? And I said: No, if I don’t have grandchildren, I don’t have grandchildren, you know.”

*Another change is relationship change.* Many of my friendships have changed “but it’s not all to do with my son.” Divorce changes friendships as well. When I happen to run into friends that I had before my son’s illness “not many of them ask about Mark much.” Those friendships have changed. They don’t understand and they don’t know what to say. “I certainly have found new friends. That’s for sure.” There is one new friendship that I particularly value. This friend “takes a great interest in human psychological dynamics…He gives really sensible advice. No other friend can do that.” When I get reactive and need to hear it, he will say “this is about you not about him [Mark].” He will remind me that “I can’t change Mark. I can only change myself.” He will help me explore what I’m thinking and what I’m feeling and help me to see that “I have to become more tolerant.” When I’m in crisis, he is the friend I go to. He will help me to recognize when the crisis is “exactly what’s happened before. [e.g.] Mark is going to end up in the hospital…Nothing’s changed.” He helps me to not get caught up in expectations
over and over again and to consider other perspectives. For example, when Mark said: “I’m worried that I’m not going to get better” my friend helped me to see the possibility that “Mark is maybe miserable right now because he is actually accepting…that he has got this chronic illness…He might be sad for awhile and maybe eventually get over it and…start then building his new life.” My friend also “understands that [my experience as a mother] is hard.”

*My relationships within the family have also changed. I treasure my relationship with my daughter*, maybe more than I would if my son was not ill. I’m not sure. When she comes home “I’m so happy to see her because I have a kid that I actually have a normal relationship with. We can talk, we can have fun.” *I think that my relationship with my son has also changed for the better since the onset of his illness.* “It is better now because I’m more accepting of his situation and I just have to leave him ‘be.’ So I’ve grown.” I think *I appreciate my family more as well.* “Everyone is nice to him. Everyone includes him…They accept him. They understand it is an illness [and] there is nothing I can do about it.”

Perhaps it goes without saying that *since the onset of my son’s illness I have gained a greater understanding of mental illness.* Of course, I learned about mental illness in my medical training, but that “is a lot different than living with it.” Being a parent of an adult child with mental illness “has humbled me. You know, for sure it has humbled me.” I know that parents understand things about mental illness that doctors don’t. There are things I have learned that are contrary to what I learned in my training. For example, I have learned that “people with mental illness can often hold it together” outside of the home. As medical professionals we were taught that “if the behaviour is there just at home and not on the outside, it’s probably a behaviour problem, whereas a mental illness goes through all areas of your life. I don’t really believe that anymore. I think a mental illness is far worse in the family home.” *My experience has also made*
me much more open to talk about mental illness. When my husband first became ill, I didn’t say much because of the stigma around mental illness. There are still some people that I wouldn’t talk to, but I have been able to help others by talking about my experience. My openness has helped others become more open and want to learn about mental illness. I think parents especially need to learn as much as they can because it is all too easy to “blame themselves … [and end up] thinking that they have been a bad parent.”

I also want to say something about the changes around some of my beliefs about life. Before my son’s illness I had a strong belief that: “If I kept working away at something it will get better or I’ll get what I want or something. That didn’t happen in my marriage and it certainly can’t happen with Mark. I can’t make him better.” I also had the belief: “What goes around comes around right? You know that is pretty basic. It doesn’t happen like that.” Then there is the belief that: “You really have to let go and let life work out for them [your children].” This belief, unlike the first two, has been confirmed and become stronger through my experience of mothering. I also had beliefs about others that have changed. I used to have more “faith in people,” trust that they will care and look out for “others besides themselves…They look out for themselves.” What I have found is that I can “rely on family.” I have also come to believe that “there’s always some benefit of something that’s negative – the other side of it.”

Lastly, my hope has changed. People say “there’s always hope, but I don’t want to have unrealistic hope.” My hope for Mark is “to have some kind of life - a life that I never expected he would have, but a life that he would get some satisfaction out of.” ‘Some kind of a life’ might look something like the life that one of our extended family members had. He had a partner and a little place of his own that his family helped him to purchase. He “took pride in it and took care of it.” He was able to go on vacations. To my way of thinking “that’s not a bad life. You know,
my son doesn’t have anything close to that.” I think that if my son were to accept his limitations maybe he could have some kind of life. Through the experience of Mark’s illness I also learned about the risks associated with hope when hope is unrealistic. When Mark sounds better “the hope comes up…which is probably a bad thing you know, because the hope is that he’ll be better. And I think I really haven’t completely lost that.” So the kind of hope I need “is a different kind of hope. There’s not a hope that he will be better, better and not have this illness” but a hope that he will have some kind of a life.

There is no question that my journey to acceptance has not been, and is not, an easy road. There have been a lot of difficulties along the way and there will likely be more. At times I get discouraged, but overall I am encouraged when I look back and see how far I’ve come. As I’ve said a number of times, I’m still not where I want to be, but I’m a whole lot closer. What I have learned along the road to acceptance has shaped and formed me and continues to shape and form me in ways that I value. That said, I wish with all my heart that I didn’t have to walk this road. “If someone would wave a magic wand and make him quite normal I would be delighted, but I don’t know, I’ve kind of accepted it to some degree.”
### Table 3 Themes and Subthemes in Catherine's Story

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<th>Major Themes</th>
<th>Expectations</th>
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<th>Frustration &amp; Distress</th>
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<td><strong>Sub-themes</strong></td>
<td>Struggling with expectations before the diagnosis</td>
<td>Sadness related to losses in her son’s life: - Loss of who her son once was - Loss of healthy functioning - Loss of friendships and social support network - Loss of her son’s ability to meet developmental norms - Loss of her son’s ability to enjoy life - Loss of hope for recovery</td>
<td>Distress related to difficult / confusing behaviours Distress related to the instability of her son’s illness over time Uncertainties exacerbate and complicate distress Worry, helplessness, dread Frustration related to her son’s demands Frustration with herself when caught up in expectations Frustration with advice from others</td>
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After the diagnosis:  
- Changing expectations for the future  
- Letting go of expectations of control

Changing expectations requires tolerance and hard work

Struggling not to impose expectations on her well child

Struggling with her son’s unrealistic self-expectations

Letting go of expectations of the mental health system

Increased acceptance, tolerance, patience, and less judgment

Changed priorities

Increased self understanding

Intentional emphasis on self-care

Changed mothering

Strengthened relationships

Changed friendships

Increased understanding of mental illness

Changed beliefs about life

Changed hope
Karen’s Story: Working, Watching, and Waiting

Main findings in Karen’s story. The unifying thread in Karen’s story; Working, Watching and Waiting; summarizes the hard work of living with multiple uncertainties and responding to the challenges of parenting an adult child with mental illness in the context of shifting needs over time. Her metaphor of “wheat being blown about in the wind with the constant awareness of possibly being cut down with a scythe” vividly describes the ongoing sense of vigilance and struggle for balance in Karen’s life. Karen’s story also emphasizes what she has called “the constant dilemma,” the struggle with questions such as: How much do you do for your child? When do you let them be ill when that is what they truly want? Her story also provides insight into how a mother’s level of distress and struggle becomes intensified and complicated when her child does not accept her illness and does not want her mother to be involved with her mental health caregivers or even with the mental health system generally. Karen also described the anguish related to enduring loss as well as the importance of taking action, as she put it: “getting on with it.” Action, for Karen, involved advocacy and at times pulling her daughter “out of the gutter.” Karen also emphasized how her life has changed since the onset of her child’s illness, drawing particular attention to: having gained a greater sense of empathy for "the greater human struggle;” how her goals and beliefs about life have changed; and how relationships within the family have strengthened, especially her relationship with her husband. Her story also highlights her intentional focus on self-care.

Introduction. Karen is the mother of two children, a daughter (28) and a son (25). Her daughter, Ann, has been ill for approximately 15 years. At age 16 Ann was diagnosed with schizophrenia. Approximately seven years ago the diagnosis was changed to schizoaffective disorder. Since the onset of her illness Ann has lived in and out of the family home and has had
multiple hospitalizations. At the time of the first two interviews with Karen, Ann was living at home with her parents. By the time of the third interview, Ann had moved into an apartment where she is living on her own. Karen is in her late fifties and retired from her career as a journalist. She is currently actively involved in competitive golf. Karen lives with her husband with whom she has parented Ann throughout the course of her illness. This is Karen’s story as I have interpreted it, written in the first person.

Karen’s Story…

My daughter’s illness has “coloured every single thing in [my] life” and so growth and change have been inevitable. That said, I struggle with the positive connotation associated with the word “growth” as it is hard for me to think of benefitting in any way from my daughter’s illness. “I can be grateful in a certain way for it [growth] ….but it’s not important to me that I grow and change…. I mean my daughter is important. I mean I would give anything if she was well, you know.”

My story could be entitled ‘Working, Watching, and Waiting.’ Working, watching, and waiting have been, and are, ongoing for me - immersed in a context that includes sadness and loss and, at times, emotional anguish and frustration. Through the challenges and uncertainties associated with Ann’s illness I have maintained and honed my ability to “rise to a challenge” – a personal characteristic that has always been an important part of who I am. My experience as the mother of an adult child with schizoaffective disorder has also shaped and formed me in personal and relational ways. My story is told around the following four themes: (a) Challenge, commitment, and purpose; (b) Enduring sadness and loss; (c) Anguish and frustration; and (d) Personal and relational changes.

Challenge, commitment and purpose. Rising to, and dealing with, the challenges
associated with Ann’s illness, reflects the “working” part of my story. I work hard and have 
always been an action-oriented person: “I do tend to take action. I am not afraid of it.” It is 
important to me to find out what can be done and then ‘get on’ with doing it. When Ann first 
became ill I was “very much wanting to deal with it.” I learned as much as I could about the 
ilness with a determination to accept ‘what is.’ Knowing about the illness and accepting what 
could not be changed, then allowed me to focus on doing what I could do to help my daughter 
maintain as stable a life as possible. For me, ‘doing what I could’ included taking on an advocacy 
role in the mental health system. It also included using my insight and experience to help others 
by becoming involved in education about mental illness and in the training of professionals who 
work with persons who have a mental illness.

One of the first challenges I faced when Ann became ill was the challenge of acceptance. 
“It’s very hard [but] I do believe I accept it [the illness].” I know that “I’m not a hugely 
optimistic person, but I am, as I say, a fairly straight-forward person so I just move ahead and 
whatever will be, will be and I will accept it.” To me it is the only way to be able to cope with 
this illness – the “only way to keep your head above water is to ... make the best of it ... accept 
the illness and all it’s going to bring.” That said, there is also an ongoing tension around 
acceptance for me – a tension around accepting the illness and also wanting to do everything I 
can for my daughter. For example, “I’ve always thought I totally accepted the illness, accepted 
her having the illness and yet I still fight to want to see that she’s got her hair trimmed. You know 
the stuff you do as a parent, right? Maybe that’s not a good outfit to wear today, or whatever. It’s 
like ‘let it go, let it go.’” While I know that she has “a lifelong illness. ... I absolutely accept it, it 
doesn’t mean that I still don’t push to have her work or, you know, look presentable or be polite 
or be all those things that you expect your kid to be.” It is especially difficult for me to accept
that my daughter does not accept that she has an illness. Many times I have unsuccessfully tried to help her to accept her illness and in the end I have had to tell myself: “Well, yeah, alright, just let it go. Just don’t go there.” The up and down course of the illness makes the work of acceptance more difficult. Recently I was again at a place where I had to remind myself: “So that’s where it stands. That’s where we’re at.” I have to “accept all over again her decline and accept the cycle again.”

Given what I cannot change, I have a strong commitment to doing what I can for my daughter. As I said earlier, “my whole approach to life is sort of ‘get on with it’…. Just a sense of rising to the challenge. A sense of this is a big mountain here and I’m up to it.” I know that I “can’t give in to the illness” because giving in “can kind of drown you” and so taking action is empowering for me. Right from the start of my daughter’s illness there was “very much a sense of … We’ll deal with it. We will survive and we will succeed. This will be just fine or not fine, but it is one of life’s serious bumps in the road. That was our first approach and to some degree still is.” For example, I have a straight-forward action-oriented approach to working with my daughter’s mental health team. “What’s in her best interests you know? Just let’s get to the point. What can I do as a parent? What can you do as a medical team? Let’s deal with it the best we can.” My commitment to action has also been helpful in times of crises. I remember well a crisis call I received from my daughter several years ago. She had been missing for several days and it was clear from what she said that safety was a concern. Action was needed and so I took action. I knew I had to “get on with it and find her. Phone the police and phone the hospital. Get on with it.” There have also been times when ‘doing what I know needs to be done’ has meant “pulling her out of the gutter.” I am reminded of that when I “see the guy on the street with his little shopping cart. There, but for the grace of God, goes our daughter, right? And of course, she’s
been there and up and down, but she’s got somebody to keep hauling her back.” Recently ‘doing what I know needs to be done’ has meant finding a place for her to live. When she started to relapse again and wanted to move out on her own, I knew we needed to find another place for her to live. This time taking action was also a way to help me cope. “I couldn’t stand to watch her go downhill.” When I look back, I can see that my “tendency to take action,” although honed through my parenting experience, was strongly developed through my job as a journalist. “I had deadlines, very much so. I had to produce a story each day and therefore I had to … get it done and move on.” So as I see it, being action oriented has “been cultivated” in me. “It’s part of my life, part of my personality cultivated by my job to a big extent, and consistent with how I approach the issues around our daughter.”

Taking action has also meant a commitment to advocacy. Given that my daughter has never accepted that she has an illness, it was clear to me from the beginning that she needed an advocate. I began my role as an advocate with a very optimistic attitude and believed “that we could somehow get this on the right track.” I worked hard to keep the professionals responsible for her treatment informed. I have taken, and continue to take, a “proactive stance.” For example, “I fax them a note every couple of weeks before her appointment saying she’s doing this or done that. This has happened in her life or this is going on. … I have no idea what they talk about in their appointments, but this gives them some background.” I believe it is important that her treatment team “get my info whether they want it or not.” Sometimes I feel that it is important to talk with her case worker and so “I’ll phone him and we chat. He knows Ann wouldn’t be happy about it, but whatever – like whatever, we’re all in the same world trying to help her, aren’t we? Again it comes back to this: Let’s get on with it. What’s in her best interests?”

Overall I have been “impressed with the mental health system” and I have a great deal of
respect for mental health professionals “and their workload and generally what they’re trying to do.” As an advocate, I’ve “recognized that we have to get along” and “I’ve got to keep them on my side,” although sometimes it feels like I’m in this dance – a dance in which I am negotiating not just my child’s illness, but also the mental health and medical systems that my child needs to manage her illness. I have had very positive experiences with several of the community mental health teams, however, as an advocate, I have also faced some challenges: (Later I will say more about the anguish and frustration related to some of these challenges. Here I will describe my role as an advocate). When the mental health team let her off her mandatory medication without consulting with, or informing us until after the fact, I wrote to the team and to the Ministry of Health to let them know: “You’ve got to at least inform the family on this.” There have also, at times, been challenges around confidentiality issues. Once, when I returned a call from Ann’s case worker, I “got his associate and the guy immediately launched into the privacy [talk]. ‘I can’t talk to you.’ This tiresome old tale we’ve all been through. …I was quite short with him.” After the call I knew I had to write a letter of apology, but I also saw my letter as an opportunity to educate this case worker about the experience of parents: “You could have said: How are you doing? Because…when families contact workers what they really want to do is just yack, right? They just want to say this is going on. They don’t want information. They already know more than the doctors do.” Another time a doctor at the hospital emergency department would not talk to us because Ann had clearly said: “Don’t talk to my parents.” So I immediately wrote to the head of the hospital psychiatry department and, in fairly short order, “we got a doctor who was willing to phone us. That was very good because you felt ultimately it was in her best interests.” As an advocate, I have learned that there are times when I must not “take ‘no’ for an answer” – times when “you have to wrangle your way through this and that.” I think I started learning that
“as a kid.” I remember the principal saying to my mother, “She’s not a ‘yes’ person, you know. She’s not a ‘yes’ person….I just have a focus now.”

My role as an advocate has also been crucial at review panel hearings where Ann has contested her condition of being on mandatory treatment by injection. Up until her most recent review panel, she has never won her case. I believe that was, at least in part, because I have always submitted letters to the review panels clearly articulating the family perspective and letting them know: “If you don’t know about it, she’s not one to take meds. She won’t even take a Tylenol. She won’t even take a vitamin pill. She’s not going to take oral meds. So if you think she is, here’s another thought.” The most recent review panel responded differently to my letter than previous review panels and, as a result, I was spurred on to become more vocal. “I think my speaking out has taken off” as a result of my experience with the review panel. “Anger makes you speak out more …What else have I got, you know? What else have we got other than sitting and watching our daughter lose out to this illness? That is so difficult. So I guess it is a bit of a fighter mentality.” That said, I have not been involved in activism as some people have. I have written letters/articles and I do “as much as I can but it’s not my all [consuming focus].” For me there is a personal cost associated with “speaking out on behalf of mental illness” given my daughter’s adamant stance that I not become involved. And so, if I speak publicly at all, for example, when I sent the newspaper a copy of the letter to the Ministry of Health, I struggle with questions such as: “Was that a right thing to do? Would I regret it if it came out?” Despite this tension I continue try to make a difference in the mental health system where, and as I can. I have served on the family advisory committee of the local health authority and have become involved in education and training. I do presentations for professionals who work with the mentally ill –the police and others, helping them to understand the family experience, which I
Enduring sadness and loss. The theme of sadness and loss is related to the “watching” in the title of my story. I am sad when I see the effects of the illness in Ann’s life. There is sadness around the loss of a trusting relationship with my daughter. There are also other losses such as the loss of employability and normal work life, loss of control, loss of normal family life, loss of a close friendship, and loss of hopes and dreams for the future. At times sadness is central to my experience such as when I’m driving the car and “a song comes on” that reminds me of “losing a child” – for having a child with schizoaffective disorder feels like “losing a child” sometimes. There is also sadness associated with “this mini black cloud that’s upstairs” when Ann is living at home. At other times, sadness is more in the background of my experience, but it never completely goes away. “That’s never going to go away - that as a human being I have to feel and I have to cope with this sort of searing pain that I have a child who in many ways is a sort of a living death when her illness is at its worst.”

There is sadness around Ann’s loss of cognitive ability – one of the effects of the illness. “She’s lost a lot of cognitive [ability] I can see. They talk about every time a person gets ill again it gets harder to climb back up. Certainly after the last hospitalization I could see marked changes.” Sadness also comes up for me when I face Ann’s firm belief that she does not have an illness. I remember saying to her recently “At some point, you’ve got to stop blaming us for your illness. Of course then she said: ‘I’m not ill’.” I ache for her when she has to defend herself at a review panel hearing. “They are very difficult for her because a lot comes out. There’s a lot of stuff in her face saying: ‘Well, look, how about that? How about this?’ So I know it’s not easy for her to go through her illness and explain herself away and say she’s not ill”

There is also sadness around the loss of a trusting relationship with my daughter. “We
take her to the hospital when she needs to go to the hospital and then we suffer her wrath.” She resents our decisions to act on her behalf because she is convinced that she is well and does not need our help. In many ways I’m missing a normal mother – daughter relationship. I can’t plan to do things with her like other mothers and daughters can do. I can’t “phone Ann up and say: ‘Do you want to go shopping?’”

Then there is the loss of employability and a normal work life. In a concrete way this is Ann’s loss, but the meaning of Ann having and losing a job is also a loss for me. Until recently Ann was employed as a legal secretary. Being a “legal secretary” gave her “a sense of identity” – people would associate the occupation with something good and normal. When I was asked “how she is” I could say, “Well, she’s still working.” I was proud of that, but at the same time I worried about what it would be like when she no longer had a job. That time came all too soon. During her latest relapse “she quit her job shortly after moving” to her own apartment and out of the family home. I knew the move would be “quite a strain for her.” Not having employment or normal work life “was a huge blow, but it was not unexpected.”

Perhaps one of the most difficult losses for me is the loss of control. With this illness there are times when it feels like “things whirl around you” and there is nothing you can do about it – “letting this illness take its own course, however that will be.” At times like that I struggle for some aspect of control. For example “I still like to hang on to….wanting to try to keep her apartment in some kind of a sense of order so that it felt more controlled even if her life was going crazy downhill, a sense of wanting to keep things tidy and neat.” The loss of control was probably most prominent when the recent review panel decided to let Ann off her mandatory treatment. It was a strong reminder to me that ultimately I can’t control what happens to my daughter. Perhaps that is why it is so important to me to have some things in my life that I can
control, like golf. “Golf is something I can control. Golf is something I’m good at. Golf is something I can do. I know the more I sit on this path of tournament golf, even at my level, a senior amateur level, it’s in part because of Ann. It’s in part because this is something I can manage, right? If I work hard at it, if I do my exercises, if I do this, if I do my training there will be an outcome that I can predict - that I can control, that I can manage. Would I do that if I didn’t have an ill daughter? No.” That said, with her recent relapse even my golf game is suffering and I have begun to question: “I should give up golf” because I’m playing “so poorly right now?” Maybe I should just stay at home and “keep the house. …This I can control. When Ann comes home I can be here…. I can manage that. I can be successful at that, but managing a relatively high level of golf and our daughter I don’t think I can handle that.”

Then there is the loss of normal family life. We likely will never have “a stable relationship” with Ann. Her illness has also had a profound impact on our son’s life. He has had to suffer “the embarrassment of having a sibling with a mental illness.” He has gone through “enormous stages of…. wanting to get her as far away as he could, but he’s going to have to face it and does, and as he gets older is facing it more and more.” As the only sibling he “feels hugely responsible for her” and worries “that she worries us.” He is “an incredibly competent successful young man. I have no doubt he will remain that, but I also know that he has been impacted enormously by this – having a sister [with a serious mental illness] and that’s never going to go away.”

Life for my husband and myself is also quite different given that we have an adult child who needs our help. We can’t easily do things, like travel, the way other parents of adult children can. Right now we are facing the question of whether or not to cancel the trip we have planned for the fall given “how quickly she’s going downhill.” It would not be the first time we have had
to cancel a trip, but this time, my husband “is very determined that we carry on with this one. It is still a debate in my mind, you know, whether to go.” So I live with the tension around the possible costs of exercising my freedom by going on the trip. In so doing I would be giving up some control in the event that something would happen to Ann when we are gone. If something were to happen, I would have to live with knowing that I chose to do something for myself instead of being there ‘in case’ for my daughter.

Having a daughter with schizoaffective disorder has also cost me the loss of a close friendship. “I remember dropping a friend like a hot potato. It was the oddest thing…. It was when Ann was in that 14 to 17 period of total chaotic mess.” My friend was a social worker and I remember talking to her about Ann, but “there was nothing there. There was no recognition of an illness or a mental illness.” I still feel strange about losing this friendship because I was close to her. I still don’t really understand what happened. “Maybe I couldn’t have space in my life for an ill daughter and a friend at that time.” I’m not sure, but I think it was more about: “Why didn’t you get it? You’re a social worker. I was surprised. …It was tough.” To be fair, when I look back on it I also realize that maybe she “took the brunt of my two years of grieving, which was grieving in one way, but it was also my sort of stoicism or just the way I guess I deal [with things].” As I’ve tried to make sense of it, I sometimes wonder if it was about “the loss of a child and probably two years of coming to grips with that loss. I just couldn’t deal I guess with a friend who didn’t get it.”

There is also the loss of hopes and dreams for the future. Prior to the onset of my daughter’s illness I assumed that I would go through the normal stages of life that most people go through. Why should my life be any different? There would be “my young person’s life, my working life as a journalist, my parenting life, you know, retirement life. I guess I assumed that
those would go ahead actually relatively smoothly and I think it goes along with my somehow assumption that my kids would be OK. That they just would. Why wouldn’t they be? It hasn’t worked out that way.” I assumed that I would have “two relatively content happy children and reasonably successful. I guess I assumed that both of them would marry, assumed I would be a grandparent” but now I “doubt if she’ll ever produce grandchildren.” Then, at some point after Ann was diagnosed, “it dawned on me …. that this girl was ill and I would not ever see her develop or blossom like one kind of dreams of seeing their children blossom.” That said, “I guess we sort of thought there would be, not an end to it, but a sort of stability to it or a pattern to it.” When that didn’t happen, I began to hope that “she would recognize her illness and go on to be an advocate and take her pills and have her own life in some way that we were a big part of.” Those hopes haven’t been realized either. When it comes to the hope that she would go on to become an advocate for others with mental illness, I think sometimes “one kind of has to take that high road to [feel OK].” I think I still haven’t given up this “sort of vague dream” that she will go on to become an advocate. I’m “sort of sustained by these vague impressions of what will happen.”

Over time there has also been a loss of hope that the mental health system would help Ann to eventually attain a relatively stable life. The loss of hope for stability probably hit me hardest after the recent review panel decision. “I remember it was just like − I can’t believe that. No! You’re wrong. No! And as I say, for the first time I went to this incredible sadness. Unbelievable sadness. I couldn’t stop the sensation of feeling like I was going to cry at any minute.” My sister helped me make sense of my reaction when she said: “It’s the first real sensation of a lack of hope. It’s the complete …It’s just a total lack, a total lack of any hope of stability, really.” I felt completely and utterly powerless. There was nothing I could do to change
the situation. All I could do was watch and wait.

That feeling has lifted a bit over the past three weeks and as it has I’ve wondered if perhaps this profound sadness and loss of hope was “delayed grieving.” I began to wonder if I ever really “adequately grieved. … I think one does grieve in little bits as you go along.” For those three weeks after the review panel decision I really struggled with wanting to “let go” and “have a huge cry and I probably should have,” but I didn’t. Letting go like that is difficult for me. “I always have this feeling - What good is that? Is there an end to this? What is the value in this? or Is that helpful? I’m not so sure it’s helpful.” What I do know is that it was an experience of sadness and loss quite unlike any I had ever had before. “I couldn’t get rid of it. It was there. I woke up with a sense that I was going to break into tears. I went to bed with a sense I was going to break into tears. I was on the golf course in a competition and I couldn’t - I was trying to focus and I’m sure I did to the best of my ability and there were many times when I forgot all about it and did focus, but then it would come back as a wave – this horrible pit feeling in my stomach of just wanting to cry.” The sadness is no longer as consuming, but it is “amazing” to me “that after all these years I hit a depression that I had never had before and it was over that issue” – the complete loss of hope after the review panel decision. It was an experience of ‘doing something’ that didn’t help and now there was nothing to be done. I was left with nothing but grief.

Anguish and frustration. In addition to grief, there have been other forms of emotional distress. There is the anguish associated with watching the effects of the illness over time, anguish around the “constant dilemma” of what to do or not do, and anguish about the future. There have also been times of frustration and anger. At times I also experience the “hurt” of being the target of my daughter’s wrath. Then there are those times when I must endure the anguish of watching and waiting, when there is nothing that I can do.
The early years of Ann’s developing illness were years of “intense focus” – *watching in anguish* “the stages leading up to [the diagnosis]…very, very ill, chaotic and turbulent, police involved and so forth.” Then there was anguish around the realization that “this doesn’t just go away” and the growing awareness of “just how difficult it is.” There has been, and continues to be, anguish associated with the “constant up and downs” of the illness and the tensions around burden and love, hope and despair – “the troughs” that we have sometimes found ourselves in with our daughter. Watching signs of relapse after a period of stability is agonizing. “Watching her decline and listening to her talk to her voices and sort of loving her for who she is and yet watching this disintegration. I mean it’s very painful” – seeing “all the old signs” of relapse: Wanting to move. Wanting “to leave her job. She wants to get out of Dodge, you know. … the same old patterns.” When I see these signs I can foresee what will happen because it has happened over and over again. I know that it is only a matter of time before she is going to become “so ill that she will go into the hospital …. I will once again step in when I feel we have to, probably if the police don’t already.”

At times I struggle with the tension around relief and guilt. For example, when Ann moved out this last time there was a sense of relief and, at the same time, guilt about feeling relieved. I was relieved because it is so very trying on all of us to have her live with us and yet “not [be] part of our lives” and also because when she is not living with us, I can “see things clearer.” The guilt is about feeling relieved that “I don’t have to deal on a daily basis with her.”

Over the whole course of her illness, there has also been the anguish of living with someone who is profoundly ill but “just does not believe she’s ill.” There is also the anguish/stress of dealing with “crazy eccentricity” and the anguish associated with acute disturbances, for example, when hearing: “The devil’s telling me to kill my friend.”
Then there is the anguish over what I call the “constant dilemma.” By that I mean the constant struggle with so many uncertainties/unanswerable questions: “How much is the illness? How much is her? How much is just lethargy from the illness?” What do we “accept as a kid with an illness and also just a kid?” And then there are the questions of: “How much do you do for them? How much? How much do you provide them with constant, constant support?” When I go over to her place it’s “a disaster zone” and I ask myself: “How much do you keep picking up after them or bringing in the cleaners, doing a thorough cleaning? How much do you keep doing that?”

Now that she has won her review panel hearing and she is not taking her medications there are even more difficult questions like: “When do you let them be ill if that’s what they truly want? Or when do we stop this constant fight to demand a relative level of stability for her?” The “constant dilemma” is very real, but it is rarely talked about. How do you talk about these things with someone who doesn’t acknowledge that a problem exists? “She would never stand to discuss the issue of schizophrenia.” So I also struggle with questions like: Does her illness “not allow her to accept it” or, does she choose “not to accept it?” My sense is that both are happening. “It is a symptom that she is unable to accept it.”

All these questions increase the burden of caring – “Why carry on this burden? Why not let her go?” Doctors have told us “on and off in various ways - let her sink.” To some extent we have to let her sink “because I just can’t be there” all the time. I know that if we are going to be in touch it is up to me. It is the “endless dilemma over how much? If she thinks she doesn’t want help, how much do we force ourselves on her? Yet, as parents…. [we] want to know she’s still around.” I know that “there is no right answer. There is no single answer. … It’s back to that nonsense – endless, endless debate over whether one allows people to become ill. It’s this
endless debate in my mind of forcing her to become well or not.”

There is also anguish about the future. “Will we be at some point saying we can’t do any more for you? …. How much as we get older can we cope with?” When I think about the future “will we always make sure that we have a basement suite in case she always just comes back?” Where is she going to “end up?” Will she eventually be on a disability allowance and if so, “What’s that going to do to us?” – our “self esteem?” In the back of my mind there is also “a fear of letting her down, one time or making the wrong [decision]. Well, of not being there for her. Making the wrong decision. Saying this time: No, you are on your own, and having it go really wrong. …Do we one day stop talking to her doctor? Stop fighting to be a part of her treatment team …and having that go wrong and having her treatment go sideways.” I wonder if I could live with the consequences if I stopped “staying so involved” with my daughter’s life and well-being? When I think about the future I am also aware of the possibility of suicide. “You think about that every day. You know the risk of suicide is 10% with these people and I know - I don’t think she’s a particularly big suicide risk…. but there’s that, that lingering [thought].”

Frustration and, at times, anger with the mental health system, have also been part of my experience, although as I said earlier, my overall experience with the mental health system has largely been positive. When I think of frustration and confusion, what comes to mind is the day the doctors at the hospital “sat us down” to talk about the diagnosis. They didn’t give us the great big word ‘schizophrenia’ at that time. There seemed to be “this fear of saying the word in case we all collapsed around in horror. I remember the doctor, he said: ‘Well we have the block but we don’t have the address.’ What on earth are you talking about? I think they were even looking at schizoaffective at that point probably. Looking back at it, I think that’s what he meant. I think it’s schizophrenia but we don’t – you know, he didn’t have the address. Well for heaven’s sake
just say the damn word.”

On another occasion I remember that I was “just furious” with a doctor who had “released her from [the hospital] after one day” when I knew she needed in-patient treatment. And then there was the “kick in the stomach” that I felt just recently when the review panel decided to let Ann off her mandatory treatment. I could hardly believe what I was told by Ann’s doctor: “One of the reasons she was allowed to go off meds was precisely because of the support of the family – precisely because we’re there to catch her! … What he gathered from some of the questions that were being asked and from the tone of the meeting was that the reason was, and I certainly stressed it in my letter, that she had our support and things were going reasonably well. From my perspective that meant things should stay as they were, but what the board found, apparently, was that because, precisely because of the support, that we were there to pick her up, pick up the pieces, [they let her win].”

The frustration and anger at the injustice and betrayal that I felt was overwhelming. “I proceeded to write a letter to the Minister of Health to tell him exactly what I thought of these review panels, so called experts. Given her history of six or seven times in hospital, what on earth did they think they were doing?” In my letter I made it very clear that “this isn’t freedom. This isn’t triumph for civil liberties.” Then, shortly after the review panel decision when Ann, as I predicted, went off her meds and quit her job, “I wrote a strong letter to the newspapers” outlining what had happened: “It was an open letter to the review panel and basically it said: So this is what you did and this is what has happened since. She’s lost her job or she quit her job. She is talking nonstop to her angel voices. I just went through the symptoms and her decline. I just said again. It was just a horrible shame and basically a dereliction of duty to her first of all, to us as a family, to her employer and to BC taxpayers who have to put up again with her
probably being back in hospital.” To me the review panel decision was unthinkable. It was: “an aberration of the panel’s duties… a total distortion of the mental health act which is designed to keep people out of hospital, not to have them go right back in, which is what will happen with her.” Everything within me screamed: “It’s not fair to her. It is not fair to our family. It is not fair to taxpayers. She’ll go back in hospital. The same old cycle. Not fair to her employer. It’s just - you know, it’s just so−!” Words are inadequate to express how “angry” and “distraught” and “confused” I felt over this. “That was not a right decision to make. I thought you guys knew what you were doing.” I can’t help but wonder “What does make them wake up? I mean, how many times do they have to go into hospital and then back again? … The injustice of it is so enormous in my mind.”

And then there is the “hurt” of being the target of my daughter’s wrath. As I’ve said earlier, when she needs to be in hospital we get her there “and then we suffer her wrath for the next few years. That will never end - her wrath at us for putting her in hospital - her wrath at me in particular. …I just know she’ll pull it out whenever she wants” I want to be genuine and open with her, but I can’t. I feel forced to lead “a double life.” I can’t let her know what I am doing in the mental health system because “she would be furious. She’d be furious if she knew I was doing this interview.” I remember years ago when I wrote a letter to the newspaper about a mental health issue I “lived in total fear that our daughter would find out or read it. She never did.” When she temporarily moved back into our home I remember thinking I better hide the files − the communication I have had with her mental health workers over time, a thick file by now. When I send articles to the newspaper I wonder: “If they do come out will I feel this awful sense of betrayal to her? It’s not something she would want so am I sort of betraying her?”

Finally, there is the anguish of just watching and waiting, knowing “she could crash at
any time.” I know that when she goes off her medications “we’re headed for another crash.” I know that “she is going to become ill again. We’ll pick up the pieces. … We’ll wait for the disintegration.” Waiting is like “watching water drip.” I’m surprised at how fast her situation is deteriorating since this last review panel decision. “Now, I just wait, absolutely. We just wait. We just watch.”

Personal and relational change. Given that my daughter’s illness has “coloured every single thing in my life,” change has been “very prominent.” In a summary way, I would say that I am “more human” and more “resilient.” I have developed a changed sense of the world and an enhanced understanding of persons who have a mental illness including my daughter. I have developed a strengthened commitment to loving and caring for my daughter no matter what happens and also to the rest of my family. I have an increased sense of gratitude and a greater capacity for patience and empathy. There have also been changes in my goals and beliefs about life and self-care has become an intentional focus.

It is clear to me that “my path is different” than it would have been had I not had a child with a mental illness. I now have a changed and “expanded” sense of the world and my place in the world. By that I mean that living with my daughter’s illness, “this crazy world of craziness,” has expanded the “horizons” of my awareness and “made me more open.” I have a “greater appreciation for people who are different.” I don’t “shut them out as much as I might otherwise [have done] or look by them.” I also have a greater overall sense of “almost global struggles of people. …a profound sense of the difficulties of life – poverty, mental illness, famine, or war. I mean it’s this background all encompassing sense of sensitivity to the rest of the world.” I also have a sense of my “place” in the “human struggle”; I feel “closer to people who are less fortunate” and along with that, a greater awareness of being “privileged” – I am very aware that
many people do not have “the chance at happiness” that I do. My experience has also “expanded me in terms of my toughness to an illness that could otherwise break you in many ways.”

I also have an enhanced understanding of persons with mental illness, especially my daughter. This morning when I was downtown I passed “a couple of guys” who were possibly mentally ill and homeless - “just pushing their carts along.” I remember thinking that I know “what they are going through and what our daughter is going through. I’ve felt a very close kinship to anybody like that because, Lord knows, if some [day] ... I’d pass Ann [on the street]. … I wonder what that would be like if I ran into her.” Every time I see “the guy standing outside the grocery store” I have this sense that “I know you. I know your life. I know where you’re coming from.” Understanding the illness and understanding my daughter is very important. “You have to know the symptoms, understand what you are coping with.” I have studied my daughter and “I do believe that I get it. I understand the illness. I understand her.” I am fascinated by how her mind works: “It’s weird and wild and wacky. … It’s scary, but it just shows me the extremes I guess of how a brain can work. … [it] puts you into another element of humanness.” I know that I understand my daughter in a way that no-one else can. “Nobody gets it like a parent. Nobody gets it like a parent and it’s kind of mind expanding to know that you alone, you alone, understand this kid - the illness that she is going through because everybody has different symptoms.” I am so aware of her symptoms that I can “see subtle changes in her” that no-one else sees and “I can act instantly. I know what’s going on with her instantly.”

I also have developed a *strengthened commitment to loving and caring for my daughter no matter what happens*. My husband, Paul, and I share this commitment. Paul says: “We’re never going to stop [caring for her]. It’s just the way it is.” We know that “wherever she goes we will help her” and check up on her. We know she can become very vulnerable on her own. We
are committed to helping her cope and live as stable a life as possible. We try to help each other keep a realistic perspective on how to help Ann. We are both aware that the doctor “sort of implies that we are over caring,” but “we’re not really. I know we’re not.” At times I use her language/reality to help her manage in the real world. For example, I’ll say: “I just don’t want the angels to take over your life, and you back on the street living with your angels.” Sometimes I will use what I’ve learned from her to help her manage the future. For example, I once heard her say that her thoughts speed up when she is not well, so I’ve asked her: “Are the thoughts [speeding up?] Your thoughts are speeding up aren’t they?” When she is relatively well, I have tried to gain her cooperation by asking: “So when you get sick again …. what do you want us [to do]?” Another way of caring for our daughter is knowing how much to say to others who don’t understand mental illness. Sometimes when I talk about her illness, I’ll just say “depression because people really get it. They get depression. They never quite get the other thought disorder stuff. That is another whole dimension as you know, but they get depression and there’s a certain sympathy for depression.”

Another important change is the strengthened relationships within my family. There is no doubt that the experience with our daughter’s illness “has strengthened our marriage.” Right from the start Paul and I realized that it was “very important that we maintain a connection as a husband-wife pair.” We knew “we had each other and couldn’t rely on our kids” and so we have become a strong “team, a partnership.” Both of us appreciate that we “couldn’t do this alone. …We have our roles with her.” Paul and I are both involved in the “physical stuff and just being there” and he provides “expertise” and a very “steady hand” in the management of financial things. Paul is “incredibly supportive and incredibly patient” and I know that “we’ve learned a lot from each other.” We also take care of each other. When I was so discouraged in the early
days after the latest review panel hearing “Paul was just very thoughtful, as he is and it was very
nice as a partner and a husband to have that support.” We try “to be open and honest about
what’s going on.” There are times when “I worry about Paul” because I’m retired, but he is still
working and “doesn’t need that kind of stress you know. He takes things on way more than I do.”
In many ways “Paul is the rock, really, in the family” and I “appreciate him” more and more.

I also feel a stronger connection to my daughter. “I experience her illness when other
people don’t see it.” As I’ve said earlier, “I know what’s going on with her instantly and so it’s
that sort of connectedness to her that has enlarged me and made me in some ways very close to
her.” As for my son, he “is very much the apple of our eye and probably too much.” I worry
about that sometimes because there is “more pressure on him in a way – subtle pressure perhaps
in our closeness to him - glomming on to him as almost an only child now.” Sometimes I wonder
if “he has become super competent or super successful in part because he has a sister that he
feels he has to compensate for.”

I also have a greater sense of gratitude. I am grateful that Ann has a case worker who is
“so good with me” and a doctor who understands her. “I’m so appreciative of that you know.” I
am also generally more grateful. “I mean I am hugely fortunate in my life to have a wonderful
partner. To have kids. To have a great job. I’m financially comfortable obviously compared to
many people. The whole gamut. …That just grows on me.” I am also grateful that we are able to
provide good housing for Ann, knowing “not every family can do that.” I am grateful for my
family, who, when I was feeling so depressed, helped me “get a wider perspective of life again”
and reminded me that there are “other things in life besides a sick kid” and “life will go on … No
matter what happens to our daughter, life will go on.” Just talking to my family was a very good
thing when I was so “incredibly down.”
Through my parenting experience I have also gained greater empathy and patience. When “you have a grown child that lives such an incredibly chaotic life … you become more attuned to anybody who is in a similar situation.” When I meet and talk to other parents who live with challenging situations I “feel this connection and empathy.” Many times you just “know what they are going through because you are going through the same darn thing.” As for patience, “you do learn patience, don’t you, with somebody who is incredibly difficult. You just have to - to survive.”

And then there are the changes around goals and beliefs about life. “They have been greatly altered” since the onset of my daughter’s illness. My greatest goal is to have my daughter “become stable and relatively content with her life, whatever its limitations.” The goal to become “a strong team” with my husband has not changed, but my goal to “be very happy, content, laughing into our retirement is not without struggle, not without serious effort.” We had not “envisioned” that Paul would continue working as long as he has and it’s not entirely “because of Ann, but it is in part. I know it is in part.” A goal we never anticipated before the illness is the goal to help our son manage the lifelong impact of his sister’s illness. My goal/hope for him would be “that he grows from it in some way and I think he can.” A belief that has changed is the belief that I would find solutions to the problems that came my way – like in my news reporting job where “I tended to wrap things up in a nice little package of story - showing one side of the story and the other side of the story and then wrapping it up in a neat little parcel that could be edited. I think I tend to think that that’s how life can be with my daughter. I’ll wrap this up. We’ll get some solutions. We’ll put it together and that will be it. And of course it’s not like that. It’s much more raggedy - much more messy.”

I’ve also become much more aware of my limitations and that life is short. My
experience has reinforced my belief that I “can’t rely on [my] children for [my] gratification.”

When I look at the “big picture” – of “how turbulent life can be” and that “so many people are not dealt good cards.” I believe that “how we respond to challenges is what’s going to define us in many ways.” The best that I can do is “make an impact through [my] actions as best [I] can, as imperfect as that is.”

*My experience has also taught me the importance of self-care* and so my advice to parents beginning this journey is to “take care of yourself.” That means “holding on tight to people who love you and who you love because you are going to need all the support you [can get].” It also means “holding on tight to your own sanity … your own sense of well-being …common sense and what’s right.” These are essential when you face many of the difficult decisions that are part of parenting an adult child with schizoaffective disorder. Taking care of yourself also means “trying to maintain a balance” in your life even when “extreme stuff is happening.” I think I have done well with maintaining balance. Yoga has had, and continues to play, an important role in helping me maintain balance. I also “make sure” I have “joy” in my life. Being with our dogs is a “huge” joy. For both Paul and myself “animals are a really big part of …settling and calming.” We will always have animals in our lives. “I just know they are important to us” and help us cope with the illness. “I know they are important for that reason.”

Another source of joy for me is music. Music “gives me a great deal of pleasure.” I find that I “need” it. I “crave” it. Listening to music is part of what I do every day when I walk the dogs down at the river. I “constantly” have music on in the house and seem to crave a little more support that way ….whereas I don’t think I would have that if I had two healthy [children].”

Another important way of coping with my daughter’s illness for my husband and I, especially in the early years, was with “very black humour.” It seemed to be “the only way you
could deal with this craziness, lunacy ....I mean what else can you do? I don’t know.” Sometimes we just had to “roll our eyes because it was one thing after the other. I don’t know, we had some pretty good laughs out of it in the most dire situations.” We would “just laugh and then, I mean, get on with it” − Do whatever we needed to do. Sometimes we just have to laugh about her “great plots to make millions.” Sometimes we just have to “roll [our] eyes” when we listen to her singing, but over time, the ever present burden of the illness has changed our coping needs somewhat. “You know, in years past we would have really launched into it, a good joke, but now we’re a little more weary of it all.” So humour “has been a very important way for us to deal with it. Less so now, but through the very acute phases, yes.” I have never thought of myself “as a totally serious person, but it [the illness] probably has made me a little more − less light as a person.” That said, I really do “appreciate humour when it happens” like when I am having “a wonderful laugh with friends over dinner or something .... I really appreciate those times so much because they are in contrast to this dilemma that’s with us constantly.”

Another part of self-care for me is talking. It is helpful for me to talk with someone who can listen to what it’s like to be “a parent of a child who is troubled.” Sometimes it just helps to “yack about your kid just to get it off your chest.” There is a “certain cathartic” benefit for me just in doing this interview and doing the presentations that I do for the BC Schizophrenia Society.

When I was asked to identify what has contributed the most to my growth and change, I immediately responded with “the extreme harshness of it. The harshness of the illness, the severity of it, which is sometimes a bit beyond comprehension.” The “harshness” has “prompt[ed] a softness in me [that] rounds me out more in the end.” As for a metaphor to describe my parenting experience, what came to mind is: “Wheat blowing around in the wind,
yeah. I don’t feel particularly [strong] just because of the uncertainty of it all. [Early on] I was probably a little more sure that everything would just be stabilized at some point” and because that hasn’t happened, a weariness has set in. “I was always aware that we would go through these waves of up and down, but I guess as a younger person [I thought] I just would weather that. I would just be cool with that. That would be the way it is. I, as a parent, and she, as a daughter. That’s the way it would be. We would all weather this together and soldier bravely on, you know. Now it’s all a bit more messy and a bit more wavy and like a field of wheat there’s no way of knowing which way things are going to go. Again I will have to be defined by how I manage that, but it doesn’t make me feel any different necessarily. I mean my experience of being rooted is with these dogs and with my husband. That’s how the overall experience has been. ….I’ve sort of worked my way through that path and I will continue to do so because that’s just me, sort of stubbornly carrying on [but] I feel like I could be plucked out at any moment or cut down with a scythe.”

And so the tensions, uncertainties, and challenges continue, but they are set in the context of a greater sense of the world and a deeper connection with those I love. I live with greater “softness,” empathy, patience, and gratitude. I will strive to maintain balance in my life and “face the difficulties of this illness with grace and maturity.”
Table 4  Themes and Subthemes in Karen's Story

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Ellen’s Story: Coming to Terms and Moving On

Main findings in Ellen’s story. The unifying thread in Ellen’s story, Coming to Terms and Moving On, draws attention to the possible course of this parenting journey over time. Ellen’s journey started with marked worry, confusion and distress in the early years before her daughter’s diagnosis of schizophrenia was established. These early years were then followed by many years of intense focus on the illness and trying to make her daughter’s life OK. The intensity of these years culminated in a turning point for Ellen, after which she made an intentional decision to no longer “live the illness” and to move on with a deliberate focus on her own life. Ellen’s metaphor of her parenting experience, the experience of a rat in a maze, draws attention to the contrast between the “frenzy” of activity that she described as characteristic of the many years when she was intensely focused on the illness, with how her life changed after making the decision to "move on."

Ellen's story highlights her many years of volunteer service and the significant difference she has made in the field of mental health through her service. Her story also draws attention to the “emotional umbilical cord” that linked her emotions to the up and down course of her child’s illness, as well as the additional distress she experienced related to having a child who is unwilling to accept her illness. Her story vividly describes the painful experience of being rejected by her child. Of particular importance, Ellen voiced the need for mental health professionals to be aware of, and sensitive to, the possible precariousness of the relationship between a parent and their mentally ill child particularly when the child does not accept his/her illness. Ellen also voiced an enduring sense of loss although she specifically stated that she had made an “academic” decision not to dwell on this sadness and loss. Her story also highlights the personal and relational changes that reflect how she now engages with life in new and
meaningful ways. Central to these changes are: changed assumptions about life, a strengthened relationship with her partner, and an intentional focus on self-care.

**Introduction.** Ellen is the mother of two children, a daughter (approximately 40) and a son (a few years younger). Her daughter, Lynn, has suffered from mental illness for over 20 years. Lynn was diagnosed with schizophrenia at approximately age 19 and has had multiple hospitalizations. In the early years of her illness she was living at home with her parents and since then has lived on her own. Ellen is currently in her mid sixties and lives with her husband with whom she has parented their daughter throughout her illness. Shortly after the onset of Lynn’s illness, Ellen left her career as a medical professional in order to care for her daughter. Over the course of her daughter’s illness Ellen has provided many years of volunteer service in the field of mental health and has held leadership positions in several non-profit organizations. Her work has significantly contributed to increased awareness of, and investment in, research focused on mental illness.

Ellen’s story is a story of coming to terms with her daughter’s illness and moving on. The process of coming to terms was a lengthy one, culminating in a painful crisis, a point at which Lynn decided to cut her mother out of her life. Her daughter’s rejection marked the beginning of another chapter for Ellen, a chapter that is about “moving on.” Lynn continues to rarely meet with her mother, but now is willing to meet with her father “every week or two.” In Ellen’s words “[It is] the best we can do.” This is Ellen’s story as I have interpreted it, written in the first person.

**Ellen’s Story…**

My story of growth and change through living with the challenges and uncertainties of my daughter’s mental illness is about coming to terms with the reality of her illness and moving
on. Coming to terms was a lengthy process for me. “For many, many years” after the onset of my daughter’s illness, my life “revolved around the illness and it was not OK.” During those years I was desperately trying to do everything I possibly could to fix her life. I eventually came to the realization that “I can’t make it OK for my daughter.” Over the years of her illness I was also trying to make a difference in the field of mental health and that I was able to do.

Looking back on my parenting journey, I can see a point where the focus of my life began to shift. At this turning point I entered a new chapter, a chapter that I call “moving on.” Moving on is largely about “making life OK for myself.” Although I have made a conscious decision not to dwell on it, throughout my parenting journey there has been, and continues to be, an underlying and enduring sadness and loss. As for growth and change, there is no question that there has been “a huge amount” of change in my life as a result of having a daughter with schizophrenia. However, I hesitate to use the word “growth” to describe these changes when I think of “the negative, cynical, tough sides” of the changes I have experienced. “Growth” has this positive ring to it that doesn’t quite fit for me. That said, the changes “are not all negative…the growth and change in many ways is positive.”

When I was asked for a metaphor to describe how my life has changed through living with my daughter’s mental illness, I thought of the experiences of a rat in a maze. A rat’s first experience in a maze is like my parenting experience from the beginning of my daughter’s illness until the point where I came to terms with the illness and began to move on. It was like “banging your head against a wall as you are finding your way through the maze. I think of mazes as being dark - being frenzied because rats move fast going through a maze and scramble around and try to get out. They try and climb up but usually most rat mazes don’t have a way for a rat to get over the wall. And so you might try getting up over the wall, but you never quite can. Sometimes
you might see over the wall, but you can’t quite stay up there. And then the rat runs out of energy. Slowly it either lies down in the middle of the maze or finds a way to the end of the maze, but I do think at the end of the maze the rat has no great knowledge - simply no energy left.” The rat’s second experience in the maze is different, as my parenting experience after coming to terms with my daughter’s illness is different. “This time it is a lot easier.” The frenzy is no longer there. It has been replaced by an ability to move on in a steady way. With this analogy in mind, I will tell my story around the following four themes: (a) The process of coming to terms with my daughter’s illness, (b) Making a difference, (c) Enduring loss, and (d) Personal and relational changes.

The process of coming to terms with my daughter’s illness. As I look back over my parenting journey and try to make meaning of the changes I have experienced, I see that the process of coming to terms with my daughter’s illness can be described by a number of subthemes: confusion/lack of understanding especially in the early years, hope for a cure, fear, years of all-consuming focus on the illness, working to make my daughter’s life OK, reaching a turning point, adapting to the realities of the illness, resignation, and finally looking back and moving on.

The early years of the developing illness were marked with confusion, “sheer lack of understanding of what our daughter was going through” and a desperate search for answers. “I had never dealt with any kind of mental illness nor had my husband. I can remember just pacing up and down the kitchen thinking: Who can I call? Where’s some answer for this?” Our family doctor recognized early on that Lynn needed a psychiatric assessment and referred her to a psychiatrist, but it still took a long time to get a diagnosis – for us to know what we were dealing with. During these early years of confusion it felt like we were “fighting with the system …
trying to get information from the doctors who won’t give you a diagnosis.” Finally we were told: “Well maybe what we’re looking at here is first break.’ Well, what does first break mean? What does any of what you are saying mean?” Several months later Lynn was finally diagnosed with schizophrenia and that “was a relief … because we knew there was something wrong and, OK, now there is a name to put on this. Now we can start reading. Now we can start seeing and start learning.”

“Starting on this journey hope is huge.” I hoped for and expected a cure. “I truly thought that there would be some way to fix this.” I was socialized to “expect a cure for things.” I just thought that if we did all the right things then “this would go away … you know. [If we] just played nice music or just kept the environment quiet or just repainted her bedroom the colour she wanted” then we would see improvement. Well, that didn’t happen and it took a long time for me to realize that my expectation of a cure was a false hope. Over time I also began to realize that “false hope is not very useful in terms of getting on with aspects of the illness” – it catapulted me into a frenzy of activity that was not helpful, but I will say more about that later. I do remember a doctor saying something that was helpful shortly after Lynn was diagnosed. He told me that it was going to take time. And so I began to stop thinking: “Well if I just do something tomorrow or next Friday that this is all going to go away.” I began to realize: “This is slow. They can’t give her a shot and make her better.” Over time I also learned that hope fluctuates. “You get into this big hope thing and then it changes … with constant shifts in the need you are addressing.”

Fear was also prominent in the early years of the illness. “The whole thing scared me.” A big part of this fear was the fear of the unknown. For example, having heard stories from a friend about someone who had been “put into an experimental treatment,” we were “scared of what might happen to her in a psychiatric hospital.” We wanted to be sure she was safe and so we
purposefully “made ourselves kind of obvious” so that the staff would know that “she had family behind her.” Other fears came later, such as: fear around loss of control related to housing and fear related to the future. I’ll say more about these fears later in my story.

After receiving the diagnosis I entered a phase of all-consuming focus on the illness. “I stopped dead doing broader things in the world” and “fixing this” became the focus of my life. “From morning till night I was seeking an answer.” I was “storming around” and “stuck” on the thought that “something you do is going to make a difference.” This all-consuming focus was consistent with being the “kind of black and white dedicated person I am – not good at juggling a lot of balls at the same time… When I start something I will focus on that until it’s finished.” Perhaps not surprisingly, my all-consuming focus and frenzied activity was “very hard on the relationship between my husband and I … as I always felt if we did one more thing we could fix it and he would say: ‘We’ve done everything we can.’” I didn’t understand what he meant at the time. My thinking was: “Of course we haven’t done everything we can do. There’s always something more you can do. There’s something more you can find out - a different drug you can try or a different doctor or whatever it might be.” I was frantically ‘doing’ and “for every one thing my husband did, I did twenty.” Not only that, “my moods were determined by the phase of my daughter’s illness on a day to day basis.” When I look back on this period of my life, it seems to me that I “stagnated rather than grew – stayed in one spot trying to make that spot OK.”

I was working very hard to make my daughter’s life OK. I wanted to give her all the support and care she needed, so when she was first hospitalized “we used to go there every night.” I also helped her to complete her education thinking that it would make a difference. “I helped her get a degree. She wanted a degree, so I learned how to write an essay and use the university library, but it made no difference.” I can see now that I was trying “to make this
middle class life for somebody that can’t handle it.” I was “clutching at every straw to make her life right.” We even decided to buy an apartment building so that we could have some control over who would be living around her because “the whole housing thing scared me.” Well, that didn’t work out either. “In hindsight there are all sorts of things I would do differently, but you can only walk a journey the way you do.”

Eventually I hit a turning point. It didn’t happen overnight. There were a few things that led up to it — like my husband’s comment when I turned sixty: “If you’re not having fun now, you’d better start.” And so, the focus of my life began to shift. I began to take stock of where I’d been and where I wanted to be in the future. I remember thinking: “It’s been 20 years, 20 years since Lynn was diagnosed… I’ve got maybe 20 years left and so, I can repeat the last 20 years, like giving up my job and not exactly giving up my life to her, but giving up a lot of my personal interests. …That’s what it was. Clearly that decision [to live differently] came after a series of little decisions - just saying: OK, I’m not doing it anymore because I don’t really see how what I’ve done for 20 years has made any real difference.” What really “finished me” was when Lynn “threw out everything that she owned − absolutely everything. She was in her apartment with a sheet.” This was after years of helping her with moves and “years of trying to make a nice environment [for her], trying to meet her needs.” The “getting rid” of things “was so complete and 100%.” When I saw her things in the dumpster at the back of the apartment, “I didn’t think I had it in me to go through it again.” At this point I began to understand what my husband had been trying to tell me for a long time: “‘We have done all that we can do.’” We had done everything we could do “short of tying her up and putting a tube down her throat and filling it with drugs.” To me it was just “beyond belief to throw everything in your life out. That finished me. … it just represented for me the end of the line.” Gone went the thought that if she had “her
own sanctuary” she would get better.

While she was still in the process of throwing things away, I tried to get a case worker to intervene, but that backfired on me. I was “hoping that if somebody went to see her that they could change [what was happening],” but it didn’t work and I paid a high price for trying to intervene - Lynn cut me out of her life, refused to see me. “I haven’t pursued her” and metaphorically I cut the umbilical cord to the grip this illness had on my life. Up until this point, “if things were going well for her I [would] feel happy and OK and if things were not going well, it [would be] all I could think about.” I could no longer live this way.

I had to adapt to the realities of the illness. At the beginning of her illness I had to adapt to seeing her on a psychiatric ward and that was not easy. “It was not exactly like out of a movie, but it was fairly close to that for us - people wandering the halls who were talking to a bottle cap in their hand or a radio. So there was really quite a big adjustment.” I had to adjust to not having control and that was hard. “I like things to unfold in a well planned way and I will usually try and make them go my way and, of course, with this illness nothing goes one’s way and so, I have had to squelch that part [of me].” I also had to learn about my daughter’s experience of her illness and how to live with it. I learned that when she was “very quiet and withdrawn” she was likely experiencing hallucinations and delusions. I learned about her reality. For example, one day she came home from school and said: “‘My French teacher thinks I’m a swan’” and I asked: “Well, why?” She then told me about a poem they were studying and how her teacher looked at her every time she said the word ‘swan.’ “Well if you haven’t had anything to do with mental illness, you just take this as being some kind of 19 year old fancifulness,” but it was not. I also learned that “staring and staring” at me for long periods of time, was a way of communicating in her reality. As she put it: “‘That’s how my friends and I communicate.’” I learned not to argue
with her about her experience. “When somebody has a mental illness rationalizing with them is not possible and I have to keep reminding myself [of that].”

And then there is the adjustment to the need for simplicity in Lynn’s life. It has taken me awhile, but I’ve learned that people with serious mental illness “can only function if they keep their lives really, really simple.” Lynn has done that by not having “much furniture or anything now. She has three dinner plates and two side plates. And that’s pretty much it.” When she had more stuff, “for her, everything was out of control.” I no longer buy anything for her that will make her life complicated because I know it will just be thrown away. When I look back I can see that “Lynn tried so hard to live what she believed was a normal life. … She wanted to live the life she grew up with [and I wanted that for her too] and she worked herself to death trying to do that and couldn’t handle it.” Now all she needs to keep track of is what “she is going to eat this week.” She has no commitments. “Now her life is simple. Now she walks all over the city … It’s enough and so that’s how she has made her life OK.” Also, by simplifying her life she no longer loses things, which used to be a big problem. Although I have adjusted to the realities of my daughter’s illness in many ways, “I still find it astonishing. It is still a surprise to me - this illness. I just can’t believe it. I guess because I hadn’t had any family members with mental illness. My daughter looks the same so it is hard to grasp the sheer depth of the changes in her. I want a reason for all the irrational choices and behaviours. Maybe everybody else feels the same way - except for most of the people I know [who have a child with a mental illness] do have a family history so I guess when this happens they say ‘Oh yes. There is something happening and it looks like mental illness.’”

Ultimately, I arrived at a point of resignation and letting go. I had to let go of trying to fix this illness or save my daughter. I no longer “think there is a ‘fix.’ There is a ‘maintain,’ and
there’s a ‘help’ and you want to gain those moments of recovery,” but I now know that I cannot, nor can anyone else, cure my daughter. So I “no longer expect people in the medical community to ‘fix’ as such.” I have even had to let go of the expectation that I could influence, if not control “difficult behaviour…. There’s nothing you can do about it…You can worry yourself sick, but in the end it doesn’t make an ounce of difference.” I can’t even find rational explanations for her thoughts or behaviours. Schizophrenia “is an irrational illness” and that is “particularly hard for a rational person like me” to accept. For example, when “I look at how her hair is cut, [I] want to put a rational answer to that. There probably isn’t a rational answer.” So I just have to keep telling myself - Don’t even try to figure it out. It is particularly hard for me to accept the unpredictability of this illness, because “for me anyway, predictability is … important.” With this illness you never know what is going to happen. The needs are “constantly shifting” and “you never know what those delusions are going to bring. I’ve heard enough of them to know that I can’t begin to guess them.” I also know that I am powerless to make my daughter take her medications. “She cuts down on her medications as soon as she gets well, but that’s just the way it is.” To me her life looks “awfully boring and narrow and terrible,” but there is nothing that I can do about that either.

All that said, there are some things that I can do for my daughter and for myself. For my daughter I can “try to be there when the crises happen, but I am not able to prevent them at all.” For myself, I can “try to keep [anger] away from my life as much as possible” and I can accept “the bad cop” role and make the tough decisions that need to be made even when Lynn is not in agreement. And, I can accept that it will be my husband, not me, who will meet with her every week or so, because she has not given us the choice. We “want to know that she’s OK” and right now that’s the only way we can know. “So having shut me out and met everything that I might
have said or done with a “no,” I guess I had to make it OK for myself and make it all right. I will let her go if that’s how she views she has to live. The only thing I couldn’t let go of was not knowing where she was, so we found a method of handling that.” I have learned that all we can do is “hope to keep her healthy physically, and safe, and we do our best to do that – more and more that realization gets cemented.”

As I look back on the process of coming to terms with the illness, I can see that I have moved on. I am no longer “thinking about the illness all the time.” My “emotions and choices in life” are no longer determined by the illness. I have made the decision that “twenty years is enough. It’s just enough.” I will not let the illness consume my life “to the detriment of many other things” that are important to me. When I did, “I just got so completely and utterly burned out.” There has been “a mental coming to terms with the illness.” I am now “making life OK” for myself even though “I can’t make it OK for my daughter.” I am also no longer interested in reading “books that people with schizophrenia have written and I don’t go to movies about it…. having decided that there is nothing further I can do, I don’t want to think about it.” Clearly I haven’t “completely walked away” because I know that “I will be taking care of my daughter all of my life,” but I have “made an academic decision that I am not going to ‘live’ the illness.” And, very importantly, I am not going “to be disappointed in myself for that. We have to go forward.”

Making a difference. I was brought up to believe that I had a responsibility to make a difference and so when my daughter became ill, I focused on making a difference through advocacy and service in mental health. As an advocate, I dealt with issues that affected my daughter and learned how to work within the mental health system and with mental health professionals. I also provided many years of volunteer service to expand research in mental health and increase awareness and understanding of mental illness.
Right from the beginning of her illness it was clear that *my daughter needed an advocate* - in part because, until you get to know her, it may not be obvious that she has a mental illness.

“My daughter is very, very good at passing [as not having an illness]. She’s tall. She is good looking. She can converse with people.” Even the mental health team “refused to see her” when she left her psychiatrist, because when they met with her “they said she was not sick enough.”

She had a medical history of “eighteen years of diagnoses and hospitalizations!” Several months later she went back to the mental health team and they are now following her. That said, for the first few months after the team agreed to take her on, I think the psychiatrists just “had a conversation [with her] while she told them that everybody thought that she was sick, but she wasn’t really that sick.”

Over the years, I have been the one who has informed her doctors about what has been going on and *dealt with the issues* that come up. For example, “she gets into big debt and so I had a meeting with a lawyer who told me what to do.” I was told that Lynn “has to go into debt.” I now have power of attorney for her and when her creditors call, I just have to say: “Tough beans.” When they tell me that she “will get a bad record,” I respond with: “That’s exactly what we want. That’s the only way you will stop giving her credit.” It feels harsh to me when I have to advocate in that way. It’s not “nice,” and I wish I could be nice, but I have learned that “being nice is not the useful way to be.” To be useful and helpful I have had to take on the bad cop role and, as I’ve said earlier, there has been a price to pay – my daughter does not want to see me and that hurts. As we have cared for our daughter over the years, my husband and I have learned so many things about how to manage the issues that come up with Lynn. Recently I have become aware that we haven’t really “talked about what we actually do” to those who will take responsibility for our daughter when we are unable to. “They have no idea … what things we
have learned over the years … I think we should make a tape or something … [because] it is a long learning curve.”

As an advocate, I have also had to deal with challenges within the mental health system often related to confidentiality issues, especially in the early years. That said, our more recent experience with the mental health team has been largely positive, as I will describe later. During one of Lynn’s early hospitalizations, I remember being concerned about what was going on and not getting any information. All we knew was that every day she was attending a program that was supposed to “help her sort through her problems, whatever these problems were.” But as far as we could tell, the program seemed “totally inappropriate” — focused on grief, not mental illness. What particularly concerned us was that Lynn “was convinced either by the other people or staff” that she was not ill, that: “There’s nothing wrong.” When we were finally able to meet with the psychiatrist and a nurse we were also given that same message, at least initially. It was a “very strange” meeting. I remember the psychiatrist started the meeting by telling us: “We don’t see that there is anything wrong.” I immediately responded with: “My daughter right now is out in your hall huddled in a phone booth. Two years ago she was hiking in Alaska. There’s something wrong.” Finally they told us that they thought Lynn had schizophrenia. “The whole conversation felt rather odd.” Why had they started the meeting by saying: We don’t think there is anything wrong? only to end with: We think she has schizophrenia. Why not be clear from the start? Why does it take mental health professionals “so long to come to this diagnosis or even to approach it?” Were they worried about how we were going to respond? Did they feel that “saying somebody has schizophrenia is a life sentence?”

There is another incident around confidentiality issues that stands out vividly in my mind. Again it was during a hospitalization when the medical staff “would not speak to my husband or
myself and tell us what was going on” and I was “very annoyed.” Then, unexpectedly, I had the opportunity to speak directly to the head of the hospital psychiatry department. I “went up one side of him and down the other [and said]: You are dealing with mental illness. What makes you think that you should be answering only to the person who is mentally ill and not to the families? My daughter is living at home. I have no idea what your recommendations are, what her problems are, how we can help, and you guys won’t even talk to us.” That conversation made the difference - within 24 hours we had an appointment with the psychiatrist to talk about our daughter and her treatment.

As I’ve said, our recent experience with the mental health system and mental health professionals has been much more positive. Last year when Lynn was hospitalized “they were terrific in calling us every day.” I was even asked for my opinion on what would be helpful and responded with: “Well she’s been on such and such a drug. We figure that she’s been taking much less than she is supposed to be taking. We would like her to go on injectable medications so that we can see if this works.” The psychiatrist seemed quite surprised at what I said and asked: “‘How do you know about injectable medications? Do you have schizophrenia?’ That’s exactly his response!” And so I explained to him “No [I do not have schizophrenia], but I’ve worked with my daughter for 18 years and I’m an active person in the BC Schizophrenia Society and I read, so that’s how I know about these things.” I couldn’t help but wonder why he would be so surprised that a parent would know about treatment options?

It underscored for me that mental health professionals need to understand the important role of parents in the treatment of their mentally ill child. It is also very important for them to be sensitive to the relationship between parents and their child, which reminds me of an incident that emphasizes this point: A psychiatrist and a social worker were meeting with me in Lynn’s
presence and the psychiatrist addressed me in a blunt hard-edged tone of voice: “‘Well what is it you want, Mrs. P?’ It felt very confrontational! So what do you say when your child is there?” I can also tell you about a recent meeting with Lynn’s current mental health team that stands out in a positive way. Lynn was invited, but decided not to attend the meeting. The team “seemed to be happy that we had gone in.” They invited our input and valued it. The social worker, in particular, was sensitive to the nature of our relationship with our daughter and suggested that, because she does not have a “direct relationship” with our daughter, she would be a good person to call if we had concerns that we did not wish to talk about in our daughter’s presence. That was helpful. The meeting was also helpful because we were able to provide the team with a lot of relevant information about Lynn that they were totally unaware of. For example, “they didn’t even realize that she had changed her name because they just deal with the medical number. [And] there were just masses and masses of behaviours that they knew nothing about.” Most importantly, we were able to let them know that “we had a Representation Agreement, that we are here, that if at any time they feel that she needs extra support, or if they find out that she has gone in hospital or something, we would appreciate knowing.” We appreciated how “very pleasant” the team members were and felt comfortable being open and straight-forward. “I straight out told them that we thought we had done everything we could to cure our daughter and we haven’t been able to, so we don’t expect them to cure her, but we are very grateful to know that she has the community support.” We understand that mental health professionals have a difficult job to do. This became clear to us when Lynn was last committed and discharged from hospital on injectable medication: “She walked over to the psychiatrist’s office and fired him and then she walked to her family doctor and fired her. And they’re [the doctors] not going to fight, even though in theory, the police should go and pick her up, because she’s under a committal.
They don’t have the will. They’re too busy. They don’t want the costly legal hassles of all this stuff.”

I have also been able to make a difference through service in the broader world of mental health. My involvement with the BC Schizophrenia Society has enabled me to “accomplish a lot that I wouldn’t have done otherwise.” One of my biggest goals was “to influence the research situation” at the university level and I was successful in doing that. Through my work, research interest in mental illnesses has significantly expanded and government funding for this research has been established. This was a huge and very gratifying accomplishment. “I could say, OK, even though there is endless more work to do [I did make a difference].” My work has also helped to advance public and professional understanding of, and counter misconceptions about, mental illness.

However, a number of personal experiences have emphasized to me how much work still needs to be done in these areas. For example, not long ago, I was surprised by the response from a medical professional when I told him that I had a daughter with schizophrenia. He said: “Who told you that?” It came across as “an immediate denial.” Many medical professionals “have very inaccurate views of the illness.” I don’t think you would get that kind of response to any other illness. Another time, when a security guard stopped our daughter for stealing an orange at a grocery store and she told him she had schizophrenia, the response was: “Oh my god, do you have a knife?” So yes, there is still a lot of work to be done.

I am grateful for the opportunities I have had to make a difference in mental health, but at this point, I don’t think I will go back to working with mental illness. “It is just simply too …hard to keep my distance, keep my equilibrium in terms of my moods about my daughter or my relationship with my husband and those things are more valuable to me [now]. … I’ll save
the world another way, if at all.”

Enduring loss. “We lost a lot over this illness.” That said, I have made “an academic decision” not to dwell on the feelings associated with these losses. “If I wanted to I could burst into tears right now, but I’m not going to.” Keeping my feelings at bay helps me to not become engulfed by this illness, but “I certainly haven’t got rid of the sadness or the disappointment.” The losses associated with my daughter’s illness include: loss related to the effects of the illness, loss of who my daughter once was, loss of relationship with my daughter, and loss of normal family life. There is also the loss of transparency/authenticity related to an unacknowledged part of my life, loss of career, loss related to the future, and loss of expectations.

When I think of the “sheer irrationality and the sheer horror of this illness and how it consumes my daughter no matter what,” my heart aches for her. I carry “the sadness of seeing her life become … so very empty. It took quite a long time for that to happen. I would say it took 15 years of mental illness for her to become a really ill person in terms of how she lives and looks.” I have seen the “cognitive impairments and watched them happen.” She can “barely read now,” although in the first few years she “went back to school and got a job.” I am also aware that “the dementia side of this bloody illness … is common” and can onset at an early age. “I understand that their life is shortened for many reasons including diabetes and dementia.”

My daughter is no longer the person that she once was. “She just went from being a bright, fun, interesting person to being somebody who is so ill and unable to do things.” Yes, there is “sadness and disappointment” when I compare how my daughter’s life is now to “what her life was before she got sick. She was good company and she and her brother got along well.” I have to fight the tears when I think about the loss of my relationship with my daughter. As I’ve said earlier “she essentially shut me out of her life” after she threw all her belongings away and I
tried to get someone to intervene. “I think she decided then, that I was not on her side” and her rejection of me “was very severe.” When she would see me on the street she would turn her back and that was “a very hard thing for me.” Since her rejection of me a few years ago, I have seen her “only every second month or so.” For quite a while we didn’t even know where she was and that was “very scary.” She wouldn’t answer the phone “so sometimes we would go over and look up at the apartment and hope that she was in there.” Now she is willing to see her father and meets him every week or two for lunch and that seems to be “the best we can do” to keep in contact. He tells me that when they are together sometimes they “don’t really even talk … just sit down, order a lunch, and leave.” I would not be able to do that, but he is not a verbal person like I am, so it works for him. Sometimes “he takes her picture because otherwise I wouldn’t have any idea how she looks.” I think that in order to cope with her rejection “in some parts of me I have built a pretty thick wall, which might sound cruel, but that is my only way of describing it. It did help that she changed her name… We think of her now as Lynn which is not who she was as our baby and child. Her name was Sarah.”

As much as it was and is painful, her rejection is also a relief in a way because “for so long what I hated about things was that my whole emotional level rested on her emotional level and that was so bad for me. … You know, your child’s doing well and everything in the world’s possible and then, when your child’s not doing well, it’s like … I couldn’t think beyond that.” Now “having decided that I’m not going to be angry and that I’m not going to fix things any more, I [sometimes] find it very strange – not so much to think that I have a daughter, but to remember about her.” That said, sometimes I have these moments of “sadness – I remember the last time she was acutely psychotic or the time before and she was here and I thought to myself: All I want to do is lie down with her, just lie down and hold her. Kind of like if you could just
hold them enough, that you could make it OK.”

Then there is the loss of normal family life. When Lynn became ill we no longer did things as a family the way we used to. “We stopped camping in the summer. We stopped - just stopped so much stuff.” Especially for my son “it was a big loss.” From the time when he was fifteen there were no more family holidays. I think that all too often when a child becomes mentally ill “the other child is just supposed to get out there …. and deal with life.” It is also hard for me to see “that lack of bonding” between Lynn and her brother and his wife, “but by now, I sure know it is, like everything else, something I can’t do anything about.” They have a new baby now and Lynn doesn’t seem to have any interest in the baby. I wish I understood more about that: I wonder if “it makes her sad when she sees what the possibilities [might have been for her]? or … Is it that she never really even thinks about it?” As for family events, at this point Lynn chooses not to attend, and “I’m relieved when she doesn’t want to come for Christmas because if she does, I’m going to be tense the whole time because she will be sitting at the end of the table staring at me.”

There is also another loss in my life that is difficult to describe. It is related to “a big chunk of my life” that is often not acknowledged - that part of me that is related to Lynn, her illness, and my work in mental health. I am especially aware of this loss of transparency/authenticity, an unacknowledged part of my life, when I think about extended family members who never ask about Lynn, although they certainly know she exists. I can’t help but think that they “must have some questions,” but they never ask. I suppose this is because “it is an extremely difficult topic and people have such huge preconceived ideas” about schizophrenia. I hope that someday they will “visit with Lynn and she will be a face to them and not an illness.” I want the family to understand us better, so it’s “hard” for me not to be able to talk about Lynn,
her illness, or my work in mental health. “Sometimes it feels like a big lie when you are just not
addressing at all that part of your life.” On the other hand, I realize that “the kinds of things we
have had to deal with, with Lynn they can’t begin to understand. … If you haven’t had a child
who’s mentally ill, or on drugs, or stealing, or lying, how can you really understand?”

It does bother me though, to think that people who know nothing about my work in
mental health, likely perceive me as “a nonworking woman who spends her time playing cards
and going out with her friends.” Which brings me to another loss – career loss. When Lynn got
sick I had just started on a new career path and soon found out that dealing with this illness “was
just too much so I stopped [my career].” What I did do, as I’ve said earlier, was “put my heart
and soul and brain into doing what I can … to improve the situation with schizophrenia rather
than into my own career.” As a result, I restricted my life “career-wise - definitely.” I am very
aware of that restriction when I look at “how my friends’ lives have evolved over the last twenty
years.”

There are also losses related to the future. When I think about the future, “I have gone
away from hope in terms of things changing very much” for my daughter. “Just [having her able
to] do something is the bottom line.” Sometimes I wonder how she will be cared for when my
husband and I are no longer able to care for her. There is a part of me that thinks: “It doesn’t
matter what you set in place, how hard you work at it,” there is no way that we can adequately
prepare whoever takes on the responsibility for her care. And, when I think about my own future,
there is a loss of confidence and a sense of dread when I think about “being really old … and
reliant on my children to meet my needs.” I don’t ever want to be in a position of being left in the
care of my daughter when I am “vulnerable and unable to protect myself mentally or
emotionally. I find that scary.” As I say this I am aware of the paradox here, because patients say:
“I don’t want to see my parents when they are in the psych unit and I’m saying: I don’t want to see my child, or not alone anyway.” I do want somebody else “to be there if I should ever be incapacitated.”

I end this part of my story by acknowledging that, although I intentionally do not dwell on the sadness and loss, living with schizophrenia is living my life in a context of loss. All the losses I have talked about ultimately contribute to yet another loss, and that loss is the loss of expectations. On this parenting journey “one loses a lot of expectations about how life should go.”

Personal and relational changes. I was always a “very careful” person. “I don’t like change and I don’t adapt to change quickly, [but] once I’m adapted I’m one hundred percent adapted.” When my daughter became ill, I was thrust into this unknown world of mental illness where I had to come to terms with my powerlessness over the illness and, in order to cope, change was inevitable. It was like “schizophrenia came along and all of a sudden you can’t march to your own drummer.” As I have come to terms with the illness and moved on I have experienced changes personally and relationally. There have been changes in my assumptions about the world. Some of my goals have changed. I am more tolerant, less judgmental, and have an increased sense of gratitude. There have also been changes in my relationship with my husband and self-care has become an intentional focus in my life.

There have been changes in my assumptions about the world and how things are supposed to be. I “rarely put myself in a position that I am not in control of” but when “schizophrenia came along” I couldn’t control it. I had been brought up to believe, and thus assumed, that “if you just put enough effort in, enough thought, or enough grinding on an issue, you’re going to be able to solve it, and this was not solvable and it was not going to mend.” I
also believed that if “you get yourself educated … life will follow along a certain path.” Now, “I definitely have that recognition that it is a lot of good luck.” I now see life “much more on a continuum … There are winners and losers and that is just plain, it seems to me, luck or birth or whatever you want to call it. Some people are winners by virtue of what they have been born with and been granted in life. Some people are losers in the sense that a lot of the good parts of life are lost to them and it doesn’t really matter what they do, they are lost to them.” I now believe that “this is what she is stuck with in life and I can make miniscule changes or make miniscule goodnesses happen for her, but I can’t make her life into a winning life.” My assumptions around issues like homelessness have also changed. “I no longer think that all these people on the street could just get a job…. I no longer think that just providing some housing is going to make the world a different place for anybody who is on the street.” I am so aware that “people aren’t making decisions to be losers. Crumby stuff has happened to them.”

Since moving on some of my goals have also changed. An important goal for me now is to maintain balance in my life and decide for myself where I can be most useful, rather than to be driven by the needs of my daughter’s illness or the mental health system. I no longer want to be “carrying a banner, going out and really trying to activate change in the system” the way I did for many years. I want to focus less on my daughter’s illness and more on being with our son and his family. We are now at a place where “we can play a role in his life and he plays a role in ours and we don’t need to think about sickness all the time.” We want to be close to the new young family and want to experience that joy. Our retirement goals have also changed. We had thought about moving out of the city when my husband retired, but that has “completely gone out the window.” We need to make sure that our daughter is OK and we don’t know what’s ahead.

How have I changed in personal ways? Well, “I have become much more tolerant,”
“much less judgmental,” and I have “learned to be more grateful.” I am grateful that I have not been completely beaten down” by the illness. I have seen that happen to others, especially “women who are walking that [parenting] journey alone” - who don’t have support or the “money to keep saving their child from dumpster diving and that sort of thing.” I am grateful that we are financially stable, and that “we were able to send our son away to university so he didn’t have to, from morning till night, live our grief.” I am grateful that I was able to serve as a volunteer in mental health and to establish research funding in the field. “I actually feel blessed that I was able to do that.” And, I am grateful for her mental health team. “I’m just glad that there is a worker that is there, and has the patience, and is at the end of the line, when I need to call them.”

One of the changes I value most is the strengthened relationship with “my longstanding, patient husband.” Over the years I have watched him “accept what’s coming” and not “need to make life be a certain way” and I am now trying to follow his modeling. Over the years he has kept on giving me what I now perceive as a gift of freedom by reminding me: “‘We’ve done all we can.’” As I’ve said, for a long time I was not able to take that in. It wasn’t until my turning point, that I began to understand what he meant. He meant that “if somebody presented him with something that he could do that would help Lynn he would be eager to do it,” and he doesn’t need to “keep delving deeper and deeper and deeper into what is going on. She’s sick. That’s it.” And he will deal with situations as they arise. I now also appreciate that just because “he is not verbal like I am, is not to say that he isn’t feeling [what I feel].” Understanding him, as I do now, has helped us to work together better on the issues that we face with our daughter. He currently has more direct involvement with Lynn than I do, given her willingness to meet with him rather than with me. As a result, he has a greater appreciation of my experience with her. The last time
she was hospitalized “I was so glad that, when the doctor committed her, it was him there receiving the order, having Lynn break down and scream, and be chased by police through the parking lot and stuff, because he handled it very well, but also he felt it, and he had not had that before. You know, [before] it was me that … [dealt with whatever] had to be dealt with. ….I didn’t feel abandoned, but I certainly felt that to a degree he was critical that I maybe should have handled one thing or another differently. So I was glad that he had that [experience] and felt how awful it is. It is embarrassing. You don’t know what to do and you do your best.”

Now we have a mutually agreed upon “division of labour” around meeting our daughter’s needs. I look after the financial end of things and he meets with her. I have learned to stop “always wanting to know about how he felt” and “I believe I have become kinder.” I have ‘let go’ “of my own distress to a degree. I am not needing to lash out at the person closest to me” as I tended to do when I was “so unhappy” and Lynn’s illness was “the overriding and complete and utter topic of conversation” between us. We have learned how to work as a team and when we met with the mental health team, I reminded myself to “be quiet and let him have time to talk.” What we now do for our daughter “is much more evenly spaced. I know that he is way more aware and so we are just partners walking this path together.” And, I appreciate how he helps me keep on track as he did just the other day when I was reading the 24 emails in my inbox related to schizophrenia. He saw what I was doing and said: “You’re not going to do anything about it, are you, because you can’t, you just can’t fix the world. You can’t fix your daughter. You can’t fix the world.”

My parenting experience has also confirmed to me the importance of self care and so I am intentional about it. Key to self-care for me are accessing support as I need it, maintaining friendships, physical fitness, setting boundaries, keeping life simple, and finding/experiencing
joy. My advice to parents starting on this journey is: “Take care of yourself … It is really important to have something else going on in your life besides your child’s illness.” I then emphasize the need for support: “Get yourself a support group because nobody else that’s not dealing with schizophrenia can really understand the issues that one is going to face. Friends can listen to the grief and they can listen to the day to day things, but things go on [with this illness] that are really not so socially acceptable … It is much easier to discuss these things with somebody else who is dealing with the same things.” I have accessed support as I’ve needed it. Being in a support group has given me strength when I needed it. Having supportive friends has helped me carry on when carrying on was hard to do. Talking with counsellors has also been helpful at times, but “one day I just got sick of listening to myself talk at the counsellor so that was finished. … I guess that’s all part of letting go too.”

Maintaining friendships has been so important to me and “I have fabulous friends.” When I think back to the early days of this illness, “my god, I was a dreary friend for a long time and I have to hand it to my friends that stuck by me for so long. We had endless conversations about Lynn and they were very good… For somebody who is a verbal person like me, it is a really big part of your own healing, but maybe not so easy to find people willing to listen.” My friends have been there over the long haul, but at this point in our lives, we have agreed not to talk about mental illness or Alzheimer’s or these kinds of issues. This agreement “has come with age and a change in life” – we have all moved on in different ways. Now I get together with someone for exercise almost every day. “I do a lot more fitness and sort of keep myself eating well and that kind of thing.”

Before I leave the topic of friends, I want to say something about a friend who has been a great positive influence in my life. She has this way of seeing “life from the point of view of joy
most of the time.” So if I happen to be “overly critical of someone, she’ll say: ‘Just stop for a minute while I knock that halo off your head.’ That’s such a good expression isn’t it?” She can say things like that to me because I know “it is meant in love.” When she notices that I am getting stuck in negative thinking, she will say something like: “Pardon me, get with it. Life is not like that.” It is just so good to be around someone like that.

Another important part of self-care for me is *setting boundaries around the issues that come up with Lynn*. For example, I have made an intentional decision not to answer the phone when she calls. If I do, I am at risk of going “into fix-it mode and it’s not helpful to her and it’s not helpful to me.” If she leaves a message, I have time to think about how to respond and then I’m not “jumping all the time.” It is also a way for me to manage the repetitive lengthy calls about constantly changing requests. For months in advance I get calls around the list of things that she wants for her birthday and with each call the list changes. I know that if I “buy into phone call number one, I’m into this vortex. These discussions can go on for hours and you know what? They are exactly the same discussions as twenty years ago.”

I am also trying to *keep my life relatively simple*, in part, “by not engaging and trying to improve her life.” Keeping my life relatively simple also means that I think carefully about how to respond to requests to become involved in causes related to mental illness. “It has given me the ability to not have to beat myself up to do everything that’s asked in the hopes that it will make a difference.”

Finally, and importantly, self-care for me is also about *experiencing “joy.”* A psychologist once asked me “What gives you bliss?” At the time I didn’t really know what she was talking about. Then I read a book called, *Follow Your Bliss*, which got me thinking about joy. When I asked myself “What gives you joy?” I discovered that “I couldn’t answer that. I have only maybe
recently started to answer that. It was not something I was brought up to recognize. I think I spent a lot of time not experiencing joy, just doing my duty – doing what I thought I should be doing… It was certainly not ‘following my bliss.’”

So I have begun to be more purposeful about appreciating and doing things that bring joy into my life. Making my home “comfortable” and beautiful gives me joy and “is extremely important to me.” My home is a “place where everything is OK… It is always completely quiet and like an oasis for me.” I also try to “discipline myself to be in the moment… I say to myself ‘Enjoy this moment.’” I want to be in the moment when my grandchildren come over. I think I am “a better grandmother than I would have been” had I not had the experience I’ve had with my daughter. When my grandchildren come over, “I am prepared to put my concerns away … and feel that joy [of being] involved in their lives.” I try to be flexible, to “access” that joy, and keep it “uppermost,” and I am intentional about this. I dare not “put myself back in that maze of frenzied activity because you are sure as heck not living in the moment when you are in that.” So I have “learned to let go, to be easier on myself and on those around me. To understand that life can hurt.” I try “not to let too many things become important and to take one step at a time.”

Now “I put tulips in a vase, you know. I didn’t do that for a lot of years.” I am more able to say and to feel: “Isn’t it beautiful.”
Table 5 Themes and Subthemes in Ellen's Story

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| Confusion/lack of understanding | Through advocacy:  
- Dealing with issues related to her daughter  
- Dealing with the mental health system and with mental health professionals | Losses related to the effects of the illness | Changed assumptions about world |
| Hope: Expecting a cure | Through service:  
- Expanding research on mental illness  
- Increasing awareness and understanding of mental illness | Loss of of who her daughter once was | Changed goals |
| Fear | Through service:  
- Expanding research on mental illness  
- Increasing awareness and understanding of mental illness | Loss of relationship with her daughter | More tolerance, less judgment, and increased gratitude |
| All-consuming focus on the illness | Through service:  
- Expanding research on mental illness  
- Increasing awareness and understanding of mental illness | Loss of normal family life | Strengthened spousal relationship |
| Working to make her daughter’s life OK | Through service:  
- Expanding research on mental illness  
- Increasing awareness and understanding of mental illness | Loss of transparency\ authenticity | Being a kinder person |
| A turning point | Through service:  
- Expanding research on mental illness  
- Increasing awareness and understanding of mental illness | Loss of career | Intentional focus on self care:  
- support  
- maintaining friendships  
- fitness  
- setting boundaries  
- keeping life simple  
- experiencing joy |
| Adapting to the realities of the illness | Through service:  
- Expanding research on mental illness  
- Increasing awareness and understanding of mental illness | Losses related to the future | Being a better grandmother |
| Resignation and letting go | Through service:  
- Expanding research on mental illness  
- Increasing awareness and understanding of mental illness | Loss of expectations | |
| Looking back and moving on | Through service:  
- Expanding research on mental illness  
- Increasing awareness and understanding of mental illness | | |
Lisa’s Story: Coping, Growing, and Changing – A Spiritual Path

Main findings in Lisa’s story. As reflected in the unifying thread in her story; Coping, Growing and Changing: A Spiritual Path; Lisa viewed much of her experience of growth and change from a spiritual perspective. The context of her parenting experience was particularly complex given the multiple bereavement losses and care-giving experiences related to life-threatening illness in her extended family. These bereavement losses and care-giving experiences, unrelated to her son’s mental illness, were part of Lisa’s life prior to, as well as concurrent with, the development of her son’s mental illness and continue to be part of her life today. Lisa’s story, as the story of an Asian Canadian mother, also draws attention to the impact of culturally different understandings of, and ways of coping with, and making sense of, mental illness.

Enduring loss and sadness as well as distress and struggle also figured largely in her story. For Lisa, distress was related to the effects of the illness in her son’s life and also tension in the family, particularly in her relationship with her husband in the early years of her son’s developing illness. The struggles she experienced were related to uncertainties inherent in living with mental illness, but also related to feelings of guilt and regret when looking back on her early parenting. Lisa also voiced concern about how her son’s needs would be met in the future when she and her husband will no longer be able to care for him and the lingering question: Might he someday die by suicide? Advocacy and activism were also important parts of her parenting experience. For the most part Lisa’s experience with the mental health system was reportedly positive, especially the interactions with her son’s current psychiatrist, although she did report some negative encounters with professionals in in-patient settings. With regard to personal and relational change, Lisa used the metaphor of the two rails of a railway track to draw attention to
the coexistence of “loss and distress” and “valued, positive aspects of life” such as spiritual
growth, greater empathy, and the growth and change that she perceives in her family as a
consequence of living with her son’s illness. Lisa’s story also emphasizes the important role of
counselling and self-care in engaging with life in new and meaningful ways.

**Introduction.** Lisa is an Asian Canadian mother of three children, a son David (27), and
two younger sons (24 and 22). She is in her mid fifties. Lisa is a health care professional and is
currently working in her profession part-time. Her oldest son, David, was diagnosed with
schizophrenia five years ago, although he has been ill for approximately seven years. Early signs
of David’s illness began to develop while he was a third year university student. Throughout his
illness, with the exception of a few months when he lived independently in a basement suite in
his grandmother’s home, David has lived at home with both of his parents. He is currently
employed on a regular part-time basis two days a week and is also taking one course as a part-
time university student. David’s younger brothers are both students and living at home.

Lisa described the early years of the developing illness as extremely difficult and marked
with relationship tension between David and his siblings and also between Lisa and her husband,
who was unable to accept their son’s mental illness. The family relationships have markedly
changed over time. David’s siblings and his father now accept his illness and his father is now
actively involved in helping his son. It is also important to note that in addition to living with the
challenges and uncertainties associated with her son’s illness, Lisa has lived with multiple life
threatening health challenges and losses in her immediate family and extended family over the
past decade. She has provided care for, and experienced the loss of, her sister, sister-in-law,
brother-in-law, and mother. She is currently caring for her mother-in-law who also has a life-
threatening illness. Lisa herself was diagnosed with a life-threatening illness two years ago and
subsequently went through surgery and medical treatment. Her husband has also recently been
diagnosed with a serious illness and, at the time of our last interview, was about to begin medical
treatment. This is Lisa’s story as I have interpreted it, written in the first person.

Lisa’s story…

Caring for my son, David, through his illness has taken, and continues to take, “the whole
of me.” The challenges I’ve faced related to his illness have been “tremendous” — far greater
than the challenges I’ve faced in caring for my family members through their illnesses. Through
these challenges of David’s illness I have grown and changed. The change that stands out most to
me is my “spiritual growth.” My story could be entitled: Coping, Growing, and Changing – A
Spiritual Path. It is a story of how I have coped and made meaning of my experience primarily
through my spiritual faith. It is also about the influences of my involvement in advocacy and
political action and my experience of ongoing loss and sadness. Distress and struggle have also
contributed to how I have changed. For me, change has been personal and relational. The
following themes are central to my story: (a) Coping and meaning-making, (b) Advocacy and
political action, (c) Enduring loss and sadness, (d) Distress and ongoing struggle, and (e)
Personal and relational change. I will tell my story around these themes.

Coping and meaning-making. As I’ve said, I have coped with the challenges and
uncertainties related to my son’s illness primarily in spiritual ways. I read and meditate on
Christian scriptures and writings. I pray and listen to songs with lyrics that remind me of what
God is “doing in my life.” Journaling has also been an important part of my coping process, as
has incorporating into my life activities that I enjoy. I have also made meaning of my experience
in spiritual ways. Through my experience of living with my son’s illness I have gained an
understanding of strength through adversity, purpose in suffering, and faith in God’s care. I have
also gained an appreciation of heaven and experienced the presence of God. I have also learned how to wait with uncertainty.

Since the onset of my son’s illness my spiritual faith has become more important and vital in my life than ever before. Every day I take time to focus on spiritual things. I read and meditate on scriptures, and pray. “It is almost like a ritual.” During this time I try to “empty myself,” acknowledge my helplessness, and “trust and have faith that God will help me and help my family to go through this [the challenges associated with the illness].” I meditate on “promises” such as: “When you pass through the waters I will be with you. When you pass through the rivers they will not sweep over you. When you pass through the fire you will not be burned for I am the Lord your God. Do not be afraid for I am with you.” It helps me to “pray and know that God will take care of it [challenges I am facing], no matter what.” I pray a lot, not just during my regular prayer time, but also when I notice that my son is stressed or doing something that I worry about like “when I see him outside in the backyard smoking.” Listening to music also helps me, especially music with spiritual lyrics. For example, the following lyrics written by Laura Story in her album Blessings encourage me as they validate my understanding of the challenges I’ve faced: “What if your blessings come through raindrops? What if your healing comes through tears? What if a thousand sleepless nights are what it takes to know you’re near? What if the trials of this life are your mercies in disguise?”

Writing in my journal has also been “very healing… very helpful.” I write about the things I think about and whatever seems to stand out to me at the time. Some of the topics I have written about are: “God speaks at the perfect time . . .; One day at a time; Restore, revive, and joy; Do not give up; The secret of care-giving; Learning God’s love through our struggles and sufferings; God uses bad experiences; … Fear of the unknown.” Sometimes in my journal I write
out scripture verses that are especially meaningful to me at the time and then I write out my
response to these scriptures. For example, at a time when I felt fearful and lonely I wrote about
how I experienced God’s comfort through the verse: “My grace is sufficient for you for my
power is made perfect in weakness.” Another time, when I was struggling to understand the
suffering I was experiencing, I reflected on: “Blessed are those who have not seen and yet
believe.” In my writing I frequently remind myself that I am not alone — that God is with me
and gives me strength — “always enough strength just for that day.” When I reread what I have
written over time, I am reminded of how I have grown and changed and “how God has worked
in my life and in the life of my son and my family.” Sometimes “I surprise myself” when I read
what I have written – at the insight I had when I wrote what I did.

Another important part of coping for me is to make sure that I take advantage of
opportunities to engage in activities that I enjoy. “Have laughter, have joy, leave the dishes.
Watch a figure skating show” — do whatever I need to do to bring some lightheartedness into
my life and into my family’s life.

Spiritual meaning-making has also been an important part of my experience. I now
understand “that through the experience [of living with the challenges of my son’s illness] I will
become stronger and that my family members, even the two younger brothers, will become
stronger.” We have already become stronger as we have been able “to hold on, to walk with God,
know where the strength is.”

I also have come to understand that there is a purpose in suffering. It is very painful for
me to see my son in the grips of his illness and, on days when he is not doing well, it “hurts a lot
to see him like that, but do I regret it? I don’t really regret that experience because through it I
know he is gaining a lot. I’m gaining a lot, my husband is gaining a lot.” I tell myself that if my
son did not have this illness he likely would have been successful in pursuing his goal of being “rich and famous,” but I think through his illness he has discovered “that there is more to life than just wealth and fame and being able to finish university, have a good job, a good life, and enjoying everything.” The purpose in suffering, I believe, is at least in part, “to refine us, to make us better people, to be able to help others, to be closer to God, to know what He is doing in our lives, and to be more sensitive.”

As I’ve lived with the uncertainties, the unanswered questions associated with the illness, I have also come to understand what it means to have faith, to trust in God’s care. I like to think about what I once heard someone say — that our children are on loan to us from God, and that after the years that we are responsible for their care, “God will know how to look after them and will take care of them because they are God’s children and they will eventually be looked after or they will look after themselves.” I believe that my son belongs to God and through his illness “has met God” even though he asks difficult questions such as: “Where is God and why am I like this?”

I also appreciate heaven more. For me, “heaven more than compensates for the losses on earth … the gain of looking beyond our earthly life.” I have also come to know what it is like to experience God’s presence. I have experienced his presence “even more when it is darkness in my life… when I’m struggling” than when things are going well. “God is in my darkness. There is darkness but in it, through it there are some treasures.” There has been “a lot of pain, a lot of wounding” through David’s illness for me and for my family and I think that maybe part of “the real meaning” of the suffering in my life is for me to experience God’s presence by “letting him touch me… touch those wounds.”

The biblical story of Moses and the Israelites travelling in the desert, reminds me of, and
could be a metaphor for, my experience of living with the ups and downs of my son’s illness and *waiting with uncertainty*: When the cloud settled over the Israelite camp “they couldn’t see, so then they sat still. And when the cloud disappeared, then they moved on.” Sometimes the cloud didn’t lift for days or months, or a year. They never knew how long it would take and so they waited with uncertainty and with faith that someday the cloud would lift again. Waiting with uncertainty is a big part of the experience of parenting a child with mental illness. There are “many cloudy days… where you just stay” in that waiting, uncertain place where there is nothing you can do, but have faith. “The message I get from Moses’ experience is that it is during these times [of waiting with uncertainty] that I need to be still and wait on God for his grace by having some quiet moments, reading his words, praying. It is during these times that I need to allow myself to be sad and to mourn, to take a walk and to grieve. And then, when my son is better again, like when the cloud is lifted, I move on and enjoy moments of laughter and joy like Moses and the Israelites when they set out on these clear days.”

Advocacy and political action. Advocacy and political action have also significantly influenced who I have become. As an *advocate* in the early stages of my son’s illness, I did what I could to find help for him. I tried to get *clarity on his diagnosis* and then to *learn as much as I could about his illness*. I also tried to establish and maintain positive *relationships and good communication with the mental health professionals* involved in the treatment of his illness. I have to say that overall my experience as an advocate has been positive, although I have *faced some challenging situations*. *Political action* has also played an important role in my life. I *organized, and provided leadership* to, a group of parents who were concerned about changes in the mental health system that we considered detrimental. We lobbied for change and took our concerns to members of the provincial legislature.
Early on as an advocate for David, I tried to get clarity on his diagnosis. Even after he was hospitalized it seemed like a long time before he was given a diagnosis. Eventually “they told us it was schizophrenia,” but I had questions about this diagnosis because I knew that what “really bothered him more was panic attacks.” So later when he went to the Early Psychosis Intervention Program, I asked the doctor to “please look again and see … whether it is really schizophrenia.” When the diagnosis was confirmed, I knew that in order to be effective as an advocate, I needed to learn as much as I could about his illness. So I started to read books and research information on the internet and I continue to do so. “I am always looking for ways that I can help my son.” For example, when I hear about presentations on the illness, I will “push myself” to be there because I am “really interested to learn.” My husband and I learned a lot about the illness at the information sessions provided by the Early Psychosis Program. They were “very, very good.” In addition to learning about the illness at these sessions, we had opportunity to meet other parents of children with mental illness and that was helpful for us too.

To be effective as an advocate I also knew that it was important to build and maintain a strong relationship and be in communication with the mental health professionals who were overseeing David’s care. This continues to be a priority. Overall, we have been “very fortunate to have, so far, very good psychiatrists.” I particularly appreciate the “openness” of his current psychiatrist. He is “very approachable, really more so than I ever expected.” He welcomes my questions and is open to alternative treatments such as dietary measures and acupuncture, in addition to the more traditional pharmaceutical forms of treatment. With my son’s consent, his psychiatrist is open to having me attend appointments with my son. We have an understanding that, if at any time David “wants his own time, then that is fine too … It has worked out very well.”
That said, as an advocate I have also faced some challenges with mental health professionals. I remember well the difficulty I had when trying to communicate with the psychiatrist at the university health service when David was still a student. His psychiatrist at the time “really didn’t want to talk to parents… [and so] the things that we observed at home we were not able to tell him.” I sent messages to him and one time I wrote him a letter, but we were never able to talk with him personally.

I have also faced challenges when David was on an in-patient psychiatric ward. I remember well the helplessness and powerlessness I felt as I witnessed what I considered “inhumane treatment” on the ward. David was acutely ill at the time and had escaped from the hospital. When he was found and returned to the hospital, he was locked in a room without a washroom. “It was just a traumatic experience to see him locked up and then he needed to go to the washroom, so he knocked on the door and the nurses didn’t open the door for him … It was just so inhumane. It was just terrible. So then he got really upset … He got so mad one day that he banged the metal bed against the door. It was like almost the whole building was shaking. He was so angry and [it was excruciatingly painful] to see about five of these security guards open the door and pin him down. It was just like, just terrible.”

Another time while David was still in hospital, I felt judged by one of the nurses who thought I was an overprotective parent. David was being transitioned to the Day Program at the time. I knew that he was still acutely ill and that he would likely have a panic attack if he was forced to use public transportation to get to the program, and so I wanted to drive him. I also knew that if he did have a panic attack on the bus, it would interfere with his ability to manage at the Day program. Unfortunately, my concerns were not taken seriously. He was forced to take the bus and did have a panic attack on the bus. “When he got to the Day Program he was
vomiting” because he was in such an anxious state. My son suffered unnecessarily because the mental health professionals responsible for his care did not understand that sometimes I understand my son’s needs better than they do. I have since learned from other parents, that my experience was not unique.

*Political action* also became an important part of my life when I and a number of other parents became aware that the local health authority was planning to close, or possibly relocate, a very important educational and recovery program for persons with mental illness. Political action was totally new to me at the time, but I couldn’t just sit back and ignore this, so I organized and provided leadership to a group of parents who were opposed to these plans. As I said, “I am not a political person. I never get involved in anything like this. But for my son … for these young people somehow I had the energy to do it, because I knew, and I had a strong conviction, that it was a good program.” I and the group of parents I represented were convinced that this program had been “tremendously therapeutic” for our children and that it was important to keep this program at the then current location on the university campus. A number of our children had been students on the campus and so for them “it was like they were going to school … just going to a different program.” They had a sense of being part of the university “community,” they had a schedule to keep, and their day was structured which was all very helpful. “The facility was good” too. They had access to a gym, a swimming pool, and a recreation center. They were able to go on short walks to interesting places such as the museum on campus. Perhaps most importantly, “it was a safe place for them.”

For over a year we fought the closure of this program and took our concerns to members of the provincial legislature. “We brought a petition to the provincial legislature. We talked to Members of Parliament … [attended] board meetings of the Health Authority … wrote letters.”
Advocating for my son and for this program brought out a side in me that I did not know was there. I “put all my energy into it” and almost “killed myself doing it.” I remember staying up nights until four o’clock in the morning writing letters, getting things organized and preparing what I was going to say the next day. “I was determined … to stop this thing,” but in the end, we were not successful and the program was closed. That said, I was pleased to be able to play a key role in this political action. At the time “I had the energy and the words for it, and was able to represent [the concerns very well].” I was pleased to receive positive feedback on what I had said and done from a member of the Family Advisory Committee of the local health authority. She told me that “the message was there and I wasn’t really adversarial.” Throughout this process of political action I was also proud of, and grateful for, the support and participation of one of my younger sons who “helped me write most of my scripts” and supported me all along the way.

Enduring loss and sadness. There have been multiple losses associated with my son’s illness and these losses are intertwined with the many losses I have experienced in my family over the past decade. The losses associated with my son’s illness are a continuing presence, although not always in the forefront of my experience. There are multiple losses due to the effects of his illness. There is loss of understanding, in particular the loss of understanding related to the culturally different understanding of mental illness in the Chinese community. I have also experienced loss of support and sadness comes up for me when I think about how the loss of our family members may be affecting my son. Sadness also comes up for me when I realize that I am not able to “be there,” to help others the way I used to. There is also sadness when I think about what life might be like for my son in the future when my husband and I are no longer around to care for him.
Not long ago in the parent support group that we belong to, we talked about the many losses associated with our child’s illness and came up with the following: “For our children: They lost their normal development, their school, their motivation, their youth, their whatever - personality change. Our own losses: Time for ourselves, our expectations for our family member [who has a mental illness] - They were moving on, but now they can’t. The expectation of our future freedom, we lost that. I am now in my fifties and it is time for me to be free and let the children go and grow up. I lost that. Lost the relationship of spouse and some of the friendships. Energy. Sleep. Appetite. Focus. Personal space.” Many of these losses are invisible losses as a consequence of the illness and therefore not understood or appreciated by others outside of the family.

Which brings me to the loss of understanding. “People who have not gone through the experiences [associated with a mental illness]” can’t really understand what it is like. “Having a child with mental illness is unlike any other kind of illness.” And for me and my family we also face the culturally different understanding of mental illness in the Chinese community. “In the Chinese community it is very different.” It seems to me that in western culture it is difficult to talk about mental illness, “but in Chinese culture it is even more hushed. It’s like people don’t want to talk about it. … It is something that you do not talk about. It’s shameful. It [having a mentally ill child] is something that you do not want other people to know about.” In Chinese culture “your children are your pride and joy” and so you when you talk about your child, you talk about his/her accomplishments. “It is not a culture where you say, ‘Oh my son is mentally ill, you know, and has all these problems.” Knowing this helps me to understand why it was so difficult for my husband to accept that our son has a mental illness and why “he is very much against talking to other people about mental illness and that our son has mental illness.”
Then there is the *loss of support* that I have experienced, especially in the early years of the developing illness. For years as I watched what was happening to my son, I felt like I was carrying this burden alone. I was unable to express my loneliness and need for support to my husband because he was “unwilling to talk about it. Unwilling to accept it. Unwilling to sense my need or if I wanted to ask him how he felt, it was almost like a door was shut… When I did want to talk to him, he would think that I was trying to blame him. I remember I would say: ‘I feel really lonely going through this journey with David - like I am feeling very lonely. Like wanting to communicate to him that I do have some need and perhaps we need to support each other, but he got really upset and thought that I was trying to blame him for not being sensitive. I was really going through a very difficult time.’”

My husband has since accepted our son’s illness and become very involved with helping him and I will say more about that later, but for a long time I was alone in my grief around the illness. At the same time I was grieving the losses of my family members and there didn’t seem to be a place for me to process my losses until I went to see a counsellor through the Employee Family Assistance Program provided by my employer. The counselling support I received through my EFAP service was wonderful, but it was also associated with loss because I was only allowed about eight sessions and the issues I was dealing with could not be adequately addressed in eight sessions. My counsellor stretched the number of sessions to ten, but that was the best she could do. It was extremely difficult “for me to lose her then, because that was something of my own.” I had found a place where I could speak freely - be heard, understood, cared for and supported in a way I had not experienced before. “To be able to have someone look after me and to be able to hear me, was very new to me,” for until this point I was always the one giving the support and care to others. Giving up the sessions with my counsellor was very, very hard and it
brings tears to my eyes when I think back to that time. Of course, my counsellor referred me to another counsellor outside of the EFAP system, but it took months “to be up to seeing someone else” and when I did, it took a long time for me to build a trusting relationship with my next counsellor. Eventually I did, but then I lost this counsellor as well when she died of cancer. By that time I had “grown very close to her too. Losing her was also very difficult. She was almost like a mother figure to me.” The loss of support in counselling just added to “that loneliness … that loss of all those people” in my life.

Sadness also comes up for me when I think about how the many losses in our family may be affecting my son. He is “very sensitive” and “he has a good heart” and so I think that he must feel these losses deeply, although he doesn’t talk about them. Of all the people in our family, I think these deaths have “probably affected David the most … he must be so lonely” and just thinking about that brings up tears.

I also feel a loss related to no longer being able to help other people like I used to. I now need all the energy I can muster up to manage what’s on my plate - looking after my mother-in-law and my son, and so “I just can’t talk to anyone else… When I start to hear a lot of their problems, I just can’t deal with them. I would like to help them, but I am unable to, whereas before, I was there for everyone.”

And then there is the sadness that comes up when I think about my son’s future. I know that “mental illness is a lifelong journey … there are still many years ahead” and at some point my husband and I will not longer be here to look after David. I wonder if he will be looking for us when we are no longer here and think: “I wish that Dad was here. I wish that Mom was here.” I can’t help thinking that he may be very lonely and “if he is so lonely, he will be thinking about us … What if he, you know, gets down in the dumps and he wants to kill himself? What if he
will do certain things and there is nobody there?”

Distress and ongoing struggle. Distress and struggle have also been part of my parenting experience. There is the distress related to difficult behaviours, and, as I mentioned earlier, there has been distress in family relationships particularly in my relationship with my husband related to his inability to accept our son’s illness. Although that has dramatically changed over the years, there are still feelings that come up for me from time to time related to our relationship that I find difficult to manage. I also struggle with how best to help my son. Sometimes when I think back to my early parenting days I find myself struggling with feelings of guilt. I also, at times, find myself struggling to accept what I cannot control.

It’s distressing when difficult behaviours come up with David and I don’t really know what to do. There were particularly distressing behaviours in the early years before his diagnosis like the times when he was convinced that people on TV were talking to him. Sometimes when he would see a police car parked outside, he would think that “they had been chasing him.” Particularly distressing for me, were the times when he was convinced that his brothers were against him and I would struggle to understand if this was “really true?” His panic attacks have also been very distressing. I will never forget the urgent ‘middle of the night’ call from my mother-in-law - pleading with us to come and help David who was having a panic attack in her basement. He had been “very depressed … like just broken” and trying to self-medicate by drinking and smoking. We had been worried about him for some time and would regularly come over to check on him while he was living in his grandmothers’ basement suite. On the night we received the call from my mother-in-law “he was shaking and in total trauma … it was terrible.” It was one of the worst panic attacks he has ever had. Panic attacks could “just totally take hold of him. Like his stomach would tighten and he couldn’t breathe” and this could continue for up
to ten hours. I have never seen anyone have such severe panic attacks. During his panic attacks he has terrifying thoughts and doesn’t know what to do with himself.

At his worst, he believes that: “that there is no purpose in life, he is the worst, he can’t do anything, and there is no hope.” Sometimes, in total desperation he can get to the point where “he wants to kill himself and he’ll go to grab a knife and you have to stop him and he is so big and so strong and you have to talk to him.” It is very distressing and because I am emotionally strongly connected to him, when David is really “down, I feel so bad and I just don’t know what to do.” On the other hand, “if he is happy, then I feel relaxed.” So for me “it’s like a roller coaster. I move up and down with his up and downs… It is a daily struggle.”

The difficult behaviours combined with the lack of understanding about the illness in the early years, led to significant “family discord.” When I look back “It was like living in hell. It was very terrible. There was a lot of [pain].” David’s brothers were distressed in response to his delusions that “they had something against him… and were going after him.” My relationship with my husband was also “very broken” because he would insist that there was nothing wrong. He would normalize David’s behaviour and say: “Well, I’ve gone through this… [It’s just a] process of growing up … he will just get over it.” My younger two sons believed, as I did most of the time, that there really was “something more to it” and so we were divided as a family. At times I didn’t know what to think. “Which side you are going to be on?” I am grateful to be able to say that we are no longer divided. We all accept David’s illness and understand his behaviours in light of his illness.

That said, I now experience a different kind of struggle in relation to my husband – a struggle that I am reluctant to say anything about, because I feel somewhat guilty about it and I want to be absolutely clear that I am very grateful for the way that my husband has changed. I
am very grateful for his involvement with, and commitment to, helping David. My struggle is about feeling “left out” of the close relationship that my husband now has with David and about my desire to be closer to my husband. Sometimes I feel that “maybe my husband cares more for my son than for me” and I wonder if my husband is “distancing a little bit from me because he knows that I am strict, like I am more conventional.” I struggle to manage the feelings that come up for me around this because I know that it is “very, very good for David” to have a close relationship with his father. Sometimes these feelings come up rather strongly. One of those times was during our recent house renovations, when David and his father went off to have a good time together leaving me with a lot of clean-up work: “I knew that David needed that, but I was actually a bit angry… Why didn’t they stay home” and help me or at least “be more caring for me?” It seems to me that my husband’s thoughts are so focused on David that he thinks less about me, but I also need closeness and support, and it hurts to be taken for granted. When I start thinking like that, I tell myself that I am probably “not looking at it from the right perspective.”

Then there is the ongoing struggle of how best to help my son. After David became ill “the focus of my life totally switched to …how to bring him back, how to help him in recovery.” I struggle to know how best to help him manage stress. I can tell when he is getting stressed because he will then go out on the deck to smoke, so I try to be more open to talking with him at those times. I am also aware that his stress level goes up when his skin condition worsens. He then “feels that people don’t accept him because of his skin and so it just compounds” his stress. I struggle with how to be available to him and to encourage him at these times when he gets down on himself. “Sometimes I ask him: ‘Well what do you think would be helpful?’ … and we talk a little bit.”

I am also trying to help him by being more positive, recognizing and drawing attention to
the positives in his life. This is difficult for me especially when the positives seem to be overshadowed by behaviour that I am not happy about. It is a real struggle for me to “learn to say things in a different way. … to be more positive;” because for a long time I have been the “bad guy… — the one to say ‘no.’” I became more aware of this struggle to recognize the positives recently when I attended my son’s appointment with his psychiatrist. I heard David telling the psychiatrist about behaviour that I did not approve of and at the time “I kept silent and I didn’t say anything, but I am sure that David probably felt my body language … that I didn’t approve.” My husband later pointed out that at least David was open to talk about his behaviour and that was a good thing. It made me wish that I could have said something in the moment like: “I am very happy that you were so open to the psychiatrist even when I was there - and that you were open to me too.” It reminded me that I have a lot to learn about seeing the positives. It is something I am striving for.

Another way that I am trying to help my son is to let go and let him take more responsibility for himself. I struggle to find the balance between trust and needing to protect. For example I want to let him be responsible for taking his medications. “Like to let go and to know that it’s OK, he can do it.” I struggle because I don’t want him “to fall. What if he forgets his medication and then has a relapse — like that is the toughest thing to think about.” It is scary to let go because the course of this illness is unpredictable and there are potential life threatening consequences of getting it wrong. There is a “part of me that is not willing to let go.” But then I also know that by not letting go, I am restricting his life and his potential to be able to manage more independently, especially in the future when we are no longer able to care for him. So I continue to struggle with questions like: “How do I help myself to help him help himself?” How much will I trust him? What is he able to do for himself? This struggle to let go came up again
recently when my husband wanted to take David with him on a trip to China. “Before they left I was having second thoughts about whether it was a good idea for David to go. … What if something happens and then it would be such a bad trauma when he comes back and [maybe he] is going to have a relapse and this kind of thing. I think for a large part it is probably me not letting go, not able to trust and say they are going to have a good time.”

Sometimes, when I think back to my early parenting days, I struggle with feelings of guilt. I wonder if I was “too strict with him” and if, in some way, I unknowingly increased his level of stress. And then I wonder if this increased stress may have played a role in his illness. I remember that when he was a child “I would always have to say ‘no’ to him. Sometimes in a very bad way, like impatient. …I always have to get mad at him. Sometimes I wonder if all these things added to his trauma. … Like maybe if I was more sensitive to him. Maybe if I knew better how to say things less abruptly I wonder if he would have it [the degree of illness] coming out maybe less with less stress. I wish that I had been more sensitive to his hurts and pains and expressed to him that I understood when he was having a bad time or having anger fits or whatever … that I could have told him that I understood, so that he could feel more supported.”

What I do know, is that I always “wanted the best for my kids – always. I did everything I could. I went to whatever there was at school such as parent meetings, sports days. … I was always there, but then perhaps I couldn’t see some deeper emotional needs of my kid.” It hurts when I think about that.

And then there is the struggle to accept what I can’t control. For example, “Maybe someday he will get addicted to cigarettes. How do I deal with that?” When I see him smoking or drinking or doing something that is harmful to him “I feel very sad,” but it is beyond my control. I also need to accept that living with this illness means living with ongoing uncertainty, and
living with ongoing uncertainty means living with ongoing struggle. “Life’s struggles never end … Yeah, just one thing after another thing. It never ends. When one isn’t even finished that other one starts.” I suppose part of helping my son is helping him to manage the struggles that come his way.

Personal and relational changes. I have “grown a lot… definitely I have grown.” It feels like my experience of living with my son’s illness has “just changed me totally.” The biggest change, and the change I value most, is my spiritual growth. I have also grown stronger. I now have greater empathy for my son and for others, and I have gained an awareness of the depth of love I have for my son that I did not have before. There have also been relational changes in the family. My priorities have changed and I now have an intentional focus on self-care.

Although “I had my faith before my son became ill, it became stronger through his illness.” I now treasure “the presence of God in my life” in a way that I did not before and “I am more sensitive to what He is doing in my life.” I also have a desire to learn more about spiritual things and so I read and “take the time to think about [spiritual] things. I think those are really big changes in me.” I would summarize my spiritual growth by saying that I have become “closer to God.” Through David’s illness I and my family have also become stronger: “We have found strength from it — through our difficulties, through our struggles, actually we have become stronger people.”

I also have greater empathy. Before David became ill “I didn’t understand what he was going through” and I didn’t have the “empathy and understanding” that I have now. Now I really want to understand what my son is experiencing – “to really read behind the lines, you know,” to understand what might be going on inside. “It hasn’t become spontaneous for me yet, but … I am learning.” Sometimes in the moment I miss opportunities to talk with him about his feelings,
but then I go back and talk about it later. For example, recently David was telling me about a friend in the hospital that he was worried about. “He must have felt sad. He looked sad, like when he was saying it.” I wasn’t able to reflect his sadness and pain in the moment, but I did talk to him about it later — that “it must have been hard” for him to see his friend go through such a difficult and painful time. So whenever I can, I try to “go in a little bit deeper and ask him for his feelings …— perhaps echo his feelings.”

I am now much more aware of the interplay between what is happening emotionally, physically, and spiritually with my son and also with others. This awareness has helped me become more sensitive to the needs of the clients I work with — “more sensitive to the way I say things … to help them.” I am now generally “more compassionate towards others, more understanding … of people who are hurting.” And when I meet other parents of children with a mental illness, I really “empathize with what they go through.”

Also, when I look back over my parenting experience, I can see that “my son’s illness has taught me the meaning of love, patience and understanding. Despite how he functions, how he reacts … he is loved.” I love him very much. “I did not know that I loved David this much until after his illness.”

Another change is the relational change in our family. “David’s relationship with us is much more closer now that it was before.” My relationship with him “has somehow mended,” as we have come to understand each other better. And, my husband’s relationship with David has greatly changed – from not being able to accept that he has a mental illness to being “totally dedicated to his recovery.” I attribute much of David’s recovery to my husband’s involvement with him. My husband just does “everything with him.” For example, he takes him to movies and sometimes they work on projects together. Recently they set up an aquarium together.
Sometimes “my husband will take David out for a beer and they talk.” I think that David is “actually closer to my husband” than to me. I think this is, at least in part, because I tend to “restrict him too much, but my husband is more open…. I am very happy that David has someone to talk to and that my husband is able to have that time with him.”

David’s relationships with his younger brothers have also improved now that they understand that he has a mental illness. One of David’s brothers in particular, has taken an interest in learning more about mental illness and has expressed a desire to make a difference in the field of mental health. This has strengthened my relationship with this younger son and it touches my heart when he tells me about what he is learning about mental illness or when he calls my attention to things that come up in the media about mental illness. There is so “much less tension” in the family now than at the beginning of David’s illness.

Still another change is how my priorities have changed. I now “treasure things that are more eternal,” hence the importance I place on spiritual growth. I also value the relationships in my life more than I ever have, and I have a deeper appreciation of “the precious moments in life,” such as the moments of closeness with others. Personal growth has become more important as well. For me, personal growth “means building character, to move on to be better than I was before. It is almost like being refined like gold under fire.”

As a result of my parenting experience through this illness I now have an intentional focus on self-care. “I have grown a lot from the experience of having to look after myself” and my advice to other parents is: “Spend some quiet time alone to give yourself some space daily. Get to know some other parents to support each other. Do not to be afraid to seek professional help for yourself… if needed. Look after yourself…. Get to know the resources that are out there… Get as much support as possible. Keep in touch with other people – families who have
gone through similar [experiences]. It’s invaluable.” Since the onset of my son’s illness, I have learned to give myself time. I have also learned how important it is to have support — “having someone to talk to, to share the hurts and the difficulties with.” As I said earlier, I was able to do this through counselling, which “helped me tremendously.” My counsellor helped me learn “to be kind to myself, to allow myself to be sad, to mourn, to be depressed… to be gentle to myself. And that it is OK not to feel well, to be anxious, to panic, to be down.” That was so important for me to hear and to learn.

My husband and I have also found support through an Asian parent support group that formed after the political action related to the closure of the Day Program that I talked about earlier. The members of this group “share a common bond” – we all have a child with mental illness and most of us attend churches around the city. We meet monthly and talk about our common concerns. We can be there for each other in the desperate times because we understand each other. We also help each other with practical things - like how to apply for RDSP [Registered Disability Savings Plan] or PWD [Persons with Disability] or making our wills. I think the greatest issue most of us face is around the question: What will happen to our children after we die? “It is a pain in all of us…every time we meet it is a very common thing that we think about and we talk about.”

We also plan social events as a group. Very importantly, the group has given my husband and other men opportunities to meet and talk with other Asian fathers who have a child with a mental illness. Since participating in the group, my husband is more “relaxed and able to talk about these things [like mental illness] openly with other people.” The purpose of the group is to care and support each other, but we also, as we become aware, extend our support to other parents within the Asian community who have a child with a mental illness.
When I was asked for a metaphor of my experience of growth and change through living with the challenges and uncertainties of my son’s mental illness, I thought about what Rick Warren in his book *Purpose Driven Life* says about life being like a railroad track. What he says about the two rails of the railroad track fits my experience: “At all times you have something good and something bad in your life [two tracks]. There’s good and there’s bad at the same time. No matter how good things are in your life you always have something bad that needs to be worked on. No matter how bad things are in your life there is something good you can thank God for. So for me, [although my experience] with a child with mental illness often feels like a roller coaster as I live through my child’s good and bad days, I now try to remind myself to think of life as a train track. There are many bad days, but at the same time there is good — My personal growth and change. My son’s personal growth and change and our whole family’s growth and change.”
### Table 6  Themes and Subthemes in Lisa's Story

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<th>Coping and Meaning-making</th>
<th>Advocacy and Political Action</th>
<th>Enduring Loss and Sadness</th>
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<td>Spiritual coping through: - Reading and meditation - Prayer - Music Coping through: - Journaling - Incorporating enjoyable activities</td>
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<td>Distress related to difficult behaviours Distress within the family: - Division in the family - Struggles with spouse Struggle with how best to help her son by: - Managing stress - Recognizing positives - Struggle to find the balance between letting go and maintaining safety - Struggle to let go Struggle with guilt Struggle to accept what can’t be controlled</td>
<td>Spiritual growth Increased strength Greater empathy Awareness of the depth of her love for her son Changed relationships within the family Changed priorities Intentional focus on self-care</td>
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Sharon’s Story: Learning, Helping and Living Well

Main findings in Sharon’s story. The unifying thread in Sharon’s story; Learning, helping, and living well; emphasizes her strong desire and commitment to learn about and understand her son’s illness, as well as her strong commitment to helping her son in whatever way that she possibly can. Sharon situated her parenting experience within a context of enduring loss. Her story also provides important insight into the prolonged strain and distress that may be experienced by parents when their child’s mental illness develops slowly over a long period of time, as well as the struggle with regret/guilt and the tendency toward self-blame that may be experienced when the illness is not recognized and treated in its early stages. Sharon's story also describes what “new normal mothering” looks like on a day to day basis and how this new way of mothering contrasts with mothering an adult child who is well. Her story also highlights the importance that Sharon places on modeling for others what it means to live well with this illness.

There is a noticeable sense of optimism regarding her son’s recovery in Sharon’s story, although this optimism is still somewhat guarded given the uncertainties associated with the illness. Volunteer service in the mental health system also figures importantly in her story and her experience with the mental health system has been positive throughout her parenting journey. Like the other moms, Sharon emphasized the important role of physical exercise. She also emphasized the importance of actively building a supportive social network for both her son and her family.

Introduction. Sharon is the mother of two children, a son Christopher (30), and a daughter (27). She is in her early sixties and retired from her business career approximately five years ago, the year before her son was diagnosed with schizophrenia. Sharon’s husband is not yet retired and is frequently away from home on work-related business. His work has always
involved a lot of travelling. Sharon’s daughter lives independently in another province. Christopher has always lived at home with both of his parents with the exception of one year, a few years prior to his diagnosis, when he was attending university in another town. He was diagnosed with schizophrenia four years ago, although he has been ill for about eighteen years. Christopher currently works regularly four days of the week in several volunteer positions in his community.

When Sharon looks back on her parenting experience and considers the changes she has experienced through her son’s illness, she thinks about two distinct periods of parenting – before and after the diagnosis. The period of parenting before the diagnosis was by far the longest and began when Christopher, at age 13, started “having trouble dealing with life and the world.” At the time the family had just moved back to Canada after living in central Europe for several years. In our conversations, Sharon talked about how difficult the transition back to Canada was for Christopher and shared her belief that the stress of the move may have triggered the onset of his symptoms. She reported that his illness progressed very slowly over the first thirteen years and that the early symptoms of his illness were not recognized by mental health professionals until approximately four years ago, when for the first time, his symptoms became acute. Up until this time, although with difficulty, he was able to complete a college program and was able to work outside of the home. For several years prior to receiving the diagnosis of schizophrenia, Sharon was under the impression that Christopher had Asperger’s Syndrome. The psychologist who had been working with Christopher concurred with this diagnosis. When Christopher was 26 and his symptoms worsened, Sharon made an appointment for him to be seen by a psychologist who specialized in the treatment of Asperger’s Syndrome. During the time of waiting for the appointment with this specialist, Sharon and her husband decided to take
Christopher with them to visit family in Europe. While in Europe, Christopher’s symptoms became acute. On his return to Canada he was referred to a psychiatric centre and diagnosed with schizophrenia.

Sharon described her experience of parenting before the diagnosis as worrisome, extremely “draining,” and centered around the struggle to help her son but not knowing how. As she put it: “You want to help him, but you don’t know how because you don’t know what’s wrong. So there is this constant challenge and worry. What can we do … maybe we should try this and maybe that.” When Sharon thinks about the impact of this initial parenting period on her life, what stands out to her is the loss of the “happy” and “carefree” spirit that was a big part of who she used to be. After the diagnosis she reportedly experienced change in more “subtle” ways. As she sees it, this “subtle” rather than more obvious change is due, at least in part, to being a “pretty solid” person. In her words: “A very calm and very grounded person … It would take a lot to shake me off my feet.” Sharon reported that her son, Christopher, is similarly a “not easily shaken” person. Her story includes her thoughts on the implications of being a person who is “not easily shaken.” This is Sharon’s story, written in the first person, as I have interpreted it.

**Sharon’s Story…**

Growth and change are important to me and when I think of personal growth I think of “becoming a better person – more caring, kinder, less judgmental… more patient with people … [as well as] being open to opportunities and trying new things … acting on things you want to do or that you think you should do.” That is what “I strive for.” My story could be entitled: Learning, Helping and Living Well. To a large extent it is a story about learning and understanding the illness, and doing everything I possibly can to help my son live the best life possible within the limitations of his illness. It is also about living life well myself, which
inevitably includes living well with the losses that are associated with my son’s illness. I believe that by living well, I am able to help others around me to live well – my family, friends, and the people in my community. “I think [personal growth and change] affects the people around you in your life and if you get stuck in one place, then it’s not good for them. It’s not healthy for anybody.” I will tell my story around the following themes that are central to my experience of learning to understand and live with my son’s illness: (a) Learning about and understanding the illness, (b) Commitment to helping my son, (c) Enduring sadness and loss, and (d) Personal and relational change.

Learning about and understanding the illness. After receiving the diagnosis it was very important for me to learn and understand as much as I could about the illness, because for so long I had been in a place where I didn’t know what was happening with my son and so I didn’t know what to do. Once he was finally diagnosed with schizophrenia I knew I could gain knowledge and skills, I could begin to understand what my son was experiencing, and I could begin to establish realistic expectations of life with this illness. I could also help others learn. Almost immediately after gaining insight about the illness myself, I started helping other parents learn about the illness. I also learned about the mental health system and, through volunteer work with the Schizophrenia Society, I endeavoured to make a difference more broadly by increasing public awareness of mental illness and the needs associated with mental illness.

I was very fortunate because, almost immediately after Christopher was diagnosed, I was able to enrol in the Family to Family course offered by the Schizophrenia society. That course “was a very enabling experience for me.” Not only did I learn “all kinds of things about the illness” that I didn’t know, because “I really didn’t know anything about schizophrenia” at that point, but I also learned some very important practical skills. For example, “if you’re dealing
with a person with schizophrenia you really cannot criticize. And so I don’t think I criticized a lot before, but I have learned to sort of keep my mouth shut more. I’ve learned that it doesn’t do any good, it just doesn’t help to ask questions or harp on something. I know there is a good chance that it will upset him. So I just back off.” This reminds me of something that happened in the summer. Christopher had taken on the responsibility to keep our garden watered and one day I saw that he was struggling with the hose and I noticed that the hose winder was broken. When I asked him about the broken hose winder, he did not want to talk about it, so I left it at that. I simply helped him deal with the hose. By not needing to know what happened and avoiding issues of blame, I was able to maintain the good working relationship I have with him and then help him continue with his job. Having learned in the course about “how to talk” with a person with schizophrenia, “I felt a whole lot more confident dealing with my son.” My advice to other parents who may be starting out on this journey is: “Arm yourself with knowledge and information.”

I also began to understand my son’s experience of his illness. “I’ve come to realize that he is a lot more sensitive than I ever thought he was — way more sensitive than I thought,” and I’ve gained an understanding of how horrible this illness has been for him. “I think everybody with this illness just goes through horrible things, like awful things. It’s hard for us to imagine I think. I know that he has gone through really, really, really tough times.” When I look back, I can see that he “tried so hard to overcome his problems” on his own and “he was very good at holding it in. Very good at putting on a good face and not letting on that anything was really, really wrong.” That said, he was only able to hold it in for so long and then “things just broke out.” I think that if he wasn’t the kind of “rugged person that he is” — not easily shaken, he “would have told us he was having trouble sooner and he would have asked for help sooner.” I wish now that he had,
because I had no idea how difficult it was for him. I can’t imagine how hard it must have been for him to complete the studio art program that he took at a local college — “to be creative when he was so ill, but he did very well.” That said, it was obvious that he was struggling at the time because he “spent many hours at home doing nothing” or so it seemed. Now I feel “like I know him better. At least I know him better the way he is now.”

I have also learned to establish realistic expectations. It helped me when I realized that living with schizophrenia means “you are in this for the long haul…It is a slow journey, and nothing is probably going to happen quickly.” I also had to let go of “any illusions that Christopher would have a very good recovery in terms of the damage that’s been done to him already.” That said, I continue to be “fairly optimistic” because “I think that the circumstances of his life can improve greatly to the point where hopefully he can be much happier and more functional.” My hope is based on the fact that he is “getting very good help … and he is made of good stuff.” I remember being encouraged when his psychiatrist told him: “‘I think your life in five years will be a lot better than it is now and that’s because, from what I see, you have very strong character.’” So I expect slow, not “miraculous” recovery. I don’t think that “all of a sudden his brain is going to be way better. No, that is not going to happen.” And I am also “quite realistic about the fact that he could have relapses. He could go backwards at any time.”

Much of my learning has been consolidated as I have helped others learn about the illness. After taking the Family to Family course, I taught the course myself. Given the huge amount of information in the course, I picked up lots of things when I taught the course that I didn’t pick up the first time. Through teaching the course I also became aware of the experiences of other parents who are dealing with this illness — how a lot of these parents “were in a way worse situation than I was in … I got a much better understanding of actually what some people
are up against. And that was really quite enlightening.” It was gratifying for me to help other parents who initially had little understanding of the illness or of their child’s behaviour. I could see how gaining understanding helped them to better support their mentally ill family member and to better manage their own level of frustration. It can be very frustrating “if you think somebody is just being lazy or silly” and you can’t understand why your son/daughter is not “getting on with life.” I also gained a lot of respect for the people I taught and “I found it quite humbling to hear their stories.”

Helping others learn helps me cope with the illness. Just being busy is helpful. As a volunteer, I serve in a number of ways including being on the board of the Schizophrenia Society. I “go into high schools giving talks on schizophrenia. I walk in the parades. I distribute posters. I just started trying to do whatever I could to somehow raise awareness of what this illness really is about.” I am encouraged by the recent media efforts to highlight issues around mental illness. And, when I see corporations “taking up the torch,” it gives me hope that public awareness of the needs of people with mental illness will continue to grow and “put some pressure” on government to increase funding for mental health. The needs are great. “Mental illness just affects so many people and so many people are affected in their families in some way … It is a reality for many.”

I have also learned a lot about the mental health system. “I’ve gained a whole new respect for the job that mental health professionals do. I am fairly positive about the health care system. I’m positive about the experience that we’ve had.” That said, I have also “met a lot of people who are really critical [of the mental health system] and have legitimately had really bad experiences.” I think it is important to acknowledge that. So, when the topic of the mental health system comes up, I always tell people that our experience has been good, “but I never
negate the fact that they haven’t [had a good experience], because they haven’t.” I just want to
give “credit where it’s due.” We have never had a problem getting our son into the hospital and I
know that hasn’t been the case for many parents. “Mind you, he was definitely suicidal” at the
time that he was admitted, so there was no question that he needed in-patient care. We also did
not have any trouble getting him into a more long-term treatment facility where I know there is a
waiting list. I attribute our good experience with the mental health system to two things: “I credit
his doctor – yes. Also it was just the circumstances because Christopher was so severely ill.
There was no wondering. It was clear. The writing was on the wall, therefore, he got in [to the
hospital when he needed it].”

Regarding the situation for the mentally ill in Canada, I think there is still much more we
can do. There are people with mental illness out there that aren’t getting the help they need,
especially in the homeless population. And, it is worrisome to see psychiatric hospitals being
shut down. Also, “I really feel for people who have mentally ill family members who somehow
get in trouble with the law.” So often mentally ill persons don’t “really know what they are doing
and don’t really understand the consequences.” That said, I think the situation in Canada is much
better for the mentally ill than it is in many other countries.

Commitment to helping my son. Through my experience of parenting/living with my
son’s illness I now “want to help him more [than I ever have]. Now that I understand how
horrific some of those years for him were, I want to do whatever I can to make his life nicer…
just by trying to set up a situation where he’s going to have a nice life.” For so long I felt
helpless/powerless to help him. I searched for answers and couldn’t find them. The diagnosis
was devastating, but with it also came a sense of relief. I am fortunate to have a strong working
relationship with Christopher’s psychiatrist and to be included in decisions around his care. I am
also fortunate to have ready access to helpful resources at the community psychiatric centre in the municipality where I live. That said, I have faced numerous helping challenges including how to ‘be a good mother’ for an adult son who is mentally ill, which, I have found, is quite different in many ways than mothering an adult child who is well. When I think about my mothering of Christopher during the years when I did not know what was happening or how to help him, sometimes I struggle with feelings of regret and guilt. That said, I try to focus more on moving ahead and this requires me to accept what is possible and work with it.

As I’ve said, for a long time — thirteen years, we “tried to help him and get him going, get him out into the world,” and it was a struggle, and there was a sense of helplessness and powerlessness around that struggle. At the time we did not realize that he had a mental illness. We just thought that he was different. “Christopher was always just Christopher. He was always quiet. He was always shy. He was always a really nice guy and the family just accepted him as just that way.” Although we were concerned about the difficulties he was having in school, we also knew that he was going through a transition, having moved from Europe back to Canada and “we knew that he did not handle change very well. We knew that the move would be hard on him, but I think it was much harder on him than we ever expected. I think it was the stress of that move that triggered his illness.” After the move I increasingly felt that there was something “really not right … something I should be doing something about,” but I didn’t know what to do, because I didn’t know what it was I should be doing. It’s like “there’s this hole in your life that you can’t fix even though you want to fix it … the helplessness [of that].” It seemed to me that Christopher was “stuck in this grey area, for lack of a better word. He wasn’t bad enough so that it was acute …and you find out what it is, and he wasn’t good enough to have a normal life. So you are stuck in this grey zone. You just don’t know what to do because there is nothing that you
can latch on to. … [When a child becomes ill] very quickly it’s horrible, but sometimes I think, my gosh, maybe it would have been better because then they get help. I would never wish that on my child, but maybe in the long term it would have been better.”

I began searching for answers when Christopher was in grade nine. I took him to a psychologist who saw him throughout his high school years. “He had a very good rapport with her, but she did not pick up on any possibility of schizophrenia.” Once, when Christopher was in grade twelve, I took him to a psychiatrist but the psychiatrist “did not really pick up on it either. … So it could have been caught much earlier, but it wasn’t.” Then one day my sister read an article about Asperger’s syndrome and she thought the description fit what she saw with Christopher and when I read it I thought so too: “My gosh, this is Christopher, because he had so many characteristics that were so similar.” I then asked the psychologist Christopher was seeing if she thought he had Asperger’s syndrome. She said ‘yes,’ but had not wanted to suggest this diagnosis to me because she didn’t want to give Christopher a label. I wish now that this psychologist had referred Christopher for some testing to get some clarity, but she didn’t. So, from that point on “we were going under the assumption that he had Asperger’s. We were told that if we waited until he was twenty five and if nothing bad happened, things would start to improve, so we got into this waiting mode.” While we were waiting I kept on “trying to get him out into the world … get him busier, but nothing worked.” When it became obvious to me that he was going “downhill,” I decided to take him to another psychologist, someone who specialized in Asperger’s syndrome. As this point Christopher started saying things to me like: “I think I really should see him or I think we really should do something.’ That was his really understated way of saying things are getting bad.”

During this time of waiting for Christopher’s appointment with the psychologist, my
husband and I decided to take him with us to visit family in Europe. “That was where he really started showing signs of bizarre behaviour” – “wild-eyed staring,” sudden frantic recording of messages, and on one occasion, running wildly along a major European freeway. Until that point he had been having a lot of difficulties “getting out into the world, but he didn’t show any signs of what I would call bizarre behaviour. … Over there, he couldn’t [hold it in] any more. … [and] I knew things were bad just from his behaviour.” He had a terrible panic attack on the way home and once we got home he was out walking the streets all night and alluded to wanting to kill himself by saying things like: “I wish the wolf would just kill the moose and get it over with.”” So, I knew this was serious. His behaviour and what he said didn’t disturb me as much as it confirmed to me that “this is bad.” When the psychologist saw him, he immediately directed us to “urgent psychiatric care.”

We got an appointment with a psychiatrist right away, and when he saw Christopher, he told us that he thought Christopher had schizophrenia and immediately started him on medication. I remember him saying: “I hope this is not too little too late,” and that was rather “alarming.” Hearing the diagnosis was both devastating and a relief. “I don’t know how to describe it – profound. Like you just got a blow to the stomach. It was like a boulder fell on your head. At the same time it was almost like relief because finally we knew what we were dealing with. And finally maybe somebody was going to help him, because up until that time we had never been able to help him very much. At least we didn’t think so. I mean other than support. Give him a nice home. Try and help him. …Even though it was terrible… it was a lot better now knowing how we could help him.” Christopher and I also “came closer together again” now that we finally knew what we were dealing with. I think this was because “he knew he needed help and I knew what kind of help he needed finally. And so I think I was able to help him more and
he was more able to accept it.”

Right from the beginning, Christopher’s psychiatrist included me in my son’s care. I continue to have a good working relationship with him and have a great deal of respect for him.

“He welcomes family input, which I think is very important. We’re welcome to phone him at any time. I can go and sit in when Christopher goes to see him. I can go and be right there or not. It’s up to me and Christopher. Christopher has never said for me not to come, and so when he’s really not been doing well, I go with him to his appointments with the doctor … I sit there and I don’t say a lot unless I’m asked, or unless I think of something.” If I don’t attend an appointment and the psychiatrist has a question, he will call and ask me to fill him in. “He talks to us whenever and as much as we want. There is no withholding of information.” There have been times when I’ve called because I’ve noticed something concerning and he has said: “‘Bring him in right away. Make an appointment and come tomorrow.’” So we are able to deal with things as they come up. That said, “I only phone him if I think that it’s something that’s important,” but I always know that my concerns will be taken seriously.

Helping my son also involves accessing the resources that are available to him. As I said earlier, I was “lucky” to be able to attend the Family to Family course shortly after Christopher was diagnosed. The course was an invaluable resource for me. I have also found a lot of helpful resources for people with mental illness and their families in the municipality in which we live. I realize that that may not be the case in other locations. The psychiatric services are very comprehensive: For example, for Christopher there are “occupational therapists, recreational therapists, [as well as a personal] case manager. They are doing a lot of work to keep him busy right now. They find him things to do in the community like volunteering” and I am very grateful for their help and support.
Helping my son also means discovering what it means to be a ‘good’ mother for an adult child who has a mental illness. That is challenging because mothering a mentally ill adult child is different than mothering an adult child who is well. For example, mothers of adult children who are well “can stand back” and let their child “live their own life a lot more” whereas mothers of adult child with schizophrenia need to be much more “intensely involved.” Mothering an adult child with a mental illness is also much more complicated and the focus of day-to-day mothering is often on issues usually associated with mothering a young child – for example, monitoring medication and maintaining basic self-care. In many ways mothering a mentally ill adult child is like finding a ‘new normal’ way of mothering.

So, as a mother for Christopher, “I have to know whether he is taking his pills or not. And make sure that he gets to his blood test, and make sure he gets his pills on time.” This is much more complicated than simply reminding him to take his medication, because repeated reminders may be necessary and repeated reminders can easily come across as nagging, which in turn can be irritating and then jeopardize our relationship. So, I have to be very careful about how, when, and how often, I remind him. The medications themselves make things more complicated both for him and for me, because they interfere with his ability to maintain, and my ability to help him maintain, an acceptable level of cleanliness. For example, although I try “not to tell him what to do too much,” there are times when I have to remind him to take a shower or change his clothes — especially when he’s slept and lived in the same clothes for several days. This happens all too easily because his evening medications are “pretty powerful” and make him so sleepy that he frequently falls asleep in whatever clothes he happens to be wearing. He also likes to sleep in his clothes. “Well, I’m not going to drag him out of bed and try to force him to get out of his clothes when he is almost asleep, so I let it go. And then I let it go another night.
And then pretty soon he’s sleeping in his clothes.” Then, with this pattern in place, it is much more difficult to help him be clean.

I also worry about his eating habits and try to help him eat in a healthy way, but there are times when he goes out and buys “bags of junk food, big bags of marshmallows and eats them,” so then what do you do? “I would take away ninety percent of his junk food in a heartbeat if I could,” but I know that I can’t treat him like a seven year old and take away this stuff because he will just go right out and buy some more. So “I feel like I’m dancing around trying to figure out how to deal with this without treating him like he’s six years old or being a nag” because nagging is “no fun for anybody.”

As a mother for Christopher I also find myself “walking a fine line between protecting him … and pushing him.” Right now he has “this nice, very protected life” — living at home and having his meals prepared and sometimes I wonder if “maybe it would be better for him and for his life long term, if he was pushed out into the world a little bit.” At the same time I know that stress “is not good for him” and so I try to keep his stress level down. The balance between protecting and pushing is not easy to find and I constantly ask myself: How much should I push? What I do know is that it is not good for him to sit in a chair for “long hours doing nothing,” and so I’m “very proactive about trying to keep him active, especially physically active.” I get him exercising even when he is not well and when his illness flares up. For example, a year ago he had a serious relapse that lasted for several months and he was “not in good shape.” It got to the point where “I couldn’t leave him for more than about two and a half hours because his anxiety level would just [sky rocket].” I knew that exercise was vitally important for him even at this time so “I got him out a lot walking and hiking. And there were times when he would be going so slow and I would say: ‘OK Christopher, now a little bit faster’ … and if he picked up even the
littlest bit, then that would be fine. I wouldn’t push any more after that. Just a little bit and often he would get a second wind and then we’d go. So I spent hours walking with him and hiking — just getting him out there doing anything, and I think that helped him.” So mothering Christopher can be very intense and demanding and I am with him a lot. Sometimes I wonder if he gets “kind of tired of always being with me – me always having to tell him what to do.”

This “new normal” way of mothering also means “trying to figure out what makes him tick.” I frequently ask myself: What is he thinking about? This reminds me of an important conversation that I had with him recently. We happened to be driving by a particular bus stop — the bus stop where Christopher had experienced a major psychotic break a few years before. “Every time I drive by that bus stop I think of that, every single time,” and I wondered if Christopher was thinking about that too as we drove by. So I asked him: “Christopher, when we drive by this bus stop, do you think of the day you had your psychotic break?” And he told me that he did. It felt like I “was going out on a limb” by asking him that. Maybe it was not a good thing to ask him. Maybe it was risky, but as it turned out, asking that question gave me an opportunity to say: “I hope you know that that was not your fault. I hope you know that it’s just an illness and it’s not your fault that that happened.’ He didn’t say much, but I think he got the message.” So being a good mother for Christopher also means being sensitive to opportunities for important and meaningful conversations. “You have to be mindful … on your toes a little bit more than you would with another grown child… and know what’s happening.” Over time I have become much more sensitive to him and I can now readily recognize “when he’s not feeling well.”

Overall, my goal as a mother is to help him “set up a situation where he’s going to have a nice life. Well, I don’t know if I should say a nice life, but a life where he is not going to be
subjected to undue stress.” This means that I have multiple hats to wear as one of the doctors at the psychiatric hospital once told me: “It’s difficult for you to be a mother because you are nurse, recreation director, and mother all at the same time. When you are in that situation it is difficult for you to fulfill the normal mothering role.” I really understand that now.

*Being the best mother I can be for Christopher* is very important to me, and I know that I am doing everything I can for him, but when I look back on how I have mothered him over the years, I sometimes *struggle with regret and feelings of guilt*. “I wish I had recognized earlier that he needed help” and I think that was in part because “I was too calm. I think that that is a source of a great deal of guilt for me, because one of the hardest things I have had to deal with is the feeling of guilt for not doing anything for so many years. Which leads him now to the situation he is in - where he does not have a very good recovery because he had it for so long. And so I think, good heavens, what was I doing all those years, you know? Why didn’t I do something sooner or better or whatever?”

Through most of his illness, I was also working at a “very demanding job and so I think if I had not been working, if I had been at home and I could actually see this more, then I would have been more alarmed.” Sometimes I wonder if I was “too optimistic.” I kept thinking that it was going to get better. I remember thinking: “Oh well, he’s going to university now and that’s good, or he’s working now and that’s good … And so I don’t think I really dealt with it head on the way I should have.” All those years when he was struggling, “I was the person he was closest to and I didn’t realize he was struggling that much.” I realize now that during those years “I lost that really close connection I used to have with him … I lost the sense of Christopher. You know, I was dealing with Christopher who was having trouble at school and Christopher who doesn’t have any friends and Christopher who doesn’t go out and Christopher who spends hours and
hours in his room. I was dealing with all of those things and I lost the dealing with Christopher
[as a person].” I wish that I had kept “that connection going better. I would [then] have dealt with
everything else better.” I realize now, more than ever, how important that bond is. “I value it
more and I deliberately try and look after it more. So no matter what’s happening now, I try to
make sure that I’m looking at Christopher, that I am connecting with him, not with the
circumstances surrounding him and not with the things that have to be looked after - all that
stuff, but that I keep my connection to him and never give up on that … And I’m not talking
about being overprotective.”

When I get caught up in regret and self-blame, my husband helps me by reminding me
that “‘We did the very best we could.’… That calms me because it is true. It is true. We did the
best we could, but it never seems like it was enough.” The “what ifs” surface now and then “even
though you know in your mind that you didn’t know [what was happening or what to do]. And
what you don’t know - what nobody’s told you, you can’t know.” So I try to stay away from
feeling guilty “because I don’t think that’s a useful place to go, but none the less, sometimes I
do.”

When I think of the future, I recognize that there will be ongoing challenges around
helping Christopher and that I need to accept what is possible. “I would love it if Christopher one
day could get to the point where he could live independently. And if he doesn’t, that’s fine.”
Meeting Christopher’s need for help in the future will likely have “a large impact on our family. I
just don’t know what that will be and it depends on how long my husband and I live, and it
depends on how well Christopher does.” I expect that he may need help physically and mentally.
I expect that “at some point in the future, if my husband and I are no longer around or no longer
capable, there will be a big impact on my daughter because she will be the one that looks after
him or oversees his care.” I am not concerned about her ability to meet his needs, but sometimes I think about the impact on her life. I have told her that “I don’t want her to feel burdened to change her life plan because of her brother’s illness.” “I don’t know what is going to happen with Christopher [but] I have learned enough to know that people get used to their medications or the medications stop working. I would not rule out the possibility of suicide at some point in the future. I would not rule out the possibility of a serious physical problem just from possible weight gain or diabetes or a heart condition or something.” I don’t think about these things “too much” but these thoughts do come up and they are worrisome. I have to accept them as possibilities. In the future, we may also need to find a care person who can stay with Christopher in our home for short periods of time, so that my husband and I can get a break, perhaps take a short trip together once a year or so. We will “work it out and … do whatever we have to do so that Christopher is OK.”

Enduring sadness and loss. “I think sadness has crept into my life” as a result of my son’s illness. After he was diagnosed “I became more sad for him. I experienced great sadness for him.” The sadness often sits more in the background of my experience. I don’t think about it a lot nor do I express it much, but it is always there. It is related to many losses – losses due to the direct effects of the illness in my son’s life, loss of understanding and support in the extended family, loss of joy and light-heartedness in our own family, and loss of freedom. “I don’t think I coped very well [with my sadness]. I just tried to find things for him to do and, you know, get him in things and get him somehow busy doing something.”

As I’ve said, sadness is a “constant [in my life] but at a very low level.” I’m sad “when I think that he is unhappy,” or lonely or bored. Sadness comes up most “when I notice that his life is really not that great” — when I see the direct effect of the illness on his life. He “had real
trouble with school work. His cognitive abilities, in retrospect, I can see that they declined.” He also “never had any friends after the age of thirteen.” He had peers that he was friendly with, but it wasn’t like having a real friend. “It’s sad when your child has no friends and sort of no life. It’s very sad to watch that.” Sadness also comes up for me when I see that “loss of potential that will never be realized if he had not gotten this illness.” Christopher used to have a “love for mathematics and physics, a quest for knowledge. He was artistically very creative and an excellent writer.” I will never forget the comments his school principal shared with me - comments he had received from a visiting scholar in response to Christopher’s work: “Take care of this gentle genius.”

Then there is the loss of fun. “There is not a lot of fun in his life” and there aren’t a lot of things that he is interested in. He “gets pleasure out of certain things like watching Star Trek on TV and that’s fine,” but overall I don’t see much enjoyment in his life. Since he was diagnosed and the realization of these losses “I feel more sad than I ever did before. I don’t get depressed. It’s not something that hangs around me. It’s just that sometimes I look at him and I just feel sad for him.”

Then there is the loss of understanding and support in my extended family. “I have generally been disappointed in [my extended family].” Although I know that they all “care about him a lot,” I think that “there’s a little bit of family blaming going on. … You know, that we did something wrong or at least we didn’t do something right. We should have done something sooner.” It hurts to think that my family members are thinking this way and I struggle with that because how can you know what to do when you don’t know what is going on?

I remember well the disappointment and lack of support I felt a few years ago when I asked my family members for their feedback on a story I had written in preparation for a
presentation about my experience as a mother of an adult child with schizophrenia. Only one person responded and this person was not a member of the immediate family. It was, and still is hard for me to understand why no-one else in the family responded. “If somebody had poured their heart out like that to me, I would have responded.” I have also been disappointed in my family’s lack of support in practical ways. I think that when people “have empathy in their mind, [they think] that they are supporting you … but if that person never ever picks up the phone and calls … or never, ever offers ‘So do you need any help?’ … then to me, that’s not really very supportive.” That said, one family member did offer to help, but I later discovered that this person was actually not comfortable providing help when it was needed. And so, I think “I was more friends with my family before [Christopher’s illness]. I think I considered them to be very close friends of mine and now I don’t. Not as much at least … Maybe I expected too much and maybe I expected more than what I received from my family. I think that it’s fair for one to expect their family to be supportive and caring.”

There is also the loss of joy and lightheartedness in the family. Before the onset of Christopher’s illness, “we all laughed a lot more.” My husband used to get us laughing a lot, but over time he has “become a lot less carefree. He used to be a real ham.” He would just do “crazy things, crazy goofy things that would make us laugh and I notice that’s gone from him – gone, and I know that it is because of Christopher. It’s sad. It is really sad and I hope that it can come back one day.”

I also don’t have the freedom in my life to do things like other mothers with healthy adult children can. “If Christopher is not doing well and he needs me, then I’m there.” There was a period not long ago “when I didn’t do a lot of things that I normally would have for two or three months because I just couldn’t leave him for very long.” Then, when I wanted to attend an event
out of town that was very important to me, I had to work for months to find someone who could look after him while I was gone. “There is no respite care … there was nobody that he felt comfortable enough with and he wasn’t in a state where I could just bring a stranger in to the house to live for three days.” So my husband and I have to plan our lives very strategically to make sure that one of us is always home to be with Christopher. Given the travel demands of my husband’s work and the involvements in my life, this means “there are long periods of time when we don’t see each other” — a significant cost in our relationship that we would not have if our adult children were both well.

I am also aware of this loss of freedom when I think about the future. My husband and I “have always wanted to travel a lot and we have always talked about when we both retire … we wouldn’t mind going somewhere, living somewhere else and doing something different.” We have thought of all kinds of interesting possibilities both inside and outside of Canada. We may never have done some of the things we dreamed of, but “the possibility was always there and now it’s not. …The whole rest of our lives is looking different than it may otherwise have.” That said, it doesn’t really bother me because that’s just how it is. “I can be very happy living here, you know, doing a lot of things. I’m fine with it. It’s just different.”

Personal and relational changes. When I think about how I have changed through my experience of mothering Christopher, the following changes come to mind: I now have an expanded awareness and understanding about mental illness, increased empathy and ability to help others, greater willingness to go out of my comfort zone, and greater openness. My experience has also strengthened my belief about the preciousness of life. The relationships with my husband and my friends have become stronger and self-care has become an intentional focus. And, I have a deeper sense of admiration for my son.
“Learning more and trying to deal with the illness. … added a whole element in my life that was never there before - the whole issue of mental illness and how it affects people and how it affects families and how society deals with it.” I would never have expanded my awareness and understanding in this way if my son had not become ill. “I have had my mind broadened quickly.”

Through my experience I have also “become more empathic … I understand more what people are going through.” It has helped me be with people who are hurting. I have learned when “to say something – ask a question, show concern.” I have also learned the importance of “just being there … Sometimes you don’t have to say a lot. You just have to be there.”

I am also more willing to venture out of my comfort zone. “If something came up that I was a little bit not so comfortable with …something that was out of my comfort zone that came up as a result of my son being ill, I think that I would do it. I would go there … I would give it a try.” For example, if I was asked to be a chaperone on a camping trip for a group of adults with mental illness, I would do it even though it would not be easy for me. It would mean dealing with some new, difficult challenges, but I could do that now.

Also, without experiencing what I have, I “might not have ever been as open [about mental illness] and as tolerant to people with mental illness as I am now.” I am very open about Christopher’s illness. “I am deliberately open, in part, to fight the stigma of mental illness.” All my neighbours and friends know that he has a mental illness. “I just don’t try to cover it up and I think [my openness about his illness] has helped Christopher.” Because I am very open about his illness, my friends “are really good with him and he likes them. He can be with them and … be himself. He knows that they know he is ill and that doesn’t bother him, and it doesn’t bother them.” I am also very open with my family, including my son. For example, when I was
preparing to give a presentation on schizophrenia, “I gave the presentation to him to read because I didn’t want to go out and say all these personal things about him without him knowing. I wanted his OK. … and when he was done he said, ‘Yeah, OK, it’s good.”

Through my experience I have also gained a deeper appreciation for the preciousness of life – “That life is very precious … We all know at some level that life is precious, but I think that if you’re a parent of children that are totally fine and everything is going well … I don’t think you ‘get that’ the same way you ‘get it’ when you have a child who’s life isn’t going along well. My experience with Christopher has taught me that life itself, even if it is not going well, is precious … Maybe you get that more when you become close to losing somebody.”

Another change resulting from Christopher’s illness is that my relationship with my husband has grown stronger. “When you have a child that is having real problems, but there is nothing that you can latch on to … and you don’t know how to help him, [it’s like] there is only the two of you against the world.” And so, as you work together to try to find ways to help him, you do grow closer. I have also grown closer to some of my friends since Christopher became ill. “I really do appreciate my friends more. I appreciate their caring, their compassion. I really value that.” I have a wonderful group of friends. My friendships have also grown stronger because I have been able to spend more time with my friends since I retired, which happened just one year before Christopher was diagnosed.

I have also learned the importance of self-care and I am very intentional about it. I emphasize self-care when I teach the Family to Family course. Two very important aspects of self-care for me are social support and physical exercise. I stay in close contact with my supportive friends. “It has been very encouraging and supportive to me when I see my friends being so good with Christopher and genuinely interested in him … I don’t know what the word
is for me. It makes me feel happier, warmer inside. You know, it makes me feel like this isn’t so bad and look at how great the world is. Look at all these great people. It’s a very rewarding, encouraging thing.” Continuing to be socially active with my friends is one way that I continue to live life well. Frequently the activities I do with my group of friends are out of town and it isn’t easy to participate when Christopher isn’t doing very well. Whenever possible I take him with me. Not long ago, when it was difficult for him to be around people, I “sort of nudged him into it [saying]: ‘So we are going to go this weekend and you’ll be fine. If it gets too much for you, you can always just go to your room.’ And he just did what he had to do and it turned out to be a very good thing.” It worked, in part, because my friends are “just really good people” and they care about him and about me.

My social support network also includes neighbours, some of whom are willing to spend time with my son when I have to go out for more than a few hours. My husband and daughter are also very supportive. Just a few weeks ago my husband, daughter, and son all worked together to host a surprise birthday party for me. Their appreciation of, and care for me really touched my heart. And, also very encouragingly, “so many people, who came to that party, commented to me how great Christopher was … I think that is the result of all of those people becoming friends with him and they all know that he has schizophrenia and that doesn’t matter, and he knows that they know. It’s just all out there and the air is clear.” It has also been very helpful to me to talk with people who are going through similar things, like the people I met in the support group through the Schizophrenia Society soon after Christopher was diagnosed. “Meeting with you has also been helpful for me. To be able to talk about this. I appreciate the opportunity.”

Another very important part of self-care for me is physical exercise. “I do a lot of outdoor activities” and when I’m feeling sad, it often helps to “go for a good long walk.” Sometimes I
just know that I need to be outside. It might be when things “just get to me or there is a particular worry … or things don’t look very promising - That’s when I know, that yes, I need to go hiking for myself. Hiking particularly is great. Hiking is fantastic because you can walk it off.”

Sometimes I go with a group “and so it is quite social … as we go along, we talk, but if you don’t want to talk you don’t have to, and if you’ve got something on your mind, you can just walk and think … I find it very therapeutic.” Sometimes I take Christopher with me and when I do, it’s like I get to help myself and Christopher at the same time. For example, when I go snowshoeing with another retired friend we take Christopher with us. So, “I am out there snowshoeing having a great time and getting exercise, but he is too, which makes me feel even better. Even if he is not enjoying it, at least he is benefitting from it because he is getting exercise and fresh air and he is not watching TV.” It is important to do “something for your soul.” I remember learning that at a stress reduction workshop long ago. For me, hiking is doing something for my soul. “I love gardening” too. Another thing I like to do, and want to do more of, is drawing. I like “drawing people’s faces.” I’m good at it and I think “I’m going to take this and see how far I can go with it. Now that to me is personal growth.”

Finally, I have increased admiration for my son now that I understand more of what he has been through. “I’m proud of him. I’m very proud of him … I think that he is in many ways like a hero. He’s had the courage to go through all that and somehow come out the other side. He has not killed himself. He has not given up. He has maintained being the person that he is in many ways, the nice guy, not jaded, not bitter, accepting his lot in life and going with it.”

When I was asked for a metaphor to describe my experience of living with the challenges and uncertainties of my son’s illness, I thought of how I used to get to school through the prairie mud. On the prairie where I grew up “the soil was a heavy clay, a very heavy clay and when it
rained, oh my gosh, … it made mud. If you walked in that mud, pretty soon your foot would be caked with mud and it would stick. And, my father would do anything to get us to school, a little one room country school house about four miles away. When it was really muddy like that, we would start off in the car and he would have to stop twice on the way to school and twice on the way home - four times … [because] the mud caked in the wheel wells and the wheels wouldn’t turn. So he would take all the wheels off, clean the mud out, put the wheels back on, and then we would go for another two miles. And then he would do it again until we got to school … Years later they graveled the road. Now, as soon as you gravel the road, you’re fine … You can get by. You can get to where you are going if you take long enough and if you put enough effort into it … You can get there, but it’s a hard slog … All of a sudden you are on stronger ground. It is a lot easier. You can go forward easier. It is still hard. It is still not a great paved road. It is still, you know, a bit of a difficult journey, but it is a lot easier than it was before.”

“Going through the mud” is like going through “the years of helplessness when we didn’t know what we were dealing with.” Travelling on the gravel road is like the experience after the diagnosis, when we finally found out what we were dealing with. It is still difficult, it is not like “travelling on a paved road,” but it is a lot easier that it was. As I’ve travelled the muddy and the gravel roads I have grown and changed in the ways I’ve described. And, I believe that my growth and change has helped my daughter, my husband, and the people in my community. It has been good for my daughter to see me “trying to actively deal with the whole situation and not just sit back and say: ‘Oh my God, this is horrible.’” She sees me reading books, speaking [about the illness], going to support groups, and teaching classes. My response to the illness has also “in a positive way… affected how my husband deals with it.” Our community has also been affected. “It is [now] a better environment for Christopher.”
Table 7 Themes and Subthemes in Sharon's Story

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<thead>
<tr>
<th>Major Themes</th>
<th>Learning about and Understanding the Illness</th>
<th>Commitment to Helping Her Son</th>
<th>Enduring Sadness and Loss</th>
<th>Personal and Relational Change</th>
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<td><strong>Sub-themes</strong></td>
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<td>Understanding her son’s experience of the illness</td>
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<td>Learning about the mental health system: Giving credit where credit is due</td>
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Findings of the Cross-Narrative Analysis

This section presents the major common themes, significant threads, as well as broader dimensions that emerged through a cross-narrative analysis of the six stories presented in the previous section (see Table 8 on the following page). Each of the common themes, significant threads, and broader dimensions are briefly described. This sections ends with a diagram (Figure 1) that illustrates the relationship between these major common themes, significant threads, and broader dimensions, and a brief discussion of how the diagram itself is a story.

Major Common Themes

Four major themes were common to the experience of each of the participants in this study. These themes were experienced in somewhat different ways and to difference degrees by each participant. The order in which they are presented reflects the degree to which these themes stood out to me through the process of the cross-narrative analysis. The order does not reflect the prominence of these themes in all of the individual narratives, nor does it represent the sequence in which these themes were experienced by each of the participants.

Enduring sadness and loss. All of the participants reported an enduring sense of sadness and loss in their lives. The intensity of this sadness and loss fluctuated with the up and down course of their child’s illness. During the more stable periods of their child’s illness, the sense of loss was reportedly more in the background rather than the foreground of their experiences. As Sharon put it: “constant but at a very low level.” Several mothers like Ellen, were intentional about not focusing on their experiences of sadness and loss. Ellen reported that “keeping these feelings at bay” helped her to “not become engulfed by this illness” and thus more able to carry on with her life. During the more acute periods of their child’s illness the mothers in this study experienced a more poignant sense of sadness and loss. As Karen described, when her daughter’s
Table 8  Findings of the Cross-Narrative Analysis

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<th>Major Common Themes</th>
<th>Significant Threads</th>
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illness is at its worst it is like having “a child who in many ways is a sort of a living death.” The participants identified multiple losses including losses related to the effects of the illness in their child’s life, their family life, and in their own lives as mothers.

All of the participants talked about the sadness and loss they experienced as they watched the pervasive and debilitating effects of the illness in their child’s life. As Ellen put it: “the sheer horror of this illness and how it consumes [my child].” The pervasive effects of the illness referred to by these moms included cognitive losses and impairments, the inability to meet developmental norms, and the loss of healthy functioning. Some of the moms emphasized how painful it was, and continues to be, to witness their child’s loss of the ability to enjoy life. For example, Ellen described her daughter’s life as “so very empty.” Catherine put it this way: “[My son] has no life at all right now. No life. No friends.” The memory of who their child once was highlighted the sense of loss for these moms. Catherine recalled the “naturally clever, naturally athletic” son she knew before he became ill. Ellen described how her daughter “went from being a bright, fun, interesting person to being somebody who is so ill and unable to do things.” Karen emphasized the impact of her daughter’s loss of a normalizing identity through employment and her inability now to have a relatively normal work life. Perhaps the ‘loss of who their child once was’ was most powerfully reflected in the line from Laura’s poem: “Just a reflection of my former self.”

All of the moms also expressed sadness around the loss of relationship with their child. For some mothers such as Laura, this loss of relationship was related to the loss of being able to communicate with their child given their child’s cognitive losses. Other moms, like Catherine, talked about how challenging it was to maintain a close relationship with her son when it meant letting go of expectations and accepting behaviours incongruent with her values for example,
smoking and eating junk food. The loss of relationship was perhaps most strongly experienced by those moms like Karen and Ellen whose children were unable or unwilling to accept that they were ill and consequently rejected their mother’s involvement in their lives or in the mental health system.

Loss of normal family life was also a common loss, although experienced and expressed in different ways. Some mothers described the loss of being able to enjoy holidays and other family occasions. Several mothers talked about the loss of joy and lightheartedness in their families given the relationship challenges and tensions related to their mentally ill child.

The participants also identified significant losses in their own lives. For example Catherine, who described herself as “a natural caretaker,” talked about how painful it was not to be able to meet her son’s needs. Several mothers, in particular the mothers of a child who did not accept his/her illness and/or who had family members who found it difficult to talk about mental illness, also reported a loss of transparency or authenticity. As a consequence of this loss, Karen for example, described living “a double life.” Ellen put it this way: “sometimes it feels like a big lie when you are just not addressing at all that part of your life.”

Other losses in the participants’ own lives included loss of control, loss of support, loss of freedom, loss of career, and loss of dreams for their future. Loss of control was voiced by several mothers who described themselves as being “careful” and liking “predictability.” As Karen put it, with this illness “things whirl around you” and there is nothing you can do about it. In Catherine’s words: “I have to keep telling myself I have no control over what my son is going to do. He can walk out of the hospital tomorrow. I have no control over it.”

Loss of support was experienced in different ways depending on the participants’ individual situations. For example, Lisa and Catherine reported a lack of support from their
partners, particularly during the early stages of their child’s developing illness. Lisa reported that her experience of this loss was in part influenced by a culturally different understanding of, and response to, mental illness in the Asian community. On the other hand Karen and Ellen emphasized the importance of the strong support they received from their partners throughout their child’s illness. Some mothers, such as Karen and Catherine, also reported strong family support while others like Sharon, described their disappointment related to a lack of family support.

All of the mothers also reported a loss of freedom. They described how the illness, and therefore the need to provide for and help their child, had restricted their lives. For example, the freedom to travel has been and continues to be difficult if not impossible for most of these mothers. Ellen also talked about restricted career-related freedom as a consequence of pouring energy into “improving the situation with schizophrenia rather than into [her] career.” Sharon pointed out how caring for her son within the context of her husband’s complicated work schedule has severely restricted their freedom to spend time together as a couple.

The participants also reported losses related to their dreams for the future. As Karen put it: “I [will] not ever see [my child] develop or blossom like one kind of dreams of seeing their children blossom.” Losses in terms of dreams for retirement were also identified by most of the mothers. The ongoing need to “be there” for their child required living in close proximity to their child, necessarily curtailing any retirement plans to move away from the city.

Sadness was also expressed related to changes within the mental health system such as the closing of mental health facilities and funding cutbacks in programs for the mentally ill. As a result of these changes, Laura predicted that there will be individuals [with a mental illness] who will “fall between the cracks,” thereby increasing the burden of care for families.
Distress and struggle. Distress and struggle was also part of the experience of living with the challenges and uncertainties of their child’s illness for all of the participants in this study. The early years of their child’s developing illness were particularly marked by distress. As the illness progressed, various situations specific to their individual child contributed to fear, worry, or concern. The participants struggled with the up and down course of the illness and also with the need to change expectations – to accept and work around “what is.” In addition, some of the mothers experienced distress related their child’s inability and/or unwillingness to accept their illness. All of the mothers in this study described situations when they struggled with a sense of powerlessness.

Not surprisingly the early years of the illness were marked with distress and struggle for all of the mothers in this study, although more for some than for others. As described in their individual stories, the participants struggled with their child’s confusing, and at times frightening and bizarre behaviours. For some of the moms, tension with their partners exacerbated the distress. Although receiving the diagnosis was described as a relief by some of the moms, as the illness progressed, distress and struggle continued to be part of their experience in various ways. For example, Karen described the anguish associated with what she called the “constant dilemma”- the ongoing struggle with questions such as: “How much is the illness? How much is her? How much is just lethargy from the illness? What do we accept as a kid with an illness and also just a kid? How much do you do for them?” Catherine described her struggle to set boundaries in the face of her son’s demands given that, as she put it, “he knows how to push his limits as far as he can go.” Participants described times when fear, anxiety and worry were at the forefront of their experience. Ellen reported that initially “the whole thing [mental illness] scared me.” As she explained, a large part of her fear was the fear of the unknown. Karen voiced her
fear at the possibility of “making the wrong decision” and “having it go really wrong.” Several mothers experienced turbulent and frightening situations with their children that required police involvement. In addition, for some moms such as Laura, housing challenges were, and continue to be, a persistent source of worry and concern.

Distress was accentuated by the up and down course of the illness more for some moms than for others depending on the individual course of their child’s illness. Karen, for example, described the agony of watching and waiting, knowing her daughter “could crash at any time” and then the anguish of seeing early signs of relapse, “watching her decline …. watching this disintegration.” Ellen vividly described the impact of the up and down course of her daughter’s illness when she said: “My whole emotional level rested on her emotional level ... You know, your child’s doing well and everything in the world’s possible and then, when your child’s not doing well, it’s like .... I couldn’t think beyond that.” As Lisa put it: “It’s like a roller coaster. I move up and down with his up and downs ... it is a daily struggle.”

The struggle to let go of expectations and to accept “what is” was also part of the experience of these moms. This was particularly prominent in Catherine and Ellen’s stories, where letting go became a process of moving from expectations of what their child should and will do and be, to an acceptance that their child will do and be whatever their illness allows him/her to do and be. Catherine reported that the process of acceptance required her to “change [her] expectations completely.” For Ellen “letting go” meant no longer “clutching at every straw to make her [daughter’s] life right” and coming to the realization that: “I can make miniscule changes or minuscule goodesses happen for her, but I can’t make her life into a winning life.” For Lisa, letting go centred around the struggle to allow her son to take more responsibility for himself. For all of the participants acceptance included, as Sharon put it, the realization that “you
are in this for the long haul.”

Distress and struggle was notably present in the experience of the participants who had children who were unable and/or unwilling to accept that they were ill. These moms struggled with questions such as “When do you let them be ill if that is what they truly want? Or when do we stop this constant fight to demand a relative level of stability for her?” As previously noted, these moms at times felt like they were living “a double life” and sometimes found it difficult but necessary to take on “the bad cop role.” Karen pointed to the high personal cost of making decisions against her daughter’s wishes when she said after stepping in “we suffer her wrath.”

Distress also took the form of anger and frustration for some of the moms in response to a number of injustices including perceived stigma, lack of consultation, or decisions made by mental health professionals that were perceived as harmful. For example, Laura voiced her distress around the rejection and stigma she faced when trying to find housing for her son. She also expressed anger and frustration in response to placement/treatment decisions made by mental health professionals without consulting her. Both Laura and Karen voiced their distress in response to review panel decisions that they considered unfair and not in their child’s best interests. Lisa described how upset she and other parents were in response to the decision to close a program that had played a vital role in helping their children manage their illness.

All of the moms in this study also experienced a sense of powerlessness, although in different ways and at different points in their parenting journeys. For Sharon the sense of powerlessness was most poignant in the years prior to her son’s diagnosis when, as she described it: “There’s this hole in your life that you can’t fix … You’re stuck in this grey zone. You just don’t know what to do because there is nothing that you can latch on to.” Laura voiced a similar sense of powerlessness when her opinion was not taken into consideration in placement
decisions for her son. Lisa described an excruciating sense of powerlessness when she witnessed what she perceived as “inhumane treatment” of her son when he was a patient on the psychiatric ward. For Catherine the sense of helplessness seemed to be most present when she was told by her son’s psychiatrist to watch her son carefully because he was at high risk of suicide. Karen reported feeling “completely and utterly powerless” in response to the review panel that allowed her daughter off mandatory medication. Perhaps the sense of powerlessness was best summarized by Ellen when she said: “There is nothing that you can do about it ... You can worry yourself sick, but in the end it doesn’t make an ounce of difference.”

Commitment to helping / action. All of the mothers in this study were, and continue to be, committed to helping their child. They also all recognized that this commitment is life-long and they were committed to action – to doing what they could to help their child. Helping for all of the moms involved learning about the illness and studying their child to understand his/her individual needs. Helping also involved an ongoing search for balance between protecting and nudging/pushing their child to take more responsibility for him/herself.

All of the moms made it clear that they were committed to loving and caring for their child no matter what. As Karen put it in reference to both her own and her husband’s role in their daughter’s life: “We’re never going to stop. It’s just the way it is. We know that wherever she goes we will help her and check up on her … We are committed to helping her cope and live as stable a life as possible.” Ellen put it this way: “I know that I will be taking care of my daughter all of my life.” Metaphorically the challenge of helping was described by Karen as a “big mountain” to climb. She voiced a “sense of rising to the challenge,” and emphasized that giving in to the illness was not an option. According to Karen, “giving in can kind of drown you.”

It was clear that all of the moms were committed to action, although in somewhat
different ways depending on their individual context and their individual child’s needs. They all sought professional medical help for their child. For some this was easier than for others. Once their child’s diagnosis was confirmed they all learned as much as they could about the illness. For some moms such as Lisa, the desire to learn about the illness continues, while other mothers such as Laura and Ellen reported that over time they have become satisfied with their level of knowledge related to their child’s mental illness. The focus of their commitment to action also changed over time for some of the moms. For example, Ellen’s early commitment to action involved years of intense focus on trying to “make her daughter’s life OK”. More recently she has focused on setting boundaries and working together with her husband to establish what can/can’t be done to help their daughter. Importantly, all of the mothers reported that taking action was empowering for them and helped them to cope with the challenges they have faced, and continue to face.

Their commitment to helping also involved studying their child in order to understand their child’s unique experience of the illness and to discover how to respond to their child’s unique needs in the most effective way. Karen, for example, reported that she studied her daughter to the point where she can “see subtle changes.” As she put it: “I can act instantly. I know what’s going on in her instantly.” Lisa put it this way: “I really want to understand what my son is experiencing – to really read behind the lines, you know.”

The search to find a balance between protecting and “doing for” their child was perhaps most clearly voiced in Lisa’s questions: “How do I help myself to help him help himself? How much will I trust him? What is he able to do for himself?” As Sharon put it: “[I’m] walking a fine line between protecting him and ... pushing him... maybe it would be better for him and for his life long term if he was pushed out into the world a little bit.”
As I heard the participants voice their commitment to helping it was clear to me that this commitment was motivated by a deep love for their child. I was struck by Lisa’s words: “My son’s illness has taught me the meaning of love, patience, and understanding. Despite how he functions, how he reacts, he is loved. I did not know that I loved David this much until after his illness.”

**Personal and relational change.** A wide range of personal and relational changes were reported by the participants in this study as a consequence of living with the challenges and uncertainties associated with their child’s illness. These personal changes included: an expanded sense of awareness and sensitivity to others and to their child; increased tolerance, personal strength and determination; increased openness; a greater sense of gratitude; changed priorities, as well as changes related to assumptions about life. All of the mothers also talked about their intentional and increased focus on self-care. Relational changes were also reported both within and outside of the family.

All of the mothers reported an expanded sense of awareness and sensitivity to others, although this change was experienced in somewhat different ways by each participant. For example, Karen talked about gaining an awareness of the “global struggles of people” and a “profound sense of the difficulties of life.” She also pointed out that “[when] you have a grown child that lives such an incredibly chaotic life ... you become more attuned to anybody who is in a similar situation.” Sharon reported that her increased sensitivity has enabled her to be more helpful to others who are hurting. Similarly, Lisa reported having gained more compassion for her clients at work. All of the mothers also reported having gained an increased awareness of their child’s unique experience of the illness and thus an increased sensitivity to their child. Over time they all became highly sensitive to their child’s symptoms. In Karen’s words: “Nobody gets
it like a parent and it’s kind of mind expanding to know that you alone, you alone, understand this kid.”

All of the mothers also reported having gained increased patience and tolerance, personal strength, and determination. Karen stated: “You do learn patience, don’t you, with somebody who is incredibly difficult. You just have to, to survive.” Catherine talked about learning to tolerate behaviours that she previously found offensive. She also talked about becoming more “tolerant to other people about their judging and their advice.” Regarding personal strength, Laura reported: “the storms have strengthened me.” Once “really afraid of what to do and what to say,” Laura now doesn’t feel that she has “any issues that [she] needs to keep quiet about.” Reflecting on increased strength and courage, Sharon similarly voiced her willingness to venture “out of her comfort zone.” Speaking for herself and her whole family, Lisa put it this way: “through our difficulties, through our struggles, we have become stronger people.” Regarding determination, Laura emphasized her “ongoing firm resolve,” while Karen emphasized her commitment to “rise to the challenge” – to accept what is and do what she can within the limitations of the illness. Ellen used the word “striving” – initially “striving to make her [daughter’s] life OK,” and later, striving to make her own life OK.

Several of the mothers also reported having gained a greater openness to talk about mental illness and their experience of living with their child’s illness. For example, Catherine talked about how her openness has helped others living with mental illness become more open to talking about their experience. Sharon emphasized that her “deliberate” openness is also a way to fight the stigma of mental illness as well as a way for her to facilitate a caring social environment for her son with her neighbours and friends.

All of the mothers also reported that they had gained a greater sense of gratitude and
appreciation. Most of the mothers expressed gratitude for the collaborative relationship with, and help received from, specific mental health professionals who “understood” their child and were “family friendly.” Several moms also expressed gratitude for caring, supportive family members and friends. Karen, for example, pointed out that family members had helped her to “get a wider perspective of life again” at a time when she was feeling hopeless. Several moms, such as Laura and Ellen, expressed gratitude for the opportunity to serve and make a difference in the field of mental health. Laura also reported that she was grateful to be able to provide a legacy for her children – an example of what it means to stand up for what you believe in and to make a difference. Sharon also emphasized having gained a deeper appreciation for the preciousness of life. In her words: “My experience with my son has taught me that life itself, even when it is not going well, is precious... Maybe you get that more when you come close to losing somebody.”

All of the moms also reported that, after becoming aware of the experiences of other mothers whose children were also living with this illness, they were “grateful that the road [they had] travelled with this illness was not worse.”

The participants also described how their priorities had changed through their experience of parenting their children throughout the course of their illness. “Living in the moment more, not thinking ahead” as well as leaving her son’s treatment plan in the hands of mental health professionals, reflect Catherine’s changed priorities. Changed priorities for Ellen are reflected in her desire to focus less on her daughter’s illness and more on being with her son and his family. Lisa reported that she now “treasures things that are more eternal.” Sharon emphasized the high priority she now places on strengthening the bond she has with her son. As she put it: “I realize now, more than ever, how important that bond is. I value it more and I deliberately try and look after it more.”
Changes in assumptions and beliefs about life were also part of the personal changes reported. Catherine stated that she no longer believes that by “working away at something it will get better,” or that “what goes around comes around.” Similar changed assumptions were voiced by Karen and Ellen. In reference to the problems associated with her daughter’s illness, Karen reported that she no longer assumes that she can “wrap this up … get some solutions … put it together and that will be it.” Similarly, Ellen stated that she no longer believes: “If you just put enough effort in, enough thought, or enough grinding on an issue, you’re going to be able to solve it.” Ellen also voiced that in contrast to former assumptions about how to deal with the problem of homelessness, she now believes that “there are winners and there are losers …. people aren’t making decisions to be losers. Crumby stuff has happened to them.” Catherine reported that she used to assume that people will care and look after others besides themselves and now believes that people “look out for themselves.” Most of the mothers, also no longer assumed that their own lives would follow the “normal stages of life that most people go through” and that these stages would go “relatively smoothly.” Gone were the assumptions that their children would be “relatively content [and] happy” and “reasonably successful.” On a personal level, the women in the study no longer assumed that they would have grandchildren some day.

Another personal change reflected by all of the participants was their increased intentional focus on self-care. Their often hard-earned advice to other parents facing similar challenges regarding self-care included: “maintain a balance” in your life even when “extreme stuff is happening;” have “something else going on in your life besides your child’s illness;” “hold on tight to people who love you;” and “hold on tight to your own sanity.” Some mothers stressed the importance and value of being in a parent support group. Most of the mothers also
stressed the importance of physical exercise and talked about a number of physical activities that they had found helpful in taking care of themselves including: swimming, biking, hiking, dancing, and walking. Karen emphasized the important role of having animals in her life.

All of the mothers also talked about the relational changes that they experienced as a result of living with their child’s mental illness. They talked about changes with partners, family members and friends. Of the five mothers who were married and living with their spouses during the early stages of their child’s illness, three described this time period as very hard on their spousal relationship. Lisa reported feeling “alone in her grief.” Ellen stated that her “all-consuming focus and frenzied activity” focused on “making life OK” for their child, contributed to significant strain in her spousal relationship. Although it was not the primary factor, Catherine reported that the disagreements and the stress related to her son’s behaviours contributed to the breakup of her marriage. Over time, however, both Lisa and Ellen witnessed their spousal relationships mend and grow stronger. In reference to her current relationship with her husband, Ellen said: “We are now partners walking this path together.”

In contrast to the experience of the three mothers just described who struggled in their partner relationships during the early stages of their child’s illness, two of the married mothers reported that their spousal relationship became stronger throughout their child’s illness. Sharon reported that she and her husband supported each other throughout the many years of her son’s illness. Karen, similarly reported that “right from the start” she and her husband were committed to “maintain[ing] a connection as a husband-wife pair” and emphasized that over the years they have become a strong “team, a partnership,” supporting and learning from each other as they have cared for their daughter. With obvious appreciation for his “steady hand,” she described her husband as “the rock in the family.”
Several of the participants also reported that their relationship with their other children (siblings of their child with the illness) had become stronger over time. Catherine, for example, talked about how much she treasures “the normal relationship” that she has with her daughter. Karen described similar sentiments towards her son, who as she put it, is “very much the apple of our eye.” Laura and Lisa also talked about having a closer relationship with their other children as they drew attention to the admiration and appreciation they felt for these children’s desire to make a difference in the field of mental illness/mental health.

Relationships with friends also changed for some of the participants in various ways. Karen, for example, spoke of a close friendship that ended at least in part due to her friend’s lack of understanding about mental illness. Other mothers, such as Sharon, reported that their relationships with friends had strengthened over the course of their child’s illness.

**Significant Threads**

The following four significant threads, although not necessarily common to the experience of all of the participants and experienced in somewhat different ways for each woman, emerged through the cross-narrative analysis as significant subthemes in most of the participants’ stories: concern about what will happen when they are no longer here to care for their mentally ill child, concern about the impact of their child’s illness on other siblings, fluctuations in hope, and regret/guilt. The order in which these significant threads are presented reflects the degree to which these threads stood out through the process of the cross-narrative analysis.

**What will happen when I am no longer here?** This question was deeply concerning for all of the mothers in this study – a concern that for most mothers was accompanied by a sense of dread. Several mothers expressed their concerns related to housing and health challenges. All of
the moms referred to the lingering question of whether their child would one day die by suicide. Karen reported that this question comes up for her every day. Lisa openly expressed her grief as she imagined her son’s future loneliness in the absence of his parents. She wondered if her son might search for them and “wish that Dad were here ... that Mom were here.” Ellen reflected on the impossibility of adequately passing on what she and her husband have learned about caring for their daughter to those who will have to assume this responsibility. Lisa words summarize the shared concern of all of the mothers in this study: “What will happen to our children after we die? ... It is a pain in all of us.”

**Impact on other siblings.** All of the mothers in this study also expressed concern about the impact of the illness on their mentally ill child’s siblings. Laura drew attention to the danger of “ignoring any other child” when so much energy and attention is focused on the child with the illness. In Ellen’s words: “I think that all too often when a child becomes mentally ill the other child is just supposed to get out there ... and deal with life.” Ellen also talked about the losses for well siblings, given that events like family holidays, are often no longer possible. Catherine pointed out that her daughter’s accomplishments are often not celebrated, given that her brother seems to get worse at these times. Both Karen and Catherine emphasized that there may be more pressure on the well sibling “to be the perfect child” – to somehow “make up for what their mentally ill sibling cannot be or do.” Karen wondered if her son “has become super competent or super successful in part because he has a sister that he feels he has to compensate for.” Some of the participants also voiced their concern about how the illness might affect the future for their other children. Karen talked about the “huge” sense of responsibility that her son feels for his sister. In reference to her daughter, Sharon put it this way: “I don’t want [her] to feel burdened to change her life plan because of her brother’s illness.”
Some positive influences of the illness on siblings were also noted. Laura and Lisa both expressed their admiration for their well child’s desire to make a difference in the mental health system as a result of having a sibling with mental illness.

**Fluctuations in hope.** Over time all of the mothers in this study also experienced changes in their levels of hope as they faced and lived with the uncertainties and challenges associated with their child’s mental illness. As Ellen pointed out: “Starting on this journey hope is huge.” She reported that her initial hope was based on the “expectation of a cure.” Other mothers described their initial hope as hope for “recovery.” Ellen reported that over time she gradually came to the realization that her expectation of a cure was a false hope and that “false hope is not very useful in terms of getting on with aspects of this illness.” Laura’s hope changed to the point when, in reference to her son’s illness she said: “I don’t see much changing that is going to be hopeful.” Karen described a point, following the review panel decision, where she experienced a “total lack of any hope of stability” for her daughter. No longer devoid of hope, Karen reported that she is currently “sort of sustained by these rather vague impressions of what will happen,” a “sort of vague dream” that her daughter will go on to become an advocate for others at some time in the future. Of all the moms in this study, Sharon and Lisa seemed to hold the most hope for their child’s recovery. Sharon stated that her hope for recovery is largely based on what she knows about her son’s character and the expert care of his psychiatrist. That said, she also voiced the recognition that recovery will be limited given the damage caused by the illness prior to the onset of treatment. Lisa similarly voiced a sense of confidence and hope in the treatment decisions of her son’s psychiatrist, although her hope for recovery was also based on the positive impact of her husband’s involvement in their son’s life, as well as her faith in God.

Several of the participants also expressed changes in hope related to changes in the
mental health system. As Laura put it: “the services that the professionals have been able to provide have been watered down and so the changes that I see occurring – we’re not going forwards, we’re going backwards.” That said, she also saw the fact that families have “become stronger and more organized” as a hopeful sign.

**Regret/guilt.** Four of the six mothers talked about feelings of regret and guilt related to various issues. Two of the moms struggled with feelings of regret/guilt when they reflected back on their mothering experiences before their child was diagnosed. They wondered if some of their early parenting responses may have contributed to their child’s overall level of distress and whether this increased stress may have contributed in some way to the degree of difficulty their child experienced after he/she became ill. Lisa put it this way: “I wonder if I was too strict with him … I wonder if he would have it [the degree of illness] coming out maybe less with less stress. I wish I had been more sensitive to his hurts and pains.” Sharon’s feelings of guilt were somewhat different and related to the many years it took to establish a diagnosis for her son and thus the many years before he received treatment. As she put it: “I wish I had recognized earlier that he needed help ... One of the hardest things I have had to deal with is the feeling of guilt for not doing anything for so many years.” Karen voiced yet another source of guilt, related to feeling relieved when her daughter moved out of the family home. She also talked about feeling guilty when leaving on a holiday, given her strong desire to always “be there” should anything happen to her daughter.

**Broader Dimensions**

Four broader dimensions emerged in this study: new normal mothering, changes in mothering over the course of the illness, involvement with the mental health system, and the process of adaptation and engagement with life in new and meaningful ways.
**New normal mothering.** For the mothers in this study normal mothering changed when their child became ill. These moms began, and continue to mother differently than how they had mthered their child before he/she became ill and also differently than how they currently mother their other adult children who do not have a mental illness. New normal mothering is different for these women in part because new normal mothering is mothering within the context of multiple losses and the ongoing uncertainties and challenges associated with their child’s illness which are different than the uncertainties and challenges associated with mothering adult children who are well. It means anticipating the possibility of sudden unexpected changes, and always being ready to manage crisis situations. At times it means mothering in response to confusing and difficult behaviours and wrestling with the dilemma of “what is illness and what is not?” It also means walking a fine line between protecting their child and pushing him/her to take more responsibility for him/herself. New normal mothering also requires living with the awareness that “getting it wrong” can have devastating consequences. Additionally, as Catherine emphasized in her story, new normal mothering means letting go of expectations for their child as well as expectations in their own lives as mothers. For several of the mothers in this study new normal mothering also involved a struggle with the “emotional umbilical cord” that linked their moods to the ups and downs of their child’s illness. For some mothers, particularly the moms whose child did not accept his/her illness, new normal mothering also required taking on the “bad cop” role and, at times, living “a double life.” New normal mothering also required the development of skills that enabled and continue to enable these moms to live with their child’s different reality on a day to day basis. As Sharon pointed out, often it means mothering their child like one mothers a much younger child, in particular when focusing on the management of medications and basic self-care.
In addition to responding to the direct effects of the illness on their child’s life, new normal mothering also required managing involvement with the mental health system (to be discussed later in this section). The demands of new normal mothering also included managing changes in the family in response to their child’s mental illness. As several of the participants pointed out, new normal mothering is often not understood by others and is, at times, held in judgment. As a result, several mothers reported that at times they felt lonely in their mothering roles. Given the demands of new normal mothering, all of the participants voiced a need for balance in their lives. Several of the participants also pointed out that mothering for them included admiration for their child − admiration of the courage to live and to keep going in the face of such a devastating and unpredictable illness.

**Changes in mothering over the course of the illness.** A broad overview of the individual stories of the mothering in this study appears to suggest changes in mothering over time. Prior to the diagnosis, mothering seemed to be marked with confusion, crises, and a desperate search for answers. Following the diagnosis, mothering for the participants was marked by a commitment to helping their child and a commitment to action. As described earlier, this commitment included intense learning about mental illness, studying their child’s unique experience of the illness, and the development of a new normal way of mothering. For all but one of the mothers, the commitment to action included becoming an advocate for their child within the mental health system. Some mothers also became involved in mental health activism. All of the mothers looked for support, and for some of the women being a member of a support group was helpful. The journey of mothering over the years was more turbulent and intense and marked more by change for some mothers than for others. Ellen, for example, reported that for many years she was “thinking about the illness all the time” and “her emotions and choices in
life [were] determined by the illness.” This changed when she made an intentional decision to “move on,” no longer “live the illness,” and not be “disappointed in [herself] for that.” Sharon on the other hand, described more “subtle change” in the years following the diagnosis. For most of the mothers in this study, in particular those whose child had been ill for over ten years, new normal mothering over time included a coming to terms with “what is,” a letting go of many expectations both for their child and for themselves, and an intentional focus on finding balance in their own lives. That said, these mothers clearly stated that they will always “be there” for their child and voiced the need to think about what they can do to provide for their child’s needs in the future when they are no longer able to meet their child’s needs.

Involvement with mental health professionals and the mental health system. With the exception of Catherine, a trained medical professional who advised other parents not to get “too involved” in the medical treatment of their child, to varying degrees all of the participants stressed the importance of ongoing involvement with mental health professionals and the mental health system. Catherine voiced her belief that parents should “let the system ... take over even if they are not completely competent” because as she put it: “otherwise you just get worn out and you can’t do it.” On the other hand, Karen stressed the importance of ongoing advocacy. She kept her daughter’s mental health team informed about what was happening through letters and phone conversations. She also provided a family perspective for review panel hearings and publically responded to issues about which she felt strongly. Most of the mothers also served, and several continue to serve, in a voluntary capacity within the mental health system providing education to trainees in the helping professions about the experience of families living with mental illness. Several of the mothers also served on a family advisory council for their local health authority. Importantly, Karen’s story drew attention to the possible personal costs
associated with speaking out on behalf of mental illness when the child with the illness objects to parental involvement.

The two mothers in this study who have been involved in the mental health system for the longest period of time have both been strong advocates for change, although in somewhat different ways. Through her presentations to trainees in the health profession Laura has, and continues to deliver a strong message: “You’ve just got to include us in the dialogue about the treatment of our people.” She also has a strong message for parents: “Keep on asking for what your family member deserves ... Aim high. Aim high.” Ellen has advocated for change in the mental health system through her administrative and fund-raising skills which have been instrumental in expanding research interest in mental health at the university level and also have significantly advanced professional and public understanding of mental health issues. Both of these mothers also reflected on the positive change that they personally have experienced in their relationships with mental health professionals over time. In their stories they described some of the challenges that they faced with mental health professionals in the early years of their child’s illness, and reiterated how much they appreciate the mutually respectful and helpful relationships that they currently have with the mental health professionals involved in their child’s care.

The mothers of a child diagnosed within the past six years also spoke very positively about the help that they currently receive from the mental health professionals involved in their child’s care. Two of these mothers, Sharon and Lisa, were particularly grateful for the open relationship that they have been able to establish with their child’s current psychiatrist and the psychiatrist’s interest in working collaboratively with them. Sharon commented on how privileged she feels to have this kind of collaborative working relationship with her son’s psychiatrist given her awareness of the negative experiences of many parents with mental health
professionals. In terms of involvement in the mental health system, Sharon teaches the Family to Family course offered by the Schizophrenia Society and serves on the board of the society. Lisa’s involvement with the mental health system was through political action. She has also been instrumental in the establishment of a support group for Asian parents of adult children with serious mental illness.

**Adaptation and engagement with life in new and meaningful ways.** All of the mothers in this study adapted to living with their child’s illness and engaged with life in new and meaningful ways after the onset of their child illness. As described above in previous themes, after their child was diagnosed each mother learned about the illness and her child’s unique experience of the illness, and was empowered through action. These moms also identified additional important contributors to their process of adaptation and meaningful engagement with life. Collectively these included: humour, assertiveness, an intentional focus on living in the moment, spiritual meditation, journaling, writing poetry, talking with others who were able to listen and understand their experience, relationships with friends, and physical exercise.

The importance of humour was underscored by Laura and Karen. Laura reported that her humour would “kick in at a pretty awful time” and had kept her from sinking into despair. Karen reported that black humour was an important way that she and her husband dealt with some of the “most dire situations,” particularly in the early chaotic stages of her daughter’s illness. As she put it: “[We would] just laugh and then, get on with it.”

Assertiveness and boundary setting were also important in the process of adaptation for several mothers. For example, Ellen described how she has learned to set firm boundaries in response to her daughter’s requests without which she felt at risk of “going into fix it mode” which, she stressed, is “not helpful to her and it’s not helpful to me.” Laura talked about setting
boundaries with mental health professionals and reported saying: “I am a mother and I simply am unable to do all the things that you feel I should do in the time frame that you expect me to do it.”

Several moms emphasized the importance of having an intentional focus on living more in the moment. For example, Catherine stressed the importance of focusing on being fully present when she was visiting her son. Living more in the moment was also one of Ellen’s goals. She emphasized that living in the moment was easier when she kept her life simple and when she intentionally focused on doing things that she enjoyed, like making her home beautiful and spending time with her son and grandchildren.

Lisa was the only mother in this study who spoke about the importance of spiritual practices in adapting to the challenges of living with her son’s illness. She also emphasized the “healing” role of journaling in her life. Laura reported that writing poetry was helpful for her to process her experience early in her parenting journey and was encouraged to learn that her poetry has also had a positive impact on others.

For all the mothers, talking to someone who could understand their experience also played an important role in their ability to adapt to the experience and engage with life in new and meaningful ways. Catherine referred to a friend who helps her to explore her emotions and to consider perspectives on her situation that she might not otherwise have considered. Ellen and Lisa emphasized the helpfulness of support groups. As Ellen put it: “get yourself a support group because nobody else that’s not dealing with schizophrenia can really understand the issues that one is going to face.” Karen emphasized “holding on tight to people who love you and who you love because you are going to need all the support you can get.” Lisa talked about the help she received through counselling and put it this way: “To be able to have someone look after me and
to be able to hear me was very new to me…. it help[ed] me tremendously.” All of participants also commented that participating in this study has been helpful for them.

These mothers also stressed the importance of physical activities, in particular physical activities that they enjoyed. Across the stories of the six mothers many forms of exercise were reported as helpful including: walking, hiking, swimming, biking, dancing, yoga, gardening and snowshoeing. For example, Ellen talked about the helpfulness of regularly meeting with her friends for exercise. Karen also described the “huge joy” of being with her dogs, and explained how listening to music has been helpful in coping with the stresses of her child’s illness. The value of exercise was perhaps summarized best by Sharon who suggested that hiking was “something for your soul.”

**Relationships Between the Common Themes, Significant Threads, and Broader Dimensions**

Figure 1 on the following page illustrates the relationship between the common themes, the significant threads, and the broader dimensions that emerged through the cross-narrative analysis. The arrows in the diagram indicate the major direction of influence between these themes, threads, and broader dimensions. The four circles at the centre of the diagram represent the major themes that are common to all of the narratives. The most prominent theme, "Enduring sadness and loss," forms the centre of the circle. As the arrows suggest this theme informs the theme of "Distress/struggle," which informs the theme of "Commitment to helping/commitment to action," which informs the theme of "Personal and relational change." The arrow extensions illustrate the further influence of each of the four major common themes, i.e. each common theme ultimately informs each of the four broader dimensions. The four broader dimensions and the arrows between them provide a framework that informs the context in which the four common themes are situated. Within this framework the dimension of "Involvement with mental
Figure 1  Relationships between the Common Themes, Significant Threads and Broader Dimensions

A - What will happen when I am no longer able to care for my child?
B - How is my child’s illness influencing siblings who are well?
C - Fluctuations in hope
D - Regret/Guilt
health professionals and the mental health system" informs the dimensions of "New normal mothering" as well as "Adaptation and engagement with life in new and meaningful ways." The dimension of "New normal mothering" informs the dimension of "Changes in mothering over time," which then informs the dimension of "Adaptation and engagement with life in new and meaningful ways." The diagram also illustrates how the significant threads (represented by the small circles) are imbedded within the common themes. "Impact on other siblings" is imbedded within the major common theme of "Enduring sadness and loss." "Regret/guilt" is imbedded within the major common theme of "Distress/struggle." The two threads, "What will happen when we are no longer here" and "Fluctuations in hope," are each imbedded within two major themes, i.e. "Distress/struggle" and "Enduring sadness and loss." The diagram itself suggests a story that will be briefly outlined below in answer to the question: What is this story?

What is this Story?

This is a story about enduring loss and enduring love. It is an adaptation tale – a formation/construction tale. It is a tale about what can happen when stories break – stories of hopes and dreams, stories of expectations, stories of what it means to have a good life, stories of what it means to be human. It is a story about being formed through the breaking of a story and engaging in the construction of a new story.

Enduring loss is central to this story and the reconstruction process. Reconstruction must honour the presence of this loss and build around it. The loss must be held and cared for tenderly, for at times it breaks out in unexpected ways. The loss adds to the other distresses and struggles that can be part of this mothering experience: What will happen to my child when I am no longer here to care for him/her? How is this affecting my other children? How can I hold on to hope? What is realistic hope? What happens when hope seems lost? If only I had been able to get help
sooner. I wish I could have done some things differently. What is illness? What is not? Will he/she someday die by suicide? How can I be who I need to be for all of those I love and care for? I need to be ready for the unexpected. Commitment emerges through the losses and the distress and struggles – a commitment to helping fueled by love and a commitment to action that empowers and enables. These mothers’ reconstructed lives are changed in every way – physically, psychologically, socially, spiritually. Relationships are changed – some are left behind, others deepened.

This adaptation story is ultimately about mothering in a new normal way, informed by a deep “knowing:” knowing their child in a way that no one else can, and informed by a different involvement in their child’s life and also involvement with the mental health system and with mental health professionals. Mothering has not only changed, it continues to change with the ups and downs of the illness and with the changing needs of everyone in the family. New normal mothering involves engagement with life in new and meaning ways. Life balance is important. Self-care is a priority. Joy is sought and found. Life is understood differently. There is greater empathy. Patience and tolerance increases. The sense of gratitude increases. The roots of love grow deep.

This adaptation story is a story about finding the pieces. About reassembling the pieces in a meaningful and creative way that makes sense and is liveable. It is a story about finding ways to live well with what is. Adaptation, reconstruction is like the crafting of a quilt that is multicoloured and fragmented, and where the lines don’t meet. The new story is like a quilt with broken fragmented pieces that form beautiful patterns that are wondrously dynamic. The patterns are framed in the life that now is – the black and blue and also the brightly dancing polka dots.
CHAPTER FIVE: DISCUSSION OF THE FINDINGS

This chapter begins with a restatement of the purpose of the study and the guiding research question, followed by a brief overview of the research findings. Attention is then drawn to the convergence or divergence of the findings of the current study with the existing research on this parenting experience. This is followed by a discussion of the ways in which the findings of this study are empirically and theoretically important. Implications for counselling psychology practice and future research are discussed and the limitations of the study are addressed. The chapter ends with my personal story of change through the research process, a revisitation of the metaphors of change provided by the participants and my own metaphor of change.

As stated in chapter one, the purpose of the study was to expand on the theme of personal growth and change that emerged in my previous research on the experience of fathers of adult children with schizophrenia. It was my intention to provide a greater understanding of this parenting experience by beginning to uncover the nature, development, and role of personal growth and change in the lives of parents of adult children with schizophrenia or schizoaffective disorder. The overarching research question guiding the study was: How do parents of adult children with schizophrenia or schizoaffective disorder experience personal growth and change as they live with the challenges and ongoing uncertainties associated with their child’s mental illness? A qualitative, narrative research method was used to address this question and to provide a rich description of this subjective experience.

Brief Overview of the Main Findings

The main findings of this study are the individual stories of the six mothers who volunteered to participate in this study. These stories represent possible ways of living with the challenges and uncertainties associated with mothering an adult child with schizophrenia or
schizoaffective disorder. Each story is somewhat different given the unique context of each mother’s life, the nature and course of her child’s illness, as well as individual personal differences between these women. The unifying threads for each story (Commitment to Change; Journey to Acceptance; Working, Watching and Waiting; Coming to Terms and Moving On; Coping, Growing and Changing: A Spiritual Path; and Learning, Helping and Living Well) each represent a strongly held personal value for that participant and reflect individual personal differences. The similarities in these stories are reflected in the common themes, significant threads and broader dimensions that emerged through the cross-narrative analysis. These are briefly summarized below.

Enduring sadness and loss was described as a constant presence in the lives of all of the mothers in this study. It was a palpable presence in some of the interviews. However, for most of the mothers, the sadness and loss was more in the background than the foreground of their experience. It periodically surfaced more intensely in response to situations that reminded them of how different their child’s life was currently, compared to how their child’s life had been, or how they had expected their child’s life to be. Importantly, these mothers spontaneously spoke about their sense of sadness and loss. The questions in the interview protocol did not directly focus on sadness and loss. All of the mothers identified multiple losses in their child’s lives, their family’s life and their own lives.

The second common theme, distress and struggle, also emerged spontaneously in all of these mother’s stories. However, unlike the theme of enduring loss, distress and struggle was not a constant part of their experience. Rather, distress and struggle were experienced in different ways and in response to somewhat different issues including in response to their child’s difficult behaviours, family disruptions, the multiple uncertainties associated with the illness, and for
some participants, their frustration related to the mental health system.

The third common theme, commitment to helping their child, was prominent for all of the mothers in this study and involved a commitment to action. Most of the mothers reported that taking action was empowering for them. Action for most of these women included direct involvement with their child, mental health professionals, and the mental health system.

The fourth common theme, personal and relational change, was likely a response to the research question given that the participants were directly asked to describe their experience of personal growth and change. Four of the six mothers were hesitant to use the term growth (discussed further later in this chapter), but all of the mothers readily acknowledged that their lives had significantly changed through their parenting experiences. Common changes included changed assumptions about life, greater tolerance and empathy, changed relationships in the family, and an intentional focus on self-care.

Several significant threads also emerged in the stories of several of these mothers. As illustrated in Figure 1 of chapter four, three of these threads: impact on the sibling who is well, what will happen when I am no longer able to help my child?, and fluctuations in hope, significantly informed the common theme of enduring sadness and loss. The common theme of distress and struggle was also informed by three threads: what will happen when I am no longer able to help my child?, fluctuations in hope, and regret/guilt. Also, as illustrated in Figure 1, when taken together to various degrees the common themes contributed to the four broader dimensions: new normal mothering, changes in mothering over time, involvement in the mental health system, and adaption and engagement with life in new and meaningful ways.

The Convergence and Divergence of the Findings with the Existing Literature

The convergence and divergence of the findings in the current study with the findings in
the existing literature are discussed below in relation to the major common themes, significant threads and broader dimensions.

**Enduring Sadness and Loss**

In each of the individual participant’s stories the common theme of enduring sadness and loss is consistent with the significant and multiple losses associated with parenting an adult child with a mental illness reported in the research literature. More specifically, the findings in the current study are similar to the losses reported in the literature related to the pervasive effects of their child’s illness (Atkinson, 1994; Eakes, 1995; Howard, 1994, 1998; Miller et al., 1990; Nystrom & Svensson, 2004; Richardson et al., 2011; Ryan, 1993; Tuck et al., 1997; Wiens & Daniluk, 2009), as well as losses related to family life (MacGregor, 1994; Ryan, 1993; Teel, 1991; Tuck et al., 1997; Wiens & Daniluk, 2009). The following losses reported in the current study are also consistent with the findings in the existing literature on the experiences of parents of children with a serious mental illness: loss of personal freedom (MacGregor, 1994; Jones, 1997); loss of hopes and dreams for the future (MacGregor, 1994; Wiens & Daniluk, 2009); loss of joy and lightheartedness – at times to the point of burn-out and depression (Jones, 1997; MacGregor, 1994; Jungbauer & Angermeyer, 2002); loss of control in the face of uncertainties (Howard, 1998; Jones, 1997; Jungbauer & Angermeyer, 2002; MacGregor, 1994); and loss of support specifically from friends who do not understand the parent’s experience (MacGregor, 1994; Milliken, 2001; Milliken & Northcott, 2003).

In the current study Karen and Ellen’s stories in particular expand on the understanding of loss reported in the literature, given their rich descriptions of losses related to parenting a child who does not accept his/her illness and who opposes parental involvement in their treatment. Additionally Lisa’s story highlights a loss of cultural understanding not previously reported in
the extant literature, likely a reflection of the fact that few studies to date have included non-Caucasian participants.

Importantly, it appears that the experience of enduring sadness and loss reported by the mothers in this study is consistent with the concept of chronic sorrow proposed by Olshansky (1962; described in Chapter 2). All of the mothers in this study experienced enduring losses. Karen and Ellen's stories in particular support the reports that parental grief associated with this parenting experience often occurs in recurring cycles and sometimes at a higher degree of intensity than initially experienced, depending on the course of the child’s illness (Atkinson, 1994; MacGregor, 1994; Miller et al., 1990). Ellen, Karen, and Catherine's stories are consistent with the report in Eakes (1995) that over time the sense of sadness associated with chronic sorrow is more in the background than in the foreground of the parent's experience. The stories of the women in this study are also consistent with Olshansky's observation that the presence of chronic sorrow does not preclude the ability to experience joy. Notably, Ellen and Lisa talked about their intentional decision to incorporate joy into their lives. Similar to the reports of fathers in the study by Wiens and Daniluk (2009), Laura and Sharon shared their positive feelings of admiration for their child.

**Distress and Struggle**

The theme of distress and struggle was also common to the experiences of all of the participants in this study and is well documented in the literature (MacGregor, 1994; Howard, 1998; Lefley, 1989; Jones, 1997; Jungbauer & Angermeyer, 2002; Ryan, 1993; Wiens & Daniluk, 2009). More specifically the distress and struggle of these mothers related to: their fears and anxiety around how to respond to, and manage, their child’s difficult behaviours (Lefley, 1989; Milliken 2001; Wiens & Daniluk, 2009); worry about their child’s future particularly when
they are no longer around to take care of them (Richardson et al., 2001; Wiens & Daniluk, 2009); worry related to the ever-present possibility that their child will someday die by suicide (MacGregor, 1994), and distress related to family disruptions (Howard, 1998; Lefley, 1989; MacGregor, 1994; Tuck et al., 1997; Wiens & Daniluk, 2009). Consistent with the report of MacGregor (1994), several of the mothers in the current study also talked about the distress experienced in their spousal relationships due to differences in how they and their husbands understood and responded to their child’s behaviours, as well as differences in their styles of coping and grieving. Importantly, Karen and Ellen’s stories provide a description of the additional turmoil and anguish experienced by parents whose child does not accept his/her illness and the possible personal cost to the parent when decisions need to be made against an adult child’s will – an experience that has yet to be described in-depth in the existing literature.

The findings in the current study also provide some support for the frequently reported feelings of anger and frustration related to the stigma of mental illness (Eakes, 1995; Lefley, 1989; Ryan, 1993), although anger in response to stigma was significantly less prominent for the mothers in the current study than participants in these previous studies. Only Laura and Sharon talked about experiencing stigma related to their child’s mental illness. Perhaps this is a positive sign that may reflect increased public awareness, understanding and acceptance of mental illness.

The findings also provide some limited support for reports of anger and frustration with the mental health system (Jones, 1997; Milliken 2001; Milliken & Northcott, 2003; Wiens & Daniluk, 2009). It is interesting to note how the mothers in the current study presented a more balanced picture, also speaking positively about some of their more recent experiences with mental health professionals who were involved in the care and treatment of their children. This is encouraging and may be a reflection of positive changes within the mental health system related
to understanding the important role of parents in the treatment and management of their child’s illness. In relation to anger, it is interesting that when I met with Ellen to hear her response to the story I had written, she told me that her participation in the study had increased her awareness of feelings of anger in her life, although this was a topic that she did not wish to discuss. In her study of the parental experience of chronic sorrow, Eakes (1995) reported that anger “permeated” the experience of grief for the participants in her study. It is unclear as to why anger was not a predominant emotion expressed by the women in the current study. Perhaps this is a cohort effect, or it may be that these mothers have been living with their child’s mental illness for a longer period of time and have moved past the sense of anger and injustice that might characterize the experiences of parents who are in the earlier stage of acknowledging and coming to terms with their child’s diagnosis.

In the current study and in the previous research literature, it is clear that the distress and struggles associated with this parenting experience are exacerbated by the multiple uncertainties inherent in living with the ups and downs of the course of the illness, and that these uncertainties can at times result in feelings of helplessness and powerlessness (Jungbauer & Angermeyer, 2002; Milliken, 2001; Milliken & Northcott, 2003; Richardson et al., 2011; Ryan, 1993; Wiens & Daniluk, 2009). In particular, Karen’s description of the “constant dilemma” expands our understanding of this uncertainty by explicitly drawing our attention to the specific unanswerable questions that she struggles with, including "When do you let them be ill if that is what they truly want?" All of the mothers had to find ways to cope with their sense of powerlessness and helplessness. Laura, Karen, Ellen and Sharon directed attention to activities that provided a sense of control such as advocacy and making a difference in the mental health system. Lisa turned to
her spiritual faith. Catherine adapted to these multiple uncertainties through intentionally letting go of expectations.

**Commitment to Helping / Commitment to Action**

The findings associated with this common theme highlight the important role that making a commitment to helping and to action may play in coping with, and responding to, the challenges of parenting a child with a mental illness. Consistent with Lefley (1989) and Richardson (2011), the commitment to helping for the participants in this study required significant time and energy as they navigated the mental health system in search of help for their child. Consistent with the descriptions of the endless nature and the burden of care-giving reported in previous studies (Howard 1998; Jones, 1997; Jungbauer & Angermeyer, 2002; Milliken, 2001; Milliken & Northcott, 2003; Ryan, 1993; Tuck et al., 1997), the participants' commitment to helping was also reflected in care-giving that was described as long-term and at times all consuming and complex. Also, similar to the reports of participants in previous studies (Eakes, 1995; Jungbauer & Angermeyer, 2002; Milliken, 2001; Ryan, 1993), the participants in the current study expressed a sense of responsibility to meet their child’s needs to the best of their ability and a commitment to ‘being there’ for their child for the duration of their lives. Like the parents in the studies by Milliken (2001) and Milliken and Northcott (2003), the mothers in this study expressed their commitment to action primarily through advocacy and activism.

**Personal and Relational Change**

The personal and relational changes reported by the participants in the current study are consistent with the personal and relational changes that have been mentioned in, although not expanded on, in previous studies of the experiences of parents of children with a mental illness. For example, there have been general reports of: “positive personality change” (Nystrom &
Svensson, 2004, p. 375); becoming a “better, wiser, more spiritual and discerning person” (Tuck et al., 1997, p. 124); and increased acceptance, patience, assertiveness, and increasing awareness of the importance of self-care (Bulger et al., 1993). Additionally, participants in the study of fathers of adult children with schizophrenia by Wiens and Daniluk (2009) reported increased self understanding and admiration for their child. In Marsh et al.’s (1996) study participants described “new competencies, new insights, new directions” (p. 9). The convergence of the findings in the current study with these general reports of change underscores the possibility of valued changes in the midst of the context of multiple losses, distress and ongoing struggles that are associated with this parenting experience. The stories of the mothers in this study also provide an expanded understanding of some of these changes. For example, with reference to new insights Karen and Ellen described how their view of the world and of mental illness had changed. With reference to new directions, all of the mothers elaborated on how the personal changes they experienced affected how they became involved with others especially as advocates in the mental health system. With regard to spiritual change, Lisa’s story described a possible role that spirituality can play in coping with, and making meaning of, this parenting experience. Regarding self-care, the findings in this study highlighted specific activities that have helped these mothers cope with the ongoing challenges and uncertainties associated with their child’s illness. Finally, it is noteworthy that while all of the participants in the current study readily affirmed the many changes in their lives, four of the six participants expressed discomfort with the term "growth." This is consistent with the negative responses reported by Marsh et al. (1996) in relation to their question about the positive aspects of this parenting experience. This discomfort is also consistent with the sense of surprise expressed by the participants in Bulger et
al.’s (1993) study when participants were asked about personal growth. It appears that at least for some parents, the use of the term "growth" with its positive connotations, is an inaccurate term to describe their sense of the changes in their lives. Perhaps this reflects the extent to which the undesired changes that resulted for the women and their family members outweighed other changes in their own lives that they felt resulted from the challenges of this mothering experience. The term ‘growth’ implies a desirable personal gain. Several mothers expressed that it was difficult and felt incongruous for them to consider personal gain at the expense of their child's illness.

**Convergence and Divergence Related to the Four Significant Threads**

The first significant thread, “What will happen to my child when I am no longer able to care for him/her?” echoes a concern reported by participants in other research studies on the experience of parenting a child with a serious mental illness (Jones, 1997; Jungbauer & Angermeyer, 2002; Nystrom & Svensson, 2004; Ryan, 1993; Tuck et al., 1997; Wiens & Daniluk, 2009). This question underscores the challenges associated with the unpredictable course of the illness, the life-long nature of parents’ commitment to their child, and the need for parents to prepare as best they can for their child’s future when they are no longer there to watch out for them and respond to their needs.

The second significant thread, concern about the impact an adult child's mental illness on siblings who are well, has also been reported in numerous studies (Howard, 1998; Milliken, 2001; Wiens & Daniluk, 2009). The importance of this concern to all of the mothers in the current study underscores the need for more research to gain a greater understanding of the impact of mental illness on siblings, and to identify how concerns related to the impact of the illness on siblings may be addressed.
The third significant thread, fluctuations in hope, has been widely reported in the literature (MacGregor, 1994; Howard, 1994; Jungbauer & Angermeyer, 2002; Milliken, 2001; Milliken & Northcott, 2003; Ryan, 1993; Tuck et al., 1997) and has significant implications for counselling which will be discussed later in this chapter. The mothers in this study and parents in the literature experienced fluctuations in hope in response to the up and down course of the illness and, at times, in response to unmet expectations in the mental health system. These fluctuations in hope contributed to ongoing stress/tension and a sense of vigilance, and interfered with parents' ability to plan ahead and maintain a sense of life balance.

Feelings of regret and guilt have also been widely reported in the literature on the experience of parenting a child with a mental illness (MacGregor, 1994; Jungbauer & Angermeyer, 2002; Wiens & Daniluk, 2009). However, it is interesting to note some differences in the way in which the mothers in this study talked about their feelings of regret and guilt. For example, in previous studies parents reported feeling regret and guilt based on their inability to recognize the illness and access treatment for their child sooner. Some parents in these studies (e.g. Jungbauer & Angermeyer, 2002) also reported guilt based on a perception that their parenting may have caused, or contributed to the course of their child’s illness. In the current study, although feelings of regret/guilt were also related to the length of time before their child’s illness was accurately diagnosed and treated, none of the mothers believed that their child’s illness had been caused by poor parenting. This encouraging finding may be a reflection of the advances in identifying and understanding the neurobiological changes associated with the etiology of these illnesses (Pennington, 2005; Walker, Kestler, Bollini, & Hochman, 2004) in contrast to the literature in the mid twentieth century that emphasized parental inadequacies as an etiological factor in the development of schizophrenia and schizoaffective disorder.
Convergence and Divergence Related to the Four Broader Dimensions

The broader dimension of new normal mothering is consistent with, and further expands on, the descriptions of the mothering experience in the extant literature (Milliken, 2001; Milliken & Northcott, 2003; Howard, 1994; Ryan, 1993). For example, new normal mothering is clearly viewed as normal but different than mothering an adult child who is well. Sharon’s story identifies some of the everyday challenges associated with new normal mothering, such as medication management and supervision of personal hygiene. The broader dimension of new normal mothering also validates the expertise of these mothers. As the mothers in this study clearly stated, they not only know their particular child better than anyone else, they have developed a specific skill set to meet their individual child’s needs.

The second broader dimension, the process of mothering over time, supports the process of change described by Milliken (2001) and Milliken and Northcott (2003) as well as the theoretical model of change over time proposed by Howard (1994). Although the processes of change were worded somewhat differently in these studies, consistent with the findings of the current study they included an early period in the development of the illness that was marked by confusion and crises. They also included a commitment to help-seeking and care-giving, and a strong desire to learn about the illness and the particular needs of their child. Advocacy and sometimes activism also became a strong focus. Over time the process of parenting included a change of focus centred around finding a balance between providing for their child and meeting their own needs. Importantly, these changes in the process of mothering over time do not appear to occur in a linear way. Rather, the findings of the current study suggest that this process of change – of adjusting to, and coming to terms with, the reality of their child’s illness – appears to be cyclical, with some stages in this process having to be revisited and renegotiated throughout
the varied course of their child’s illness and in response to changes in each parent’s life and relationships.

Regarding the third broader dimension, involvement with the mental health system, similar to the participants in Milliken (2001) and Milliken and Northcott (2003), all but one of the mothers in the current study served in the mental health system in various volunteer capacities, in addition to advocating for her child. However, unlike the reports of participants in previous studies (MacGregor, 1994; Milliken, 2001; Milliken & Northcott, 2003; Nystrom & Svensson, 2004; Wiens & Daniluk, 2009), the experiences of these mothers with the mental health system were more positive than negative. This finding may reflect a greater recognition of, and appreciation for, the important perspective/role of parents in the treatment of mental illness.

The fourth broader dimension in this study was adaptation and engagement with life in new and meaningful ways. As pointed out previously, although studies by Bulger et al. (1993) and Marsh et al. (1996) have reported resilience and personal growth, the current study provides more detailed and specific examples of the ways in which the participants adapted, and engaged with life after the onset of their child’s illness. These included the use of humour, assertiveness, an intentional focus on living in the moment, spiritual meditation, journalling, writing poetry, talking with others who were able to listen and understand their experience, relationships with friends, and a variety of physical activities all of which had practical significance. These coping strategies will be discussed further in the section on implications for counselling practice.

**Implications for Theory**

The findings of this study are empirically and theoretically important. When taking into consideration all of the findings, and contrary to what I originally thought, the Models of Stress-
related Growth that informed the initial stages of this study and the research question did not appear to be the best fit for understanding these data. This became increasingly more apparent as the study progressed. It is my belief that the theoretical framework of nonfinite loss provides a better conceptual lens for understanding the findings of this study. In this section I will discuss my reasons for concluding that the models of stress-related growth, in particular the Comprehensive Model of Posttraumatic Growth, may not be the most appropriate way to understand the findings of this study, followed by a discussion of the conceptualization of the findings within the theoretical framework of nonfinite loss.

Why Models of Stress-related Growth Do Not Appear to Fit the Data

As the study progressed it became increasingly clear that four of the six participants in this study were uncomfortable with using the term “growth” to describe their mothering experiences even though they had confirmed at the beginning of the study that they met the criteria for participation, which included having experienced personal growth and change. As described in my researcher story of change in the epilogue at the end of this chapter, over the course of the study I also became increasingly uncomfortable with applying the term “growth” to the stories and experiences of the research participants. At times, using the term “growth” even felt offensive. This was in sharp contrast to the use of the term “change” which was readily acknowledged by all of the participants – and a topic that elicited increasingly ready conversation and description as the research progressed.

Also, when taking the findings as a whole, stress-related growth did not appear to be central to the participants’ experiences. In contrast, what was most important to them was how their lives had been forever changed given the enduring losses that informed the context of their lives since the onset of their child’s mental illness. Although the sadness associated with these
multiple losses was not always in the forefront of their experience, all of the participants acknowledged loss as an ongoing presence and influence in their lives.

Additionally, in the theoretical literature Tedeschi and Calhoun (2004) describe posttraumatic growth as transformative. The participants in this study did not use the word “transformative” in relation to their mothering experiences. While they acknowledged that their lives have been irrevocably changed – sometimes in positive ways – their stories are stories of adaptation rather than transformation – adaptation to a changed life context. These are stories of how each of these mothers engaged with life in meaningful ways, given the reality of the protracted and uncertain course of her child’s life and future – as well as her own. All of the participants spoke about their personal strengths and the characteristics that they believe have helped them to cope with the difficult challenges of their child’s illness. They reflected on how their lives have changed, and are continuing to change through the process of responding to the challenges of their child’s mental illness. For example, Laura talked about how she drew on the advocacy and activism skills that she had developed prior to the onset of her son’s illness, to help her address her son’s needs and to facilitate changes in the mental health system. Catherine’s story revolved around the changes associated with her journey to acceptance and how, in meeting the challenges on this journey, she drew on her life-long desire to understand and let go of expectations that are no longer realistic. Karen’s story reflected her life-long ability to “rise to a challenge,” and Ellen’s story reflected her personal characteristics of determination and commitment to action. Lisa’s story was a story about drawing and expanding on her spiritual beliefs, to cope with, and make sense of, her son’s mental illness. Sharon’s story reflected a life-long commitment to mothering well, to helping others, and to personally living well.

Finally, as presented in the theoretical models reviewed in chapter two (Calhoun &
posttraumatic growth and stress-related growth seem best understood as an outcome of dealing with a discrete, highly stressful event, not an experience that is ongoing. Additionally, the Comprehensive Model of Posttraumatic Growth (Calhoun & Tedeschi, 2006) suggests that, once passed, the experience of the “traumatic” event can then be integrated into a person’s self-narrative, primarily through a process of cognitive engagement. The experiences of the participants in this study are different in several ways. These mothers are living with multiple ongoing challenges in response to the uncertain course of their child’s illness. The levels of stress associated with these challenges are unpredictable and necessarily fluctuate in response to changes brought about by the stage of the illness or by changes in their child’s medications, living circumstances, or mental health providers. Living with these multiple challenges and uncertainties requires a continuous process of coping and adaptation that includes making meaning of these changes, but also requires other ways of processing and coming to terms with the multiple ongoing losses and challenges that these mothers face.

Notably with respect to cognitive engagement, at the beginning of the study it seemed that most of the participants had not extensively engaged in a cognitive meaning-making process related to their mothering experiences. Ellen’s story of “Coming to terms with the illness and moving on” is an exception, perhaps because of the length of time she had been living with her daughter’s illness. For the other participants who had been living with their child’s mental illness for a shorter period of time, their primary focus was on the day to day realities and challenges of helping their child while also attending to the needs of the other members of their family. That said, the experience of participating in this study appeared to facilitate a cognitive process that included reflecting on, and making sense of, their mothering experiences for all of the
participants in this study. By the end of the study the women spoke about the value of engaging in the process of thinking and talking about their mothering experiences. Several participants used the word “therapeutic” to describe the interviews and reflection process.

The stories of the participants in this study suggest that their process of “adaptation” included multiple levels of processing and integrating their experiences in addition to cognitive processing in terms of physical, psychological, social, and spiritual levels of processing. Perhaps the physical activities that these mothers emphasized as being very important in helping them deal with the changed realities of their lives, may have also served as a mechanism of processing their experiences. As Harris (2001) suggests, the integration of intangible, nonfinite losses may in part involve the unconscious processing of experience that is associated with physical activity.

Nonfinite Loss: A More “Fitting” Way to Understanding the Findings

As suggested above, the findings of this study may be better understood through the conceptual lens of “nonfinite loss.” This was a largely ignored phenomenon in the psychological literature until the 1990s, when through the research and extensive clinical experience of Dr. Elizabeth Bruce, attention was drawn to the theoretical and clinical importance of this type of loss (Bruce & Schultz, 2001; Schultz & Harris, 2011). Recently, researchers and clinicians such as Cynthia Schultz, Darcy Harris, Howard Winokuer, Eunice Gorman, Susan Roos, and Robert Neimeyer have continued to draw attention to the theoretical and clinical importance of nonfinite losses. These theorists and researchers have highlighted the differences between nonfinite loss and bereavement loss following death (which has traditionally informed the understanding of loss in the psychological literature). This section will begin with a definition of nonfinite loss and the ongoing experience of chronic sorrow, followed by a discussion of the nature of nonfinite loss and chronic sorrow. The discussion will focus on how the findings of the current study are
consistent with the conceptualization of nonfinite loss and the experience of chronic sorrow.

Unlike bereavement loss, nonfinite loss is an enduring loss that “retains a physical or psychological presence with an individual in an ongoing manner” (Harris & Gorman, 2011, p. 2). Nonfinite loss is experienced as chronic sorrow, which has been described by Roos (2002) as the ongoing experience of the presence of a loss that involves “living with unremovable loss and unmending wounds” (p. XV). Consistent with these definitions, all of the mothers in this study lived with the ongoing and unpredictable course of their child’s illness. They lived with the knowledge that this illness would always be a part of their child’s life and would shape and limit their choices, abilities, relationships, and future opportunities. They also lived with the loss of who their child once was, as well as the multiple losses of the dreams and hopes and expectations they had about their child’s potential future life. Karen used the term "living death" to describe this experience when her daughter’s illness was at its worst.

The nature of nonfinite loss. According to Harris and Gorman (2011), nonfinite losses are usually precipitated by a negative life event. For the mothers in this study the negative life event was the diagnosis of their child’s schizophrenia or schizoaffective disorder. All of the mothers reported that since the diagnosis of their child’s illness they lived with a “constant” sense of loss, although the sadness associated with this sense of loss was not always at the forefront of their experience. Even Ellen, who had made an intentional decision not to focus on the sadness and loss in her life, remarked: “I could burst into tears at any point.” Schultz and Harris (2011) also point out that nonfinite loss is associated with a significant attachment, which for the mothers in this study, was their enduring love for, and attachment to, their child.

According to Boss et al. (2011), nonfinite loss has a way of “insinuating itself into our lives gradually” (p. 163). This was the case for the mothers in this study – the nature of their
losses and the losses their child would continue to experience throughout his/her life – became more apparent as their child’s illness progressed. Nonfinite loss also involves a loss of normal developmental expectations (Harris & Gorman, 2011). According to Roos (2002), when dealing with an ongoing and unpredictable illness like schizophrenia, there are “crisis markers” (p. 151) rather than developmental milestones. This too is consistent with the findings of the current study. All of the mothers in this study talked about the unrealized expectations and hopes, and the multiple losses faced by them and their child, due to the pervasive and sometimes insidious effects of the illness. As the illness progressed, it became less likely that their child would be able to achieve normal developmental milestones such as completing an education, becoming gainfully employed and developing a stable and satisfying career. It became less likely that they would be able to establish a social support system, get married or have a family. For some of the mothers in this study, the debilitating effects of their child’s illness also interfered with their ability to function on the most basic level. Some of these adult children were unable to independently manage activities of daily living such as personal hygiene and personal safety.

Also consistent with the findings of this study, nonfinite loss is associated with multiple ongoing losses (Schultz & Harris, 2011). The mothers in this study talked about the multiple losses in their child’s life, in their family life, as well as in their own lives as mothers, as a consequence of the effects of their child’s mental illness. Also consistent with the findings of this study, the magnitude of the losses associated with nonfinite loss are often unrecognized and unacknowledged by others (Boss et al., 2011; Roos, 2002; Winokuer & Harris, 2012). This can result in a sense of disconnection or distance in relationships with friends and, in some instances, with family members. Certainly, for many of the mothers in this study, friendships and familial relationships were challenged and sometimes ruptured, due to a lack of acknowledgement or
understanding of the burden these women and their adult children had to bear, and the accommodations they had to make, due to the multiple consequences of living with a debilitating mental illness.

Nonfinite losses are also primarily internal and intangible (Boss et al., 2011; Harris & Gorman, 2011; Schultz & Harris, 2011; Winokuer & Harris, 2012). Although they are very real, they are often difficult to describe (Harris & Gorman, 2001). Particularly during the first data collection interview, the mothers in this study often struggled to find the words to describe the ways in which their lives and the lives of their adult child and immediate family had been impacted by their child’s mental illness. For example, Ellen struggled to find words to describe the loss of transparency and loss of authenticity in her life.

Nonfinite loss is also associated with a loss of certainty that necessarily requires repeated adjustments (Bruce & Schultz, 2001; Harris & Gorman, 2011; Roos, 2002; Winokuer & Harris, 2012). This loss of certainty was repeatedly reflected in the stories of the mothers in this study. The uncertain course of their child’s illness required these mothers to be ever watchful and ready to adjust to whatever their child’s illness might bring, including the possibility that their child’s illness might progress and that their quality of life might deteriorate even further – perhaps to the point of their son or daughter dying by suicide.

Living with nonfinite loss involves “life-altering change” (Harris & Gorman, 2011, p. 2) and life-altering change according to Harris (2011b), requires a process of meaning-making and meaning-finding. At least in part, meaning-making for Catherine, Karen, and Ellen involved accommodating to the changes in their lives by letting go of assumptions about life that no longer “offered a sense of stability and coherence” (Harris, 2011b, p. 241). For the other mothers in this study, meaning-making appeared to be more assimilative, i.e. making meaning through an
existing meaning structure in their lives. For example, Lisa made sense of her experiences within the framework of her spiritual beliefs about life. Harris (2011b) defines meaning-finding as “becoming aware of and accepting meaning that arises spontaneously out of grief and suffering” (p. 243), perhaps through contributing to society in some way that is related to the loss. For the mothers in this study, meaning-finding was perhaps most evident through their volunteer service in mental health organizations. Telling their stories during the research interviews also appeared to be a meaning-finding activity for these mothers, as they were invited to reflect on their parenting experiences and to consider not only what had changed as a consequence of their child’s mental illness, but also what differences these changes had made in their lives.

Given that all of the mothers reported that participating in the study had been beneficial for them through "telling their story of change," they also seemed to experience what Gorman (2011) refers to as the "healing power" of telling stories. As Neimeyer (2001) also points out, storytelling itself is a meaning-making activity and process. For the participants in this study, storytelling may also have been an opportunity to voice otherwise unvoiced stories of loss (Roos & Neimeyer, 2007).

It is noteworthy that nonfinite loss for the participants in this study can also be described as "ambiguous loss" and sometimes as "disenfranchised grief." Ambiguous loss, according to Boss and colleagues (2011), is a term that can be used to describe a loss related to a loved one who is psychologically absent but physically present. Ambiguous loss is characterized by ongoing uncertainty and often confusion around what to do. This is clearly consistent with the reports of the mothers in this study as they lived with the uncertainty and confusion associated with their child’s illness particularly in the early stages of the developing illness.

“Disenfranchised grief” is described by Doka (1989) as loss that is often unrecognized by others
and associated with a sense of stigma. This seems consistent with Laura’s experience in relation to the incidents of stigma described in her story.

**Chronic sorrow: The experience of nonfinite loss.** Chronic sorrow can be described as “the painful disparity between the thoughts and dreams about what should have been, might have been, and still may be hoped for – versus what actually is the present reality” (Boss et al., 2011, p. 168). Clearly this discrepancy was acutely experienced by all of the mothers in this study. At times during the acute stages of their child’s illness, or when they were cut out of important decisions regarding their child’s care, these mothers experienced feelings of helplessness and powerlessness that are associated with chronic sorrow (Bruce & Schultz, 2001; Harris & Gorman, 2011; Schultz & Harris, 2011). Chronic sorrow includes both acute and chronic stress and the accumulation of stress over time (Roos, 2002; Roos & Neimeyer, 2007), which certainly reflects the experiences of the mothers in this study. Also consistent with the findings of this study, chronic sorrow is often cyclical or recurrent (Boss et al., 2011; Harris & Gorman, 2011) and can intensify with internal and external triggers (Harris & Gorman, 2011).

As Boss and colleagues (2011) emphasize, it is very important to understand chronic sorrow as an adaptive, normal response to nonfinite loss. This appears to be consistent with the broader dimension of new normal mothering for the women in this study. That said, at times those who experience chronic sorrow also sense a “disconnection from the mainstream and what is considered ‘normal’ in human experience” (Harris & Gorman, 2011, p. 3), particularly when the experience is not understood by others. Roos (2002) points out that when chronic sorrow is not understood, it can be confused with other losses or depression, or parents who experience chronic sorrow can be mislabelled as overprotective, as appeared to be the case in Lisa’s story.

Roos (2002) also points out that those who experience both chronic sorrow and rejection
by “the one to whom the heart is given” (p. 138) experience a very severe sense of rejection. This certainly was the case for Karen and Ellen, both of whom had an adult daughter who was unwilling to accept her illness. These moms, as Karen put it: “suffered [their child’s] wrath” when they had to make decisions against their child’s wishes.

It is also important to note that living with chronic sorrow requires “energy and persistent courage to cope with crisis and make the adaptations necessary in order to live a life of one’s own” (Roos, 2002, p. xv). Certainly the mothers in this study demonstrated incredible courage and endurance in their ability to adjust to, and cope with, the realities and uncertainties associated with their child’s life and the effects of the mental illness on their lives and possibilities, as well as the effects of the illness on the lives of the other members of their family.

It is also important to note, particularly in light of the models that informed the initial stages of this study, that there is the possibility of growth through the experience of chronic sorrow (Roos & Neimeyer, 2007). In this study both Lisa and Sharon talked about the changes in their lives in terms of growth, even though the other four mothers expressed reluctance to use this term.

Chronic sorrow can also contribute to depression, anxiety, and immobilization (Boss et al., 2011). While the mothers in this study at times experienced periodic episodes of depressed mood and anxiety consistent with the distress in their lives and the lives of their children at those times, they were certainly not immobilized. On the contrary, they were actively involved in their children’s lives and actively involved in society. Perhaps this is a reflection of the social context in which these women lived. As Harris (2011a) points out, the social context of our lives greatly influences the possibilities that exist for us. Notably, these participants were all upper middle class women, with intact social support systems, which likely contributed to their ability to
manage living with the challenges associated with their child’s mental illness. Like most individuals who experience chronic sorrow, the mothers in this study continued for the most part to be physical and psychologically healthy as they met the ongoing challenges and uncertainties they faced in their lives (Roos, 2002). They also continued to be committed to helping their adult children respond to the demands of their illness and to assisting them to have the most fulfilling and satisfying lives possible.

In summary, the findings of the current study appear to be better understood through the conceptual lens of nonfinite loss and chronic sorrow than through the models of posttraumatic or stress-related growth. While all of the mothers readily described the irrevocable changes in their lives as a consequence of their child's illness, four of the six mothers were clearly uncomfortable using the word growth to describe these changes. The stories of change in this study were stories of adaptation rather than transformation – adaptation in response to living within a context of multiple ongoing losses following the diagnosis of their child's schizophrenia or schizoaffective disorder. The sense of loss experienced by these mothers remained a "constant" in their lives, although not always at the forefront of their experience. Telling their stories of loss and change through participating this research appeared to be, at least in part, an important meaning-making and perhaps healing experience for these mothers.

**Implications for Counselling Practice**

When considering the implications for counselling practice suggested in this section, it is important to remember that the findings of this study were based on the experiences of six mothers of adult children with either schizophrenia or schizoaffective disorder and that these women were socio-economically privileged and self-selected. The parenting experiences of other mothers may be quite different. It is also important to remember that every mother’s experience
will also be somewhat different given the specific context and circumstances of her life and her family's life, as well as the unique and cyclical presentation of the illness in her child's life. The implications for counselling practice presented in this section should therefore be considered tentatively.

When considering implications for counselling, it is also important to remember that many individuals who experience chronic sorrow continue to live well as they meet the challenges they face (Roos, 2002). Consequently, similar to three of the mothers in this study, mothers may not need help through counselling or may prefer to consult and process their experiences with others who share their experience. Indeed, four of the six mothers in this study turned to educational and peer support groups at various points along their parenting journey, as a way of accessing information and gaining support. It is important for counsellors to be aware of, and be able to provide information about community support groups, to those who wish to access this kind of support (see Mental Health Professionals Support Resources for Families at resources@reachingfamiliesproject.org). These moms emphasized that “no one gets it like a parent.” They pointed out that support groups can provide the safety and mutual understanding that makes it easier to talk about some of the socially unacceptable situations they and their children face in coping with and responding to their illness. Further implications for counselling are suggested below in relation to the common themes, significant threads and broader dimensions.

The consistency of the findings of the current study with the concepts of nonfinite loss and chronic sorrow suggest that it is important for counsellors working with this population to be aware of the possibility of nonfinite loss and chronic sorrow and to gain an understanding of the multiple losses frequently associated with this parenting experience. Resources such as Darcy
Harris’ 2011 *Counting Our Losses* and Torrey’s 2006 *Surviving Schizophrenia* may be helpful for gaining a comprehensive understanding of these topics. Additionally, the descriptions provided by the mothers in this study regarding the fluctuating nature of their experience of loss – as Karen put it “[You grieve] in pieces over time,” – suggest that it is important to recognize and honour the individual journey of living with loss. When mothers appear to be doing well, counsellors cannot assume that mothers are “finished” grieving and will continue to cope well. Their ability to manage/cope well may fluctuate based on the latest challenge or how stable their child is at any particular point in time.

The finding that all of the mothers in this study experienced sadness related to the loss of relationship with others who seemed unable, and in some cases unwilling to understand their experience/situation, be they friends or family members (e.g. in Ellen and Sharon’s stories), suggests the importance of providing a safe, caring, empathic presence in counselling – a presence characterized by a genuine desire to listen and to understand (Neimeyer & Sands, 2011; Winokuer & Harris, 2012). A genuine desire to understand may be particularly important when seeking to help mothers process some of the intangible losses that can be associated with this mothering experience, such as the loss of transparency and authenticity described in Ellen’s story. As Schultz and Harris (2011) and Winokuer and Harris (2012) point out, it is also important for counsellors to be aware that, in contrast to bereavement loss, there are no rituals associated with nonfinite losses that can validate and honour these losses and thus rally the understanding and support of others. For some clients it may be helpful to acknowledge, and collaboratively create, rituals to honour these losses in individually meaningful ways.

Counselling may also be a safe place to validate, normalize, and process the many difficult and distressing emotions that can be associated with this parenting experience. For the
mothers in this study these emotions included fear, anxiety, worry, frustration, relationship tensions, anger, as well as changing levels of hope related to the up and down course of the illness. Additionally and where applicable, counsellors may be in a position to help clients negotiate the “emotional umbilical cord” between themselves and their child – as was poignantly described in Ellen’s story. In terms of distress, all of the mothers in this study also talked about their awareness of the possibility that their child might someday die by suicide. Counselling may be a place to talk about the impact of this concern, how to assess risk of self-harm, as well as how and when to intervene when risk is high. Counselling may also be a place to talk about and work through the limits of a parent's control over whether this actually happens and their feelings of responsibility.

Some of the mothers in this study also spoke about feelings of regret related to their inability to understand the nature of their child’s illness and to access treatment, particularly in the early stages of the illness. Counsellors may be in a position to help clients work through and let go of feelings of accountability. It may be helpful to acknowledge that parents could not have known at the outset, how to interpret and understand their child’s behaviours when set against the backdrop of normal adolescent challenges and struggles.

The findings of this study also suggest the need for counsellors to be aware of the possibility of additional stress that may be experienced by parents related to culturally different understandings of mental illness, as was the case in Lisa’s story. For example, Lisa talked about the high level of stress and the shame that she and other Asian parents of adult children with mental illness experience when their children are unable to achieve socially desired success. Counselling may be a helpful place to explore the influence of social and cultural contexts on individual experience and how to respond to these influences.
Implications for counselling are also suggested related to the theme of commitment to helping and to action that figured prominently in the parenting stories of all of the mothers in this study. For example; Laura, Karen, and Ellen explicitly pointed out that taking action was empowering for them. Counsellors may be in a position to enhance a parental empowerment by validating the commitment to helping their child and taking action especially at times when clients are struggling with a sense of powerlessness. One of the ways that mothers in this study reflected their commitment to helping was through their strong desire to learn everything they could after their child’s illness was diagnosed. As Sharon advised: “arm yourself with knowledge and information.” This finding suggests that it is important that counsellors be familiar with reliable sources of information about mental illness and the resources available through websites such as The BC Schizophrenia Society at www.bcss.org, and The National Association on Mental Illness at www.nami.org. The commitment to helping for the mothers in this study was also reflected through the way they studied their child in order to gain understanding of their child's experience and know how best to communicate and respond to their child's needs. As a result these moms developed a high level of expertise in mothering an adult child with mental illness. As reflected in Karen’s words – I can “see subtle changes in her” that no-one else sees and “I can act instantly. I know what’s going on with her instantly.” These reports suggest that it is important for counsellors to recognise, respect, and learn from parental expertise. Counsellors may also be in a position to help mothers recognize their expertise and support them as they seek to communicate their knowledge to mental health professionals. As both Ellen and Karen emphasized, the information based on their mothering expertise that they were able to pass on to the mental health teams was important in the management and treatment of their child’s illness.

Although their interactions with the mental health system were positive for the most part,
the stories of the mothers in this study also included negative experiences with mental health professionals as they sought to help their child through advocating for them. For example, Lisa experienced being judged as overprotective when she tried to intervene for her son, and after expressing her opinion to the contrary, Karen experienced the devastating impact of the review panel decision to allow her daughter to stop taking her mandated medications. Situations such as these suggest that counselling may be an important, safe place for mothers to process and address negative experiences with mental health professionals. That said, counsellors need to be aware of and respect that it may take time for mothers to develop a trusting relationship with counsellors when they have experienced negative interactions with professionals.

Counsellors may also be in a position to validate personal and relational changes that reflect strengths and values such as those by the mothers in this study: greater empathy, courage, determination, patience, tolerance, self-awareness, sense of gratitude, and spiritual growth. The mothers in this study also placed importance on self care and balance in their lives as they tried to cope with, and manage the challenges and demands of responding to the needs of their adult children – particularly during times of heightened vulnerability and crisis. Various physical activities (e.g. walking, hiking, swimming, snowshoeing, dancing) were also described as helpful for the mothers in this study. Counselling may be a place where mothers can talk about ways to maintain a sense of life balance within the specific context of their lives.

The relational changes reported by the participants in this study also suggest possible implications for counselling. For example; Catherine, Ellen and Lisa had to negotiate challenges in their spousal relationships – particularly in the early years of responding to, and coping with their child’s illness. All of the moms also talked about negotiating changes in the relationships with their other children (siblings of the child with the illness) as well as with other family
members and friends. Counselling can be a place to validate relationship strengths and collaboratively work with parents as they address relationship challenges with family members and find common ground in their response to the needs of their adult child.

All of the mothers in this study also expressed concern about the future — what will happen to their child when they are no longer able, or around, to care for him or her. Counselling may be a place to collaboratively work with mothers and/or parents who wish to develop a plan around future care that may include the establishment of trust funds (as suggested by Karen, Ellen, and Lisa).

The moms in this study also expressed concern about the impact of the illness on siblings who are well such as: a) the pressure on siblings to make up for the inabilities of their sibling with the illness expressed by Karen and Ellen; b) concern about the effects of stress and stigma expressed by Karen; and c) concern about the future burden of care on siblings expressed by Laura, Ellen, and Sharon. Counsellors can be a place to talk about these concerns as they arise. It is important that counsellors be aware of findings in the research literature regarding the impact of mental illness on siblings. For example, Kirby (2009) reported a sibling sense of responsibility to protect and a struggle with survivor guilt. Friedrich, Lively, and Rubenstein (2008) drew attention to the sibling need for support and resources when preparing to become a future primary caregiver. Barnable, Gaudine, Bennett, and Meadus (2006) pointed out the emotional struggles of siblings associated with trying to understand the illness and care for a mentally ill brother/sister, as well as the concern around the genetic legacy of the illness. These researchers also drew attention to the potential for siblings to develop strengths through caring for a brother/sister who has a mental illness.

The broader dimension of new normal mothering that emerged in this study suggests
possible ways that mothering an adult child with schizophrenia or schizoaffective disorder can differ from mothering an adult child who is well. Counsellors may be in a position to normalize these differences and validate the strengths and skills associated with new normal mothering. For example, Laura and Karen's stories emphasize the ongoing advocacy demands of new normal mothering and describe the strengths and skills these mothers demonstrated as they advocated for their child. Catherine's story highlights how she addressed the challenge of new normal mothering associated with attentively 'being with' her son in the moment without expectations as well as her ongoing struggle to let go of expectations for the future. Karen's story identifies some of the central questions associated with new normal mothering such as: What is illness? What is not? How much do I keep doing for her/him? Ellen's story reflects the intensity of new normal mothering and the struggle to find life balance. In Lisa and Sharon's stories we hear about the depth of love that motivates new normal mothering for these moms, as well as the importance of support as they mother in this “new normal” way. For Lisa, this support involved counselling, spiritual faith and the support of other parents in her Asian community, whereas Sharon found support primarily through the development of a strong social network of friends. Sharon’s story also describes some of the difficult challenges of new normal mothering such as managing an adult child's every day self-care needs, and the skills that are required to meet these challenges.

The broader dimension of changes in mothering over time provides an awareness of the need to be sensitive to parental needs as they arise – often in response to a crisis or significant challenge in the lives of their adult child. For example, all of the mothers' stories identified the period of the developing illness as a confusing time, marked by chaos and distress. Lisa in particular suggested that counselling was invaluable for her during this time. Her counsellor provided a nonjudgmental, empathic, supportive space where she could address her own needs
when the context of her life demanded attention to the seemingly unending needs of her family.
The up and down course of the illness described in all of the mothers stories suggest that it may
be important for counsellors to help clients anticipate shifting needs over time and to maintain an
"open door" policy with this population – the invitation to consult on an "as needed" basis.

Regarding the broader dimension of involvement in the mental health system, Karen, Laura, Ellen, Sharon and Lisa's stories provide examples of the ways that these moms have
learned to meet the advocacy needs of their particular child. For example, Karen faxes information to her daughter's mental health team prior to her daughter's appointments.

Counsellors may be in a position to help clients discern how to most effectively advocate for their child, given their particular situation. Ellen’s story, suggests that it is important for counsellors and other mental health professionals to be sensitive to the nature of the relationship between the child with the illness and his/her parent. For example, Ellen talked about how much she appreciated being able to communicate her concerns to the team in a way that did not jeopardize the fragile relationship she has with her daughter. It is also noteworthy that all but one of the moms in this study expressed that volunteer service in the mental health system had been, and for some moms continues to be, very important to them. As suggested earlier, volunteer service may be a way of meaning finding for these women, and counsellors may be in a position to validate this involvement, without implying that mothers should devote time and energy to this type of volunteer work.

The findings of this study also suggest caution when using the word "growth" with reference to this parenting experience. As previously noted, four of the six participants were uncomfortable with the word "growth." Over the course of this study I also became increasingly more uncomfortable with this term. Through this study I have been made aware of the value-
ladened nature of “growth” and the possibility that this term can be associated with flawed assumptions (e.g. If I don't perceive growth in my life then I am deficit in some way).

Finally, it is noteworthy that all of the participants reported that telling their stories had been a beneficial experience for them, underscoring the therapeutic nature of storytelling (Gorman, 2011; Pennebaker, 2000). Counsellors can facilitate the therapeutic effects of storytelling by listening well and honouring the stories of mothers such as those in this study who live every day with the challenges and uncertainties associated their child's mental illness.

**Implications for Future Research**

The current study used a narrative method with a sample of six mothers of adult children with schizophrenia or schizoaffective disorder. The purpose was to learn how these mothers experience personal growth and change as they live with the ongoing challenges and uncertainties associated with their child’s mental illness. Future studies with different samples could result in different findings. Given that the findings of the current study suggest that the term “growth” may not be appropriate to describe the changes experienced by these mothers, further research with a focus on change rather than “personal growth and change” may be helpful to expand our understanding of the changes experienced by mothers throughout this lifelong parenting experience.

Other qualitative methods, also have the potential to add to our understanding of the needs and experiences of this population. For example, a grounded theory approach may contribute to the development of a theory of change through this parenting experience. A phenomenological approach could potentially identify themes that form the essence of the experience of change related to this parenting experience. A longitudinal study over more than two years may provide valuable insight into the process of change over time. Incorporating the
use of focus groups in future studies of this parenting experience may facilitate additional insight as the interaction between parents may prompt recall of experiences that would otherwise be missed.

The findings of the current study suggest that the experiences of the six mothers who participated in this study can be understood within the conceptual framework of nonfinite loss, a term that has yet to be associated with this parenting experience. Although a number of studies (Atkinson, 1994; Eakes, 1995; Howard, 1998; Miller et al., 1990) as discussed in chapter two, have provided evidence of an ongoing pattern of grief in this population that appears to be consistent with the concept of chronic sorrow, there is more to be learned about the experience of nonfinite loss in this population. Winokuer and Harris (2012) point out that few studies have focused on the process of grief following such non-death losses. A greater understanding of nonfinite loss in this population may be important in identifying the support needs of parents of children with a serious mental illness.

There are also a number of as yet unanswered questions that could inform the focus of further research. For example: Are there mothers or fathers in this population who do not experience nonfinite loss/chronic sorrow, and if so, how might their experience be different? Are nonfinite losses experienced differently by fathers and if so, how is the experience of fathers different? Is loss experienced differently by mothers and fathers of adult children with different mental illnesses such as bipolar disorder or depression? Is there a difference in the experience of parenting an adult child with schizophrenia or schizoaffective disorder related to how high functioning the child is or how debilitated? Also, given the high suicide rate associated with schizophrenia and schizoaffective disorder, it may be helpful to examine how the experience of loss changes following the suicide death of a child with these illnesses. Future research with
large samples using quantitative methods may also be helpful to determine the needs of this population at various stages of their child’s illness and across the parental lifespan.

Also, given that the participants in this study were all mothers who were socioeconomically advantaged, and lived in or in close proximity to a larger urban centre with multiple mental health resources, future research could provide additional perspectives on this parenting experience by including fathers, parents who live in rural settings or in settings that do not have readily available mental health resources, as well as parents who are economically disadvantaged. Future studies could also include participants from various cultural and ethnic groups. The one non-Caucasian mother’s story (Lisa’s story) suggests there may be much to learn about the cultural meanings and expectations associated with mental illness and how these meanings and expectations affect this parenting experience. It could also be helpful to gain a greater understanding of the couple experience by including both members of the parenting couple in future studies.

The concern expressed by all of the mothers in this study about the impact of the illness on siblings also suggests a need for further research from the perspective of siblings. The reported lack of understanding from friends (e.g. in Karen and Catherine’s stories) and sometimes family members (e.g. in Ellen and Sharon’s stories), suggests that future research could provide greater understanding of the impact of mental illness by including the perspectives of additional members of the extended family (e.g. aunts, cousins, uncles, in-laws) and/or friends. Also, given that three of the six women in the current study reported that counselling was beneficial for them, a study specifically focused on how counselling has been helpful or not helpful could potentially inform counselling work with this population.
Limitations

When considering the limitations of this study it is important to remember that the findings are based on the experiences of six mothers and that these moms were all socio-economically privileged and self-selected. They all lived in, or in close proximity to, a large western metropolitan city with multiple mental health resources. All but one of the participants were Caucasian and all were mothers of more than one child and had only one child with schizophrenia or schizoaffective disorder. It remains to be determined if the experiences of mothers of adult children with these illnesses who are economically disadvantaged, or live in rural settings or settings without ready access to mental health resources, are different. Perhaps the experiences of mothers of a single child who has schizophrenia or schizoaffective disorder are different. Lisa’s story in the current study suggests that the experiences of mothers of different cultures may be different. The fact that all of the participants volunteered to participate which suggests that these women may have been highly motivated to share their stories and/or perhaps had a strong desire to make a difference. The stories of mothers who are not interested in participating in this type of research study may be different.

The findings may also have been different if I had not included the word “growth” in the research question. This term may have excluded mothers for whom this word was even more uncomfortable than it was for four of the six mothers in this study. If I could repeat the study I would omit the word “growth” and only use the word “change” in the research question. As Lieblich et al. (1998) and Riessman (1993) point out, the findings are also necessarily limited given the use of a narrative, qualitative method which is exploratory by nature.

The research findings are also necessarily limited given my researcher’s perspective. I was familiar with the research studies that have focused on the experience of mothers and fathers
of adult children with schizophrenia prior to the onset of the study, which would inevitably influence what I heard to some degree. The findings are also limited and to an extent enhanced by the fact that I am the mother of an adult child with schizophrenia. Many of the experiences of the research participants resonated with my personal experiences since I was living a parallel process to my participants throughout the study. To familiarize the reader with my personal experience at the beginning of this study in chapter one I shared the story of my personal growth and change prior to the onset of the study. In the following section I share my personal story of change throughout the research process. Inevitably my personal experience prior to and throughout the research process will also have influenced the findings.

**My Story of Change Through the Research Process**

This story of change through the research process is based on the research journal that I kept throughout the research process. I begin with my reflections on the proposal writing process and the process of recruiting and screening potential participants. I then reflect on my experience at the heart of this study – meeting with each of the participants, the thoughts and questions that emerged through the process of analysis, writing the individual stories, the risks I encountered, and the process of meeting with the participants to check in with them to see if the story I had written resonated with their experience. I then draw attention to my experience of the cross-narrative analysis, followed by a description of my changing understanding of, and response to, the term “growth.” I end with reflections on what I have learned about the nature of narrative research endings.

**The Proposal Writing Process**

At a Family Mental Health conference I met a former research participant from my Master’s study, who told me that he continued to value his experience as a participant and that it
had been therapeutic for him. My heart warmed to hear his comments. I am reminded of the
influence of these fathers’ stories on who I have become and I want to experience this kind of
influence again. I remember what Dr. Carl Leggo said about “the heart of narrative inquiry – how
the storying is full of hope and healing, how the hope and healing require both articulation and
an experience of being heard” (C. Leggo, personal communication, May 3, 2008). I ponder what
it means to be part of this world of narrative inquiry. Suzanne Ouellette’s (2003) metaphor for
narrative research, painting lessons, is helpful for me. It catches my attention, lets me see this
work differently as I write:

**Narrative Research and Ouellette’s Painting Lessons**

> “Working on the whole canvas”
> All parts simultaneously in formation
> A “becoming” work

Questions here and there
How? Who? Where?
Waiting in expectation is important, necessary

I hear the invitation
to read, to ponder, to reflect, to question
What is this experience about?
How does it move me?
Who am I becoming as I move closer to the work?

> “Put down what you see”
> So I do

Colours blending
Context/background fuller, thicker

A text/canvas on which to rest for now…
A place to wait as I listen and watch expectantly
A balance slowly forming, nuanced with the experience of each new day.

I’ll hold this draft lightly
And remember “Sam’s recipe for a good piece of work”:
Inspiration, Passion and Conviction
And so I begin to write my proposal - chapters one, two, and three. More questions: What is important? What is relevant? How does this influence me? Where does it direct me? The “must read” pile keeps growing. Bottom line questions surface: Why do I want to do this research anyways? Because this is about real people, real life — people who have stories to tell, important stories to tell? Stories that need to be understood? Stories that can help others? I hope so. Sometimes I wonder if this is really about me, about making meaning of my own experience. What I do know is that I want to somehow help others “get it” or at least “try to get it.” That is enough for now, for “getting it” changes things and change ripples out to create more change. Change also brings new hope. I want to hang on to that.

As I write, I sense a growing awareness of the responsibility I have as a researcher to listen well to the stories I am told and to listen well to what happens in me as I hear them. I want to enter this research respecting and valuing the importance of everyday experience and keep with me a sense of wonder about it. Writing the stories is still far in the future, but I am already beginning to feel the responsibility to write the stories in a way that will grip the readers’ attention and change them in some way. These stories must not be left to gather dust on a shelf.

I struggle to write chapter one in a way that reflects both the personal and the professional side of why I am proposing this study. It feels like I am at the bottom of a mountain looking up and it is a long way up. Twice I have rewritten this chapter – climbed the mountain only to find myself back at the bottom. I talk about the chapter with my supervisor and she says “start again.” She knows that I need to climb differently, and has far more confidence in me than I have in myself. I am reminded of what one of my colleagues said: “This work is not for the faint hearted. It takes courage and fortitude. The thin-skinned can’t take it.” Am I thin-skinned? I want to be sensitively thin-skinned. I start the chapter again with courage and fortitude and it
helps. It is much better.

I move into chapter two sensitively-skinned and with courage. At times the “ache” swells, especially when I read about chronic sorrow. I begin to wonder: How can I ask about growth when all I feel at the moment is the ache? The growth that meant so much to me – the growth experienced by the fathers in my master’s thesis research – seems to have faded, almost disappeared from view. Is this growth real or just an illusion created to help me feel better about my situation? How can I ask my participants about something that seems so discrepant in my own life at the moment? Maybe I’m experiencing a temporary blindness, something that will shift and when it shifts I will again be able to see growth, the growth and change that I think exists together with this ache of unresolved grief. Perhaps this is a paradox I live with – that mothers of adult children with schizophrenia live with. Perhaps some of us have been able to live more fully with this paradox. I wait with anticipation of what my participants will say.

The word “invitation” now takes on even greater meaning for me. The ability to create an invitational atmosphere in my interviews that is safe and free, will be a vital part of facilitating rich descriptive storytelling. An invitational atmosphere will also require me to be mindful of the privilege I have to hear the story I am told. I am beginning to sense that my own experience in the interviews and over the course of the study will likely play a larger role in this study than I had anticipated. I give myself the freedom to discover my own experience of growth and change in a fuller way.

**Recruitment and Screening**

I am amazed. My committee was right. There are people out there who want to tell their story. Within 48 hours I have responses to my recruitment notice. Within a few weeks I have more responses than I need to begin the research. Although I advertise for “parents,” all who
respond to my recruitment notice are mothers. What does this mean? Do mothers in particular have a need to tell their stories and to have their experiences understood? Do mothers find it easier to tell their story than fathers? Are these mothers, women who want their stories to be helpful to others? Is the study viewed as an opportunity to address needed changes in the mental health system? I don’t know, but I do know I that I am eager to get to know these participants and hear their stories.

As I screen respondents by telephone, four of the potential participants express some hesitation and discomfort around the term “personal growth.” This stirs up my own hesitancy around this term. I don’t want to suggest that “personal growth” is something gained which makes the experience worth going through. The very idea of “growth being worth it” is abhorrent to me. I would gladly give up anything that I might have gained through my experience of mothering to have my son be healthy and free from the struggle with this illness. In a heartbeat! No question. That is clear. But I know that I don’t have that choice and that is also clear. There are things I cannot change, however much I might wish to, and so I live with what is. It is within the reality of living with this mental illness that I have been, and am being shaped — that I have grown and changed.

Meetings With the Participants

As I meet each of these mothers for the first time I am struck by how much easier it seems to be for them to talk about what has happened to their child than to talk about their own lives. It seems to be even more difficult to talk about how they have changed through “what happened” and still more difficult to talk about how they view the changes they have experienced. I wonder if I will be able to access the rich descriptions that I am looking for when most of what I am hearing seems to be contextual information. I wonder what might be
underneath their spoken words and contemplate how to access that unspoken experience and invite the telling of the stories associated with it. Maybe it feels strange to the participants to be telling their own story rather than the story of their child’s experience of the illness. Perhaps these stories are so intertwined that it is difficult to separate them. I remind myself that although I am keen to hear about their personal experiences of growth and change, understanding the context of the stories is also important. It brings to mind what Lucy Grealy, in Ann Patchett’s (2005) memoir of their friendship, Truth and Beauty, said about change – that it is “such an elusive thing to describe when it is constantly shifting… moving in the wind of life.” And so I determine to listen carefully to everything the participants say with anticipation and patience, to respect each participant’s process and recognize that the initial conversation with each participant is an opportunity to understand the context of her life. It is also an important time to build a trusting, respectful researcher-participant relationship.

With each interview the stories become richer and deeper. Our relationships grow. I feel more and more privileged to be a part of the construction of their mothering stories through my presence, and through how I listen and the questions I ask. I am aware that I too, am being shaped through our meetings – in different ways by each of these moms.

Listening to Laura and hearing about the story breaking events in her life – the times when life didn’t go as expected, when as she put it: “the storms hit,” I wonder about the impact of previous breaks and reconstructions on the construction of her current stories. I wonder if the process of reconstruction becomes easier over time and with ‘reconstruction’ experience? Does one go about the reconstruction process in much the same way? How have the story breaking events such as the suicide death of Laura’s husband and the drug and alcohol experience of her daughter influenced the story of mothering her son with schizoaffective disorder? I am struck by
the importance that Laura places on finding quiet places and I feel honoured as she invites me to accompany her to some of these places. Again I sense the importance of “invitation” in this researching work. In Laura’s presence I also feel, and am moved by her passion for, and deep commitment to change, which provides me with a greater understanding and appreciation of advocacy and activism. I am also struck by the importance and role of humour in Laura’s life and personally experience the impact of her humour as we laugh together at various points in our interactions. I become aware of the lack of humour in my life and wonder if that could be changed, and if so, what difference that would make.

Meeting with Catherine, I hear about the need and the struggle to let go of expectations. Catherine’s whole story seems to revolve around this struggle and I ask myself: Is this about coping with the challenges of the illness or is it more? Is letting go of expectations central to the process of acceptance in this parenting experience? I wonder: What expectations have I let go of? What expectations am I hanging on to? What difference does that make? How does ‘what I let go of and what I hang on to’ shape who I am today and who I am becoming? As I listen to Catherine, I wonder if I am hearing about transformative growth or maybe more of a gradually changing way of being – a process of adaptation and acceptance of what is. Perhaps it is a search for ways of living vitally given what is, or engaging with life in new and meaningful ways? Like Laura, Catherine has navigated the parenting journey with her mentally ill son without a partner. I wonder about the impact that ‘mothering alone’ has had on her story of growth and change.

In Karen’s presence I experience the impact of being with someone whose “eyes” seem to “shine in a pool of sadness” and I gain an awareness and appreciation of the possibility that light and sadness can coexist. I am also made aware of how fortunate I am to have a son who is compliant with treatment and willing to accept the help he needs. My own mothering experience
could have been considerably more difficult. The opportunities that I enjoy in my life and career are possible because of the treatment and housing options that are available for my son. I need to be more grateful. With Karen I appreciate our mutual understanding of the “ache” we both carry in life because of the illness affecting our children. And again I hear how humour can be helpful – black humour this time. I can’t quite imagine it and wonder what it would be like. I am also impressed by how Karen and her husband have worked together to share the burden of caring for their daughter, and how they have cared for one another and grown closer through their experience. I wonder what that is like. What difference does it make to parent within that kind of partnership? What possibilities emerge?

And then I meet Ellen. There is a settledness about Ellen that is very attractive. I learn from her that this settledness was a long time in coming and reflects for her a relatively new way of being in her world – one she has come to only in the past few years of the over twenty years she has been living with the challenges of her daughter’s illness. To me it seems that Ellen has found a way of integrating the pieces of her broken stories into a new story that sits well with her. Like Karen, Ellen tells me that her husband has had a huge impact on her new way of being. Again, I wonder what this kind of relationship is like and hope that in our future meetings I will be able to gain a richer understanding of how her partner relationship has contributed to her story. To me, Ellen’s story holds much wisdom and also compassion for other parents not as far along on this journey. I am one of those. I want to be like her. There is a sense of nobility about Ellen. She tells me that her experience has changed her drastically, but she is hesitant to call this change “growth” and so I wonder if perhaps “growth” may not be the most appropriate term to describe these mothers’ experiences. “Growth” seems so tied up with expectations and the necessary acquisition of something positive which seems incongruent with what both Ellen and
Catherine have emphasized – that expectations ‘have to go’ when living with this illness. It also strikes me that Ellen’s settledness seems to be related, at least in part, to the times when she needs to be “not nice” and take on the ‘bad cop’ role with her daughter. It seems to me that the changes Ellen is describing are part of an underlying ongoing process of change that perhaps occurs over the period of many years and through multiple experiences in response to a child’s mental illness, a change that might be quite different from the kind of transformative change that is described in the literature related to posttraumatic growth.

Meeting with Lisa confronts me with change in yet another way. I sense a determined optimism in her life that is rooted in her spirituality. Unlike the first four moms that I met, Lisa readily accepts the word growth and I wonder if perhaps her comfort with “growth” is a reflection of the high value she places on spiritual growth in her life. Perhaps it is also a reflection of the use of the term “growth” in the language of faith. As Lisa describes how she copes and makes-meaning of her experience in spiritual ways, I wonder if, similar to the change experiences of the other mothers I’ve met, the growth and change that she is describing is more about adaptation than transformation. Although Lisa’s faith has reportedly become more vital and stronger, it is not a new faith. I am also struck by the strong sense of purpose and hope for a better future in Lisa’s story. She communicates hope for her son’s recovery and also hope for an ultimately better future beyond this present life for herself and all of her family members. This makes me wonder: How much is the experience of “growth” related to hope of attaining something better? I think about Thornton Wilder’s comment, “Hope is a projection of the imagination” and wonder about the role of imagination in adaptation, in meaning-making, and in the ability to live well. I ask myself: What are my hopes? What do I imagine? How does ‘what I hope for or imagine’ influence how I live today, and how I will live in the future? What is the
role of imagination in living well?

As I listen to Sharon I am again struck by a sense of optimism and hope. I am in awe of the energy and the stamina that she has. I think of my own parenting journey and wonder if I ever had that kind of energy. If I did, I don’t remember it. What I do remember is the sense that I had no choice but to keep on going and somehow I had the strength to do that in those tumultuous early years of my son’s illness. In Sharon’s story I am also struck by the close relationship that she has with her son and I wonder: How has she been able to build that closeness with him through his illness? It seems exceptional. I wonder if his relatively high level of functioning compared to some of the children of the other mothers in this study has made it easier to develop such a close relationship with him, but I sense that it is more than that. I also notice that Sharon, like Lisa, seems comfortable with the word “growth.” Both of these women seem quite optimistic and hopeful, although in different ways. Sharon’s optimism and hope appears to be closely tied to her intentional focus on maintaining and building close relationships with her son, her husband, and her friends, whereas Lisa’s optimism and hope is more rooted in her faith. I wonder how optimism influences these women’s level of comfort with the term “growth.” I am also struck by Sharon’s “calmness” and wonder how this calmness influences her optimism and her story of growth and change?

With each meeting I feel closer to the participants, our conversations become more personal, deeper. Between our meetings we have no doubt been reflecting on our conversations and our parenting journeys, what these journeys mean, and how we have been changed by them. In some of our meetings, there is a sadness that is palpable and pervasive. At these times I ask myself: Is this about me or about the person I am with or is it about something we share? I remember well the discouragement I heard in Laura’s voice the day that she talked about having
little hope for the future of the mental health system, given the current closure of facilities and cutbacks in the system. This led me to think about how draining discouragement can be and how hard it is to muster up the energy we mothers need to help our loved ones when discouragement hits. I think about how mothers try to encourage one another in support groups and how, at times, there is little energy to do even that. I think about the times when uncertainties seem to gnaw away at us, when we seem to lose pieces of our story and wonder where they went. It is hard for me and for these women to think or talk about “growth” at these times.

I arrive one day at Karen’s home to find her wrapped in emotional pain, trying hard to be present and finding it difficult to do so. She tells me about watching and witnessing the bizarre unfolding of the illness in her daughter’s life again. Watching it wrench her daughter away from the relatively stable life her daughter had known while on medication. Witnessing what she had predicted would happen with the review panel’s decision to release her daughter from mandatory medication by injection – her daughter’s descent into yet another relapse. The review panel either did not take Karen’s concerns seriously or maybe just didn’t ‘get it.’ To me it feels cruel to be asking about growth and change when this experience is so raw, so I suggest to Karen that we reschedule our appointment, but she doesn’t want to. She says she has been looking forward to our meeting and that our past meetings have been helpful. She wants to go ahead. And so we do.

I struggle with the pull to take on a counsellor role and have to remind myself that I am here as a researcher, not a counsellor. Karen is not asking me for help. She is telling me her story. My job is to listen and to “get it.” Every part of her story is important. I want to cry with her, but I don’t. She isn’t going there and I need to follow her lead.

I leave Karen’s house, find a quiet place to sit down and write:
Palpable Pain.
Betrayal by a system
designed to insure the safety and well being of those we love and care for.

Her face drawn and sad,
Her body carrying a burden so long born with hope.
Hope destroyed.

The weight
wears away the anticipation of something better and the strength to wait.

Will it keep on being this way?
Each psychotic plunge sucks away more of the foundation needed to build a better fuller life.
How much remains?

Will it too be slowly drained away
in the name of rights and freedoms?

Reflections on the Analysis Phase

The transcribing process requires careful listening − over and over again, and as I do, sometimes the emotional pain of what I am hearing rises up in me and opens up my own pain. I cry. I fight the tears. I take a break. Sometimes I want it all to go away and ask myself: Why did I choose this topic? It hurts too much. I do not like the word “growth” anymore. It feels deceptive and seems to deny the “ache” of the sadness and loss that seems to be an important part of these stories. It colours everything. As Catherine said: “Living with the losses is a huge part of the meaning of it all.” Struggle also seems to be an important part of the context of the participants’ experience, and thus an important part of their stories of change. In the third interviews especially I sense this ‘grappling with uncertainties.” As they struggle, I too struggle. I am being shaped, formed, expanded and changed through our encounters, and as I read and reread what they have said. As I hear their voices. As I ponder their metaphors.

The more I hear, reread, sit and work with what these women have told me, the more I am in awe of their courage, their way of weathering the storms that have, and continue to come
their way. They keep on because their children matter – because doing whatever they can matters. I am struck by their trust in me and feel again the responsibility to honour that trust. Their stories have increased my understanding, given me courage, inspired me. Their questions have become my questions. Their stories have joined mine. Our stories now belong together and have an important place in the larger story of what it means to be human.

I am also struck by the continuously changing, at times dramatically changing, context of the participants’ stories. I contemplate the difficulty of revising a story when it is so immersed in a context that is constantly changing. Reconstruction doesn’t get very far before it begins again and then again. There seems to be little opportunity to take a break, to sit back and to cognitively process and make meaning of what has and is happening and come to any degree of resolution. It seems to me that the reconstruction of the stories the women in this study are living is different than the reconstruction of a story after a single highly challenging event. These women are dealing with the fallout of each challenge and then immediately watching, waiting, and preparing for the next one, especially when their child’s illness is more unstable. Perhaps they are finding their way and making meaning of their experience more on an intuitive level than through conscious cognitive processes as they just keep on going? I wonder what is happening when these moms seek out places and times of solitude? What is it about being outdoors, being with the dogs, hiking, dancing and journaling that is helpful, enabling, or perhaps restorative? It sounds to me like these activities are more than coping. They seem to be part of finding a way to live life well. There is something more holistic going on – perhaps an integration of all the parts of their lives (bio/psycho/social/spiritual). This reminds me of something Robert Neimeyer (2001) suggested about reconstructing our lives – that we need to engage the experiential world "as a precondition to reconstruction."
I hold this thought as I repeatedly immerse myself in each participant’s experiential world – listening to the voice recordings, reading and rereading the interview transcripts, listening for a unifying thread and identifying major themes. I revisit some fundamental questions: What is this unifying thread? What are these themes? What do they represent? How did they get to be what and where they are in this story? I think about the process of meaning-making. I ponder the social construction of meaning and sense that the threads and themes in these stories are formed not only in the “in between” – i.e. in the social world – but also by/in each individual participant. Each participant has made meaning of her experience in her own unique way. These meanings have been informed by the interaction with others over time and also by the infinite number of stories that have shaped and continue to shape each participant’s world. I begin to see meaning making as both within and between, reflecting both the constructivist and the social constructionist perspectives of how we come to know / make-meaning of our experience. They stand together. As Sara Bridges (2004) points out, one can bridge the personal and the social in constructivist psychology. In this study we (the participant and I the researcher) are making meaning together through the intermingling of multiple processes: I hear each participant’s personal constructions which have been influenced by the multitude of stories in her world both historically and currently, and recognize that these constructions have also been influenced by my presence, my verbal and nonverbal responses, and the questions I ask. The participant’s constructions shape my constructions. Meanings are created as we bring our personal constructions together and language our experience – the participant telling the story, and my hearing, analyzing, interpreting and writing of the story. Co-creation of meaning continues when the written story is reviewed, discussed and revised together.

There is a growing sense of confidence as I work with the data and identify a unifying
thread for each participant. I notice how the thread holds the story together and I appreciate that this thread will shape how the reader approaches the story. I appreciate that each thread is a somewhat different thread, and represents a possible way of experiencing this phenomenon of growth and change through living with the challenges and uncertainties associated with a child’s mental illness. I also experience a greater appreciation for the appropriateness of narrative inquiry. It is all about possibilities. There is a growing sense of excitement as I envision these connections in various ways, all within each participant’s story as a whole.

**Writing the Stories**

I begin to write the first story in the first person. I feel the impact of the story as I write and I remind myself that this is one of the reasons why I chose to write in the first person. I am hoping it will grip the reader and change the reader in some way. I want the reader to hear each participant’s voice. I want to honour each participant’s voice. I like the “up close and personal” nature of writing in the first person. It has the feel of listening to the story in the presence of the storyteller. I also feel the responsibility I carry and repeatedly ask myself: Did I hear this correctly? What is this about? Is there more? Am I making more of this than is there? Is this important/not important? What, if any, difference does this make? These questions get louder as I put words to more challenging emotional experience like anger, fear, shame, pain, grief, and guilt. I begin to feel concerned about how the story might be received. What will I do if my participants view their experience differently than I have interpreted it? I am also aware that I have developed a closer relationship with some of the participants than with others and wonder how that will influence the interpretation of their stories. Catherine’s story speaks quite loudly to me and I ask myself why that might be. Do I want to give up the management of my son’s treatment to the mental health team and trust them more? I am also drawn to Ellen’s story. She
has learned to accept what is, the unpredictable, and takes that acceptance with her as she focuses on living her own life well. How would my life be different if I was more like Ellen?

The story writing process is suddenly and unexpectedly punctuated by another acute episode of illness for my own son. He is in hospital and I am back in that hurting place, wondering what will happen, remembering and reminding myself about what I know: I love him. I will always love him. No matter what, I will love him. I do not have control of this situation nor will I ever have, nor does he. There is help in the system albeit flawed at times. His caregivers do not have a lot of control either, but they do have the means to gain some control. I need to trust them. They know about his illness. They are aware of his history. In this uncertain place I hear and am comforted by the voices of my research participants: It’s OK to feel devastated, heartbroken, deeply sad. It is part of living with this illness. It will not destroy my life. I will do what I can do and that is enough. I can be his mom. I can live meaningfully with ‘what is.’ I take a break from the story writing for a while. When I feel ready I will return.

After several weeks, I return to writing and as I do, I feel a ‘pull’ to make the story I am writing more hopeful. The sadness and losses feel too bleak and so I ask myself: What is this ‘pull’ about? Is this about my own losses and the need to manage those losses well? Perhaps it is too difficult to be immersed in this story right now. I am reminded of what one of the participants said – that it would be a relief to put the losses behind you, kind of like moving to another town where no-one knows you and you get to be a new person. Easier perhaps, but not possible, or even helpful. There are times when I want it all to go away. Right now I am also eager to complete this study. I acutely feel the weight of responsibility to complete the study for my participants. It seems to be taking so long. I am reminded of the unifying thread in Ellen’s story – Coming to terms and moving on. As a researcher I want to move on. I am immersed in these
stories so intensely – I am in the trees and having difficulty seeing the forest.

**Risks**

I have hit a tough spot in the research. One of the participants has decided to withdraw. She has read the story I’ve written and says that the story does not resonate with her experience. Writing in first person is also unacceptable to her. She does not recall hearing my description of how the narratives would be written in the first person. We meet and I hear her thoughts and reactions. We end our researcher – participant relationship in a mutually respectful way, but the parting is painful for me and I sense it is for her as well. I learn through this experience and am grateful for the learning. I have experienced and am now more aware of the risks inherent in qualitative research, and I begin to have conversations about these risks with colleagues who are also using qualitative methods.

I begin to think about the risks I could have anticipated and didn’t, and consider what I might do differently if I were to begin this study again. I think about the possibly that the participants and I may be coming to the study with quite different perceptions and expectations. I think about the intent and purpose of informed consent. Can a participant ever be fully informed? Can a researcher ever totally predict or anticipate what participation will involve? How much am I able to say to potential participants about the “unknowns” in the research process. Can I in advance fully inform them about what the interview process will be like, the possible emotionally triggering material that could come up, how often we will meet, and how we will know when we have met often enough? In the future I resolve that I would like to provide more than a simple description of the research process. I would like to show potential participants a sample interview transcript and a participant story before they agree to participate. I would anticipate that participants may have stronger reactions to their story if it is written in the first
rather than in the third person. I would also anticipate that I will experience a heavier weight of responsibility to listen well and to understand each participant’s experience well when writing in the first person.

I have also become more aware of the risks associated with being a researcher who has personal experience with the phenomenon. Although I anticipated that my personal experience could facilitate the development of a strong trusting relationship between me and the participants, and I think this was the case in the current study, I am also now much more aware of the potential risks for the participants. In relating to me as another mother, there is the risk of forgetting that I am also a researcher and that the recorded conversations are data. Perhaps this risk is compounded when I am also a counsellor. Stories told to a counsellor may be different than stories told to a researcher.

There is also the risk that I face as a researcher given the multiple roles in my life (researcher, counsellor, mother). I feel the pull to be a counsellor when participants talk about parts of their experience that are troublesome for them, and have to remind myself that research participants are not coming to me for help. I also need to resist the tendency to write tentatively, (characteristic of counsellor responses) when I write my participants’ stories in the first person. As a researcher, I need to anticipate the power of written language when writing about difficult and sensitive feelings such as regret, guilt, and shame, and I must be aware of the risk of minimizing or overemphasizing experience. While my sensitivity and interest in emotional experience developed through my counsellor training could be an asset, I may also be at risk of leading participants to describe their experience in ways that they otherwise might not, thus necessarily privileging certain aspects of their experiences.

I am also more aware of the risks associated with researching a highly sensitive
experience like mothering. Mothering is “up close and personal,” core to identity, and I am reminded of my own reactivity and defensiveness around my mothering role. Mothering is “holy ground,” and must be explored carefully and with a great deal of respect. Misinterpretation has the potential to stir up strong reactions. That said, given that the stories I write are co-constructed, I need to anticipate that there will be some discrepancies between what I have interpreted and written and each participant’s view of her story. The data has been heard and interpreted through the filter of my own experience and is but a fragment of each participant’s experiences. There is so much more that I will never know. My interpretation is also unavoidably influenced by the socially “correct” stories of mothering that I heard and to a large extent subscribed to at the time when I was raising my children, stories that were, and I believe still are prominent in western culture – Stories that suggested that my primary role as a mother is to raise my children well and that if I raise my children well they will be physically and mentally healthy, respectful and hard working and contributing members to the good of society. What then is the impact on my identity as a mother when my children are not physically and mentally healthy, respectful and hard working and active contributors to the good of society? Mothering stories are also changing stories. I am aware that by the time I present the written co-constructed story to my participants for validation, their stories will already have evolved in various ways, the salience and significance of certain threads and themes may have changed.

The Member Check Process

I approach each member check meeting somewhat anxiously. I wonder: Have I heard well, written well, interpreted well? How will this participant respond? What will this meeting be like for the participant and for me? With the exception of the participant who has withdrawn, it is a great relief to find that the participants have all confirmed that yes, their story does resonate
with, and reflect their experience. They have asked for only minor changes that clarify and add to the understanding of their experience, not changes that affect the themes or subthemes. It is gratifying for me to hear every one of the participants report that participation in the study has been helpful for them. Several participants used the word “therapeutic.” One participant described her experience as a “healing experience.” Another said she was “blown away” by the story and felt understood in a way that she did not think would have been possible if I had not also been a mother of an adult child with schizophrenia. Another participant reported that after sharing the story with her husband, they thought that it might be helpful to share the story with family members with the hope that the story might foster a greater understanding of their parenting experience and facilitate helpful conversations about mental illness. Several participants also reported that reading their stories facilitated a greater awareness of aspects of their experience that they had not given a lot of thought to. For example, one participant stated that seeing the word “anger” in her story “turned on a light” for her. I am encouraged by these responses and reminded once again of the privilege I have had of meeting and experiencing the world of these truly amazing, gracious, and caring women.

The Cross-Narrative Analysis

With the data collection and analysis completed, and the individual stories written and validated, the weight of responsibility has lessened. Themes and subthemes are all floating around in my head and I begin to wonder about similarities, differences, associations, and links between all these moving parts. There is a sense of anticipation as I contemplate important “threads.” Are there also wider dimensions as Dr. Mathison has suggested? As I ponder these questions, I remind myself that although these pieces are important, they are not the heart of the study. The stories are the heart of the study. Every story is important and I want to include them
all in my reported findings. I am grateful to find that each of my committee members support this decision and I move ahead with growing confidence.

As I reread the stories in preparation for writing the findings chapter, I face again the instability of my own son’s illness and it is hard to work. My heart aches. Perhaps I just need to accept that grief is surfacing again for me. He has lost so much, so very much. I think back to the interviews over the past two years and recognize a pattern. The interview days were “high” days for me, and were frequently followed by a more somber day. The day after an interview was a day of thinking about my own mothering – comparing the participant’s situation with my own. On those days I would feel the ache surrounding this illness and ache for all affected by it. Then I would move on, renewed in purpose and buoyed by the awareness of the privilege to meet, hear and write these stories.

**Changing Thoughts About Growth**

As I am working on the cross-narrative analysis, I am unexpectedly asked by a researcher who I greatly respect, about my dissertation topic and I find myself struggling to avoid using the word “growth.” This word seems so unpalatable to me now. It hurts to even think about asking a parent of an adult child with schizophrenia if they have grown through their experience. I wonder at how my response to “growth” has changed. Is this a reactive change? Is this an important change? Is this theoretically important? Could it be that growth is not the right/best word to use to describe the experiences of mothers of a child with schizophrenia? The word “change” seems to fit just fine. In response to my research question, four of the six participants have responded with: Change? Yes. Growth? I’m not so sure about that. But then after giving it some thought, with some reluctance, they said: OK, there are some positives. I wonder if they would have responded with a flat out “no” if I was not a fellow mother and respected as a researcher. Perhaps
the word “growth” is just too cliché, but it seems more than that. It feels disrespectful within the context of enduring sadness and loss. Somehow it feels that asking about growth discredits or minimizes the experience of these mothers’ in some way. I also think about the two participants who felt comfortable with the word “growth.” I note that both of these mothers had children who were comparatively high functioning compared to the children of the other four mothers in the study. I wonder what, if any, difference this makes? I also note that both of these mothers hold a strong hope in the possibility of a better life for their child despite the effects of the illness. What, if any difference does/may this make in their ability to see and relate to the word “growth”? 

I also think back to how the notion of growth and change resonated with me at the beginning of this work. It felt quite comfortable then. At the time I was curious to know more about the “personal growth and learning” that came up in my Master’s study on the experience of fathering an adult child with schizophrenia. I envisioned growth as a “shaping” process. The models of stress-related growth (Schaefer & Moos’ 1992 Model of Life Crises and Personal Growth; Folkman’s 1997 Revised Model of the Coping Process) and the model of posttraumatic growth (Calhoun & Tedeschi’s 2006 Comprehensive Model of Posttraumatic Growth) seemed to focus on what I was curious about. At some level ‘growth’ must also have resonated with my participants too given that, although some hesitated at first, they agreed that they met this inclusion criteria (i.e. that they had experienced growth and change through mothering their adult child). The discomfort with this term grew for me as I heard my participants spontaneously and repeatedly hesitate when responding to or using the word “growth,” and also as I struggled with my own reluctance to use this term – especially at times when the participants were describing and/or experiencing loss or distress.

Over time I think about “growth” more and more. There seems to be a sense of
judgement associated with growth, at least with respect to parenting. I wonder: Am I implying that I am not moving toward greater maturity or perhaps stuck somewhere on the road to maturity if I do not acknowledge growth? If I am not growing, am I stagnating? Declining? Am I somehow lacking, or failing to be all I could be and/or perhaps should be? The “should” seems quite loud to me: There seems to be a social injunction within many Western cultures to be open to growth through any experience, to see “the glass half full” rather than “half empty.” To “think positive” seems to be the “right” way to think. What are the implications of this kind of thinking? Does this kind of thinking/questioning diminish possibilities? Does it constrain or restrict living? The word ‘change’ and its meaning seems to be quite different. Perhaps the findings of this study are more about change than growth.

**Ending**

The conversations with my participants end with a mutual sense of gratitude. We have been changed through our conversations and these changes will continue to shape who we become. Although our meetings have ended, our stories continue. The participants’ stories, questions, and responses will continue to shape my story. In some ways the analysis also continues for me as I continue to integrate what I have learned within my own, ongoing story. Although there always seems to be more to consider, at this point the findings are recorded – the individual stories, the common themes, significant threads, and broader dimensions – all of which suggest possibilities. All of these possibilities are important. All of these possibilities have significance.

**Conclusion**

I conclude this chapter by drawing attention once again to the metaphors of change that the six participants shared with me. I end with a metaphor of my own experience. Laura's
metaphor, a willow tree battered and beaten by the storms of life, emphasizes the strength of being flexible. Catherine's metaphor of a rug pulled out from underfoot highlights the profound impact of her child's illness and the need to live differently in response to life-altering change. Karen's metaphor, wheat being blown about in a field with the ever-present awareness of the possibility of being plucked out or cut down with a scythe, draws attention to the uncertainties and the sense of vigilance that characterizes her mothering experience. Ellen's metaphor of the experiences of a rat in a maze provides insight into how this mothering experience can change over time – How early experiences with the illness may involve a desperate search for answers. How over time this desperation can fade and how over time mothering can assume a focus on maintaining a sense of life balance alongside the commitment to care for her child. Lisa's metaphor, the two parallel rails of a railroad track suggests that even when times are difficult there are things to be thankful for. Sharon's metaphor of driving on a prairie mud road and later on a gravel road illustrates that although mothering continues to be challenging, mothering can be easier after the illness is diagnosed and treated. My own metaphor is a wound that is almost healed. As I carry on with my day to day life most of the time this wound is out of my conscious awareness – that is, until it gets bumped. When it gets bumped, it hurts. If it isn't bumped hard, it gets better again fairly quickly and my life carries on much as before. But every once in a while it gets hit hard and when it gets hit hard, it starts to bleed. And when it starts to bleed I have to manage that and I do. It then slowly starts to heal again – almost, but never completely. It is always still there. It will always be a part of my life. It is with me as I continue to find ways to live well and adapt to the changing needs of my son and my family. It is with me as I adapt and engage with life in new and meaningful ways.

Having been through this journey I look back with gratitude for the opportunity to meet
and learn from the six mothers who participated in this study and entrusted me with their stories. They are truly amazing women. I have been encouraged and inspired by their courage, determination, commitment, strength, patience, love, and mothering expertise. Their stories have changed mine. They have taught me to be sensitive to the languaging of experience, in particular to the use of the word "growth." They have broadened my understanding of this parenting experience – of the life-altering changes in their lives and in my own life as a consequence of living with the challenges and uncertainties associated with an adult child's mental illness. They have taught me what it means to find one's way – to adapt to living with the non-finite losses in our lives. They have modeled for me what it means to engage with life in new and meaningful ways.
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Parents of an Adult Child with Schizophrenia

If you:

• Are the genetic parent of a child diagnosed with schizophrenia

• Feel you have grown and changed through the challenges of your parenting experience

• Would be interested in sharing your story as part of a study at UBC

We are interested in speaking with you about your experiences!

Participation in this UBC study being conducted under the supervision of Dr. Judith Daniluk, involves:

• Two or more interviews with the researcher over the period of one year to gain a comprehensive understanding of your experiences
• A brief meeting to review the findings

For More Information Please Contact:
Sandra Wiens, M.A.
Appendix B: Consent Form

Consent Form

Personal Growth and Change through the Challenges of Parenting an Adult Child with Schizophrenia

Principal Investigator: Dr. Judith Daniluk, Ph.D.  
Department of Educational and Counselling Psychology  
University of British Columbia

Co-Investigator: Sandra Wiens, B.S.R., M.A.  
Doctoral Candidate  
Department of Educational and Counselling Psychology  
University of British Columbia

Purpose:

The purpose of the study is to gain an understanding of how parents of adult children with schizophrenia experience personal growth and change through living with the challenges and realities associated with their child’s mental illness. The research is being conducted for Sandra Wiens’ doctoral dissertation.

Study Procedure:

To hear and document your experience of personal growth and change through the challenges of parenting an adult child with schizophrenia the researcher will meet with you for two or more one hour interviews over the period of one year. The number of interviews will be determined by the time required to gain a comprehensive understanding of your experience of growth and change. These interviews will be audio-taped and transcribed. After the analysis of these confidential interviews, the researcher will develop a narrative summary including key themes of your story. A final interview of approximately one hour will occur to verify that the findings accurately reflect your experiences.

Counselling Psychology • Human Development, Learning and Culture  
Measurement, Evaluation and Research Methodology • School Psychology • Special Education

Version: December 12, 2009
Confidentiality:

Your identity will be kept strictly confidential. A pseudonym will be used in the transcripts and in the communications of findings to insure your complete anonymity. Computer files will be password protected. Only the researcher and her supervisor, Dr. Judith Daniluk, will have access to the audiotapes and transcripts. Audiotapes and transcripts will be kept in a locked filing cabinet and destroyed after five years.

Potential Risks/Benefits:

As in any study that seeks to explore a personal subjective experience there is a possibility that you may recall some stressful experiences during or after the interviews that could cause you some emotional discomfort. Should the interviews become emotionally demanding, this should be communicated to the researcher who will provide you with referral sources for professional help as needed. Participation in the study may also be a positive experience. You may gain a sense of satisfaction in knowing that your experience of personal growth and change through the challenges of parenting an adult child with schizophrenia may enable professionals in Counselling Psychology and mental health to gain a greater understanding of the parenting experience and to work more effectively with parents and families living with mental illness.

Remuneration/Compensation:

There will not be any monetary compensation for your participation.

Contact for information about the study:

If you have any questions or concerns with respect to this study, you may contact Dr. Judith Daniluk or Sandra Wiens.

Contact for concerns about the rights of research subjects:

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

Consent:

Your participation in this study is entirely voluntary. If at any time you wish to withdraw from the study your right to do so will be respected.

Your signature below indicates that you consent to participate in the study.

Participant Signature Date

Printed Name of Participant

Version: December 12, 2009
Appendix C: Orienting Statement

The following orienting statement was read to each participant at the beginning of the first interview:

The purpose of this study is to gain an understanding of how parents of adult children with schizophrenia or schizoaffective disorder experience personal growth and change as they live with the ongoing and ever-changing reality and challenges of coping with, and responding to, their child’s mental illness. While we know a fair bit about the challenges and difficulties inherent in parenting a child who has schizophrenia or schizoaffective disorder, we are just beginning to learn about the growth and change that can occur as a result of the challenges and learning associated with this experience. You have indicated that you have experienced personal growth and change as a result of your parenting experience. I am interested in hearing your story of personal growth and change and learning from your experience. My main question is: “How have you experienced personal growth and change as you have lived with the challenges and ongoing uncertainties associated with your child’s mental illness?”

Throughout the interview I may ask for clarification or for more details about your experience. Be assured that you are under no obligation to discuss anything or answer any questions that you are not comfortable with.

Do you have any questions before we begin?
Appendix D: Interview Questions

General Research Question:

How have you experienced personal growth and change as you have lived with the challenges and ongoing uncertainties associated with your child’s mental illness?

Possible Additional Interview Questions:

- In which ways do you feel you have you changed since the onset of your child’s illness? – personally, and in your roles and relationships (e.g. as a parent, as a partner, as a friend, etc.)

- How do you feel “the person you were prior to your child’s illness” (e.g. traits, strengths, weaknesses, coping styles) may be related to who you have become?

- What does personal growth and change mean to you?

- What, if any, specific circumstances/events do you feel have influenced your growth and change, as a consequence of parenting your child with schizophrenia / schizoaffective disorder? In what ways?

- How have your parental role and responsibilities changed since the onset of your child’s illness? In what ways if any, have these changes contributed to or detracted from, your experience of growth and change?

- How have you coped with the challenges of parenting an adult child with schizophrenia / schizoaffective disorder?

- What issues, challenges, thoughts or questions have you encountered since your child’s diagnosis? How have they contributed to your growth and learning?

- How has your parenting experience affected/influenced your goals/beliefs about life?

- Are there any new directions or activities in your life that specifically are reflective of your growth and change?

- How do you feel your relationship with your child has influenced your growth?

- How, if at all, have relationships with family members, friends, or professionals influenced your growth experience?

- How, if at all, has your experience changed your view of the future?

- How have you managed the distress?
• What, if anything, do you think may have hindered your growth?

• In what ways have you communicated your experience to others? How has this communication influenced your growth and change?

• How important/prominent is growth and change in the overall story of your experience of parenting an adult child with schizophrenia / schizoaffective disorder?

• If you had to name the one aspect of your parenting experience that you feel has contributed the most to your personal growth what would that be?

• If you could think of a metaphor that would describe your experience of personal growth and change through parenting a child with schizophrenia / schizoaffective disorder, what would that metaphor be?